Australian Government Department of Health and Ageing (logo)

Guidelines for a Palliative Approach for Aged Care in the Community Setting

Best practice guidelines for the Australian context

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The guidelines are available from:
http://www.health.gov.au/palliativecare
http://www.caresearch.com.au

Disclaimer

This document is primarily intended for health care professionals providing care for older people in the community, including general practitioners, nurses and aged care allied health professionals. Professionals providing specialist palliative care services in the home, for example, those working for the Western Australian Silver Chain Hospice Care Service, are not a primary target for these guidelines because they concentrate on specialist palliative care provision. However, because specialist services may sometimes augment the multidisciplinary aged care team, this document will also be relevant to their practice.

Two summary documents, written in plain English, are available for: older people receiving a palliative approach to care, family members or friends involved in their care; and care workers.

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Publication approval

National Health and Medical Research Council (logo)

These guidelines were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 26 November 2010, under Section 14A of the National Health and Medical Research Council Act 1992. In approving these guidelines the NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of 5 years.

NHMRC is satisfied that they are based on the systematic identification and synthesis of the best available scientific evidence and make clear recommendations for health professionals practising in an Australian health care setting. The NHMRC expects that all guidelines will be reviewed no less than once every five years.

Prepared by Edith Cowan University Technical editing and design by Biotext Pty Ltd, Canberra

Foreword

Palliative care is an important part of Australia's health care system, aiming to improve the life of those who have a life-limiting illness, their families and carers. The care provided does not endeavour to shorten or extend the life of patients, rather it helps give those with a life-limiting illness a better quality of life through care and support.

The *Guidelines for a Palliative Approach for Aged Care in a Community Setting* is a valuable resource for Australia's palliative care system and I believe it will help further enhance the quality of palliative care we provide to older people at home.

In Australia, palliative care is provided across the health and aged care sectors by general practitioners and other health care professionals in hospitals, aged care homes, separate palliative care services such as hospices, and in community care. Carers and volunteers are also important to support people at the end of life.

Community care is a diverse and growing area of palliative care, as many people prefer to stay at home in familiar surroundings with their families. There are several care options, in various environments, provided by a diverse group of professionals and carers. This results in a complex system, and I am certain that all who are involved in palliative care will benefit greatly from these new guidelines.

The topic areas have been tailored specifically for palliative care in the community setting. They look at advance care planning and directives, symptom assessment and management, psychosocial care and spiritual support. Sections dealing with a palliative approach to Aboriginal and Torres Strait Islander people, older adults from culturally and linguistically diverse backgrounds and other adults with particular special needs or perspectives are also included.

The guidelines have been developed by skilled palliative care experts and approved by the National Health and Medical Research Council, and are based on detailed research of current literature. They augment the present *Guidelines for a Palliative Approach in Residential Aged Care*.

The knowledge that people with a life-limiting illness can be cared for in a supportive environment is a comfort to those in care as well as their loved ones, and Guidelines for a *Palliative Approach for Aged Care in a Community Setting* will help enhance and support that care.

Mark Butler
Minister for Mental Health and Ageing

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Guideline developers

Guideline development group

Authors	
Associate Professor Christine Toye	Western Australian Centre for Cancer and Palliative Care at Edith Cowan University, now in the School of Nursing and Midwifery, Curtin Health Innovation Research Institute, Curtin University of Technology
Ms Jennifer Tieman	Director, Australian Palliative Care Knowledge Network, Palliative and Supportive Services, Flinders University
Associate Professor Lynn Oldham	Western Australian Centre for Cancer and Palliative Care at Curtin University of Technology
Professor Jenny Abbey	Professor of Nursing (Aged Care), Queensland University of Technology, now Honorary Clinical Professor, Faculty of Health Sciences, University of Adelaide
Professor David Currow	Professor of Palliative and Supportive Services, Flinders University
Ms Meg Hegarty	Department of Palliative and Supportive Services, Flinders University
Professor Linda Kristjanson	Western Australian Centre for Cancer and Palliative Care at Curtin University of Technology
Project managers	
Dr Ruth McConigley	Until mid-2007
Dr Jeremy Drake	July 2007 – April 2008
Ms Kristi Holloway	April 2008 – July 2008
NHMRC Guidelines Assessment Register (GAR) consultant	
Dr Adéle Weston	Director, Health Technology Analysts

Reference group

Mr Jeff Fiebig	Manager, Program Development, Aged Care and Housing Group
Mr Paul Heath	Strategic Policy and Planning Branch, New South Wales Department of Ageing, Disability and Home Care
Ms Billy-Jo Read	Assistant Director, Community Programs and Respite Section, Community Care Branch, Australian Government Department of Health and Ageing
Ms Kate Sullivan	Social policy research consultant, Kate Sullivan and Associates Pty Ltd
A/Prof Moira Sim	General practitioner and Coordinator of Postgraduate Medicine, Edith Cowan University, Western Australia
Ms Helen Walker	Palliative Care Intergovernmental Forum
Mr Grant Martin	Pharmaceutical Society of Australia
Ms Catherine Reid	Assistant Director, Community Programs and Respite Section, Community Care Branch, Australian Government Department of Health and Ageing
Mr Gordon Gregory	Executive Director, National Rural Health Alliance
Dr Gill Lewin	President Elect, Australian Association of Gerontology
Dr Jeff Rowland	Geriatrician/general physician, The Prince Charles Hospital, Queensland
Dr Louise Welch	Honorary Secretary, Palliative Care Australia
Mr Frank Schaper	Chief Executive Officer, Alzheimer’s Australia (Western Australia)
Ms Meredith Gresham	Research Manager, Hammond Care
Ms Shirley Lennon	National Coordinator, Carer Counselling Program, Carers Australia
Ms Dee Penna	Network Development Coordinator, Carers Australia
Dr Kay Sorimachi	Director, Policy Development, Pharmaceutical Society of Australia
Dr Victor Chan	General practitioner and palliative medicine specialist, Royal Australian College of General Practitioners; Adjunct Associate Professor of Palliative Care, Edith Cowan University
Ms Phyl Crawford	Assistant Director, Palliative Care Section, Australian Government Department of Health and Ageing

Project team

Ms Kristi Holloway	Project officer and booklet development coordinator
Ms Melissa Berg	Reference database coordinator
Ms Helen Morris	Administration assistant
Ms Lesley Hastings	Librarian
Ms Leanne Lester	Statistician
Ms Jannie Piercy	Research assistant
Ms Kayty Plastow	Research assistant
Ms Ursula Ladzinski	Research assistant
Dr Anna Petterson	Research assistant
Ms Céline Fournier	Research assistant
Dr Judi Greaves	Research assistant

Conflict of interest statements for the guideline development group and reference group are shown at the end of the accompanying volume, *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Processes underpinning best practice recommendations*.

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The authors wish to acknowledge the reference group for its exceptional contribution to this project. The role of this group was to act as a reservoir of knowledge, skills and networks for the Community Palliative Aged Care (ComPAC) project. This group also provided a sounding body and an exchange point for understanding and linking into stakeholder groups.

The reference group:

- helped ensure that the project's scope matched the requirements of stakeholder groups
- guided the project team on relevant issues
- highlighted and advised on any issues outside the project that might have had major implications for its progress or outcomes.

Specific issues addressed by the reference group included:

- promoting the project
- setting parameters for focus groups during national consultation
- advising on recruitment strategies for the focus groups
- advising on domains covered in the literature review
- recommending possible sources of relevant evidence to include in the review
- promoting the use of the guidelines.

The authors gratefully acknowledge all those involved in the national consultation, including all the participants in the focus groups and other interviews, as well as the people and organisations who helped to recruit focus group participants.

The authors also acknowledge the following professionals who wrote specific sections of the guidelines:

Ms Karen Glaetzer	Nurse practitioner — palliative care, Southern Adelaide Palliative Services	Care for people with motor neurone disease (Section 11.6)
Ms Janet Doherty	Parkinson's nurse specialist, Parkinson's Western Australia Inc, Centre for Neurological Support, Perth	Care for people with advanced Parkinson's disease (Section 11.7)

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Care for people with motor neurone disease and advanced Parkinson’s disease	
Professor Frank Mastaglia	Director, Centre for Neuromuscular and Neurological Disorders, University of Western Australia
Advance care planning and advance health care directive	
Associate Professor William Sylvester	Director, Respecting Patient Choice Program, Austin Hospital, Melbourne
Ms Liz Stickland	Program Manager, Respecting Patient Choices Program, Austin Hospital, Melbourne
Professor Anne Wilkinson	Chair, Cancer Council of Western Australia and Co-Director, Western Australian Centre for Cancer and Palliative Care, Edith Cowan University
Professor Annette Street	Chair, Cancer and Palliative Care Studies, LaTrobe/Austin Health Clinical School of Nursing
Older adults with post-traumatic stress disorder or acute stress disorder	
Ms Joanne Krueger	Director, Australian Government Department of Veterans’ Affairs
Older adults from culturally or linguistically diverse groups	
Ms Jaklina Michael	Cultural Liaison Coordinator, Royal District Nursing Service and member of the Ethnic Communities Council of Victoria (ECCV) Aged Care Committee (ECCV is a member of the Federation of Ethnic Communities Councils of Australia)
Ms Michelle Clancy	Clinical nurse consultant, palliative care, Royal District Nursing Service
Ms Carmel Brown	Coordinator, Western Palliative Care Services, Royal District Nursing Service
Ms Julie Murphy	Client services manager, Royal District Nursing Service
Ms Sharon Marshall	Clinical nurse consultant, palliative care, Royal District Nursing Service
Ms Fiona McLeod	Clinical nurse consultant, palliative care, Royal District Nursing Service
Ms Jane Bourke	Clinical nurse consultant, palliative care, Royal District Nursing Service
Ms Alexandra Wilde	District nurse (specialised), Royal District Nursing Service
Ms Ros Holland	District nurse (specialised), Royal District Nursing Service
Ms Nicola Mitchell	Nurse educator, Royal District Nursing Service
Mr Mark Jenkins	District nurse (specialised), Royal District Nursing Service
Older adults with dementia (plain-English booklets)	
Ms Anne Deck	Manager Support Services, Alzheimer's Australia (Western Australia)

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Introduction

What is palliative care?

Palliative care addresses the quality of life of people who have life-limiting illnesses and their families by identifying, assessing and addressing physical, psychosocial, and spiritual concerns; it does not attempt to either lengthen or shorten life (WHO 2008). Palliative care is also appropriate for those who are becoming progressively frailer because of advanced age. Although palliative care includes addressing the needs of people as they die and providing bereavement support for families, the emphasis is on improving *living*.

What is a palliative approach for aged care in the community setting?

Most older people in Australia live in the community — either in their own homes, including in retirement villages, or with friends or relatives. As is the case in residential aged care, three forms of palliative care are important for older people living in the community. These three forms are a palliative approach, specialist palliative care and end-of-life care (DoHA 2006). Both a palliative approach and specialist palliative care are appropriate on a needs basis at any time during a life-limiting illness; end-of-life care can be a component of both a palliative approach and specialist palliative care.

In these guidelines, ‘community aged care’ is defined as health-related care and support provided in an older person’s home, including in a retirement village setting, or similar, but excluding residential aged care facilities. The term ‘carers’ (or ‘family carers’) is used to mean family or friends who care for an older person in a community setting; the term ‘care workers’ is used to refer to nonprofessionals who are employed to provide care services.

Older adults in need of a palliative approach to care are defined as people aged 65 years or older who have a progressive, life-limiting illness or frailty. Following Australian Government policy, Aboriginal or Torres Strait Islander people aged 50 years or older are considered to be older adults in the context of these guidelines.

Purpose and intended audience of these guidelines

There is an increasing amount of research in the area of a palliative approach to care for older people, some of which is specific to community settings. Therefore, it is important that findings from this research are evaluated and, when appropriate, used to provide guidelines for best practice.

These guidelines are designed for health care professionals providing care for older Australians in the community. The document is a companion resource to the existing *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) and is for health care professionals providing care for older Australians in the community, mainly in the context of general practice and aged care packages. It is not primarily aimed at health care professionals who provide specialist palliative care services at home (eg the Western Australian Silver Chain Hospice Care Service). However, people who provide specialist palliative care may still find these guidelines useful because specialist palliative care services may sometimes be offered in conjunction with the multidisciplinary aged care team.

Two brief booklets, written in plain English, are additional resources that summarise points from the main guideline document; one booklet is for older adults receiving care and their family carers, the other is for (nonprofessional) aged care workers (see Section 1.8).

As is the case with all practice guidelines, the recommendations included here are not intended to over-ride the clinical expertise of community health care professionals. There is no substitute for the skilled assessment of an older person's health status, circumstances and perspectives, which health care practitioners use to select the recommendations that are relevant to that person. Therefore, these guidelines set out best practice recommendations for practitioners, but are not prescriptive.

How to use these guidelines

The main feature of these community guidelines is the evidence-based guidelines that have been based on systematic reviews of relevant research. The evidence-based guidelines are supplemented with recommendations developed from expert consensus and with reference to the literature. These consensus recommendations are captured as 'good practice points' (GPPs). The guidelines and GPPs are shown in each relevant section of the main text and a complete list is also provided in the followed section of the document. The grades of the evidence-based guidelines have been assigned using the criteria outlined by the National Health and Medical Research Council (NHMRC 2007) as follows:

A Body of evidence can be trusted to guide practice.

B Body of evidence can be trusted to guide practice in most situations.

C Body of evidence provides some support for recommendation(s) but care should be provided in its application.

D Body of evidence is weak and recommendations must be applied with caution.

A list of the guidelines from the *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) follows the list of community-specific guidelines and GPPs as many of these can also be applied in the community setting. This latter list is accompanied by an explanation of the evidence base used for development of the residential guidelines.

Other key features of these community guidelines are the comprehensive lists of recommendations for further research to be found at the end of each chapter and the links to existing guidelines for assessing and managing physical symptoms to be found in Chapter 6.

The first two chapters summarise process and background issues, and the remaining chapters each deal with an issue that is of key relevance to a palliative approach to community aged care in Australia. Further details of processes and supporting evidence are in a separate volume, *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Processes underpinning best practice recommendations.*

Additional information about the structure of these guidelines is provided in Section 1.7.

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DoHA (Department of Health and Ageing) (2006). *Guidelines for a Palliative Approach in Residential Aged Care,* enhanced version, prepared by Edith Cowan University, Western Australia for the Chronic Disease and Palliative Care Branch, DoHA, Canberra, publications approval number 3845. http://www.nhmrc.gov.au/publications/synopses/ac12to14syn.htm

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Summary of community care guidelines

Evidence-based guidelines

Chapter 3 — Delivering a palliative approach in the community setting

Guideline 3.1 Postacute transitional care	**Grade**
Chronic heart failure Postacute transitional care programs, comprising education and support, should be implemented routinely when older adults with severe chronic heart failure are discharged from hospital into the community.	A
Stroke There is currently insufficient evidence to recommend either implementing or not implementing postacute transitional care programs for older adults who have advanced frailty or disability due to stroke.	n/a
Other specific conditions There is currently insufficient evidence to recommend either implementing or not implementing postacute transitional care programs for older adults with other specific conditions such as moderate or severe dementia or advanced cancer.	n/a
Nonspecific conditions Postacute transitional care programs should be used routinely to support discharging generally frail or unwell older adults[a] from hospital into the community.	C

Guideline 3.2 Crisis care	**Grade**
When implementing community-based health care services for older adults with specific or nonspecific life-limiting illness, frailty or extreme old age, access to crisis care should be included.	C

n/a = not applicable

a This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

Chapter 4 — Family carers

Guideline 4.1 Respite care	Grade
Support for family carers Respite care should be available to support family carers of people with moderate or severe dementia.	D
Respite care should be routinely available to support family carers of generally frail or unwell older adults.[a]	A
There is currently insufficient evidence to indicate whether respite care should be made available to support family carers of older adults with advanced cancer, severe chronic heart failure or other specific advanced disease or condition.	n/a
Outcomes for older people There is currently insufficient consistent evidence about the effects of respite care on any health or quality-of-life outcomes for older adults to warrant making any recommendations on these grounds.	n/a

Guideline 4.2 Disease-specific education for carers	Grade
Cancer Active education[b] in the area of cancer care should be made available for family carers of older adults who have advanced cancer.	C
Dementia Active education[b] in the area of dementia care should be made available for family carers of older adults with moderate or severe dementia.	A
Stroke Active education[b] in the area of post-stroke care should be made available for family carers of older adults who have advanced frailty or disability due to stroke.	C
Other advanced diseases There is currently insufficient evidence to indicate whether disease specific education should be made available routinely for family carers of older adults with other advanced diseases (eg severe chronic heart failure).	n/a

n/a = not applicable

a This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

b Active education is a combination of education and skills training.

Good practice points

Chapter 2 — A palliative approach to care

Identifying needs

It is important to take into account the individual needs of the older person and their family or carer when introducing a palliative approach to care (see Section 2.1).

2.1 Introduce a palliative approach to care on a case-by-case basis, according to the person's specific needs and preferences. Each older person will have different needs when living with deteriorating health so it is not possible to determine a fixed point at which a palliative approach should begin for all people. When a need emerges, addressing that need is appropriate and palliative measures may only be needed intermittently in some instances. Relevant needs are for symptom management and psychosocial or emotional support; they also include needs for support of family members or friends when they are providing care or in bereavement.

2.2 Remember the family's needs, including those during bereavement. Although part of the rationale for supporting the family is to allow ongoing home care for the older adult to continue, a palliative approach to care also recognises that families need support for their own health care. A palliative approach to care should also consider the family's needs after the death of the older person, as well as when they are providing care. The needs of family who provide long-distance care (eg phone support) should also be considered.

2.3 Remember that 'family' includes people who provide friendship to the older adult. Providing care for a friend may mean that their illness and death cause distress. Therefore, needs of friends, including volunteers and care workers, should be considered.

Discussing a palliative approach to care

It is important to discuss a palliative approach to care with the older adult and all those involved in their care early in the palliative care process (see Section 2.2).

2.4 Introduce discussion about a palliative approach soon after it is known that an older adult has a life-limiting illness or is becoming progressively more frail. Knowing that there are active options to promote quality of life may provide comfort. Having time to consider and discuss possible choices also empowers the older adult.

2.5 Improve the quality of the discussion by following relevant guidelines (eg Clayton et al 2007). A sensitive approach will minimise distress and focus on the positive aspects of such a discussion.

Collaborating with other professionals

Working with specialist palliative care services and using resources that are available can improve the quality of palliative care (see the introduction to this chapter and Figure 2.1).

2.6 Collaborate with specialist palliative care services. Although the aged care team will have many skills, there may be times when a specialist's input is needed as well, to address physical, psychological, social or spiritual symptoms, as well as symptom or disease-specific issues. An ongoing collaborative relationship with specialist palliative care services will facilitate this input.

2.7 Access useful resources from Palliative Care Australia (http://pallcare.org.au).

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Specific responsibilities

Delivering a palliative approach to care in the community entails specific responsibilities. These are discussed in the introduction to this chapter, and in Section 3.1.6.

3.1 Community health care staff need to take on an advocacy role on some occasions when caring for older adults in the community. Duty of care requires prompt reporting of any suspicions regarding possible ill treatment, neglect and exploitation.

3.2 Occupational health and safety and the scope of practice of those providing care in the homes of older adults are areas that need particular reinforcement with education because of the variability in home care settings and in the extent to which supervision can be provided for community staff.

Communication and teamwork

The team providing a palliative approach to care in the community setting can include pharmacists and volunteers, as well as aged care personnel and GPs. Good communication among everyone involved is essential (see Sections 3.1.1, 3.1.2, 3.1.6, 3.1.7, 3.3.2).

3.3 Good communication among care providers will help to coordinate care when older adults need to move from one care setting to another; for example, when they go into hospital and then return home.

3.4 It is good policy to include community pharmacists in the health care team, if they are willing to take on this role. The advice that community pharmacists can provide for older adults who are in need of medications may make a difference to their compliance with medications.

3.5 Volunteers are also a great resource for expanding the delivery of care. However, volunteers need clear guidance and ground rules for working with this vulnerable group of older people. They also need support. Contacting Volunteering Australia for advice is highly recommended (http://www.volunterringaustralia.org).

3.6 Local initiatives may address postacute transitional care in your area. Check with your local hospital. Also check with them about the best way you can provide information when the person for whom you are providing care is admitted to hospital.

Crisis plans and formalised plans for use at the end of life

Formalised plans for delivering a palliative approach to care in the community setting, and plans for what to do in the event of a crisis, are essential for delivering the best possible care (see Sections 3.1, 3.2.1, 3.2.2).

3.7 Having a plan for what to do in a crisis might alleviate anxiety, even if a crisis never happens. Consider the kinds of things that might cause distress for older adults and work with them and their family carers to develop such a plan.

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3.7 Having a plan for what to do in a crisis might alleviate anxiety, even if a crisis never happens. Consider the kinds of things that might cause distress for older adults and work with them and their family carers to develop such a plan.

3.8 A formalised plan for end-of-life care will help to make sure that the care is delivered in the best possible way. This plan needs to take account of any cultural preferences and should:

- make sure that advance health care plans are documented, known, understood and current
- identify the needs of the family carer for support
- identify the needs of care workers and volunteers for support
- document availability of staff or other support after hours
- identify any equipment that might be needed and its availability, especially after hours
- provide advice to the carer that death is likely to occur soon; the residential care guidelines (DOHA 2006, p 168) lists the following symptoms as indicative that death is likely to occur:
- a decrease in consciousness
- an inability to swallow
- changes in breathing patterns
- peripheral shutdown
- incontinence
- make sure the family knows what to do and whom to contact in the event of a change, a crisis, and when death occurs
- provide a plan to support the family if it is likely that the person who dies will need to remain in the home for hours after the death (eg in an area that is difficult for a general practitioner [GP] to reach)

- provide information about signs that death has occurred (those that are appropriate to the individual situation may be explained to family carers who ask for this information); DoHA (2006 p 169; based on Ferris von Gunten, Emmanuel 2003) lists the signs of death as:
  - absence of pulse
  - breathing ceases
  - 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
  - jaw may fall open
  - trickling of fluids internally can be heard.

3.9 The *Therapeutic Guidelines: Palliative Care* (2005, p 75) indicate that when a death has occurred. the following actions should be taken:

- A decision must be made that life is extinct. This is generally done by the GP but state legislation varies. In some states, this must be done before body can be moved.
- A death certificate must be completed, usually by the treating medical practitioner.
- If there is uncertainty about the cause of death (eg if there has been a fall that may have contributed to the person's death), then the coroner may need to be informed, even though death was expected anyway. The GP or attending physician will normally take this action.

3.10 Care providers may assist with funeral arrangements by:

- contacting the funeral director if the family request this (but it is generally the family's role)
- offering to contact a priest or minister of religion, or a friend to comfort the family member.

The residential care guidelines (DoHA 2006, p 170) suggest the following activities that care providers may need to consider:

- liaise with the family with regard to care of the person after death (eg washing or dressing the deceased person) as the family may choose to do all or part of this themselves and cultural preferences may be important
- consider any other relevant cultural issues
- make sure the family is given unhurried private time to say goodbye
- inform all care providers and volunteers involved in care and debrief as necessary.

Chapter 4 — Family carers

Supporting carers before and throughout the care process

The preferences and needs of the carers and family of the older person need to be considered before and during the care process to ensure they are supported, both mentally and physically (see Sections 4.1.3, 4.1.5, 4.1.6, 4.3.1).

4.1 It is important for the aged care team to consider the family's cultural preferences when supporting the family carer.

4.2 Assessing and monitoring carers' needs is crucial for effective and sustainable support. Support mechanisms need to be responsive and flexible because needs change over time.

4.3 Sensitive exploration of the older person's wishes and those of the family is needed to determine the goal of care. Although a home death is the preferred option for many people if appropriate support is available, this is a very individual preference that is determined by the older person's and the family's choices and feasibility in terms of meeting care needs.

4.4 Helping a family carer to provide effective care is one way to help them find meaning in the caring experience; also, it may help to improve the way in which they cope with bereavement.

4.5 Emphasising the benefits of good health for sustaining their role as carers may be the best incentive for encouraging family carers to look after their own health.

4.6 Providing practical support and information in ways that are easily accessible and culturally sensitive is likely to encourage their use by busy carers who have limitations because of their caring commitments.

Supporting carers as death draws near

The final stages of caring for an older person near the end of their life can be particularly stressful. Preparing carers early and making sure support strategies are in place for this stage help to minimise the trauma for carers (see Sections 4.1.7, 4.3.2, 4.3.3).

4.7 Considering end-of-life care needs in advance can allow the carer to access support quickly when they need it. This helps to ensure the best possible opportunity for a period of end-of-life caring that is meaningful and not excessively traumatic.

4.8 Supporting family carers as death approaches by helping them understand what to expect and helping them to use strategies to cope may improve carers' experiences at the time of the death and their experiences of bereavement.

Types of support strategies

Respite care and other support strategies can help carers to manage their care burden (see Section 4.2).

4.9 Flexibility in arrangements for respite care is likely to increase its effectiveness. In particular, respite care should be readily available in the case of an emergency, such as if a carer becomes sick.

4.10 Respite care needs to be made available at frequent intervals because its benefits are likely to be short lived.

4.11 Offering a range of support strategies for family carers of people who have dementia is likely to help more than offering just one option. This flexibility will allow the carer to choose an option or combination of options most suitable to their needs.

Chapter 5 — Advance health care planning and advance health care directives

Discussing plans and directives

Discussion about end-of-life care is appreciated by many older people and their families and is generally best early in the palliative care process (see Sections 5.1 and 5.3).

5.1 An understanding of cultural and individual perspectives is necessary before initiating discussions relating to advance health care planning.

5.2 Discussion about end-of-life care is likely to be appreciated by many older adults, depending on their individual perspectives. There is more opportunity to develop a comprehensive advance health care plan and/or directive when discussion occurs earlier rather than later (ie before the matter is urgent).

5.3 A prompt to initiate a conversation around health care plans and directives may be when a life-limiting illness is diagnosed or when the older adult is becoming frail. Ideally, a health care professional who knows the older person and their health issues well (eg the GP) will take on this role so that care and treatment options can be explained in a way that is sensitive to the situation of the older adult.

5.4 Palliative care options should be included in discussions with all older adults because advance health care planning is an ongoing communication process about goals, values and treatment options tailored to each person's health care needs and life circumstances. Options may also include 'time-limited trials', in which treatments are discontinued if ineffective within a limited period (Wilkinson et al 2007).

5.5 In the case of older adults with dementia, discussions about future care and treatment early in the illness that are approached with extreme sensitivity can empower the older person. Alzheimer's Australia provides resources that can help in this instance.

5.6 Older adults should have the opportunity to have a family member or friend with them when discussing advance health care plans and/or directives.

Developing plans and directives

Developing advance health care plans and directives uses the information from discussions with the older person and their family or carer to communicate decisions that have been made (see Section 5.3).

5.7 Information provided when preparing an advance health care plan or advance health care directive needs to be explained in plain English and provision should be made for older adults with literacy, vision, or hearing limitations, or for whom English is not their first language, to make sure they completely understand all information.

5.8 Advance health care planning should include:

- receiving appropriate information
- reflecting on personal goals, values and choices
- consulting and discussing with health care providers, family members and important others
- understanding current and future choices that are available
- appointing a proxy (substitute) decision maker
- communicating wishes and values.

5.9 Refer to specialist resources for initiating advance health care planning with people from culturally and linguistically diverse backgrounds (see Chapter 10) and Aboriginal and Torres Strait Islander people (see Chapter 9).

5.10 Additional education in advance health care planning may be needed by some health care professionals. This education can help to make sure that health care professionals have adequate skills and sensibilities, plus confidence, when addressing advance health care planning issues and developing advance health care directives.

Using and reviewing plans and directives

Patients' preferences may change over time; therefore, plans and directives should be reviewed, and the existence and content of up-to-date plans communicated to all those involved in the older person's care (see Section 5.2).

5.11 An advance health care directive needs to be reviewed while the person remains competent, either annually or when there is a significant change in the person's health or circumstances. This will help to maintain the directive's validity.

5.12 One key issue to be addressed with an advance health care plan or directive is the likelihood of successful treatment for acute illness (eg chest infection) given the current health status of the person. When a health care plan or directive is current and known to providers, hospitalisation for aggressive treatments that are likely to be futile can be avoided and plans for successful symptom management can be discussed in advance.

5.13 Advance health care plans and their documentation should be known and understood by the family and/or other advocates to ensure their more effective implementation. It is also important that health care providers know about advance health care plans because they need to document their existence and pass on the information when the older adult is transferred to the care of another health care provider.

5.14 When an older adult is too unwell to provide a copy of their advance health care directive to a health care provider, their advocate should provide one on their behalf.

5.15 Health care professionals should respect current and valid advance health care plans because these are an indication of the older person's wishes.

Chapter 6 — Physical symptom assessment and management

Using action plans and checklists

Checklists of tasks, medication charts, and action plans of daily activities can help family carers to keep track of aspects of care (see Section 6.9).

6.1 Family carers are often stressed and sleep deprived; this can cause them to lose track of aspects of providing care. Providing them with a form to record events relevant to care, such as food and fluid intake, and sleep and bowel patterns, may be helpful. Similarly, a notepad on which to record their questions may be useful. Also, a written record of information from the care provider may help. If there is more than one carer, they can all access this record (as appropriate) to facilitate more coordinated care and to minimise any confusion.

6.2 Polypharmacy is common in older people with comorbid illness. To minimise error and help older people and their carers manage their medication, the family carer can use a medication chart. Health care professionals need to make sure the older person and their family carers are taught about the effective use of medication charts and that these people understand requirements for the safe use and storage of medications.

6.3 During end-of-life care, older adults and their carers are required to make many decisions regarding symptom control. An action plan can be helpful that details what to do if something unexpected or an emergency occurs (eg because of an incorrect medication dose).

Promoting open and honest communication

Good communication between the older adult and their carer(s), and the health care professional is needed for effective care; this includes disclosure about any alternative medicines the older person might be taking, and respect for the older person's cultural beliefs and preferences (see the introduction to this chapter and Section 6.9).

6.4 Complementary and alternative therapies are commonly used in the community, without notification to health care professionals. Health care providers need to promote open, honest communication with the older person and family to encourage them to tell about their use of other therapies (Chan and McConigley 2006).

6.5 Health care providers need to consider specific needs relating to symptom assessment and management for people from culturally and linguistically diverse groups (see Chapter 10), and Aboriginal and Torres Strait Islander people (see Chapter 9).

Chapter 7 — Psychosocial care

Assessing and screening

Accurate detection of conditions that may be particularly helped with psychosocial care is important so that a palliative approach to care can be tailored appropriately (see Section 7.2.2).

7.1 Psychosocial assessment should be included as routine in the care of older adults living in the community so that needs for psychosocial support can be identified and addressed.

7.2 Screening older adults for depression who have had a previous major depression or who have recently experienced major life events, such as bereavement, is appropriate; these people may be at risk.

7.3 Screening older adults for depression who have severe physical illness is appropriate even when the older adult is significantly debilitated. Depression is likely to be treatable even when it occurs in conjunction with severe physical illness.

7.4 Care providers need to consider that depression may be a contributing factor for a person with dementia who behaves in an agitated or aggressive manner, as well as when withdrawal and apathy are observed. However, other considerations are also appropriate. For example, is the person experiencing pain or are they frustrated because they are having difficulties with communication?

7.5 Although depression needs to be considered, older adults with life-limiting illnesses and their family may feel sad and be experiencing adjustment problems rather than depression.

Using interventions and support

Choosing the right psychosocial intervention relies on an understanding of the older person’s individual symptoms and preferences (see Sections 7.2 and 7.3).

7.6 Psychological support and reassurance may be needed in older adults who are experiencing anger. Anger may be part of grief reaction from having an incurable disease and/or related to other losses; it can present in many forms (eg verbal and physical aggression, noncompliance, withdrawal). Careful assessment is required to determine the extent to which anger is appropriate and proportionate, and to identify possible causes (Chan and McConigley 2006).

7.7 Consideration of psychological and social reasons for symptoms is appropriate. For example, symptoms related to anxiety may include hyperventilation, which may be confused with dyspnoea from a physical problem.

7.8 An understanding of the overlap in symptoms of depression and dementia will minimise misdiagnosis in this area and, therefore, facilitate appropriate treatment. Similarly, how symptoms of delirium differ also needs to be understood.

7.9 A person’s psychological and social situation needs to be assessed at an individual level with consideration for culture, gender and beliefs when planning for care and support. No assumptions can be made about experiences of older people due to the diversity of these experiences. Treatable illness (eg depression) may also be missed if it is assumed that symptoms are caused by ageing.

7.10 Effective psychosocial interventions are most likely when a collaborative, integrated, team approach to treatment is taken, with a focus on communication and shared information.

7.11 Tailoring an intervention to the older person's preferences is likely to increase its effectiveness because compliance is more likely; this should be possible because of the many psychosocial therapies that are available.

7.12 Psychosocial treatment options should be considered to minimise problems from polypharmacy and medication side effects. For example, the use of a combination of relaxation and music therapy merits consideration in pain management. The decision needs to take into account the older adult's specific needs and preferences as well as the potential effectiveness of treatments.

7.13 Psychological interventions for older people living in the community, particularly for those living alone or recently bereaved, may be improved by strategies to promote social support (eg volunteer visits), if this approach is acceptable to the older person.

7.14 Minor modifications to the physical environment (positioning chairs to face natural external views, etc) can improve physical and mental wellbeing, and may reduce effects of confusion and disorientation associated with dementia.

7.15 Using strategies to alleviate boredom or possible distress for older adults with advancing dementia may minimise behavioural symptoms, such as agitation or wandering. Social activities are also likely to improve quality of life in most older adults.

7.16 Effective communication with people who have dementia includes using simple, clear language (Pachana 1999). Simple strategies, such as promoting communication effectiveness by educating caregivers to give only one instruction at a time, may significantly reduce agitation (Opie et al 1999).

7.17 For people who have dementia, lighting can be organised to help them to recognise their surroundings (eg to highlight the dining area when it is time to eat). Overall, increasing environmental lighting, ensuring some time is spent outside, or — for housebound people — a diurnal lighting pattern, may lessen sleep disturbances and depression (Torrington and Tregenza 2007).

Chapter 8 — Spiritual support

Recognising older people's spiritual needs near the end of life

People may become more interested in spiritual issues near the end of their life and recognising their spiritual needs can allow this key dimension of wellbeing to be addressed (see Section 8.2)

8.1 Facing old age, increasing illness or disability, and the end of life can bring about multiple losses and challenges for older people. Coping with these challenges can be improved by recognising spiritual strengths and needs.

8.2 Maintaining hope is one way of supporting spiritual wellbeing. When the likelihood of a cure or renewed health is limited, sustaining hope for relief from pain and symptoms, a peaceful death, and being with family and friends when one is dying may be supportive (Chan and McConigley 2006).

8.3 The care team needs to be spiritually sensitive because spiritual perspectives and needs evolve over time and may become more important as death draws nearer. For family carers and others, spiritual needs may continue into the postbereavement period. Showing sensitivity will ensure a responsive approach to spiritual support and care.

8.4 Recognising signs of spiritual need, such as distress seemingly out of proportion to symptoms, insomnia that is resistant to medication, and over-reacting to trivial events will allow hidden support needs to be addressed (Chan and McConigley 2006).

Incorporating spiritual needs into a palliative approach to care

The older person’s spiritual beliefs can be incorporated into a palliative approach to care in different ways, depending on what is best for the individual older person (see Section 8.3).

8.5 Making sure that spirituality is included in care assessment, planning and delivery will improve the older person’s quality of care. It is also likely to improve the wellbeing of the older person and their family. Spiritual care and support may be a key dimension of providing a palliative approach to care.

8.6 For many older people, spirituality is manifested, in part, through religion. When providing care for these people, an understanding of their core religious beliefs and practices will help to make sure that care is congruent with, and respectful of, their religion.

8.7 Including chaplains or pastoral care workers and, where appropriate, traditional healers, as part of the care team can help to deliver flexible and adaptable spiritual care for people and their families.

8.8 Affiliations with relevant religious and other organisations that may address spiritual issues can help in the delivery of spiritual care.

8.9 Supporting older people who struggle with spiritual or religious issues until death is one aspect of implementing a palliative approach to care. When the older person understands that they are dying, it may be appropriate to ask sensitively about things they want to do before they die, and any fears they may have, so the older person has an opportunity to explore these issues if they wish to do so. Equally, any indication that such a conversation is not desired should be respected; the person may instead prefer someone to provide companionship in silence (Chan and McConigley 2006), or to spend time alone.

8.10 Facilitating worship, rituals, customs, human relationships and life review may help to alleviate spiritual distress, and may even help the older person or their family to find meaning in suffering (Pronk 2005).

8.11 Recognising that medication does not fix emotional or spiritual pain is important. The older person’s distress may be helping them to work through spiritual pain and this should not be stopped by medication. However, if anxiety is preventing them from sorting through their issues, a gentle anxiolytic (anti-anxiety medication) may be appropriate to reduce panic to a manageable level (Chan and McConigley 2006).

Chapter 9 — A palliative approach to care for Aboriginal and Torres Strait Islander people

The following good practice points have been developed with reference to the key studies on palliative care in Australia's Indigenous population (Sullivan et al 2003, DoHA 2004, McGrath and Holewa 2006), recommendations from the *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) and the discussion in this chapter.

Understanding important community health care issues

Being aware of traditional beliefs and customs regarding health, kinship, and death and dying helps the aged care team to deliver the best-quality palliative care (see Section 9.2).

9.1 When Aboriginal and/or Torres Strait identity is confirmed, service providers need to consider the context and special needs of Indigenous Australians. However, service providers should not make assumptions about cultural needs.

9.2 Communication and decision making needs to be sensitive to circumstances and should involve the appropriate people, and show respect for family and kinship rules and responsibilities. If unsure, ask the patient, accompanying person or Aboriginal liaison person, 'Who is the right person for me to speak with?'

9.3 Traditional healing can be used as an adjunct to care, as appropriate.

9.4 Culturally appropriate respite services can help to sustain families during their caregiving roles.

9.5 Effective communication strategies should include honest information sharing, and use language interpreters, cultural and medical interpreters, support, and other forms of communication (eg pamphlets in plain English or computer programs). Pictorial story boards may also be useful.

9.6 Service providers need to establish relationships with Aboriginal and Torres Strait Islander communities. Health care professionals undertaking home visits should be accompanied by Indigenous staff or other cultural brokers or advocates, once invited and welcomed into the home. In some cases, being 'invited in' will involve joining the person at the (outside) fireplace; this being the equivalent of a lounge room.

9.7 Employing trained Aboriginal and/or Torres Strait Islander staff or brokers who can act as cultural advocates (eg Indigenous health workers or nurses) can help the aged care team to understand the health care needs of older Indigenous people.

Delivering a palliative approach to care

Specific issues need to be taken into account when delivering a palliative approach to care for Aboriginal and Torres Strait Islander people (see Section 9.3).

9.8 Health care professionals need to show cultural sensitivity and culturally safe practices. Respectful attention is required from the attending community care staff with regard to the older person's individual cultural beliefs and values regarding choice of care, importance of place of care, death and needs after bereavement.

9.9 Mainstream services need to work with Aboriginal and Torres Strait Islander services to provide integrated care.

9.10 Using appropriate assessment tools that have been validated within the relevant community context may provide helpful information. Tools that have not been validated in that context may provide inaccurate results and may lead to the use of inappropriate treatment or therapy.

9.11 Clear care coordination should be managed by an appropriate person who can facilitate continuity of staff and care and organise regular case conferences among all service providers.

9.12 Service providers need to recognise stressors for Aboriginal and/or Torres Strait Islander health workers, such as conflicting cultural and professional obligations and grief from (many) deaths within their own community.

9.13 Service providers need cultural awareness education and training for effective and sensitive cultural practice in this area.

9.14 Indigenous health workers need education and training in a palliative approach to care so that they can perform effectively in this role.

9.15 Health care providers should be proactive in recognising the need for, and providing, bereavement support. Practical assistance is a valuable form of bereavement support. Aboriginal and Torres Strait Islander staff may require additional support because of cultural requirements and community responsibilities.

9.16 Experienced remote and rural community nurses are likely to have extensive knowledge of local Indigenous communities and may be useful contacts, along with Aboriginal community members.

Chapter 10 — A palliative approach to care for older adults from diverse cultural and language groups

Promoting access to community health services

Providing information about the community health services that are available can encourage people in culturally and linguistically diverse (CALD) groups to use them (see Section 10.3).

10.1 Promote access to services within CALD groups by targeted strategies using media such as radio, television and ethnic newspapers. This can inform people about relevant services available within their local community (Lorenz et al 2004).

10.2 Community health care providers need to establish networks with culturally specific services that can offer advice and help as needed. This will improve the care provided to older adults from CALD backgrounds.

Planning and delivering appropriate care

Providing an appropriate palliative approach to care for older people from CALD groups requires taking into account specific issues, which are discussed in Section 10.4.

10.3 Whenever possible, include in the aged care team staff and volunteers whose background or language skills reflect the main cultural group of the area (Lorenz et al 2004, Hsu et al 2005, Rao et al 2006).

10.4 Use services tailored to specific ethnic groups to provide culturally appropriate care. For example, Italian in-home and centre-based respite care may be both viable and highly regarded in areas with large groups of Italian-speaking older people.

10.5 When appropriate, use professional interpreter services and cultural brokers. These services form part of the basis of culturally appropriate care.

10.6 When delivering care to older adults from CALD groups, prepare staff and provide ongoing education to maintain their cultural competence and cultural sensitivity.

10.7 Use information fact sheets about services and treatments, written in the languages of target groups, to provide more accessible health care information for older adults from CALD backgrounds.

10.8 When reviewing how happy older people from CALD groups or their carers are with the care provided, consider asking questions through an interpreter in a spoken, rather than written, format. In this way, the aged care team can check that people understand what is being asked.

10.9 Use culturally appropriate assessment tools to improve cognitive assessments of older adults from CALD groups.

10.10 Include on the aged care team a GP who speaks the same language or is from the same ethnic group as the older person. This GP can help to provide culturally appropriate care, especially when they have had a prolonged relationship with the older person and family.

10.11 Obtain appropriate religious or spiritual support for older adults from CALD groups, as desired by individual older people.

Chapter 11 — Other older people with special needs or perspectives

Older people living alone without nearby family support

11.1 To address the particular fears and concerns of older adults living alone without nearby support, discuss their goals of care (eg dying at home) and fears (eg dying and not being found) when developing a plan of care.

11.2 Help the older person to develop a formal advance health care plan to communicate their end-of-life wishes. Help the older person to keep this plan up to date and known to health care professionals (see Chapter 5). Providing a copy for the GP, who can then inform hospital staff of its existence if there is an emergency admission, for example, may be appropriate.

11.3 Recommend an emergency call system as a simple and effective intervention that may support an older adult who lives alone to remain in their own home for longer.

11.4 Arrange regular and frequent reviews of the level and type of care provided to an older adult with progressive health deterioration. This can help to make sure that the response to care needs is flexible.

11.5 Because of the high likelihood of depression in older adults who live alone, arrange routine screening to help prevent needless distress.

11.6 To alleviate loneliness, consider arranging psychosocial interventions, such as volunteer community visits from members of local churches or other organisations.

Older people living with a mental illness

11.7 Aged care services and mental health care services or consultancies should develop relationships with each other to help plan effective collaborative care for older people who live with a mental illness.

11.8 Use case conferences, where appropriate, as an effective way of encouraging collaborative care planning.

11.9 For a holistic care plan, the aged care team needs to make sure that staff are educated in relevant areas, staff understand crisis management, and relevant staff have access to supports such as peer mentors or supervisors (OMH 2001).

11.10 Support family carers of these older adults by providing emotional, informational and other support. In particular, crisis-management plans need to be in place and access to respite care provided. Crisis-management plans should be clearly documented, known to all family carers and service providers, and show processes to be followed in acute situations (eg who to contact first and who will be available if the first person cannot be contacted).

11.11 When caring for older people with behavioural symptoms, make sure that care has a focus on occupational health and safety for staff. This helps to provide safe and effective care for the older person, and minimises risks for staff and families (McKay 2007).

11.12 Include family carers in decision making about how to provide care (with the older person's consent).

Older people living with acute stress disorder (ASD) or post-traumatic stress disorder (PTSD)

11.13 Screen older adults at risk of ASD or PTSD, especially those exhibiting depression, anxiety or symptoms such as agitation. This may help the aged care team to provide appropriate care for these people.

11.14 When older adults are known to have ASD or PTSD, check whether the family needs additional support. This can help the aged care team deliver appropriate care and assess what resources are appropriate.

11.15 Provide appropriate information and education for health care providers who deliver care to older adults who have ASD or PTSD. This will maximise quality of care, and family carer support.

11.16 Accessing specialist support from the mental health team will also help to facilitate appropriate care and support for the family carer of the older person.

11.17 Make sure that only competent and appropriately qualified practitioners provide psychosocial interventions for ASD or PTSD, such as cognitive–behavioural therapy. Also, some interventions may be inappropriate; see the guidelines for managing ASD and PTSD under ‘Recommended readings’ for this chapter.

11.18 Help the older adult to participate in health care decision making. This is particularly appropriate for older adults with ASD or PTSD, who may be anxious and distrustful of authority.

11.19 Be aware of possible triggers for flashbacks or other adverse reactions in the older person receiving care. This awareness will allow people providing care and support to avoid inadvertently causing distress or provoking a hostile reaction. An understanding by care providers that pain and any perception of restraint may cause distress can also help to inform the plan of care.

11.20 Because older adults with ASD or PTSD can be at risk of self-harm and of harming others, the aged care team (in conjunction with the mental health team) should prioritise the management of these concerns (NCCMH 2005).

11.21 Debriefing can support care staff who are facing challenging situations when providing care for the older adult with ASD or PTSD and their family carers.

11.22 The Department of Veterans' Affairs is a good resource for those providing care for veterans and can provide additional services such as counselling and support. More information is available at http://www.dva.gov.au.

Older people who are gay, lesbian, bisexual, transsexual or intersex (GLBTI)

11.23 Actively demonstrating a nondiscriminatory policy and targeting information about services to the GLBTI community will support access to services by this group of people.

11.24 Education for health care providers about the issues facing GLBTI older adults, the particular importance of confidentiality and how to best support this vulnerable group of older people will help to ensure that a 'safe' care environment is provided for them.

11.25 Individual health care workers can promote the acceptance of care and support by establishing relationships with clients that demonstrate respect and sensitivity.

11.26 GLBTI clients can gain support by networking with GLBTI support groups and by accessing telephone support from these groups. The aged care team can provide GLBTI clients with information to help them do this.

11.27 To allow the implementation of the client's preferences, community health care providers are advised to seek the client's guidance about with whom they should discuss care, when and if an advocate is required.

11.28 Developing advance health care directives and delegating enduring power of attorney take on particular importance with this client group and should therefore be encouraged actively.

11.29 The chosen kin of GLBTI clients are at risk of being overlooked when carer support or bereavement care is provided. To avoid unnecessary distress in this group, service providers need to take steps to identify these kin and provide support as they would to other family carers.

11.30 A partnership in care with the chosen kin of the care recipient has the potential to improve care for GLBTI clients.

11.31 It may be appropriate for the aged care team to provide information about volunteer home care services for GLBTI clients when such services exist.

Older people with an intellectual disability

11.32 A collaborative approach to care among family carers, social care providers, the GP and the aged care team that also aims to identify and respect the wishes of the older adult with an intellectual disability is likely to benefit that older adult.

11.33 Because intellectual disability is also associated with communication difficulties, specialist palliative care advice may be especially useful for these people, particularly when the care team is assessing symptoms and identifying the older person's wishes regarding advance health care planning.

11.34 Bereavement care may also be more complex for these older adults, so specialist input may be helpful.

11.35 This group of older adults is likely to derive particular benefits from early advance health care planning. Additional time may be needed to identify and articulate their wishes to allow for any communication difficulties.

11.36 Health care providers who do not know the person with the disability may be reluctant to value their advance health care plans. Therefore, health care providers who have been involved in the development of these plans may need to adopt an advocacy role or support the family carer in this role, explaining the rigorous process underpinning the plan.

11.37 When someone close to the person with a disability dies, it may be helpful to involve the person with the intellectual disability in rituals, such as the funeral. Other helpful strategies include using nonverbal rituals, respecting cherished mementos and trying to minimise any major changes for 12 months.

11.38 During bereavement, behavioural changes such as development of aggression, regression, mutism (not speaking), self-harm, wandering and long-standing tearfulness may indicate that additional specialist support is required (Botsford 2000).

11.39 An older adult with an intellectual disability whose family carer dies when they are already unwell or frail themselves will be at particular risk of extreme grief, partly because this will usually result in relocation and consequent further loss. Because of this crisis in their lives, health and social care teams need to provide a high level of emotional support for the person and try to maintain as much stability as possible.

11.40 Educational and resource support for people who work for aged care services or palliative care services and provide care for people with intellectual disabilities is essential. As well as addressing skills such as symptom assessment, education and resources should explore issues around myths and stereotyping of people with intellectual disability.

Older people with motor neurone disease (MND)

11.41 A collaborative multidisciplinary approach that provides support for the family carer is essential in MND. Successful home care depends on the availability of a committed family carer, and coordinated and accessible home support services.

11.42 The level of help and support needed will vary from one situation to the next.

11.43 Contingency plans are essential for acute situations that may arise and all care providers should be aware of the wishes of the person with MND and their family carers.

11.44 All people with MND should be encouraged to complete an advance health care directive — ideally, early in the disease process (see Chapter 5). Sensitivity is essential. For example, it may not be appropriate to discuss tracheostomy and gastrostomy options immediately after diagnosis but they should be broached well before there is severe dysphagia, weight loss and respiratory muscle weakness.

11.45 Specialist palliative care services should be introduced soon after diagnosis so specialists can provide consultative advice throughout the course of the illness.

11.46 Practical aids and equipment are essential resources.

Older people with Parkinson’s disease (PD)

11.47 People with PD and their families are likely to benefit from the development of advance health care plans and directives.

11.48 Involving a speech pathologist and dietician in the care of the person with PD can help to ensure safe and adequate nutritional intake.

11.49 A bowel-management program is of key importance for people who have PD, because they are highly likely to experience constipation.

11.50 The safe mobility of people who have PD is likely to be improved if care workers are educated about people with PD ‘freezing’ (ie being unable to move for a short period) and how walking may best be assisted. Fact sheets are available on these and many other relevant topics from Parkinson’s Australia at http://www.parkinsons.org.au under ‘About Parkinson’s’.

11.51 Managing symptoms of dementia occurring in PD may require referral to a specialist in this area.

Older people with dementia

11.52 If an older person shows signs of early dementia, it is appropriate to support them to visit their GP for assessment to determine possible treatments and, as they are able, to address issues of advance care planning (see Chapter 5). However, advance care planning needs to be addressed sensitively and to take account of the degree to which the person understands and has come to terms with the diagnosis.

11.53 Alzheimer’s Australia provides useful resources for supporting people who have dementia, their family carers, and staff and volunteers providing care. These resources include training and education, counselling, advice and support groups. In particular, Living with Memory Loss is a very successful program.

11.54 Expertise in the care and support of people with dementia is of primary importance in community aged care, given the high numbers of older adults who eventually develop dementia. Staff attendance at relevant training courses is highly recommended.

11.55 Developing a brief document showing the background and preferences of the person with dementia can help staff to provide appropriate care when an acute or respite care admission is required.

11.56 Skills in assessing and managing symptoms are of key importance for older adults who have advanced dementia. Special pain assessment tools are available (see Chapter 6).

References for good practice points

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Summary of residential care guidelines

The guidelines provided in the *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) are reproduced in this section because much of the guidance that they provide may be applied within the community setting. The levels of evidence applied were those stipulated by the National Health and Medical Research Council (NHMRC 1999) as follows:

Level I	A systematic review of all relevant randomised controlled trials (RCTs)
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 evidence

The review working party for the residential care guidelines identified a number of studies that were not quantitive in design (ie not rated in the table shown above), but were considered as useful for inclusion. The review working party applied a modified version of the Cochrane Collaboration and Campbell Collaboration guidelines to provide an evaluation tool for use with qualitative studies (Campbell Collaboration 2001, Cochrane Collaboration 2002). This qualitative evidence is abbreviated to ‘level QE’ in the residential care guidelines.

Guidelines		Evidence level
A palliative approach		
When should a palliative approach be implemented?		
1	Methods used to identify survival time, such as physicians' clinical predictions, have limitations in accuracy and precision, resulting in overestimating survival. Therefore, relying only on these methods to determine when to start a palliative approach is not recommended. Aged care team members need to be aware of this tendency to overestimate survival, to reduce residents' and families' potential distress.	IV
2	Attention to residents' transition from active curative care to palliative care (with comfort care and symptom management) requires that aged care team members provide the resident and their families with sufficient information about the transition process to facilitate decision making. This provision of information can reduce residents' and families' concerns and increase their satisfaction regarding the appropriateness of a palliative approach.	QE
3	A palliative approach can be provided in the resident's familiar surrounding if adequately skilled care is available, which reduces the need for transfer to an acute care setting; thereby, avoiding potential distress to the resident and his/her family.	QE
4	A palliative approach is best provided by an effective multidisciplinary team.	III-2
5	Factors that contribute to a person's sense of dignity are a sense of control, strengthened relationships with loved ones, the capacity to communicate, recognising friends and family members, being continent, adequate pain and symptom management, and avoiding inappropriate prolongation of dying. These factors are addressed by the aged care team member when a palliative approach is implemented, thus enhancing the resident's dignity and his/her quality of life.	III-3 IV QE
6	The provision of dignity-maintaining care can facilitate a more hopeful outlook for the resident; thus reducing the resident's desire for a hastened death.	IV QE
Advance care planning		
7	Systematic implementation of advance care planning that involves communication between the resident, family, and doctor increases satisfaction with the care provided to the resident and his/her family.	II
8	Regular education programs for the aged care team and residents and their families on issues about end-of-life care and advance care plans increases the frequency of these plans being completed and implemented, which increases the resident's and his/her family's satisfaction with end-of-life care.	II
9	Developing comprehensive advance care plans that include ongoing assessments responds to changes in the resident's health and increases the resident and his/her family's satisfaction with care.	II

Guidelines		Evidence level
Advanced dementia		
10	For residents with advanced dementia, the implementation of a palliative approach that incorporates ongoing assessment, attention to distressing symptoms, avoidance of hospitalisation, and which emphasises and promotes the resident's quality of life and dignity will benefit the family as well as the resident.	QE
11	Remaining in their familiar surroundings is beneficial for residents with advanced dementia because this helps maintain their care plans and facilitates residents' feelings of orientation and security.	II
12	Assessment of residents with advanced dementia using dementia-specific pain assessment tools results in more attentive symptom relief for pain and discomfort.	IV
13	Aggressive medical treatment of infections is not recommended for residents with advanced dementia. Instead, a palliative approach is suggested for the resident's comfort, which might include short-term antibiotic therapy to ease symptoms and improve quality of life.	III-2
14	The use of restraints within [residential aged care facilities] RACFs is associated with adverse outcomes for residents such as an increase in distress and the risk of injury. Developing a policy of restraint-free care that includes strategies and an education program to minimise restraint use can reduce residents' distress and the risk of falls-related injuries.	II
Physical symptoms — assessment and management		
Symptom assessment		
15	The development of a treatment plan that is based on a comprehensive and ongoing assessment of a resident's needs and wishes, which includes early identification of the main symptoms, provides effective symptom management in accordance with the resident's goals for care and their specific treatment preferences.	IV
16	Implementation of a palliative approach that includes adequate relief of pain and effective symptom management increases residents and their families' satisfaction with the care that is provided.	IV
17	A simple method for regular assessment of symptom distress is to ask residents for their own determination of the intensity of their physical and psychological distress. Regular assessments will improve the effectiveness of symptom management and enhance residents' quality of life.	III-3
Pain management		
18	A comprehensive assessment of the resident's pain and the use of evidence-based analgesic decision making provide enhanced pain management, thereby improving the resident's quality of life.	II

Guidelines		Evidence level
19	For residents unable to verbalise their pain, accurate reporting based on observations by a skilled person using behavioural cues is particularly important in determining pain. The use of appropriate assessment tools will increase the frequency with which pain is diagnosed when compared with asking the resident, ‘Do you have pain?’	III-3
Fatigue		
20	Fatigue is the most frequently reported physical concern by individuals nearing death. Therefore, careful assessment is required of factors that may indicate or bring about fatigue (eg depression, anxiety, pain, a reduction in intermediate activities of daily living and number of medications), which will enhance early identification and management of fatigue.	IV QE
Nutrition and hydration		
Nutrition		
21	Good nutritional care requires an individualised approach that includes early recognition of weight loss and the identification and management of likely causes (eg adverse medication effects, poor oral health, or depression). This careful attention to assessment and management of residents’ nutritional requirements improves quality of life.	II IV
22	Giving residents oral foods and fluid, even in small amounts, is preferable to using more invasive enteral (eg nasogastric or percutaneous endoscopic gastronomy) feeding methods. However, a dysphagia assessment is essential to provide direction for oral feeding.	II III-1
23	The aged care team member assisting with feeding should be seated at eye-level with the resident and take time to establish and maintain a relationship with the resident to create an atmosphere that is conducive to relaxing the resident. This approach to feeding enhances the resident’s nutritional intake and improves his/her social well-being.	III-1
Hydration		
24	Recommendations regarding fluid therapy that are based on an ongoing assessment of each resident’s circumstances, including the resident’s and family’s treatment preferences, improve the resident’s and family’s satisfaction with the care that is provided.	IV
25	Regular presentation of fluids that include strategies, such as a colourful beverage cart, verbal prompting or complying with residents’ preferences, will increase the amount of oral fluid intake for those residents able to have oral hydration.	II III-1 IV
26	Frequent small sips of fluids can reduce the resident’s sensation of thirst and oral discomfort that is associated with dehydration.	IV
Cachexia		

Guidelines		Evidence level
27	A review of a resident’s clinical history, the presence of substantial weight loss, laboratory tests and physical examination are required to make an accurate diagnosis of cachexia.	II
28	For frail residents with substantial weight loss who are unable to have sufficient oral calories, a trial of single nutrients or liquid meal replacements is an appropriate alternative.	II
Dysphagia		
29	A formalised multidisciplinary management program that includes input from a speech pathologist is beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia.	III-1
30	Safe feeding techniques that are recommended by a speech pathologist or physician, which include the method of feeding and the texture, consistency, and type of food and fluid, should be undertaken as prescribed to reduce the resident’s risk of aspiration.	III-1
Mouth care		
31	Good oral hygiene, regular assessment, cleansing of dentures and oral fluids can reduce oral complications.	IV
32	Oral health assessments that include the question, ‘How would you describe the health of your teeth and gums? Would you say it is excellent, very good, good, fair or poor?’ for residents who are able to respond increases accuracy in identifying residents who require further evaluation and dental treatment.	IV
33	Rinsing the mouth with water and cleansing teeth with a soft toothbrush and toothpaste is an effective oral cleansing routine that is cost-efficient and reduces the resident’s risk of oral mucositis (mouth ulcers).	II
Skin integrity		
34	The use of high specification foam mattresses rather than standard foam mattresses can reduce the incidence of pressure ulcers.	I
35	The use of Australian Medical Sheepskins (natural not synthetic fibre) may be effective in reducing the incidence of pressure ulcers for those people who are at low to moderate risk of developing these ulcers.	I II
Bowel care		
36	Eliciting information that includes a history of residents’ bowel habits and their preferences for treatment, an awareness of complementary methods of bowel care (eg low-intensity exercise, abdominal massage and hot packs) and better documentation procedures, will improve bowel management and residents’ well-being.	II QE
37	Discussion between the doctor and nursing staff about the most appropriate laxative for use with a resident will enhance management decisions regarding bowel care.	QE

Guidelines		Evidence level
38	The combined use of bulk laxatives and suppositories is associated with the lowest rates of faecal incontinence. The use of suppositories after bowel clearing can prevent recurrent constipation.	QE
39	Where a laxative is used, appropriate compensatory measures should be taken to avoid dehydration and electrolyte depletion.	II QE
Dyspnoea		
40	A comprehensive plan of care including ready access to appropriate medication, plus nonpharmacological interventions to reduce psychological distress, may prevent residents with gradually increasing dyspnoea being unnecessarily transferred to hospital.	IV
41	A physical examination and a complete history that covers factors that are likely to have influenced the severity of the symptom, including pre-existing illnesses and exacerbating factors, will provide sufficient information to accurately determine a diagnosis of dyspnoea.	IV
42	Nonpharmacological interventions based on psychosocial support, controlled breathing and learned coping strategies can help residents cope with dyspnoea, which will reduce their physical and emotional distress.	II
43	The use of sustained-release low-dose oral morphine administered orally or parenterally can benefit individuals with dyspnoea by reducing the severity of their symptoms and improving the quality of their sleep.	II
Complementary therapies		
44	Generally, those who are unable to tolerate or who refuse pain medications as part of a palliative approach may benefit from appropriate complementary therapies. These therapies may also fit better with culturally specific preferences and enhance resident's sense of control.	II
45	The combination of traditional analgesic treatments with acupuncture, TENS [transcutaneous electrical nerve stimulation], relaxation and imagery, and hypnosis may be helpful for symptom management because they may reduce intractable pain, thereby improving quality of life.	II
46	The use of acupuncture, acupressure, and muscle relaxation with rebreathing training or rebreathing training combined with coping strategies may reduce dyspnoea and improve function (eg walking ability).	II
47	The use of aromatherapy massage for residents with advanced dementia may reduce the incidence of disturbed behaviour, the level of anxiety, and improve quality of life.	II II III-1
48	A massage with essential oils is beneficial for reducing levels of anxiety and improving quality of life for people receiving a palliative approach.	II III-1
49	The use of gingko for older persons with mild to moderate dementia or age-associated memory impairment is not recommended because it was found to have no beneficial effects.	II

Guidelines		**Evidence level**
Psychological support		
Depression		
50	The use of the Geriatric Depression Scale to screen residents for depression can increase the frequency with which treatment is provided for this disorder by prescription or via referral to appropriate health care providers.	II
51	Suicide attempts or requests for a hastened death are often an indication of clinical depression. An active response that addresses depression, hopelessness, and social support can improve the resident's wellbeing and reduce the desire for a hastened death.	IV
Anxiety		
52	Gentle massage can reduce anxiety levels or agitated behaviours for residents with chronic pain and/or dementia.	IV
Delirium		
53	A thorough assessment of the symptoms of delirium is required, which includes consideration of the persistence of symptoms (eg inattention, disorientation, and impaired memory) to accurately and quickly detect delirium in older persons, which increases residents' frequency of treatment and referral.	III-2 IV
Dementia		
54	Many residents can answer questions regarding 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 in decision-making to improve their satisfaction with the care they receive.	IV
Psychological distress		
55	Incorporating the use of a specialised palliative team who have some expertise in the assessment and care of those with depression, agitation, loss and / or anxiety is beneficial for residents who require a palliative approach.	QE
Family support		
56	Involving the family to assist with symptom distress, communicating, and assisting with the physical care needs of the resident can improve the aged care team members' relationship with the family.	III-2 QE
57	Health deterioration and the death of the resident may impact upon the physical and emotional health of family members. Family members' depression and health problems should, therefore, be informally monitored by the aged care team and, where appropriate, support provided to offset the effects of caregiving stress.	III-2 III-3 QE

Guidelines		Evidence level
58	Families appreciate good communication with the aged care team, affirmation that their input is valued, and permission to withdraw at times from the caregiving situation. When these needs are addressed, families experience increased satisfaction with care.	QE
59	Family conferences can provide emotional support to family members and an opportunity to discuss concerns about the resident's illness/ageing process. Such discussion benefits families and ultimately improves the quality of life for the resident.	III-2 QE
Social support, intimacy and sexuality		
Social support		
60	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 perception, appraisal and interpretation of the contact that is most important to them. Appropriate interventions can then be undertaken with a view to arresting/improving the resident's condition.	IV
Intimacy		
61	The use of comfort touch (eg massage, hand-holding) by the aged care team can enhance residents' sense of well-being and self-regard.	IV
Sexuality		
62	Aged care teams who have received ongoing education regarding the importance of residents' intimacy and sexuality needs, and who are discrete when sharing such information with their colleagues, provide residents with more holistic care; thereby improving residents' well-being.	QE
Aboriginal and Torres Strait Islander issues		
63	Respectful attention to the individual needs of Indigenous Australian residents, taking into account their beliefs regarding illness, healing, comfort, care practices, location of care, and death and dying, is required to provide Aboriginal and Torres Strait Islander residents with culturally appropriate and satisfactory care.	QE
64	Aboriginal health workers, liaison officers, other Indigenous Australian health care practitioners and community organisations have important knowledge about local cultural values and individual situations, and should be involved when developing protocols and when working with Indigenous Australian residents to deliver the best possible care.	QE
65	Regular review of Indigenous Australian residents' needs is required, because their needs may change over time. Communication in the resident's own language will enhance understanding and attention to his/her needs.	QE
Cultural issues		

Guidelines		Evidence level
66	Education about cultural diversity is recommended for aged care teams to enhance understanding of care preferences of residents from varying cultural groups. Efforts to accommodate these preferences promote individualised care that benefits the residents' and their families' well-being.	QE
67	Where possible, provide information about a palliative approach to residents from culturally and linguistically diverse backgrounds in their own language because this enhances cultural sensitivity for residents and their families, and ensures adequate and appropriate care.	II QE
Spiritual support		
68	A multidisciplinary aged care team that responds in an open, non-judgmental manner to residents' questions regarding spiritual needs, and that involves a chaplain/pastoral care worker with experience and knowledge of spiritual issues, is likely to provide appropriate spiritual support to residents, which will enhance their quality of life.	IV QE
69	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 their quality of life, as does spiritual counselling.	IV QE
70	Understanding the resident's current or desired practices, attitudes, experiences and beliefs by obtaining a comprehensive history, assists in meeting the spiritual needs of a resident, as does a regular review.	IV QE
Volunteer support		
71	The integration of trained volunteers into multidisciplinary teams can enhance the provision of a palliative approach to residents.	IV QE
72	Ongoing support and education from a trained coordinator of volunteers will increase the effectiveness of volunteers as members of a multidisciplinary team providing a palliative approach.	IV QE
73	Suitably screened and matched volunteers may act as companions and confidants, which can help residents and their families to feel more supported.	IV QE
End-of-life (terminal) care		
74	To be actively 'doing everything' for a dying resident, in terms of medication, positioning, and other medical and nursing interventions, together with talking to, and spending time or being present with the resident, helps family members cope with the dying process.	QE
75	Well-planned family conferences, conducted in private and attended by the general practitioner and other members of the aged care team, provide an opportunity for building trust and discussing end-of-life issues of concern, which improves the family's satisfaction with the care that is provided.	III-2 QE
Bereavement support		

Guidelines		Evidence level
76	Members of the aged care team can experience loss following the deaths of residents with whom they have established meaningful relationships. Therefore, they may require opportunities to formally acknowledge their loss and access to adequate bereavement support to reduce their levels of death anxiety and their risk of complicated grief. Aged care team members who have experienced many deaths may still require access to these support services.	QE
77	A memorial service is a useful ritual to assist in bereavement support of residents, family members, the aged care team, and volunteers because it facilitates the grieving process and reduces levels of death anxiety and the risk of complicated grief.	QE
78	The greater the level of social support that a family can access, the better their ability to cope with the bereavement of their family member; however, it is the quality of the support rather than the quantity that enhances this resilience.	IV QE
Management's role in implementing a palliative approach		
79	Implementation of formal management systems in RACFs that support the introduction and maintenance of a palliative approach through the allocation of appropriate resources will improve residents' and families' satisfaction and enhance the quality of care that the aged care team is able to provide.	QE

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Chapter 1 Guideline development process

This chapter outlines how the project and literature review were developed, including:

- the methods of the national consultation
- the intended scope of the guidelines
- the development of the evidence-based recommendations
- the development of good practice points
- response to public comment.

Further details about the meaning of a palliative approach to care, the need for guidelines, the purpose and intended audience are given in the Introduction.

1.1 National consultation

The development of these guidelines was based on an extensive national consultation process to make sure the guidelines were useful for community aged care practitioners. The guideline development group used results from the national consultation to develop the proposed scope and structure of the guidelines. The national consultation involved 172 people (see Table 1.1) who were providers and consumers of health care and services for older adults living in the community from around the country, including in rural and remote areas (Toye et al 2007).

Table 1.1 Participants in the national consultation

Role	Number
Consumers (older adults or family carers)	17
Nurses (registered and enrolled nurses, clinical nurse consultants, nurse practitioners)	79
Medical practitioners (including general practitioners, geriatricians, palliative care physicians, general practice managers)	9
Allied health personnel (including physiotherapists, occupational therapists, dieticians, pharmacists, paramedical aides, speech pathologists, complementary therapists)	10
Aboriginal health workers, Aboriginal liaison officers and multicultural officers	7
Care workers	4
Researchers or educators	4
Managers (aged care and palliative care)	24
Volunteer support workers (including coordinators or volunteers)	3
Pastoral care workers or chaplains	3
Psychosocial support workers (including counsellors/social workers)	12
Total	**172**

1.2 Scope of the guidelines

Participants were asked to consider areas in which guidance was particularly needed for community aged care practitioners when they were providing a palliative approach to care. These areas were also considered with reference to the existing residential guidelines (DoHA 2006) to minimise unnecessary duplication.

Participants reported that they needed guidance in the following areas:

- delivering care in the community setting, including respite and crisis care, after hours services, rural and remote issues, and practical matters
- supporting family carers
- providing care for older adults living alone
- assisting with advance health care planning
- assessing and managing symptoms and ways of providing treatment
- providing end-of-life care
- providing bereavement support
- supporting volunteers
- understanding issues specific to Aboriginal and Torres Strait Islander people
- taking into account cultural and spiritual issues
- providing psychosocial support.

These topics formed the basis for planning the guideline development.

1.3 Guideline development

The guideline development group prepared these guidelines using two separate approaches:

- Community service delivery and support for family carers (topics that are of particular and specific importance in community aged care) were addressed by developing questions for a systematic review that could then provide evidence-based guidelines when enough evidence was available.

- Areas important to a palliative approach to care for older adults across all settings were addressed with less rigorous processes because residential guidelines have already been written for these situations (DoHA 2006), and there are many other guidelines for symptom assessment and management that can also be applied in the community (these other guidelines are reviewed in Chapter 6).

Table 1.2 provides further information about these approaches. The guideline development process is shown in more detail in Figure 1.1. The guideline development group was supported by a reference group. This group acted as a reservoir of knowledge, skills and networks for the project, and provided a sounding body and an exchange point for understanding and linking into stakeholder groups.

Members of the guideline development group and the reference group, and further details about the role of the reference group, are shown on pages xvii to xvii.

Table 1.2 Approaches used in developing the guidelines

Topic	Approach
Community service delivery and support for family carers	• Review of descriptive studies to establish context • Development of questions for systematic reviews • Systematic reviews addressing these questions • Nonsystematic reviews in other relevant areas • Development of evidence-based recommendations from the systematic reviews • Development of consensus-based recommendations (good practice points — GPPs) from all reviews and from expert opinion
Advance care planning and directives, psychosocial issues and spiritual support	• Nonsystematic review of reviews of research in the area • Development of GPPs from the reviews and from expert opinion
A palliative approach for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse groups, and other older adults with needs or perspectives requiring special consideration	• Discussion chapters • Development of GPPs from the discussion and from expert opinion
Symptom assessment and management	• Definition of symptoms • Direction to relevant clinical practice guidelines

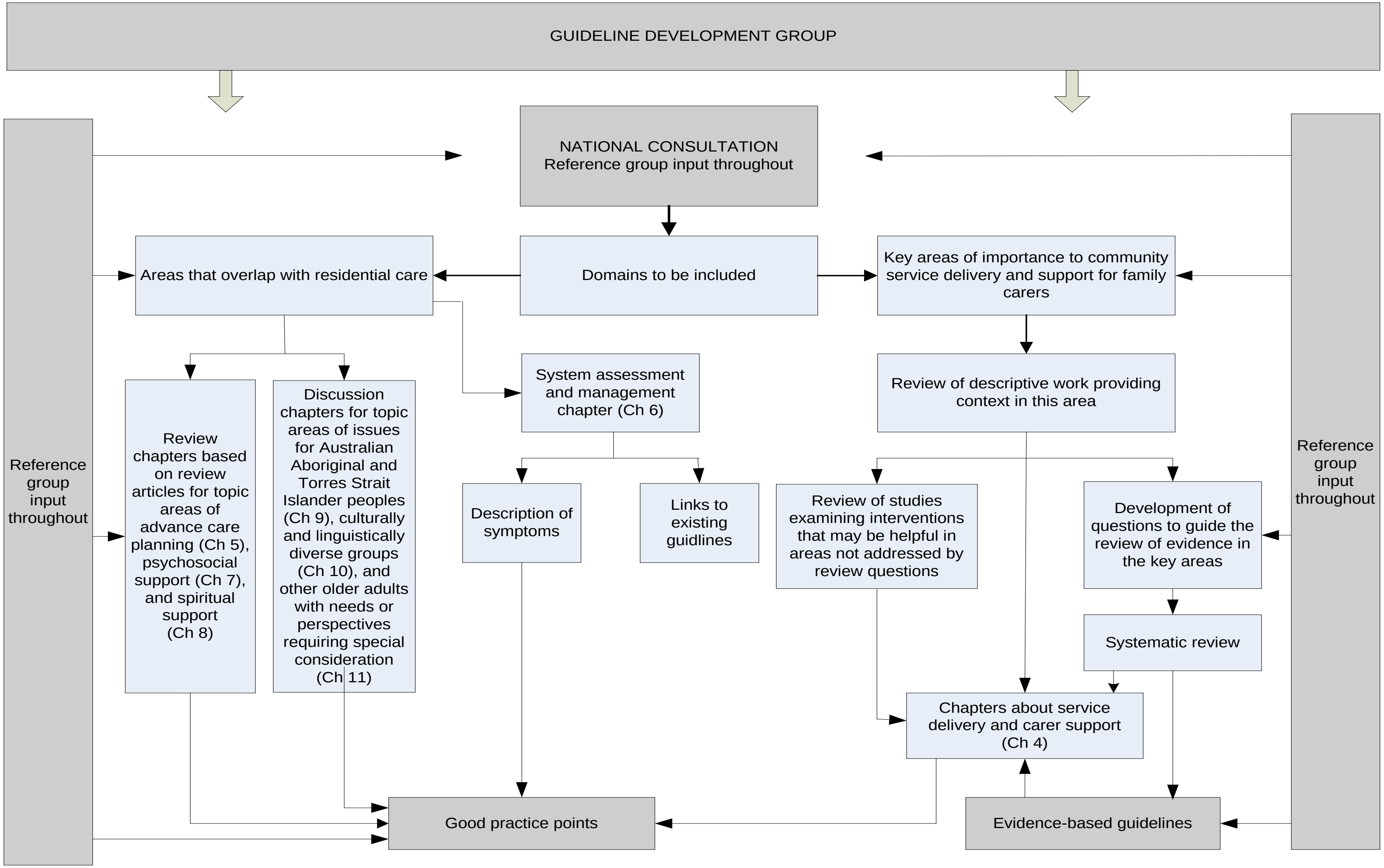

Figure 1.1 Development of the guidelines

1.4 Evidence-based recommendations

Evidence-based clinical practice guidelines are statements to guide practice that are based on a systematic review of the evidence. These guidelines followed the National Health and Medical Research Council (NHMRC) processes from *A Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines* (NHMRC 1999) and the associated series of handbooks (NHMRC 2000abcd, NHMRC 2001, NHMRC 2003). We used the levels of evidence and grades for recommendations documented for the pilot program of 2005–07 (NHMRC 2007).

The NHMRC process includes the following key steps:

- Development of the clinical questions to be addressed in the guidelines.
- Developing and implementing a clear review protocol to answer these questions, including a comprehensive and systematic search, robust inclusion and exclusion criteria, and the sound rating of the evidence.
- Applying a systematic process to develop and grade guidelines from the evidence, when appropriate, or to develop recommendations for further research when there is not enough evidence.

1.4.1 Questions

At the start of the project, the guideline development team developed the questions for the systematic review based on the results of the national consultation and on advice from the reference group. The following five questions were developed to address priority areas, as assessed by the guideline development group:

- Does the implementation of a postacute transitional care program lead to improved physical and/or psychological health of the older person and/or the family carer?

- Does a model of care that includes 24-hour crisis care (access to after hours medical, nursing and pharmaceutical support) improve physical and/or psychological health in older people and/or family carers as compared with a model of care that does not include this crisis care?

- Does a model of care that includes respite care improve physical and/or psychological health in older people and/or family carers as compared with a model of care that does not include this respite care?

- Does education for family carers in disease-specific areas (dementia care, heart failure, chronic obstructive pulmonary disease, cancer care, Parkinson’s disease) improve family carer confidence, competence, physical, psychological and spiritual health when compared with a lack of this education?

- Does education for family carers in end-of-life care improve their experience of the death of their family member and their postbereavement health as compared with a lack of this education?

1.4.2 Protocol

Appendix A contains a full report of the systematic review. We searched only for published research articles and systematic reviews but included other relevant research reports known to us if they met the criteria and were important to the review. In addition to the original search, we checked reference lists of included studies, retrieved any further studies that appeared relevant and included them if they met our criteria. We also checked all the studies included in the systematic reviews we retained, and included these studies if they met our criteria.

Included documents:

- were written in English and
- addressed the outcomes and interventions determined by the specific question and
- reported a study or a systematic review providing Level I, II, III-1, or III-2 evidence for interventions, as determined by the NHMRC Pilot Project documentation (see Table 1.3) (NHMRC 2007) and
- addressed these interventions and outcomes in older adults in the community who:
  - had progressive conditions causing physical and/or psychological symptoms likely to interfere substantially with life or
  - were clearly frail as shown by their co-existing diseases (‘comorbidities’), level of disability or life expectancy *and/or*
- reported interventions or outcomes for family carers (as appropriate for the question).

Excluded documents:

- failed to meet the above inclusion criteria *or*
- reported retrospective research *or*
- reported research without a comparison group *or*
- reported a cohort study with a sample size of fewer than 200 people *or*
- reported a cohort study that was not designed to answer a question of relevance to our review *or*
- reported study findings that were duplicates of those already included in our review.

We wrote to authors for clarification if this was required. Also, when the appropriate inclusion or exclusion of documents was not clearly dictated by reference to the operationalised inclusion and exclusion criteria documented in Appendix A, the decision was discussed between the first and third investigators with provision to approach another member of the guideline development group should the discussion not lead to an agreed decision. We completed a comprehensive data-extraction form for each study and systematic review. Appendix B lists included studies; Appendix C lists the excluded studies and the reasons for exclusion; Appendix D provides the data-extraction forms.

Table 1.3 Levels of evidence for intervention studies

Level of evidence	Description
I	A systematic review of level II studies[a]
II	A randomised controlled trial
III-I	A pseudorandomised controlled trail (ie alternate allocation or some other method)
III-2	A comparative study with concurrent controls: – nonrandomised experimental trial[b] – cohort study – case-control study – interrupted time series with a control group.
III-3	A comparative study without concurrent controls: – historical control study – two or more single arm study[c] – interrupted time series without a parallel control group.
IV	Case-series with either post-test or pre-test/post-test outcomes

a A systematic review will only be assigned a level of evidence as high as the studies it contains, except where those studies are of level II evidence.

b This also includes controlled before and after (pre-test/post-test) studies, as well as indirect comparisons (ie use A vs B and B vs C to determine A vs C).

c Comparing single-arm studies (ie case series from two studies).

Source: NHMRC 2007, p 4

1.4.3 Developing and grading the recommendations

The guideline development group convened a two-day meeting to consider the evidence. Each member was provided with copies of all data-extraction forms and had access to full copies of articles to check any issues that needed clarification. Inclusion and exclusion of studies was finalised at this meeting and all the evidence was considered for each question. Members of the group discussed the quality of each study in detail, focusing on how well the studies minimised bias during each stage (eg data analysis, transparency of reporting). Then the body of evidence as a whole was considered and graded, addressing:

- the evidence base, which refers to the design of the study and the extent to which this avoided bias
- the consistency of findings
- the clinical impact; that is, the extent to which the results were likely to make a difference to people’s lives (‘clinical importance’) versus whether they were statistically significant
- how generalisable the results were, which refers to the extent to which the study population reflected the types of people we were interested in (ie older adults who receive palliative care in the community and their family carers)

- how applicable the results were, which refers to how appropriate it is to use the specific type of care in Australia.

Each team member completed a summary form for each decision made and these forms were retained as records of the process (see Appendix E). Evidence-based recommendations were developed based on the extent and quality of the evidence (NHMRC 2007). Table 1.4 explains the ratings of recommendations.

Table 1.4 NHMRC grades of evidence-based recommendations

Grade of recommendation	Description
A	Body of evidence can be trusted to guide practice
B	Body of evidence can be trusted to guide practice in most situations
C	Body of evidence provides some support for recommendation(s) but care should be provided in its application
D	Body of evidence is weak and recommendations must be applied with caution

Source: NHMRC 2007, p 13

The guideline development group also considered changes to usual care, resource implications, care organisation and possible barriers to implementation.

1.5 Good practice points

Good practice points (GPPs) are recommendations based on a consensus of the opinions of the guidelines development group, rather than on specific evidence from studies. The guideline development group used any relevant literature reviewed in the course of the whole project (see Table 1.2), as well as expert opinion, to inform the development of the GPPs. Appendix F contains a full report of the processes that the group used to develop the GPPs.

1.6 Public comment

Both volumes of the guideline documents were released for public comment. A 30-day period was allowed for public comments from the date of placing an advertisement in *The Australian* newspaper. The public release was also advertised on the CareSearch website, via the project's newsletter, through contacting relevant professional bodies and organisations, through recontacting those who had expressed an interest during the original national consultation, and via personal contacts. The guidelines were available for electronic download via the CareSearch website, via electronic mail and in hard copy. Table 1.5 lists the access details.

Table 1.5 Documents accessed during the public comment period

Posted		Sent by electronic mail	Accessed via the CareSearch website	
Volume I	Volume II	Volume I	Volume I (times)	Volume II (times)
19	3	128	14 876	5776

Thirteen submissions were received, mainly from organisations or professional bodies. Comments were tabled for a teleconference of the guidelines development group. The guideline development group considered every comment and agreed on an appropriate response to each. Appendix G shows a list of the respondents.

1.7 Structure of these guidelines

The introduction to these guidelines sets the scene by defining a palliative approach to care and providing information on the need for community guidelines and the intended audience. This is followed by a list of the evidence-based recommendations and GPPs developed for these community care guidelines, as well as a list of the residential care guidelines. The residential care guidelines have been included to make it easier to integrate the guidance from the two documents.

Chapter 1 explains the process of the project leading to the community recommendations.

Chapter 2 further introduces the general principles of a palliative approach to care.

Chapter 3 is about service delivery in community settings. Although it contains some references to the residential guidelines, it essentially stands alone — supporting community, as opposed to residential care. Importantly, it also addresses death in the home setting.

Chapter 4 provides guidance about best practice to support family carers. As such, it is specific to the community setting and emphasises the pivotal role of family carers when care is in the home. Often, a person's ability to remain in the community is because a family member takes on the role of primary community carer.

Chapter 5 briefly covers advance health care planning and advance health care directives. The brevity of this chapter does not mean that the topic is unimportant; however, the residential document already provides guidance in this area. This chapter applies this guidance to the community setting, and updates what has occurred since the residential guidelines were written.

Chapter 6 discusses symptom assessment and management. This topic is addressed differently from the way in which it was covered in the residential document and the two approaches are complementary. First, the residential guidelines are easily transferable to the community setting and still provide an excellent resource for health care professionals in this way. Second, the community guidelines include references and links to additional guidelines — many of which have been developed since the residential guidelines were written. In this way, health care professionals can obtain evidence-based guidelines on a large range of relevant, symptom-related topics.

Chapter 7 addresses the psychosocial issues faced in community care. This chapter complements the information provided by the residential guidelines, which still have key relevance. However, more attention is provided to issues that are important for maintaining older adults in the home setting using psychosocial approaches (particularly older adults with dementia). This chapter contains references to other relevant guidelines.

Chapter 8 addresses spiritual care in the community setting. The residential guidelines are still relevant, but are supplemented by the information in this chapter.

Chapter 9 discusses care and support for older Aboriginal and Torres Strait Islander people. Because this chapter addresses community issues, it provides information that is not covered in the residential guidelines.

Chapter 10 examines issues for older adults from culturally and linguistically diverse backgrounds that are specific to providing care in the community (although material from the residential guidelines can also apply to this group).

Chapter 11 focuses on the special needs and perspectives of a number of groups to be taken into account when providing care in the community. This chapter provides much information that relates specifically to the community context (little of this is covered in the residential guidelines).

In summary, these guidelines provide extensive advice for health care professionals providing a palliative approach to care for older adults in the community. Used together, these guidelines and the residential guidelines are a comprehensive resource.

Chapters vary in structure because of the different approach used to answer some of the research questions (see Table 1.2). All chapters contain GPPs and, where applicable, recommendations for further research. Chapter 3 (‘Delivering a palliative approach in the community setting’) and Chapter 4 (‘Family carers’) both include evidence-based guidelines developed from the literature review. These recommendations are accompanied by supporting evidence tables as required by the NHMRC. References are included at the end of each chapter.

Appendixes A–O showing further details details of processes and supporting evidence are in the accompanying volume, *Guidelines for a Palliative Approach for Aged Care in the Community Setting — Processes underpinning best practice recommendations*.

1.8 Plain-English guides

People who responded during the consultation process recommended that a plain-English version of the guidelines should accompany the main document. The authors have therefore prepared two plain-English documents. One summary is for older people receiving a palliative approach to care, and family members or friends involved in their care or support; the other is for care workers. These booklets can be obtained from the Australian

Government Department of Health and Ageing. The plain-English versions were tested in four focus groups of care workers, volunteers, older adults and family carers and revised so that all appropriate areas were covered and the booklets were easy to use and understand (see Appendix H).

1.9 Other relevant documents

As already discussed in Section 1.1, the Australian *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) — referred to as the 'residential care guidelines' throughout the remainder of this document — is a useful resource in the community setting. The recommendations from the residential care guidelines are listed on pages 25–34.

Another important Australian document about aged care that is referred to in these guidelines is *Volunteers Contributing to a Palliative Approach in Aged Care: A Model for 'Helping Out'* (DoHA 2005). This document and the residential care guidelines both provide a great deal of information that is applicable to the community setting.

Palliative Care Australia (PCA) has also produced documents to help service providers and health care professionals who provide a palliative approach to care for older adults including:

- *Standards for Providing Quality Palliative Care for all Australians* (PCA 2005)
- *Palliative Care Service Provision in Australia: A Planning Guide* (PCA 2003).

1.10 References

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Chapter 2 A palliative approach to care

The aim of a palliative approach to care for older people living in the community is to promote quality of life for those who have a life-limiting illness or who are becoming progressively frailer during old age. This type of care does not attempt to lengthen or shorten the person's life. Instead, it acknowledges that death is drawing near, although this may be many months, or even years, away. A palliative approach also recognises that a range of symptoms may need to be addressed to improve overall comfort during life and around the time of death (DoHA 2006).

Because a palliative approach to care is a holistic approach, it takes account of symptoms that are psychosocial or spiritual, as well as those that are physical. Moreover, care is provided in the context of 'family' — those who may or may not be related to the person but who provide friendship and support. The family's needs are addressed in addition to those of the older adult.

A palliative approach also takes into account the preferences of the older person who needs care, as well as how the care will be delivered. For example, the practitioner needs to consider cultural beliefs, perspectives shaped by life experiences, and how best to deliver the care in all relevant settings.

Finally, a palliative approach to care involves a multidisciplinary team (people from different disciplines working together). An aged care team, including the general practitioner, can provide a palliative approach. Specialist palliative care services are also available. Networking between the aged care team and specialist palliative care services may sometimes improve a palliative approach. Also, when physical, psychological, social or spiritual symptoms are complex, or when there are disease-specific issues, the older person may sometimes need to be referred to specialist palliative care services, irrespective of diagnosis.

Figure 2.1 shows how an aged care team can deliver a palliative care approach to the older adult and their family, within the context of the older adult's living situation and individual perspective.

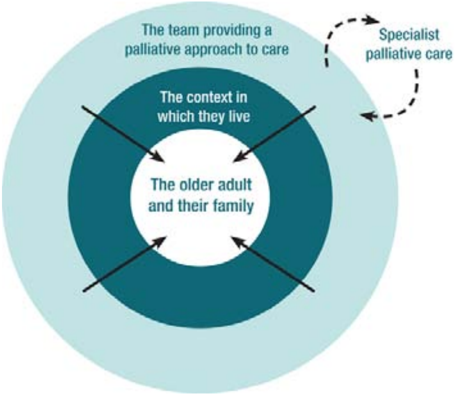
2.1 The setting for a palliative approach to care

Older people may benefit from a palliative approach to care regardless of where they live. Guidelines for providing a high-quality palliative approach to care for older people living in residential care settings (sometimes called nursing homes and hostels) are given in the *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006).

Many aspects of the residential guidelines can be applied to the community context. However, cultural and social differences or preferences need to be considered carefully before approaches to palliative care services that are used in residential care settings can be applied to people living in the community. Specifically, the residential guidelines do not apply to care provided in the following situations:

- family carer support within the older person's private home (when most care is likely to be provided by a family carer)
- service provision in the homecare setting.

These guidelines have been prepared to address these community-specific issues.



Notes: The solid arrows represent ongoing service delivery from the aged care team providing a palliative approach to care. The broken lines represent specialist palliative care services, which are available for networking with the aged care team on an intermittent basis. On occasions (not indicated in the figure), specialist palliative care services may be provided directly to the older adult.

Figure 2.1 Providing a palliative approach to care

2.2 When to provide a palliative approach to care

Older people whose care is addressed by this document are in need of high levels of care. This is because the prevalence of many diseases increases with age so many older people have more than one illness (comorbidity). Progressive diseases causing symptoms that are likely to interfere substantially with life in this age group include:

- cancer
- organ or system failure (eg chronic heart failure, chronic obstructive pulmonary disease)
- neurological conditions (the most common are those that cause dementia).

Older people are also more likely to have deteriorating senses (such as sight or hearing) caused by ageing.

Current practice guidelines suggest that palliative care should be introduced gradually as life-limiting disease progresses (Schofield et al 2006). Therefore, a palliative approach can be explained when it becomes clear that a cure for a life-limiting disease is not an option, or when a person becomes so frail that death will be the outcome. At this time, advance health care plans can be discussed, and the person and their family can be told about the holistic, palliative approach to symptom management that is available.

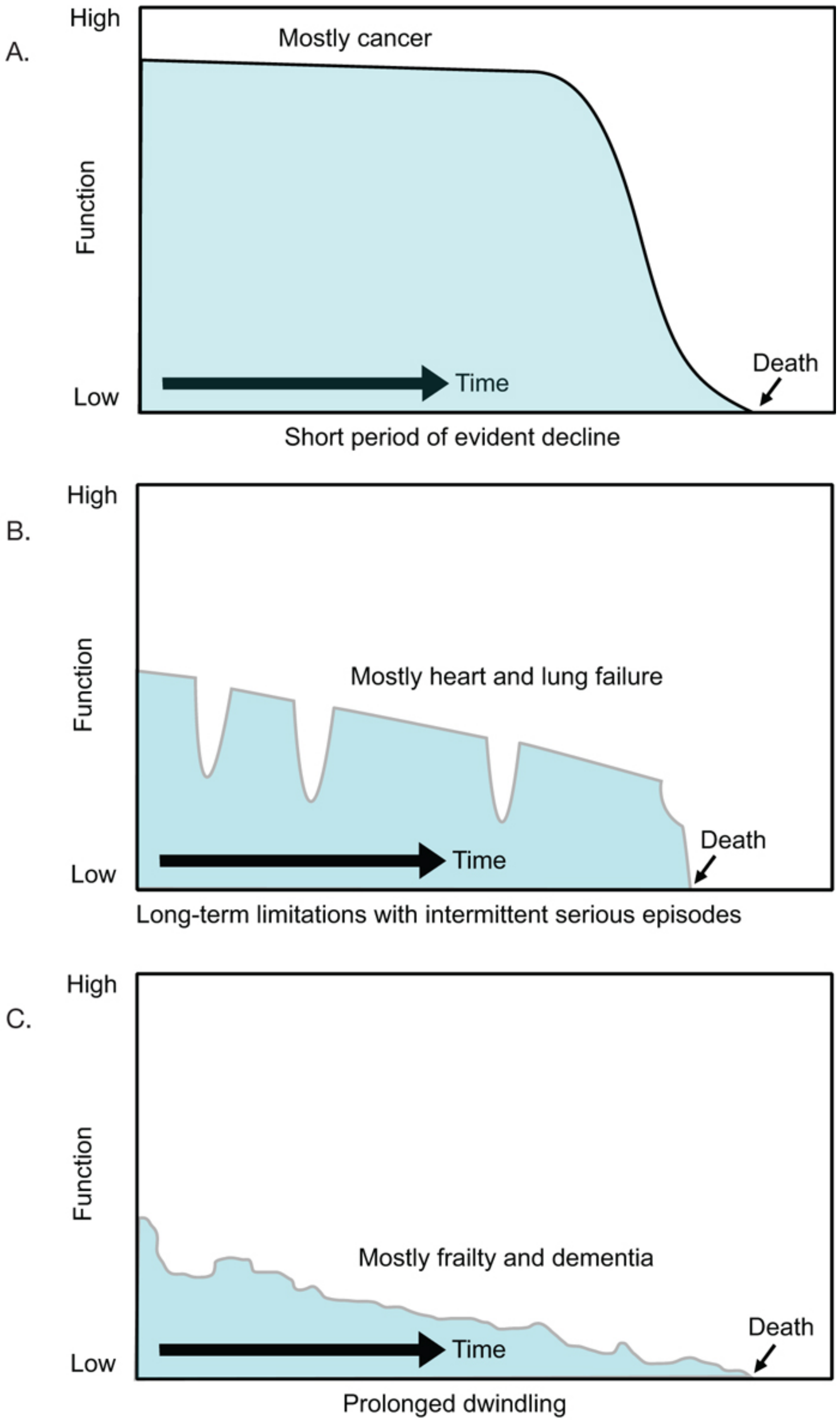
Clearly, telling older people and their families about a palliative approach to care requires sensitivity and an understanding of each person’s needs and preferences. Guidelines for communicating about end-of-life issues can be particularly helpful in these situations (Girgis et al 2006). Australian guidelines that address this issue have been prepared by Clayton et al (2007).

Understanding three main pathways of illness is helpful for older people and their families when they are discussing and making decisions about end-of-life care and whether to adopt a palliative approach. The three pathways are shown in Figure 2.2 and are explained below:

- **Cancer** often causes a clear and sudden deterioration in a person's physical health in the last weeks of life (see Graph A). People can also experience changes in their psychological symptoms before their physical health deteriorates. Spiritual symptoms may also be a concern throughout the illness. However, even in cancer care, it is difficult to predict how quickly the disease will progress (Lamont and Christakis 1999). In addition, comorbid illnesses, which can make a difference to the cancer pathway, are common in older people. Generally speaking, psychosocial and spiritual aspects of a palliative approach are the most important for older people with cancer in the earlier stages of the disease, with greatly increased physical needs in the last week of life.

- In **organ system failure** (eg chronic heart failure; see Graph B), the person's health deteriorates more gently, but is interrupted at times when symptoms flare up temporarily. Death may seem near many times before it occurs, and the person may be admitted into an acute care setting more and more frequently. For this group of people, introducing a palliative approach to care may be delayed because of fragmented care between acute and community settings. It is also difficult to predict the course of the illness accurately (Fox et al 1999), particularly when the person also has comorbid illnesses. However, introducing the option of a palliative approach sooner rather than later means that the person can have some input into a care plan that could help to minimise some of the discomfort caused by being admitted to hospital numerous times.

- In **advanced dementia or frailty**, the person's health declines gently over a long period (see Graph C). Knowing exactly when death will occur is difficult, although there are some signs, such as nutritional status (Olson 2003). Families may acknowledge that the person's health is fragile, but they may not fully understand how close they are to dying, or the fact that a sudden, concurrent illness may shorten the person's life. When a palliative approach to care is adopted sooner rather than later, the health of the older adult can be clarified and support can be provided accordingly; a proactive approach to ensuring quality of life for the older adult then becomes more likely (Olson 2003).



Source: Lynn and Adamson 2003

Figure 2.2 General trajectories of function and wellbeing over time in eventually fatal chronic illnesses

Showing these three pathways of illness as graphs is useful for developing potential scenarios for older adults. However, everyone experiences illness differently, making it impossible to predict exactly how a disease will progress. Therefore, for older people who have a life-limiting illness or who are becoming frailer, the decision to start using a palliative approach to care should be based on the person’s individual needs. In general, a palliative approach to care is appropriate when there is a need to:

- address disease symptoms
- provide psychosocial or emotional support because of the person’s deteriorating health
- provide family carer support during the disease progression or after the older adult has died (bereavement support).

In summary, a palliative approach to care for older adults in the community involves both the physical and mental health of these older adults, and also provides support for their family. The approach aims to improve quality of life as much as possible when the person’s health starts to deteriorate, including during the dying period. Family support continues in bereavement.

A palliative approach to care should be made available during the early stages of illness, and afterwards, on a needs basis. People should also be made aware of the possible benefits of specialist palliative care services. These guidelines are a resource for the team of health care professionals involved in providing such an approach.

2.3 Good practice points — a palliative approach to care

Identifying needs

It is important to take into account the individual needs of the older person and their family or carer when introducing a palliative approach to care (see Section 2.1).

2.1 Introduce a palliative approach to care on a case-by-case basis, according to the person’s specific needs and preferences. Each older person will have different needs when living with deteriorating health so it is not possible to determine a fixed point at which a palliative approach should begin for all people. When a need emerges, addressing that need is appropriate and palliative measures may only be needed intermittently in some instances. Relevant needs are for symptom management and psychosocial or emotional support; they also include needs for support of family members or friends when they are providing care or in bereavement.

2.2 Remember the family’s needs, including those during bereavement. Although part of the rationale for supporting the family is to allow ongoing home care for the older adult to continue, a palliative approach to care also recognises that families need support for their own health care. A palliative approach to care should also consider the family’s needs after the death of the older person, as well as when they are providing care. The needs of family who provide long-distance care (eg phone support) should also be considered.

2.3 Remember that ‘family’ includes people who provide friendship to the older adult. Providing care for a friend may mean that their illness and death cause distress. Therefore, needs of friends, including volunteers and care workers, should be considered.

Discussing a palliative approach to care

It is important to discuss a palliative approach to care with the older adult and all those involved in their care early in the palliative care process (see Section 2.2).

2.4 Introduce discussion about a palliative approach soon after it is known that an older adult has a life-limiting illness or is becoming progressively more frail. Knowing that there are active options to promote quality of life may provide comfort. Having time to consider and discuss possible choices also empowers the older adult.

2.5 Improve the quality of the discussion by following relevant guidelines (eg Clayton et al 2007). A sensitive approach will minimise distress and focus on the positive aspects of such a discussion.

Collaborating with other professionals

Working with specialist palliative care services and using resources that are available can improve the quality of palliative care (see the introduction to this chapter and Figure 2.1).

2.6 Collaborate with specialist palliative care services. Although the aged care team will have many skills, there may be times when a specialist's input is needed as well, to address physical, psychological, social or spiritual symptoms, as well as symptom or disease-specific issues. An ongoing collaborative relationship with specialist palliative care services will facilitate this input.

2.7 Access useful resources from Palliative Care Australia (http://pallcare.org.au).

2.4 References

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Chapter 3 Delivering a palliative approach in the community setting

Community aged care is central to Australia's health and welfare system (DoHA 2003). Demand for this type of care for older people who live in their own homes, including in retirement villages or with friends and relatives, has increased in recent years and, at the same time, the ways in which it is provided have improved. Older, chronically ill and frail people who wish to remain in their own homes have benefited from these improvements (Gibson and Mathur 1999, DoHA 2003, Thomas et al 2007). Delivering a palliative approach to care for these people may involve multiple agencies and health care professionals. Therefore, seamless and efficient care delivery requires a collaborative approach that is well coordinated. Higher quality care delivery is associated with improved survival among vulnerable adults who live in community settings (Higashi et al 2005) and may improve their quality of life. Chapter 2 provided details of a person-centred, needs-based approach to palliative care; this chapter addresses the pivotal importance of deciding on the best way to provide a palliative approach to care for older adults in the community. Topics covered in the chapter are:

- how care is provided
- evidence of how effective particular types of care delivery are
- how other aspects of care provision may help improve quality of life.

3.1 Providing care

This section explains four key models of providing care:

- case-management model
- integrated care model
- consumer-directed care model
- specialist palliative care model.

Strategies for providing short-term care, staffing matters and the use of volunteer support are also discussed. Finally, end-of-life care for older adults in the community is described. Appendix I provides the details of reviewed studies.

3.1.1 Case-management model

The case-management model of care (also known as the care-coordinator model) is used increasingly in Australia and other Western nations (Krout 1997, Wells et al 1999, Evans et al 2005, Bierlein et al 2006). Within Australia, this model is often used to provide care for older adults; for example, when providing a community aged-care package.

Case management is a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes (CMSA 2004, p 6).

The model involves a case manager or coordinator who provides a single point of contact and coordinates the team and services involved in the care and support of the older person and their family (Diwan et al 2004). In this way, complex care from a range of providers (eg nurses, physicians, pastoral care workers, volunteers) may be supported.

Poor communication among the multidisciplinary team overall can decrease the effectiveness of health care delivery. Case conferences may assist in effective communication and are likely to be of crucial importance when older adults have complex care needs (Hegney et al 2003).

Australian research findings have suggested that nurses are perhaps the most likely health professionals to produce holistic care plans (Hegney et al 2003) so they may be best suited for coordinating a palliative approach to care. Any team member can successfully take on the role of care coordinator — and staff members with allied health, social service or community service qualifications often do this. However, they should:

- understand and incorporate the needs and preferences of the older person and their family carer(s)
- be able to access all relevant local health, social and volunteering services.

Several studies report barriers to providing effective case management. Evans et al (2005) found that a lack of time was one reason why practice nurses in the United Kingdom did not incorporate case-management care readily into their practice. Krout (1997) looked at older adults in rural North America, and found that, for this population, the cost of case-management services and a lack of standards made this approach difficult. Limited availability of suitably qualified staff and minimal opportunities for staff education and training were also issues (Krout 1997). A similar study by Kelley and MacLean (1997) in a Canadian rural setting also found that rural case managers were often required to provide direct care because of a lack of suitably prepared staff, leaving them less time for the case-management role.

3.1.2 Integrated care model

The integrated care model can overcome the problem of fragmented care (Kodner and Kyriacou 2000). At least two versions of the model are being used in North America:

- the coordination model, used in Canada by the Programme of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) (Kodner 2006)
- the fully integrated care model, used in the Program of All-inclusive Care for the Elderly (PACE) (Kodner and Kyriacou 2000).

The coordination model is used for frail, elderly people who are receiving both health and social services. The model aims to minimise miscommunication and confusion by promoting coordinated information sharing among health care professionals across time, place and discipline. Features of the model include standardised guidelines, joint planning and common clinical records (Kodner and Kyriacou 2000). The Canadian program, PRISMA, aims to help older people with moderate to severe disability to maintain their independence. It has a joint governing board and service coordination committee, an integrated information system, and clinical and service coordination delivered via a team of case managers (Kodner 2006).

The fully integrated model involves developing whole new programs. These programs are run in separate organisations to manage the care of people with complex needs, but are overseen by a unified service network. Common ownership and management may be involved or there may be contractual relationships (Kodner and Kyriacou 2000). An example of this model is PACE, which has been incorporated into the United States health care system after a pilot version of the program was evaluated (Kodner and Kyriacou 2000). Only people who are older than 55 years and are disabled can enrol. Acute and long-term services are provided at adult day health centres by an interdisciplinary team that uses the principles of geriatric medicine. Comprehensive and common assessment tools are used and planning is collaborative. The rate of home deaths (rather than deaths in inpatient settings) for frail, older adults enrolled in PACE is 45%, which is approximately double the rate in the whole United States population (Temkin-Greener et al 2006).

3.1.3 Consumer-directed care model

Consumer-directed care allows people to organise and direct their own care by using cash or vouchers to purchase the health services they want (Glickman et al 1997, Benjamin and Matthias 2001). A key objective of this model is to improve the flexibility of the community care system and allocate resources efficiently. The model recognises that the consumer is the best person to choose which services will be most useful for them. Therefore, they can choose their care on their own, or they can ask for guidance to make the decisions. In a modified case-management approach, case coordinators monitor the decisions that people make when choosing care (Benjamin and Matthias 2001). However, employing a case coordinator increases the cost of consumer-directed care (Glickman et al 1997).

In a North American study of 833 home care clients, one-quarter identified that they would be happy to take greater responsibility for directing their own care, and one-third reported needing less help than they currently had from a case manager (Glickman et al 1997). However, older people may face huge obstacles when navigating their way through the community health system and further hurdles in managing their own supportive services (Benjamin and Matthias 2001). Therefore, consumer-directed care may be inappropriate or undesirable for many older adults, particularly those with complex care needs or cognitive impairment (Benjamin and Matthias 2001).

3.1.4 Specialist palliative care model

Specialist palliative care provides specialised care and practical support for people living with a life-limiting illness in all settings (the home, residential care, hospital or hospice). Traditionally, this model focused on caring for people with cancer (Kite et al 1999), but people with other, life-limiting conditions may also benefit (McNamara and Rosenwax 2007). However, the model is designed for short and rapid periods of worsening health, and decreasing independence before death (Kite et al 1999). When care needs extend over longer periods in older people with life-limiting conditions, the most appropriate roles for specialist palliative care providers may be as consultants to aged care service providers (Kite et al 1999, Evers et al 2002) or as providers of (or advisors on) staff training (Higginson et al 1998). Specialist palliative care services are particularly useful for providing advice on (Higginson et al 1998, Addington-Hall and Altmann 2000):

- complex issues relating to the detection and management of symptoms

- spiritual, psychological, and social issues related to end-of-life care.

In this way, specialist palliative care services can be an exceptional resource for aged care providers who provide a palliative approach to care.

3.1.5 Short-term care

Two types of short-term care arrangements are considered here: transitional care and crisis care.

Transitional care

Transitional care is a term given to 'a range of services and environments designed to promote the safe and timely transfer of patients from levels of care or across settings' (Naylor 2006, p 48). The quality of transitional care is particularly important for vulnerable older adults because they may need to be admitted to hospital and respite care multiple times and may eventually be admitted into residential aged care.

One example of a transitional care program in Australia is the program run by the Aged Care and Housing Group.
See http://www.ach.org.au/ (Health and community services>Health services)

High-quality transitional care depends on good communication among the community, residential and inpatient health care sectors and other health services (Thomas et al 2007), as well as good planning when the person is discharged from acute or emergency care. An Australian study (Hegney et al 2002) looked at what happens when someone is discharged from acute care, and identified the following issues that significantly affected the quality of care:

- poor organisation of postdischarge community health services before the person was discharged
- poor follow-up after discharge
- lack of information to guide appropriate follow-up care.

The goal of postacute transitional care is to ensure continuity of care from one stage to the next (that is, from hospital discharge to being cared for at home or in a residential facility). Strategies for helping this transition include using a case manager (ideally a nurse) to plan the discharge and organise assessments and referrals to appropriate services (Hegney et al 2003); and following policies on discharge planning that recognise how well the older person can care for themselves, and the skills and coping abilities of their family carers (Clark et al 1997). Also, general practitioners (GPs) can be involved more in the discharge-planning process by including them in case conferences (Hegney et al 2002, 2003).

Crisis care

Crisis care is care provided in emergency situations, such as after hours medical, nursing or pharmaceutical support in the home. Specialist palliative care services, such as home hospice, will sometimes include this kind of care as routine. A palliative approach to care for older adults can be supplemented by crisis care, as needed, if the relevant resources are available.

Malmberg et al (2003) described an example of crisis care in Sweden that included 'night patrols' — night visits available to older adults in need of extra care at any particular time. Staff reported that this approach appeared to increase the number of older adults who were able to stay at home.

Crisis care can be improved using technology, such as a personal emergency response system (a 24-hour monitoring device that people can activate when they need emergency help), or 24-hour phone or video phone access to services. A variety of medical monitoring devices, and some other devices (for example, those detecting falls) have also been found to be acceptable by older adults (Mann et al 2001).

3.1.6 Staffing matters

In all these models and approaches to care delivery, a multidisciplinary team is generally needed to provide a holistic, palliative approach to care for older adults. Multidisciplinary teams can have significant advantages because of the combined expertise of members. However, all members of the team need to make sure they communicate well with each other, share tasks, and take into account the different perspectives of team members and the older adults themselves (Cowan et al 2003).

The GP may be responsible for choosing to adopt a palliative approach to care. Traditionally, GPs have an ongoing relationship with their patients and have therefore been able to initiate discussions about end-of-life care with them at an early stage, and learn about their preferences (Good et al 2004).

Other team members usually include nurses, care workers and allied health professionals. Pastoral care workers, complementary therapists and volunteers may also be involved. Additional specialist care may be provided by geriatricians, old-age psychiatrists and mental health nurses, as well as specialist palliative care services and other specialists, such as wound care consultants. Community pharmacists can also be active members of the multidisciplinary team by working with GPs to review the older person's medications (Lane et al 2004). Medication reviews can address issues such as polypharmacy (taking many different medications) and compliance (following medication instructions correctly) — issues that are particularly important for people who have cognitive or other functional limitations (Cheah and Martens 2003).

Lack of education for home care providers is a barrier to providing high-quality services (Thomas et al 2007). Education on how to relieve symptoms (Malmberg et al 2003), as well as how to make ethical decisions or develop emotional skills for end-of-life care (Davidson et al 2004) may therefore improve care. Scope of practice issues and occupational health and safety regulations also need to be understood within the context of the community environment (Thomas et al 2007).

Palliative Care Australia provides education on a palliative approach to care.
See http://wwwpalliativecare.org.au

Members of the care team may need support when an older adult, for whom they provide care, dies. Responses are highly individual, but strategies for providing bereavement support may include counselling, support groups, debriefing, and stress management education and training. Allowing staff to attend memorial or funeral services also gives them an opportunity to say ‘goodbye’ (DoHA 2006).

3.1.7 Volunteer support

Volunteers are an important part of the multidisciplinary team (DoHA 2005). They can offer many services, including:

- companionship
- counselling
- transportation
- home help.

Volunteers also benefit from the chance to contribute to, and be involved in, their community. Volunteering is associated with better physical and psychological health and greater levels of life satisfaction (Omoto et al 2000).

Including volunteers in the aged care team requires appropriate support, supervision and coordination (DoHA 2006). Ideally, a volunteer coordinator is responsible for recruitment, training, placement, ongoing support, supervision and liaising with other members of the aged care team (DoHA 2006). Also, the following strategies help to make sure full benefits are gained from using the help of volunteers:

- selecting candidates for specific roles (Kovacs and Black 1997)
- clearly differentiating the roles of staff and volunteers (Addington-Hall and Karlsen 2005)
- clearly defining the volunteer role (Kovacs and Black 1997)
- clarifying perceived expectations and boundaries (Hoad 2002, Finkelstein et al 2005).

Want more information?

- Australian Government Department of Health and Ageing (2005).*Volunteers Contributing to a Palliative Approach in Aged Care: A Model for ‘Helping Out’*, prepared by Edith Cowan University, Western Australia for the Chronic Disease and Palliative Care Branch, DoHA, Canberra. Available from the CareSearch website at http://www.caresearch.com.au
- The Victorian Government provides useful resources related to volunteers and the provision of palliative care at http://www.health.vic.gov.au/ (Health sector information>Palliative care).
- Volunteering Australia also provides useful information on its website at http://www.volunteeringaustralia.org/

Volunteers may be exposed to demanding and emotionally exhausting relationships, particularly when an older adult dies (Payne 2001). Support strategies therefore need to take account of the role as well as the background of each volunteer.

Given the extreme vulnerability of the older adults for whom care is being provided, the care team needs to pay careful attention to the policies, protocols and standards set by community organisations who take on volunteers (DoHA 2006). The team should also follow all relevant legislative requirements (DoHA 2005). Organisations such as Volunteering Australia provide useful information and advice on using the help of volunteers.

3.1.8 End-of-life care in the community

Providing good palliative care in the home without the help of a family or a carer is difficult. Therefore, people who live alone are much more likely to die in a hospital, aged care facility or other institution (Grande et al 2003, Jakobsson et al 2006). When there is a family carer, early discussions about the preferred location of death may help to make sure that adequate support is provided. However, when people are dying with dementia (eg caused by Alzheimer’s disease), recognition of the life-limiting nature of the disease and when it is reaching its final stages can be limited (Mitchell et al 2004). Also, a recent study of people with heart failure (Haydar et al 2004) found that treatments for people with advanced disease may be given more prominence than planning for symptom relief and end-of-life care when treatment becomes futile.

Care that addresses the older person’s end-of-life needs in the community setting needs to take into account the following points:

- communication about end-of-life care is critical (both between the care team and the older person and their family, and within the care team)
- symptom management is also a major concern, especially for:
    - pain (McCarthy et al 2000, Potter et al 2003)
    - dyspnoea (Peruselli et al 1999, Potter et al 2003)
    - fatigue
    - anxiety
    - depression (Peruselli et al 1999).

Satisfaction with symptom management is an important component of quality of care and contributes to quality of life (Steele et al 2002).

Practical matters (such as sourcing suitable equipment or organising home modifications) are also important and can be problematic. For example, an Italian study of more than 400 palliative home care patients found that 30% experienced severe problems with practical management (Peruselli et al 1999).

Good practice points for managing end-of-life care and death within the community setting are provided in Section 3.5.

Information on assessing and managing symptoms is given in Chapter 6.

3.2 Assessing the effectiveness of care programs

This section presents the evidence for the effectiveness of postacute transitional care and crisis care programs for older adults in a community setting. The evidence is based on a systematic review of the literature, the full details of which are provided in Appendix A. The literature review was based on the following specific research questions:

- Does the implementation of a postacute transitional care program lead to improved physical and/or psychological health of the older person or their family carer?
- Does a model of care that includes 24-hour crisis care (access to after hours medical, nursing and pharmaceutical support) improve physical and/or psychological health in older people and/or family carers as compared with a model of care that does not include this crisis care?

These questions were used to identify key words to guide the search, as well as to develop criteria for including or excluding the studies identified by the searches in the review.

Evidence-based guidelines were developed from the findings of the included studies. Summary tables of the methods and results of these studies are shown at the end of this chapter. Excluded studies are shown in Appendix C with reasons for their exclusion. Data-extraction forms for the included studies are shown in Appendix D. Evidence matrixes, based on the National Health and Medical Research Council (NHMRC) levels and grades of evidence (NHMRC 2007) are provided below for each type of care. Appendix E contains full summary forms for evidence decisions.

3.2.1 Postacute transitional care programs

Postacute transitional care programs:

- are run either from the hospital or in the community
- aim to maintain the older person’s health in the community after they are discharged from acute hospital care, including from the emergency department.

The authors of this document did not view hospital in the home programs or similar programs designed to facilitate *early* discharge as postacute transitional care, because they provide acute care in the home, rather than improve care after discharge. Similarly, geriatric assessment or support from pharmacists after discharge were not counted as transitional care programs if they were used on their own. However, they were reviewed as potential components of a transitional care program.

Systematic review

Table 3.1 shows the research question and inclusion criteria for the effectiveness of postacute transitional care.

Table 3.1 Review of the effectiveness of postacute transitional care

Research question	
Does the implementation of a postacute transitional care program lead to improved physical and/or psychological health of the older person or their family carer?	
Selection criteria	**Inclusion criteria**
Population	Community-dwelling older adults in need of a palliative approach to care and their family carers
Intervention	A postacute transitional care program
Comparator	Any
Outcome	Any aspects of physical or psychological health, including hospitalisation and time-to-residential-placement
Study design	Systematic reviews, randomised controlled trials, pseudo randomised controlled trials, nonrandomised controlled trials, prospective cohort studies (at least 200 participants and relevant question set a priori)
Search period	1997–2007
Language	English

Nineteen primary studies and 11 systematic reviews were included for the question about transitional care (see Appendix B). Most study findings were generalisable to the target population and setting, and applicable for Australian conditions. Evidence statements are shown below for postacute transitional care in the community setting for older people with the following conditions:[1]

- severe chronic heart failure
- advanced frailty or disability due to stroke
- other specific conditions (such as moderate or severe dementia, and advanced cancer)
- generally frail or unwell.[2]

Evidence-grading matrixes are shown in Table 3.2. Tables 3.5–3.12 (which are presented together at the end of this chapter) show a summary of the methods and results of the included studies. In these tables, systematic reviews are shown in italics for ease of reference.

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[1] For further definition of these conditions, see Appendix A (Section A.3).

[2] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

Evidence statements

Postacute transitional care for older adults with severe chronic heart failure

- There is level I and II evidence relating to the effect of postacute transitional care on quality of life for older adults with severe chronic heart failure. The results of some individual studies and systematic reviews showed that care improved quality of life. However, on balance, the studies have not consistently shown a significant improvement in quality of life. More studies are therefore needed before the effects, if any, of postacute transitional care programs on quality of life for this group of older adults are known.

- There is level I and II evidence relating to the effect of postacute transitional care programs on hospital re-admission for older adults with severe chronic heart failure. On balance, the results showed that postacute transitional care reduced re-admissions. This reduction was large enough to be clinically significant and successful programs generally included an education component, as well as other forms of support.

- No studies were identified relating to the effect of postacute transitional care programs on residential care placement for older adults with severe chronic heart failure.

- There is level I and II evidence relating to the effect of postacute transitional care programs on mortality for older adults with severe chronic heart failure. On balance, the results showed that this type of care did not produce a statistically significant effect on mortality (although some individual studies and systematic reviews showed an effect). The sample sizes of these studies may have been too small to show a statistically significant effect for this outcome.

- No studies were identified relating to the effect of postacute transitional care programs on any outcomes for carers of older people with severe chronic heart failure.

Details of the included studies are given in Table 3.5 and 3.6.

Postacute transitional care for older adults with advanced frailty or disability due to stroke

- There is some level II evidence relating to the effect of postacute transitional care programs on a variety of health-related outcomes for older adults who have advanced frailty or disability due to a stroke. The outcomes studied include function, depression, anxiety, mastery (feeling capable and in control) and perceived health. However, the studies had a moderate risk of bias and results were inconsistent. More studies are needed before the effects (if any) of postacute transitional care programs on health outcomes for this group of older adults are known.

- There is level I and level II evidence relating to the effect of postacute transitional care programs on a variety of family carer health outcomes when these carers are providing care for older adults affected by stroke. The outcomes studied include energy, mental health, pain, function, health perception (that is, how healthy they feel), coping, confidence, depression, sense of burden, social functioning and quality of life. However, the studies had a moderate risk of bias (although the only review that was included had a low risk of bias) and the findings were inconsistent. More studies are needed before the effects (if any) of postacute transitional care programs on family carer health outcomes for this group of older adults are known.

Details of the included studies are given in Tables 3.7 and 3.8.

Postacute transitional care for older adults with other specific diseases

- No studies were identified that examined outcomes of postacute transitional care for older adults with advanced cancer, moderate or severe dementia or other diseases identified by the reviewers as common in the population of interest (and not previously mentioned in this section), or their carers.

Postacute transitional care for generally frail or unwell older adults

- There is level I and level II evidence relating to the effect of postacute transitional care programs on quality of life for generally frail or unwell older adults. The studies had a moderate risk of bias but the results almost entirely consistently showed no effect.

- There is level I and level II evidence relating to the effect of postacute transitional care on hospital re-admission for generally frail or unwell older adults. Although these studies had a low risk of bias, the results were inconsistent. More research is needed before the effect (if any) of this type of care on re-admissions for this group of older adults is known.

- There is level I/III-2[3] evidence relating to the effect of postacute transitional care on residential-care placement for generally frail or unwell older adults. The reviews had a low risk of bias and the results showed, on balance, a clinically meaningful benefit.

- There is level I/III-2 evidence of the effect of postacute transitional care on mortality in generally frail or unwell older adults. These studies had a low risk of bias and the results consistently showed no effect.

- No studies were identified for the effect of postacute transitional care on any outcomes for carers of generally frail or unwell older adults.

Further details of the included studies are included in Tables 3.9 and 3.10.

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[3] The designation level I/III-2 has been given to systematic reviews that include some level III-2 studies in addition to level II studies.

Table 3.2 Evidence matrix for postacute transitional care

(a) Severe chronic heart failure[a]

Outcome	Component	Rating	Description
Quality of life	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around question
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Hospital re-admissions	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	B	Most studies consistent and inconsistency can be explained
	Clinical impact	A/B	Very large/moderate
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Mortality	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around question
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context

(b) Advanced frailty or disability due to a stroke[b]

Population	Component	Rating	Description
Older adults	Evidence base	C	Level III studies with low risk of bias or level I or II studies with a moderate risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around question
	Clinical impact	n/a	–

	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Family carers	Evidence base	B	One or two level II studies with low risk or bias, or SR/multiple level II studies with low risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around question
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context

(c) Generally frail or unwell [a]

Outcome	**Component**	**Rating**	**Description**
Quality of life	Evidence base	C	Level III studies with low risk of bias, or level I or II studies with moderate risk of bias
	Consistency	A	All studies consistent
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Hospital re-admissions	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around question
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Residential care placement	Evidence base	B	One or two level II studies with low risk or bias, or SR/multiple level II studies with low risk of bias
	Consistency	B	Most studies consistent and inconsistency can be explained

	Clinical impact	B	Moderate
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Mortality	Evidence base	B	One or two level II studies with low risk or bias, or SR/multiple level II studies with low risk of bias
	Consistency	A	All studies consistent
	Clinical impact	n/a	–
	Generalisability	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context

n/a = not applicable; SR = systematic review

a No studies were identified for family carers

b For stroke, outcomes are combined

Evidence-based guidelines

Guideline 3.1 Postacute transitional care	Grade
Chronic heart failure Postacute transitional care programs, comprising education and support, should be implemented routinely when older adults with severe chronic heart failure are discharged from hospital into the community.	A
Stroke There is currently insufficient evidence to recommend either implementing or not implementing postacute transitional care programs for older adults who have advanced frailty or disability due to stroke.	n/a
Other specific conditions There is currently insufficient evidence to recommend either implementing or not implementing postacute transitional care programs for older adults with other specific conditions such as moderate or severe dementia or advanced cancer.	n/a
Nonspecific conditions Postacute transitional care programs should be used routinely to support discharging generally frail or unwell older adults[a] from hospital into the community.	C

n/a = not applicable

a This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

3.2.2 Crisis care programs

Crisis care is access to after hours medical, nursing or pharmaceutical support in the home. Crisis care is an increase in access to care that is generally expected to be available in the community setting. It does not include hospital-in-the-home, which is an alternative way of delivering hospital care.

Systematic review

Table 3.3 shows the research question addressed and the inclusion criteria.

Two primary studies and two systematic reviews were included (see Appendix B). Most study results were generalisable to the target population and setting, and applicable for Australian conditions. Evidence statements are shown below for crisis care for older people in the community setting. Outcomes are considered separately for the older person and for their family carer, rather than being grouped according to illness (the results of crisis care are unlikely to depend on what illness is present). Evidence matrixes are shown in Table 3.4. Tables 3.11–3.12 (which are presented together at the end of this chapter) show a summary of the methods and results of the included studies.

Table 3.3 Review of the effectiveness of crisis care

Research question	
Does a model of care that includes 24-hour crisis care (access to after hours medical, nursing or pharmaceutical support) improve physical and/or psychological health in older people or family carers, compared with a model of care that does not include this crisis care?	
Selection criteria	**Inclusion criteria**
Population	Community-dwelling older adults in need of a palliative approach to care and their family carers
Intervention	Crisis care
Comparator	Any
Outcome	Any aspects of physical or psychological health including hospitalisation
Study design	Systematic review, randomised controlled trials, pseudorandomised controlled trials, nonrandomised controlled trials, prospective cohort studies (at least 200 participants and relevant question set a priori)
Search period	1997–2007
Language	English

Evidence statements

Older adults

There is level I/III-2 and level II evidence relating to the effect of crisis care on health-related outcomes of older adults. The outcomes included hospitalisation, days in hospital and health-related quality of life. Almost all the studies reported benefits and the level II studies had a low risk of bias. However, in all the primary studies that were reviewed, crisis care was embedded in other care programs. On balance, the results showed that services, including access to crisis care, improved the health-related outcomes of older adults in a clinically meaningful way.

Family carers

There was only one level II study of the effect of crisis care on health-related quality of life for family carers. The study had a low risk of bias but crisis care was embedded in a broader care program (veterans' affairs) and the results were not clear enough to see whether crisis care on its own made a difference for family carers. However, the overall care program (with crisis care as a component) improved health-related outcomes for the family carer in a clinically meaningful way.

Table 3.4 Evidence matrix for crisis care

Population	Component	Rating	Description
Older adults	Evidence base	B	One or two level II studies with low risk of bias or SR/multiple level III studies with low risk of bias
	Consistency	B	Most studies consistent and inconsistency can be explained
	Clinical	C	Slight
	Generalisabilit	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context
Family carers	Evidence base	B	One or two level II studies with low risk of bias or SR/multiple level III studies with low risk of bias
	Consistency	n/a	–
	Clinical	C	Slight
	Generalisabilit	A	Evidence directly generalisable to target population
	Applicability	A	Evidence directly applicable to Australian healthcare context

n/a = not applicable; SR = systematic review

Evidence-based guideline

Guideline 3.2 Crisis care	**Grade**
When implementing community-based health care services for older adults with specific or nonspecific life-limiting illness, frailty or extreme old age, access to crisis care should be included.	C

3.3 Using other tools to improve palliative care

Many people prefer to be given end-of-life care within their home. However, this is not always the best option and may not be possible for people who live alone and need constant care. An Australian study reported that cancer patients receiving home-based palliative care, as opposed to care in inpatient palliative care units, reported better control over the effects of their illness, which, in turn, led to an improvement in their quality of life (Peters and Sellick 2006). In the United States, the Comprehensive, Adaptable, Life-Affirming, Longitudinal (CALL) Palliative Care Project was set up in response to a national survey that showed 70% of people wanted to die at home. Despite this, only 25% of all deaths in the United States occurred in the home. The CALL project addressed the home care needs of people with a variety of health issues, including cancer, chronic heart failure, respiratory disease and dementia. The project increased the rate of home deaths to 38% of people who were enrolled (London et al 2005). The participants would generally not have met criteria for United States hospice care at the time of entry. Therefore, the project provided a palliative approach to care in the community.

This section looks at the support that the older adult can access within the home as their health deteriorates, especially the support that they might need if they would prefer to die at home rather than in a hospital or other institutional setting. Three main areas have the potential to contribute to a home-based palliative approach for older adults in Australia:

- the use of technology in the home
- home visits from pharmacists
- educating staff in end-of-life care.

Educating those who provide care is likely to have the broadest impact on the quality of care provision, and using new, more efficient strategies for providing this care is important. This section does not provide evidence-based guidelines; instead, it gives examples of ways to improve care and its delivery. Appendix J gives the details of studies used for this section.

3.3.1 Technology

Older people can use technological devices to obtain support and care outside normal working hours. Technology can also help them to arrange support in their home — an important feature for people who are physically disabled. Staff members can use technology to find information and to provide support.

Telephone support

Health care professionals often use the telephone to improve the way in which they provide care in the home. The telephone can be used for counselling and education; and to extend the older person's social networks, to check on them, or to remind them to follow their treatments. During end-of-life care, the telephone is particularly important for providing 24-hour support.

After hours home support is particularly important for helping older people, their families or members of the care team to use new or unfamiliar technical equipment. A study from the Netherlands (Elfrink et al 2002) looked at people with cancer who had been discharged from hospital and how they used an after hours telephone support service for technical equipment. Over a three-year period, 157 calls were received from 52% of the participants. GPs and nurses also used the number. A nurse answered the phone and was able to solve people's problems 38% of the time without further help, and a further 52% of the time after consulting a specialist. Unsolved problems were likely to have resulted in transfer to hospital. Although this study did not involve older adults only (the average age was 54 years), the results show that using a similar telephone service for older adults is worth researching further.

Telephone consultations

A number of studies have looked at ways of passing on relevant data for telephone consultations. Because transmitting data can be more complex for people who are frail, disabled or very unwell, only studies that included older adults who were frail or unwell are described.

A small study of older adults in Italy included 20 people with severe chronic obstructive pulmonary disease (COPD) (average age 73 years) and two people with severe restrictive lung disease (average age 66 years) (Maiolo et al 2003). Both groups were given an initial 12 months of usual care (face-to-face visits), followed by 12 months of home monitoring. The equipment monitored night-time oxygen levels in participants' arteries and their heart rate during sleep via a clip on one finger and the data recorded were transmitted to a central point. Patients were also contacted by telephone twice a week while their data were being reviewed. Face-to-face clinic visits happened three times a month. Approximately 96% of the participants said they were satisfied with the monitoring. The number of hospital admissions was significantly lower in the second year for the COPD patients and the restrictive disease patients. Numbers of acute exacerbations were also lower for the COPD patients.

A study from the United States looked at older adults (average age 71 years) with complex comorbidities (Noel et al 2004). Participants were veterans who had chronic heart failure, COPD or diabetes mellitus. The control group (*n*=57) received usual care plus nurse case management, while the group that received the intervention (*n*=47) received telephone consultations plus nurse case management. All but three participants were men. For the intervention group, data were transmitted over the telephone. These data included temperature, blood pressure, pulse, blood glucose, electrocardiogram, heart and lung sounds, blood oxygen content, weight and levels of pain. Digital pictures of wounds were also transmitted. The intervention group had a lower number of days spent in a hospital bed, as well as fewer urgent hospital visits, and an improvement in mental function. Despite this, only people in the control group reported that they were more satisfied with their care. This may have been because their case management focused more on interactions rather than the technology itself.

Another study looked at managing chronic wounds in the home setting using telemedicine (using the telephone instead of face-to-face consultations) for a group of 76 older people (average age 70 years) (Kobza and Scheurich 2000). The telemedicine consultations included discussions between the home nurse and the wound expert in the home, developing a plan of treatment from that consultation, and monitoring the older person via the telemedicine link once or twice each week. Participants had an average of 60 home visits, and a total of 191 wounds were treated. When compared with data from the participants' medical charts, healing rates for all wounds had improved with the exception of Stage II pressure ulcers (a blister-like ulcer). The average time that it took for wounds to heal decreased in all wound categories. The study did not say whether participants were happy with their treatment.

In summary, using the telephone for 24-hour home support for very unwell older adults who may be close to dying can be helpful. There may also be some benefits from using telephone lines, when this is feasible, to transmit data for health care professionals who do home consultations. These consultations may then help health care professionals to give treatment that minimises adverse events that might lead to discomfort, distress and possibly to traumatic hospital admissions.

Despite the possible advantages of using the telephone more in home-based palliative care, more research is needed to see how much older people benefit, and whether using the telephone more in home-based palliative care is feasible in Australia. Telephone-assisted care is most likely to benefit people in rural and remote areas to minimise home visits that involve lengthy journeys.

3.3.2 Home visits from community pharmacists

Many older people who need palliative care suffer from a number of different diseases and conditions at one time (comorbidities). This means that older people may be prescribed many medications at a time in their lives when medication use can present particular challenges in terms of compliancy, drug interactions and side effects. Several studies have looked at possible benefits of home visits to older adults to address medication issues. Community pharmacists undertaking these visits can educate, advise, check understanding and discover the extent to which the older person is taking over-the-counter medications as well as prescription drugs.

A study from the United States (Hsia Der et al 1997) looked at 20 male veterans (with an average age of 75 years) who received home care and took at least three medications. The veterans were visited by a community pharmacist twice, with four weeks between visits. On the first visit, veterans' and carers' reports of medication use were compared with doctors' recommendations. The pharmacist assessed medication efficacy, side effects, the use of other medications, and the use of alcohol and tobacco. The pharmacist also offered to do a home inspection of medications, and counselled veterans about medication use. The pharmacists' second visit was to check for changes in the veterans' use of and problems with their medications. The study found that medication-related problems were reduced significantly by the time of the second visit.

A randomised controlled trial of home visits from pharmacists in the United Kingdom involved 872 people older than 80 years (Holland et al 2005). The study measured participants' quality of life at baseline (before treatment) and after six months. Half the participants received home visits from a pharmacist at six and eight weeks after they were discharged from hospital, while the other half received usual care. The home visits included assessment of the ability to self-medicate and relevant education. When appropriate, the pharmacist communicated with the GP and recommended aids to help the older person comply with their medication. The rate of hospital re-admissions was 30% higher in the intervention group (compared with the control group), and their quality of life was also significantly poorer. The study did not measure compliance. Subgroup findings for people with heart failure (Holland et al 2007) and for frail, aged participants (Lenaghan et al 2007) showed similar results.

Finally, a randomised controlled trial from Hong Kong (Wu et al 2006) involved 502 people (average age of 70 years) who attended a clinic and took at least five medications. Half the people received a series of six to eight phone calls by a pharmacist over two years. These calls were to clarify medication issues, remind the person about appointments and reinforce how important it is to take medications as directed (comply with directions). The control group received usual care. Results showed that compliance was better in the intervention group, as was survival (11% of people from the intervention group died compared with 19% in the control group).

Within Australia, pharmacists play an important role in the specialist palliative care team (Gilbar and Stefaniuk 2002). A home medicines review program is also available, in which the GP, community pharmacist and an accredited pharmacist can assess patients collaboratively and teach them about safe medication use.

Overall, more studies are needed before it is clear whether home visits by community pharmacists are effective for helping older adults with complex medication schedules. In particular, more research is needed to follow up the study by Holland et al (2005) to see whether home visits at six and eight weeks change people's level of compliance.

Details of the Home Medicines Review program are available from the Pharmacy Guild of Australia website under 'Programs': http://www.guild.org.au/

3.3.3 Staff education in end-of-life care

An important example of education in palliative care for home care staff is the Home Care Outreach for Palliative Care Education (HOPE) program from North America (Ferrell et al 1998). The HOPE program was developed for staff working in nonhospice settings, particularly those caring for people with cancer. Despite this, some components of the program may be useful in other settings and when caring for older adults with other conditions.

The modules in this program include:

- an overview of palliative care and related ethical issues and principles
- management of symptoms
- communicating with dying people and family carers
- death.

A pilot of the course was attended by 52 participants, including a variety of health care professionals and home health aides (Ferrell et al 1998). Self and employer ratings of the effectiveness of staff in a variety of relevant end-of-life care domains improved in most areas. However, self rating of effectiveness in managing symptoms other than pain, and of communication with the patient and family, remained unchanged.

Although the program did not look at whether staff education changed patient outcomes, it is likely that better staff education does improve palliative care. Australian studies that look at how effective these programs are for staff and patient outcomes would be useful.

The Australian Government Department of Health and Ageing has a program that provides health care professionals with opportunities to develop knowledge and skills in a palliative approach to care. The program consists of funded clinical workforce placements or workshops.[4]

3.4 Conclusion

A variety of care models can be used for the ongoing delivery of a palliative approach to care in the community setting. Additionally, care transitions and crises need to be addressed and a variety of strategies may be used to improve that care. Although it is clear that some models of care work well with particular subgroups of older adults, more research is still needed to choose the best way of providing care.

The review of studies on postacute transitional care for older adults who need a palliative approach to care found that this type of care has clear benefits for some groups of older adults. Evidence-based recommendations for postacute transitional care based on the studies included in the review are shown in Guideline 3.1. Furthermore, crisis care should be incorporated into services for older adults who receive a palliative approach to care in their own homes (see Guideline 3.2). As described in Section 1.4.3, the ratings of each recommendation indicate the extent to which these recommendations can guide practice reliably (these ratings reflect the variation in the evidence base). Although providing postacute transitional care to older adults in the community incurs costs, the study findings suggest that money will be saved in the long run because the care reduces the use of other health services.

More studies are needed before further, evidence-based recommendations can be made. However, recruiting frail and unwell older adults is difficult, limiting the evidence base for this group of people compared with other groups.

Finally, there is great potential to trial new palliative care approaches to support the team of people who provide care to older adults. This includes using telemedicine, particularly in rural and remote areas. Similarly, increasing home visits by community pharmacists and improving education of aged-care workers may improve the delivery of a palliative approach to care.

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[4] See http://www.pepaeducation.com

3.5 Good practice points — delivering a palliative approach in the community setting

Specific responsibilities

Delivering a palliative approach to care in the community setting entails specific responsibilities. These are discussed in the introduction to this chapter, and in Section 3.1.6.

3.1 Community health care staff need to take on an advocacy role on some occasions when caring for older adults in the community. Duty of care requires prompt reporting of any suspicions regarding possible ill treatment, neglect and exploitation.

3.2 Occupational health and safety and the scope of practice of those providing care in the homes of older adults are areas that need particular reinforcement with education because of the variability in home care settings and in the extent to which supervision can be provided for community staff.

Communication and teamwork

The team providing a palliative approach to care in the community setting can include pharmacists and volunteers, as well as aged care personnel and GPs. Good communication among everyone involved is essential (see Sections 3.1.1, 3.1.2, 3.1.6, 3.1.7, 3.3.2).

3.3 Good communication among care providers will help to coordinate care when older adults need to move from one care setting to another; for example, when they go into hospital and then return home.

3.4 It is good policy to include community pharmacists in the health care team, if they are willing to take on this role. The advice that community pharmacists can provide for older adults who are in need of medications may make a difference to their compliance with medications.

3.5 Volunteers are also a great resource for expanding the delivery of care. However, volunteers need clear guidance and ground rules for working with this vulnerable group of older people. They also need support. Contacting Volunteering Australia for advice is highly recommended.

3.6 Local initiatives may address postacute transitional care in your area. Check with your local hospital. Also check with them about the best way you can provide information when the person for whom you are providing care is admitted to hospital.

Crisis plans and formalised plans for use at the end of life

Formalised plans for delivering a palliative approach to care in the community setting, and plans for what to do in the event of a crisis, are essential for delivering the best possible care (see Sections 3.1, 3.2.1, 3.2.2).

3.7 Having a plan for what to do in a crisis might alleviate anxiety, even if a crisis never happens. Consider the kinds of things that might cause distress for older adults and work with them and their family carers to develop such a plan.

3.8 A formalised plan for end-of-life care will help to make sure that the care is delivered in the best possible way. This plan needs to take account of any cultural preferences and should:

- make sure that advance health care plans are documented, known, understood and current.
- identify the needs of the family carer for support.
- identify the needs of care workers and volunteers for support.
- document availability of staff or other support after hours.

- identify any equipment that might be needed and its availability, especially after hours

- provide advice to the carer that death is likely to occur soon; the residential care guidelines (DoHA 2006, p 168) lists the following symptoms as indicative that death is likely to occur
  - a decrease in consciousness
  - an inability to swallow
  - changes in breathing patterns
  - peripheral shutdown
  - incontinence
- make sure the family knows what to do and whom to contact in the event of a change, a crisis, and when death occurs
- provide a plan to support the family if it is likely that the person who dies will need to remain in the home for hours after the death (eg in an area that is difficult for a GP to reach)

- provide information about signs that death has occurred (those that are appropriate to the individual situation may be explained to family carers who ask for this information); DoHA (2006 p 169; based on Ferris von Gunten, Emmanuel 2003) lists the signs of death as
  - absence of pulse
  - breathing ceases
  - 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
  - jaw may fall open
  - trickling of fluids internally can be heard.

3.9 The *Therapeutic Guidelines: Palliative Care* (2005, p 75) indicate that when a death has occurred the following actions should be taken:

- A decision must be made that life is extinct. This is generally done by the GP but state legislation varies. In some states, this must be done before body can be moved.
- A death certificate must be completed, usually by the treating medical practitioner.
- If there is uncertainty about the cause of death (eg if there has been a fall that may have contributed to the person’s death), then the coroner may need to be informed, even though death was expected anyway. The GP or attending physician will normally take this action.

3.10 Care providers may assist with funeral arrangements by:

- contacting the funeral director if the family request this (but it is generally the family's role)
- offering to contact a priest or minister of religion, or a friend to comfort the family member.

The residential care guidelines (DoHA 2006, p 170) suggests the following activities that care providers may need to consider:

- liaise with the family with regard to care of the person after death (eg washing or dressing the deceased person) as the family may choose to do all or part of this themselves and cultural preferences may be important
- consider any other relevant cultural issues
- make sure the family is given unhurried private time to say goodbye
- inform all care providers and volunteers involved in care and debrief as necessary.

3.6 Recommendations for further research

Further studies are needed to discover the extent to which (if at all):

- quality of life (of older people and carers), hospital re-admission, residential aged care placement or death may be affected by postacute transitional care programs in older adults with specific conditions other than heart failure (eg advanced COPD, moderate or severe dementia, advanced cancer) in older adults who are frail
- hospital re-admission is affected by postacute transitional care programs in older adults with severe heart failure when those people have comorbidities that might affect how well such programs work (eg when the person with heart failure also has dementia)
- the mortality of patients with severe chronic heart failure is affected by transitional care programs (using large enough samples to detect an effect if one is present)
- the time until residential placement is affected in patients with severe chronic heart failure by transitional care programs
- involving family carers might improve post-transitional care, particularly when the older person has dementia as well as another disease, such as chronic heart failure
- all relevant outcomes are affected by postacute transitional care programs in older adults who have advanced frailty or disability due to stroke
- all relevant outcomes are improved by the availability of 24-hour crisis care for older adults who are approaching death in extreme old age, are frail or are experiencing life-limiting illness
- staff, volunteer and patient outcomes are improved when aged-care staff are educated about end-of-life care, including symptom management and bereavement care
- the use of technology may be helpful as a resource in end-of-life care for older adults in the community
- home visits by community pharmacists can improve medication compliance in older adults in the community. A focus on educating the family carer in the use of medications for managing symptoms would be of particular interest.

3.7 Key to terms and abbreviations in Tables 3.5–3.12

Terms	
Applicability	the extent to which the study findings can be applied in the Australian community aged care context
Clinical importance	how important the effect is in clinical terms (based on NHMRC-recommended terminology when confidence intervals are reported)
Comparator	comparison or control group (in review papers, the nature of comparators was often not defined; instead presence or absence was noted)
Generalisability	the extent to which the study sample has the same characteristics of the population of interest for the review
Intervention	a brief description of the program or strategy being tested in the study
Italic font	systematic reviews
Level of evidence	as determined by NHMRC criteria (see Table 1.3)
Quality	an indication of the confidence that the reviewers have in study findings

Abbreviations	
CG	control/comparison group
CI	confidence interval
COPD	chronic obstructive pulmonary disease
CVD	cardiovascular disease
ED	emergency department
GP	general practitioner
HF	heart failure
HR-QOL	health related quality of life
IG	intervention group
LOS	length of stay
n/a	not applicable
nCG	number in the control/comparison group
NH	nursing home
nIG	number in the intervention group
NS	not statistically significant at the 0.05 level
NYHA	New York Heart Association
OR	odds ratio

QOL	quality of life
R	outcomes directly relevant to patients or their carers (not surrogate outcomes, see Glossary)
RCT	randomised controlled trial
RR	relative risk
SD	standard deviation
SR	systematic review
VA	veterans' affairs

Table 3.5 Summary of included studies (methodology): postacute transitional care in older adults with severe chronic heart failure

Reference	**Type of study**	**Level of evidence**	**nIG**	**nCG**	**Applicability**	**Generalisability**	**Quality**
Gonseth et al 2004	*SR*	*I/III-2*	*n/a*	*n/a*	*High*	*Age appropriate (almost). Stage of disease more variable than in our target group*	*Very good. Includes meta-analysis*
Gwadry-Sridhar et al 2004	*SR*	*I*	*n/a*	*n/a*	*High*	*Age appropriate (almost). Stage of disease more variable than in our target group*	*Very good. Includes meta-analysis*
McAlister et al 2001	*SR*	*I*	*n/a*	*n/a*	*High*	*Almost all included studies age appropriate. Stage of disease more variable than in our target group*	*Good. Includes meta-analysis*
McAlister et al 2004	*SR*	*I*	*n/a*	*n/a*	*High*	*Most studies were age appropriate but a few were not. Stage of disease more variable than in our target group*	*Very good. Includes meta-analysis*
Phillips et al 2004	*SR*	*I*	*n/a*	*n/a*	*High*	*Most studies were age appropriate. Stage of disease more variable than in our target group*	*Good. Includes meta-analysis*

Reference	**Type of study**	**Level of evidence**	**nIG**	**nCG**	**Applicability**	**Generalisability**	**Quality**
Taylor et al 2005	*SR*	*I*	*n/a*	*n/a*	*High*	*Most studies were age appropriate. Stage of disease more variable than in our target group*	*Good. Includes meta-analysis*
Blue et al 2001	RCT	II	84	81	High	No cancer or myocardial infarction comorbidity. Otherwise good	Good
Cline et al 1998	RCT	II	80	110	Intervention could be tiring for a frail population	Age appropriate, our target population likely to have more comorbidity	Reasonable
DeBusk et al 2004	RCT	II	228	234	High	Mainly good. Participants did not have pulmonary disease requiring oxygen or other terminal illness	Good
Doughty et al 2002	RCT	II	100	97	High	Good	Moderate
Ekman et al 1998	RCT	II	79	79	High	Good	Reasonable but poor adherence to the intervention
Harrison et al 2002	RCT	II	92	100	High	Good	Good
Inglis et al 2006	RCT	II	149	148	High	Good	Good

Reference	**Type of study**	**Level of evidence**	**nIG**	**nCG**	**Applicability**	**Generalisability**	**Quality**
Jaarsma et al 1999	RCT	II	95	84	High	High	Good but high level of attrition from intervention
Jaarsma et al 2000 (same study but other outcomes reported)	As above	As above	As above		As above	As above	As above
Kimmelstiel et al 2004	RCT	II	97	103	High	High	Good
Krumholz et al 2002	RCT	II	44	44	High	Good	Good though small sample
Ledwidge et al 2003	RCT	II	51	47	High	Good	Fair
Naylor et al 2004	RCT	II	118	121	High	Good	Good
Pugh et al 2001	Quasi-RCT	III-I	27	31	High	Good	Small sample pilot
Stromberg et al 2003	RCT	II	52	55	High	Potential participants with COPD, dementia, or psychiatric illnesses were excluded	Underpowered

Key to terms and abbreviations: see Section 3.7.

Table 3.6 Summary of included studies (findings): postacute transitional care in older adults with severe chronic heart failure

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Gonseth et al 2004	*Disease-management programs*	*Generally usual care*	*Older adults with primary or secondary HF*	*Re-admission for HF or cardiovascular causes — 11 RCTs*	*30% reduction (pooled RR 0.70, 95%CI, 0.62–0.79), P<0.0001*	*A clinically important benefit for the full range of plausible estimates in every case when estimates are provided/R*
				All cause re-admission in 16 RCTs	*12% reduction (RR=0.88, 95%CI, 0.79–0.97), P=0.01*	*A clinically important benefit for the full range of plausible estimates in every case when estimates are provided/R*
				Re-admission and death in 10 RCTs	*18% reduction pooled RR 0.82 (95%CI, 0.72–0.94), P=0.04 — nonrandomised studies showed higher drop*	*A clinically important benefit for the full range of plausible estimates in every case when estimates are provided/R*
				Long-term mortality, one RCT only	*Over 4.2 years mortality 9% lower (P=0.06)*	*A clinically important benefit observed that was not statistically significant* *The possible range of effects is unknown/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Gwadry-Sridhar et al 2004	*Patient education to improve HF knowledge — multidisciplinary*	*Usual care*	*Hospitalised for HF and aged 18+, mean age was actually 71–83*	*HR-QOL (4 studies)*	*Two studies showed benefits for intervention*	*Clinical importance cannot be evaluated using effect size/R*
				Re-admission	*RR=0.55 (95%CI, 0.33–0.97) to 1.07 (95%CI, 0.82–1.38) Pooled RR=0.79 (P<0.001)*	*The point estimate of effect is clinically important BUT the confidence interval includes clinically unimportant effects/R*
				Mortality (8 RCTs)	*RR: 0.49 (95%CI, 0.20–1.20) to 1.56 (95%CI, 0.88–2.76) Pooled RR=0.98 (P<0.90)*	*The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect or a harmful effect. Not statistically significant/R*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
McAlister et al 2001	*Outpatient-based HF management (not a requirement that this was postdischarge, but that is what was included)*	*Usual care — poorly defined*	*HF patients — mean age 63–80 years*	*QOL (5 trials)*	*Only one study showed benefits in the intervention group*	*Clinical importance cannot be determined from effect size but findings are also inconsistent/R*
				Hospitalisation rate (11 RCTs)	*Eight trials — no difference. Two reported benefits — one a negative effect. Pooled data RR=0.87 (0.79–0.96) (heterogeneity P=0.003) Multi-disciplinary teams RR=0.77 (0.68–0.86), heterogeneity P>0.50. Phone contact RR=1.15 (0.96–1.37)*	*A clinically important benefit for full range of plausible estimates except in the case of phone contact for which the confidence interval is consistent with no effect or adverse effects/R*
				Total hospitalisations *(6 RCTs)*	*Seven reported positive effect. Pooled data RR=0.81 (0.77–0.85)*	*A clinically important benefit for full range of plausible estimates/R*
				Multiple re-admissions *(unknown number of RCTs)*	*Three studies reported positive impact*	*Clinical importance cannot be determined from effect size/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
McAlister et al 2001 (contd)				*All-cause mortality (6 RCTs)*	*Pooled data* *RR=0.94 (0.75–1.19) NS*	*The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or harm/R*
McAlister et al 2004 *(note: updated review)*	*Outpatient-based HF management (not a requirement that this was postdischarge, but that is what was included)*	*Usual care — poorly defined*	*HF patients — mean age 56–80 years*	*QOL (18 RCTs)*	*Nine trials reported benefits*	*Clinical importance cannot be determined from effect size and findings are inconsistent/R*
				All-cause hospitalisation rate (23 RCTs)	*Three trials reported significant reduction, 18 reported no difference and 1 a negative effect* *Pooled data RR=0.84 (0.75–0.93) heterogeneity P=0.01* *Effect better when multidisciplinary team provides care adjusted RR=0.81 (0.63–1.04) or for supported self care adjusted RR=0.75 (0.63–0.98) compared with phone follow up and contact with GP alone*	*The confidence interval includes clinically important and unimportant effects; also, one study showed negative effects/R*
				HF hospitalisation rate (19 RCTs)	*Pooled data RR=0.73 (0.66–0.82)*	*A clinically important benefit for full range of plausible estimates/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
McAlister et al 2004 (contd)				*Total hospitalisations (21 RCTs)*	*Pooled data RR=0.70 (0.62–0.80*	*A clinically important benefit for full range of plausible estimates/R*
				Total HF hospitalisations (20 RCTs)	*Pooled data RR=0.57 (0.49–0.67)*	*A clinically important benefit for full range of plausible estimates/R*
				All-cause mortality (22 RCTs)	*Pooled data RR=0.83 (0.70–0.99). Mortality reductions greater when multidisciplinary team provides support compared with:* *self-care alone; adjusted RR=0.66 (0.46–0.94); or* *phone follow up and contact with GP alone RR=0.82 (0.54–1.25)*	*A clinically important benefit for the full range of plausible estimates (just). Negative or no effect in range of possible impacts from phone follow-up or GP contact alone/R*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Phillips et al 2004	*Modified discharge for HF*	*Usual care*	*HF patients 55 years +*	*QOL (6 RCTs)*	*Improvement=27.5% (11.0–40.0) versus 13.5% (5.1–22) P=0.01*	*A clinically important benefit for the full range of plausible estimates/R*
				All cause re-admission (18 RCTs)	*RR=0.75 (95%CI, 0.64–0.88). All types of post-discharge support led to improvements except increased clinic visits or frequent phone contact RR=0.64 (95%CI, 0.32–1.28)*	*A clinically important benefit for the full range of plausible estimates overall BUT for clinic visits and phone support estimates are also compatible with no effect or a negative effect/R*
				Cardiovascular/HF re-admission (6 studies)	*RR=0.65 (95%CI, 0.54–0.79)*	*A clinically important benefit for the full range of plausible estimates/R*
				Death or re-admission (8 studies)	*RR=0.73 (95%CI, 0.62–0.87)*	*A clinically important benefit for the full range of plausible estimates/R*
				Mortality (14 studies)	*RR=0.87 (95%CI, 0.73–1.03) — trend only*	*A clinically important benefit for almost the full range of plausible estimates/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Taylor et al 2005	*Clinical service interventions not primarily focused on education or medication for people admitted with HF*	*Generally usual care*	*Older adults with at least one HF admission*	*Health-related QOL (6 case management studies)*	*Three reported improvement and three no difference*	*Clinical importance cannot be evaluated using effect size. Inconsistent findings/R*
				HF re-admission (7 case-management RCTs)	*OR 0.52 (95%CI, 0.39–0.70)*	*A clinically important benefit for the full range of plausible estimates/R*
				All-cause re-admissions (11 RCTs)	*Hazard ratio 0.71 (95%CI, 0.54–0.94) P=0.02*	*A clinically important benefit for the full range of plausible estimates/R*
				Event-free survival (death or admission) (7 RCTs)	*Five report benefits*	*Clinical importance cannot be determined from effect size or confidence intervals but inconsistent reports of possible benefits/R*
				Time-to-unplanned re-admission — 2 studies	*Both report benefits*	*Clinical importance cannot be determined from effect size or confidence intervals but possible benefits reported/R*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Taylor et al 2005 (contd)				*Mortality (10 RCTs)*	*OR=0.86, P=0.23 (0.67–1.10)*	*Consistent with no effect/R*
				Event-free survival (7 RCTs)	*5/7 studies provided results that indicated a significant positive effect*	*Clinical importance cannot be evaluated using effect size/R*
Blue et al 2001	GP and nurse home visits, and phone calls	Usual care	Older adults (mean age 75 years) post-HF admission — no cancer or myocardial infarction comorbidity	All-cause re-admissions	IG=56%, CG=60%. 0.80 (0.53–1.19), *P*=0.27	No statistically significant effect/R
				HF re-admissions	IG=14%, CG=32%. 0.38 (0.19–0.76), *P*=0.0044	A clinically important benefit for the full range of plausible estimates/R
				Per person per month all cause re-admissions	IG=0.124, CG=0.174. 0.71 (0.54–0.94), *P*=0.018	As above
				Per person per month HF re-admissions	IG=0.027, CG=0.069. 0.40 (0.23–0.71), *P*=0.0004	As above
				Mean days in hospital All causes	IG=10.3 days, CG=16.7 days 0.65 (0.40–1.06), *P*=0.081	Consistent with no effect/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Blue et al 2001 (contd)				Mean days in hospital HF	IG=3.43 days, CG=7.46 days 0.60 (0.41–0.88), *P*=0.0051	A clinically important benefit/R
				Deaths	% before discharge, IG=1, CG=7, NS % at 12 months IG=30, CG=31, NS. 0.93 (0.54–1.63), *P*=0.81	Consistent with no effect/R
				All cause deaths/re-admissions	IG=62%, CG=75% 0.72 (0.49–1.04), *P*=0.08	No statistically significant effect/R
				HF deaths/re-admissions	IG=37%, CG=53% 0.61 (0.38–0.96), *P*=0.03	Clinically important benefit for full range of estimates/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Cline et al 1998	Education and self management, nurse directed outpatients for one year	Usual care	Older adults (mean age 75.6 years) with moderate/severe HF	QOL in HF Health profile Global self assessment	No difference between groups at 12 months for all three variables	Clinical importance cannot be determined from effect size; there is some indication of a clinical benefit in some outcomes but this is mainly not significant/R
				% re-admitted over 12 months	IG=39%, CG=54%, $P=0.08$	
				Mean days to re-admission	IG=141, CG=106, $P<0.05$	
				Mean hospitalisations per patient	IG=0.7, CG=1.1, $P=0.08$	
				Mean days hospitalised	IG=4.2, CG=8.2, $P<0.07$	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
DeBusk et al 2004	Physician-directed, nurse-managed, home-based program for heart failure plus usual care instruction. Initial one-hour education session with nurse (video plus phone counselling). Phone support for one year	Usual care	Older adults (mean age 72 years). Approx 50% NYHA Grade I or II and 50% NYHA III or IV	Time to first rehospitalisation (HF)	Proportional hazards: 0.84 (0.56–1.25) (*P*>0.2).	In all cases, the range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or a harmful effect and results are not significant/R
				Time to first rehospitalisation (all cause)	0.98 (0.76–1.27) (*P*>0.2).	
				Time to death/hospitalisation/ED visit (cardiac)	0.85 (0.64–1.14) (*P*>0.2)	
				Time to death/hospitalisation/ED visit (all cause)	0.87 (0.69–1.08) (*P*>0.2)	

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Doughty et al 2002	Group education run by cardiologist and study nurse included symptoms of HF, managing HF (weight, medication, exercise, diet), daily diary. Close liaison with GP, patient and family and hospital clinic	Usual care	New Zealanders with NYHA III or IV heart failure mean age 73 years	QOL in HF	Gain for IG in physical function (IG=–11.1, CG= –5.8, *P*=0.02)	Indicates clinically important benefit in this study no effect sizes/R
				Death or re-admission at 12 months	IG68, CG=61, *P*=0.33	Compatible with negative effect but NS/R
				All cause re-admission	IG=120, CG=154, *P* not reported	Indicates clinically important benefit in this study/R
				Admission rate/patient/year	IG=1.37, CG=1.84, effect size=0.47 (0.16, 0.78)	A clinically important benefit for the full range of plausible estimates/R
				Total hospital bed days	IG=1074, CG=1170, *P* not reported	Clinically important benefit for this study/R
				Hospital bed days/patient/year	IG=12. 3, CG=13.9, effect size=1.6 (0.51, 2.7)	A clinically important benefit for the full range of plausible estimates/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Doughty et al 2002 (contd)				Number of first re-admissions, all causes	IG=64, CG=59, NS	Minimal indication of benefit in this study/R
				Number of first re-admissions, HF	IG=21, CG=23, NS	Minimal indication of benefit in this study/R
				Number of subsequent re-admissions, all causes	IG=56, CG=95, *P*=0.02	Clinically important benefit in this study/R
				Number of subsequent re-admissions, HF	IG=15, CG=42, *P*=0.04	Clinically important benefit in this study/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Ekman et al 1998	Nurse-monitored outpatient clinic combined with regular phone calls to patient, attending doctor responsible for all medical decisions. Patients were able to contact nurse if symptoms worsened or they had questions. Poor adherence	Usual care	Patients with chronic heart failure and/or chronic cardiomyopathy, aged 65+ years, NYHA III or IV	Patients readmitted once in 6 months (any cause)	IG=45, CG=48, NS	No statistically significant differences and only very minor indications of any clinical differences in this study/R
				Patients readmitted twice in 6 months (any cause)	IG=26, CG=21, NS	
				Patients readmitted once in 6 months (HF)	IG=38, CG=36, NS	
				Mean days spent in hospital in 6 months	IG=18 (SD=19), CG=26 (31), NS	
				Number of patients surviving without re-admission	IG=30, CG=25, NS	
				Number of deaths	IG=17, CG=21, NS	

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Harrison et al 2002	Standard discharge planning and care plus a comprehensive program of support (including nurse-led education on disease plus counselling)	Usual care	Patients admitted with congestive cardiac failure, mean age >75 years	QOL in HF	Significant benefits for IG at 6 and 12 weeks for IG	All clinically important benefits except wellbeing although confidence intervals not available to determine likely range of effects/R
				Wellbeing	Minimal/no impact, NS	
				One ED visit	IG=29%, CG=46%, *P*=0.03	
				More than 1 ED visit	IG=32%, CG=50%, *P* not reported	
				Re-admission	IG=23%, CG=31%, *P*=0.03	

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Inglis et al 2006	Usual care, plus home visit within 7 to 14 days of discharge by nurse and pharmacist or cardiac nurse (physical examination, review of adherence and knowledge assessment of support, knowledge, etc) remedial action taken, comprehensive report, follow-up phone call over following 6 months	Usual care	Patients admitted with chronic heart failure (NYHA II, III, IV), mean age >75 years	Event-free survival (days)	IG=1448±1187, CG=1010±999, *P*<0.001	All clinically important benefits for this study except for mean length of stay. Confidence intervals not available to determine likely range of effects/R
				Re-admission/patient/year	IG=2.04±3.23, CG=3.66±7.62, *P*=0.04	
				Day of recurrent hospital stay/patient/year	IG=14.8±23.30, CG=28.4±53.4, *P*=0.05	
				Mean length of stay	IG=8.2±5.5, CG=8.8±6.5, NS	
				All-cause mortality	IG=114 (77%), CG=132 (89%), *P*<0.001	
				Median survival (months)	IG=40 months, CG=22 months, *P* not reported	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Jaarsma et al 1999	Nurse-led education and support — lasting from hospital admission until 10 days after discharge from hospital. Program involved education about disease and support to patient and family; patients could call nurse in case of problems or questions once discharged (within 10-day period)	Usual care	Patients admitted with chronic heart failure (NYHA, III, IV), mean age 73 years	Re-admissions (all cause) %	Over 9 months: IG=37, CG=50 *P*=0.06	No significant effect detected. Range of possible effects cannot be determined but an indication of clinical benefits for percentage of re-admissions/R
				Re-admission (cardiac) %	IG=29, CG=39 *P*=0.10	
				Re-admission days (all cause) mean (sd)	IG=9 ±18, CG=9 ±18	
				Re-admission days (cardiac) mean (sd)	IG=5.1 ±11, CG=7.1 ±15	
				Self-care compliance	Better in IG at 1 month postdischarge *P*=0.01, and at 3 months *P*=0.05. Wellbeing also better in IG 1 month postdischarge	Demonstrates meaningful benefit in these variables/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Jaarsma et al 2000	As above	As above	As above	Function	No significant differences between group scores	No significant effect detected/R
				Symptom severity adjusted for missing data	Larger decrease in IG than CG (–1.2 versus –0.4) *P*=0.07	
				Symptom distress adjusted for missing data and multiple testing	Larger decrease in IG than CG (–1.3 versus –0.5) *P*=0.11	
				Psychosocial adjustment	No significant differences between group scores	
				Wellbeing adjusted for missing data	No significant differences between group scores	

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Kimmelstiel et al 2004	Post-discharge home visits re self management of HF and including 24-hour phone support. Exam and symptom assessment included. After 90 days phone support only as needed	Not described	Older adults with chronic heart failure (mean age >70 years, NYHA II & III)		At 90 days hospitalisation and LOS reduced for HF and cardiac causes. Not sustained for 12 months	RR estimates show a positive clinical impact on all outcomes, although this impact is not statistically significant for all cause hospitalisation or all cause days in hospital. Confidence intervals are not provided/R
				Hospitalisation HF	RR at 90 days=0.48, *P*=0.03	
				Hospitalisation cardiac	RR at 90 days=0.57, *P*=0.04	
				Hospitalisation, all cause	RR at 90 days=0.89, *P*=0.61	
				Days in hospital/patient/year HF	RR at 90 days=0.54, *P*=0.001	
				Days in hospital/patient/year cardiac	RR at 90 days=0.64, *P*=0.001	
				Days in hospital/patient/year all cause	RR at 90 days=0.92, *P*=0.34	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Krumholz et al 2002	Teaching modules — initial face-to-face one-hour session with cardiac nurse involving education, and then follow-up telephone sessions to review knowledge and provide support for patients. One-year intervention	Not described	Patients with HF, no comorbidity, mean age 74 years	**3 months:**		All clinically important benefits but a number of findings not statistically significant in this study (which is likely underpowered). Confidence intervals not available to determine likely range of effects/R
				All causes re-admission or death	IG=56.8%, CG=81.8%, *P*=0.01	
				CVD re-admission or death	IG=50%, CG=79.6%, *P*=0.04	
				HF re-admission or death	IG=40.9%, CG=68.2%, *P*=0.01	
				>1 re-admission	IG=27.3%, CG=47.7%, *P*=0.05	
				>2 re-admissions	IG=13.6%, CG=25%, *P*=0.18	
				12 months:		
				All cause re-admission	IG=49, CG=80, *P*=0.06	
				CVD re-admission	IG=35, CG=66, *P*=0.03	
				HF re-admission	IG=22, CG=42, *P*=0.07	
				Hospital days — all cause	IG=10.2, CG=15.2, *P*=0.09	
				Hospital days — CVD	IG=6.3, CG=12.3, *P*=0.03	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Krumholz et al 2002 (contd)				Hospital days — HF	IG=4.1, CG=7.6, *P*=0.10	
				Proportional hazards:		
				Time to 1st admn — all cause	RR=0.56 *P*=0.03	
				Time to 1st admn — CVD	RR=0.51 *P*=0.02	
				Time to 1st admn — HF	RR=0.51 *P*=0.04	
				Deaths	IG=20.4%, CG=29.56%, *P*<0.33	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Ledwidge et al 2003	Multidisciplinary care — specialist heart failure management and drug administration plus specialist nurse-led disease and diet education sessions. Phone checks until 3-month study endpoint	Usual care	Patients with HF as primary diagnosis, mean age 74 years, NYHA IV	QOL	CG=29, IG=40 (*P*=0.10)	No statistically significant effect detected. Trend towards improvement seen/R
				3 months: HF re-admission Days of hospitalisation	IG=2, CG=12, *P*<0.01 IG=17, CG=195, no point estimate	Clinically important benefits indicated, but no confidence intervals reported/R
				Hospital deaths at 3 months Out of hospital deaths at 3 months	One per group Two per group	No clinically important effects detected for deaths/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Naylor et al 2004	Three-month comprehensive transitional care (discharge planning and home follow-up) directed by study-trained advanced-practice nurses	Usual care	Mean age 76 years, 43% male, 36% African American. All admitted to hospital with diagnosis of heart failure	QOL 12 months:	Benefits for IG at 12 weeks ($P<0.05$)	Likely clinically important benefits but no effect sizes shown/R
				Rehospitalisation % >1	RR=1.24 (0.95,1.60)	No clinical impact seen on hospitalisation with a new problem but other findings are in accordance with possible intervention related benefits although statistical significance is lacking for a number of findings/R
				Rehospitalisation % >2	RR=1.20 (0.89, 1.60)	
				Rehospitalisation n index related	IG=40, CG=72, $P=0.19$	
				Rehospitalisation n comorbidity related	IG=23, CG=50, $P=0.01$	
				Rehospitalisation n new problem	IG=41, CG=40, $P=0.88$	
				Rehospitalisation n total	IG=104, CG=162, $P=0.05$	
				Rehospitalisation/patient/ year	IG=1.18, CG=1.79, $P=0.01$	
				Total hospital days	IG=588, CG=970, no point estimate	
				Total hospital days per patient mean (SD)	IG=5.0 (7.3), CG=8.0(12.3), $P=0.07$	
				Total hospital days per hospitalised patient mean (SD)	IG=11.1 (7.2), CG=14.5 (13.4), no point estimate	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Pugh et al 2001	Patients provided with improved discharge planning, taught how to manage their HF, given information book, assessed by a nurse and followed up by a nurse case manager for 6 months by phone and visits	Usual care	Diagnosis HF NYHA II to IV, mean age 77	Wellbeing	Standardised effect sizes calculated from graphs. All confidence intervals included zero; all except one indicated a positive trend from the intervention. No significant differences detected	Range of estimates include no effect and very small negative effects as well as very small positive effects but this study was underpowered and no differences were statistically significant/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Stromberg et al 2003	Heart failure clinic — one-hour sessions with nurses at a hospital based clinic comprising check-up and evaluation of treatment 2 to 3 weeks postdischarge from hospital. Written and verbal education provided about heart failure (eg diet changes) and social support offered to family	Usual care	Patients had been diagnosed with heart failure, did not have COPD, dementia or other psychiatric illnesses. Mean age 77+ years. NYHA II/III/IV	Number of patients with death or admission at 3 month	IG=19, CG=30, *P*=0.06	All clinically important benefits but some are not statistically significant in this study (which is underpowered) and confidence intervals do not provide a range of likely estimates/R
				Number of patients with death or admission at 12 months	IG=29, CG=40, *P*=0.03	
				All cause admissions 3 months	IG=33, CG=56, *P*=0.05	
				All cause admissions 12 months	IG=82, CG=92, *P*=0.31	
				Hospital admission/patient/months 12 months	IG=0.18, CG=0.40, *P*=0.06	
				Days in hospital 3 months	IG=350, CG=592, *P*=0.05	
				Days in hospital 12 months	IG=688, CG=976, *P*=0.13	
				Days in hospital/patient/month 12 months	IG=1.4, CG=3.9, *P*=0.02	
				Deaths at 3 months	IG=3, CG=13, *P*=0.009	
				Deaths at 12 months	IG=7, CG=20, *P*=0.005	

Key to terms and abbreviations: see Section 3.7.

Table 3.7 Summary of included studies (methodology): post acute transitional care for older people with advanced frailty or disability due to stroke

Reference	Type of study	Level of evidence	nIG	nCG	Applicability	Generalisability	Quality
Visser-Meily et al 2005	*SR*	*I/III-2 22 studies, 18 RCTs*	*n/a*	*n/a*	*High*	*Age appropriate. Stroke specific. Level of disability often unknown*	*Limited search strategy*
Clark et al 2003	RCT	II	32	30	High — education mixed with other components	Good (but no cognitive disability)	Control group not described & no blinding. Otherwise good
Mant et al 2000	RCT	II	258	262	High — information plus other components	Good	Treatment individualised by manager — replication problematic. Inter-group comparisons not for change scores. Fair
Rodgers et al 1999	RCT	II	107	69	Probably not feasible given high poor-attendance rate found in study	Good	Extremely high dropout rate Underpowered Intervention attendance poor. Poor

Key to terms and abbreviations: see Section 3.7.

Table 3.8 Summary of included studies (findings): postacute transitional care for older people with advanced frailty or disability due to stroke

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance or relevance
Visser-Meily et al 2005	*Interventions for carers including transitional care (information, advice, support)*	*Not in all cases — when present generally usual care*	*Family carers of stroke patients*	*Coping, confidence, depression, burden, social functioning, HR-QOL*	*12 relevant studies, positive results were found in four studies for HR-QOL, social activities. Burden improved in the uncontrolled study*	*Clinical importance cannot be evaluated using effect size or range of estimates but some indications of benefits for carers/R*
Clark et al 2003	Information pack and three visits from counsellor	No information or counselling	Spousal carers of stroke patients and stroke patients	Family functioning and carer health. Patient activities, function, health, anxiety, depression, mastery	Family functioning improved at 6 months. No impact on carer health. Better function in patients, no impact on patients' depression, anxiety, mastery, health	Clinical importance cannot be evaluated using effect size or range of estimates but some indications of benefits for family functioning and for patients/R
Mant et al 2000	Information leaflets plus support	Usual care — not described	Family carers of stroke patients and stroke patients	Emotional health, social activity, QOL for carers. Anxiety, depression, QOL for patients	Carers: positive impact on social activity, energy, mental health, pain, physical function, health perception, QOL. Effect size reported to be moderate. No apparent impact on patients	Clinical importance cannot be evaluated using range of estimates (confidence intervals) but important benefits found in this study for family carer/R
Rodgers et al 1999	Stroke education for patient/family carers. Poorly attended.	Usual care including information sheets and hotline access	Family carers of stroke patients and patients	Perceived health and function	Only difference at Time 2 was poorer social functioning in IG for carers. No benefits for patients	Indications of a negative effect on carers and no benefits for patients but study compromised by poor attendance at education sessions/R

Key to terms and abbreviations: see Section 3.7.

Table 3.9 Summary of included studies (methodology): postacute transitional care in generally frail or unwell older adults

Reference	**Type of study**	**Level of evidence**	**nIG**	**nCG**	**Applicability in Australian system**	**Generalisability**	**Quality**
Ali and Rasmussen 2004	*SR*	*I/III-2* *39 studies - descriptive work, pre-post evaluations, controlled trials*	*n/a*	*n/a*	*High*	*Age appropriate but including those less unwell. Does not include people with dementia*	*Good*
Bours et al. 1998	*SR*	*I/III-1* *17 trials, but not all RCTs*	*n/a*	*n/a*	*High*	*Includes people with chronic disease and frail elders. Good*	*Reasonable but no statistics reported*
Hastings and Heflin 2005	*SR*	*I/III-1* *19 studies, 8 with comparison, 6 RCTs*	*n/a*	*n/a*	*High*	*Includes all older adults with comorbid illnesses discharged from the ED (but not if they would have been otherwise hospitalised). Good*	*Good*
Hyde et al. 2000	*SR*	*I/III-I* *9 studies, all with comparison*	*n/a*	*n/a*	*High*	*Includes all older adults with comorbidity discharged from hospital. Good*	*Good*
Nazareth et al 2001	RCT	II	165	156	High	Good	Medium — underpowered despite relatively large sample

Key to terms and abbreviations: see Section 3.7.

Table 3.10 Summary of included studies (findings): postacute transitional care in generally frail or unwell older adults

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance or relevance**
Ali and Rasmussen 2004	*Planned and supported discharge*	*Not in all studies*	*Older adults, comorbidities — not dementia*	*Quality of life*	*Some evidence of positive impact (one study)*	*Clinical importance cannot be evaluated using effect size/R*
				Re-admission	*Some evidence of positive impact — little detail provided.*	*Clinical importance cannot be evaluated using effect size/R*
				Mortality	*No significant effect reported*	*No effect reported/R*
Bours et al 1998	*Nursing care after discharge from hospital*	*Mainly usual care*	*Older adults who were frail or had chronic disease and were discharged from hospital*	*Quality of life or related variables*	*No significant effect reported*	*No effect reported/R*
Hastings and Heflin 2005	*Interventions to improve outcomes for older adults discharged from ED, varied components*	*Generally usual care (no comparison in some). We use findings only from studies with controls*	*Older adults who had comorbidity and were discharged from ED*	*Quality of life (wellbeing and depression)*	*No effect reported in the two relevant studies*	*No effect reported/R*
				Re-admission	*Representation lower in one study, higher in another. An Australian study showed re-admission 5.8% lower at 30 days (P=0.049) and 9.9% at 18 m (P=0.007)*	*A clinically important effect is apparent but the extent to which negative effects or no effect might occur cannot be evaluated (no CIs reported for single relevant study)/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance or relevance
Hastings and Heflin 2005 (contd)				*Placement*	*A study that included nurse geriatric assessment was reported to show a decrease in NH admission at 30 days (2 patients versus 9) OR 0.21 (0.05 to 0.99)*	*Confidence interval includes clinically unimportant effects but most effects would be important/R*
Hyde et al 2000	*Supported discharge after an acute admission*	*Nine studies with controls that are usual or no support — supplementary data from 2 more*	*Older adults with comorbidity discharged after an acute admission*	*Re-admission*	*No clear pattern and effect sizes small*	*Clinical importance not evident/R*
				Placement	*Clear and consistent pattern showing benefits (seven studies) but multiple measures used — meta-analysis not conducted*	*Clinical importance cannot be evaluated using overall effect size but appears to be clinically important/R*
				Mortality	*Nine trials, 7 included in meta-analysis. OR=1 (0.8 to 1.3) no significant effect*	*The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or a harmful effect/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance or relevance
Nazareth et al 2001	Hospital and community pharmacists provided integrated discharge plan	Standard procedure	Older adults, mean age 84 years, with a mean number of three medical conditions	Wellbeing	No significant impact. Difference at 3 months=0, at 6 months=0.01 (–0.14, 0.34)	The confidence interval does not report clinically important effects /R
				Re-admission	No significant impact — difference at 3 months=0.18% (–10.6, 10.2) at 6 months=0.54% (–1.0, 9.9)	The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or a harmful effect/R
				Mortality	No significant effect: 3.26% (–1.5, 7.7) more dead at 3 months and 3.5% (–4.7, 11.6) more at 6 months	The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or a harmful effect/R

Key to terms and abbreviations: see Section 3.7.

Table 3.11 Summary of included studies (methodology): crisis care

Reference	Type of study	Level of evidence	nIG	nCG	Applicability	Generalisability	Quality
Ali and Rasmussen 2004	*SR*	*I/III-2*	*n/a*	*n/a*	*High*	*Age appropriate but including those less unwell than in our target population. Does not include people with dementia*	*Good*
Aminzadeh and Dalziel 2002	*SR*	*I/III-2*	*n/a*	*n/a*	*High*	*Age appropriate but including those less unwell*	*Fair*
Hughes et al 2000	RCT	II	981 patients 937 carers	985 patients 946 carers	Crisis care was a component of a larger intervention. This component could certainly be implemented	To older adults severely disabled or terminally ill	Good
Kimmelstiel et al 2004	RCT	II	97	103	Crisis care was part of larger intervention	Only to older adults with HF	Good

Key to terms and abbreviations: see Section 3.7.

Table 3.12 Summary of included studies (findings): crisis care

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance or relevance**
Ali and Rasmussen 2004	*Rapid response, generally run from ED*	*Not in all studies*	*Older adults, comorbidities — not dementia*	*Hospitalisation — 3 studies, 1 review*	*One study inconclusive. Remaining studies and review indicated benefits re hospitalisation*	*Clinical importance cannot be evaluated using effect size and details of benefits are limited/R*
Aminzadeh and Dalziel 2002	*Home care incorporated into emergency services*	*Unclear if there was a comparator in all studies. One RCT*	*Older adults*	*Hospitalisation — 6 studies*	*Of most relevance — 4 Canadian studies mentioned providing a quick response for older adults to access emergency care in the home, leading to a reduced need for hospitalisation*	*Clinical importance cannot be evaluated using effect size and details of benefits are limited/R*
Hughes et al 2000	Team management of at risk patients including 24-hour contact	Standard care (described)	Older adults severely disabled or terminally ill from VA centres in the United States	HR-QOL carers and patients, hospitalisation and patient function	Severely disabled IG members had significantly fewer re-admissions at 6 months mean 0.7 (1.0) versus 0.9 (1.2), P=0.03	Clinical importance cannot be evaluated using effect size/R
					Widespread significant benefits for carer HR-QOL Significant benefits for HR-QOL in terminally ill patients (role functional —emotional, social function, bodily pain, mental health, vitality, general health)	Benefits appear to be clinically significant but these benefits were from a multicomponent program/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance or relevance
Kimmelstiel et al 2004	Home visits re self management of HF and including 24-hour phone support	Not described	Older adults with chronic HF		At 90 days hospitalisation and LOS reduced for HF and cardiac causes. Not sustained for 12 months	Benefits shown to be clinically significant for HF patients using estimates of relative risk but these benefits were from a multi-component program and confidence intervals are not documented/R
				Hospitalisation HF	RR at 90 days=0.48, *P*=0.03	
				Hospitalisation cardiac	RR at 90 days=0.57, *P*=0.04	
				Hospitalisation, all cause	RR at 90 days=0.89, *P*=0.61	
				Days in hospital/patient year HF	RR at 90 days=0.54, *P*=0.001	
				Days in hospital/patient year cardiac	RR at 90 days=0.64, *P*=0.001	
				Days in hospital/patient year all causes	RR at 90 days=0.92, *P*=0.34	

Key to terms and abbreviations: see Section 3.7.

3.8 References

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Chapter 4 Family carers

Family carers are an important source of support for older adults living in the community (Grunfeld et al 2004, Dumont et al 2006). They are also a vital component of the health care team that provides a palliative approach to care. Without the input of family carers, many people with chronic and life-limiting illness would be unable to continue to live at home (Covinsky et al 2001, Grov et al 2006).

The importance of family carers is reflected in the breadth of this chapter, which includes:

- an explanation of the context of family caring for older adults in the community, including how the aged care team can assess and support carers, and information on carers' experiences of loss, grief and bereavement (Section 4.1)
- a report on the effectiveness of key types of support available for carers (including family carer education and respite care) with evidence-based recommendations for carer support in various circumstances (Section 4.2)
- a review of other support strategies that might help family carers (Section 4.3).

In this document, the term 'carer' is used to mean a family carer; 'care worker' is used to mean a person employed to provide care.

In a palliative approach to care, anyone central to the support network of the person is regarded as 'family', regardless of whether they are related; it is the bond of affection that is important (DoHA 2006). Therefore, the family carer may be either a friend or a family member.

See Glossary for further details.

4.1 The context of family care

This section explains the role of family carers and the consequences of taking on this role. The section also explains how to assess the needs of family carers and summarises the support that is available to them. A description of how bereavement affects family carers is also provided.

Appendix K contains the details of studies reviewed for this section.

Families, and the older adults for whom they provide care, have both separate and common needs. When providing care and support in the home, all these needs and how they may be intertwined should be considered.

4.1.1 Who are family carers?

Until recently, family carers were viewed as 'helpers' (Given et al 2004). However, the intensity of the impact of caring on carers' health (Redinbaugh et al 2003, Grunfeld et al 2004, Dumont et al 2006) and the widespread nature of this impact (Gonzalez-Salvador et al 1999, Meuser and Marwit 2001) have now been recognised, leading to a heightened awareness of the risks associated with caring (Brazil et al 2005a). In Australia, most family carers are women who do not work full time; they also tend to be in poor health (Lee and Gramotnev 2007). North American research suggests that more men are taking on the role of carer (Ducharme et al 2007); however, they tend to provide less personal care and use more community service support (Fromme et al 2005). Thus, some challenges may be common to all carers, yet needs may vary across carer groups.

Family carers' work is based on a pre-existing relationship, is often unpaid and is frequently under-recognised. The primary carer is the person who provides the most help to the person, although some family carers who are not primary carers also provide substantial support. Additionally, care may be shared to the extent that no one person is the primary carer.

Providing care for older adults is a dynamic process and many people take on the role of a family carer for years before the older adult needs more intense care during their final months of life (Kesselring et al 2001, Montgomery et al 2002, Kristjanson et al 2005, Thomas et al 2006, Whitlatch and Feinberg 2006). End-of-life care can be complex and community care services often become involved, or more intensely involved, at this stage (Visser et al 2004). A palliative approach to care involves supporting both the older person and their family carer (Benzein and Berg 2005); ideally this approach should be in place before the final escalation of care needs.

Approximately one in eight (2.6 million) Australians provide informal care (as a family member or friend) to a person who needs help because of a disability, chronic illness or old age (ABS 2004). If this volunteer care was substituted with formal, paid care, it would cost about $30.5 billion per year (Access Economics 2005).

However, in Australia, we do not know how many family carers provide palliative care for older adults with a life-limiting illness. An American survey showed that more than 70% of older people who had chronic disease, and who still lived at home, received help from family members in their last year of their life (Wolff et al 2007). Also, a study of Holland's chronically ill population found that family carers provided the majority of care, with services only being used when informal care was not enough (Visser et al 2004). If we assume a similar pattern of family care in Australia, using a palliative approach provides a challenge for community care providers. In addition to providing support to improve family carers' confidence and wellbeing, and assisting them in care provision, community providers also need to support families through their grief and bereavement.

4.1.2 What do family carers do?

In the United States, family carers provide an average of approximately 45 hours of help each week to people with a life-limiting illness who still live at home (Schulz et al 2003; Wolff et al 2007). Tasks of caring include helping with bathing, dressing, eating, grooming, using the toilet and mobility. Carers also help with phone calls, shopping, preparing meals, house cleaning, laundry, transport, household tasks, taking medicine and handling finances (Schulz et al 2003, Wolff et al 2007). Moreover, they provide emotional support, participate in decision making and liaise with health care professionals (Fromme et al 2005). Family carers have a role in discussing end-of-life care with the older adult and ensuring that their wishes are acted on (Kahana et al 2004). Overall, they need to be acknowledged as members of the older person's support team (Wolff et al 2007).

Family carers of people who have dementia may have many additional responsibilities, including supervising the older person because of their memory problems and managing their behavioural symptoms. To maintain the older person's safety, as well as the safety of others in the household, these carers can feel that they are ‘on duty’ 24 hours each day (Schulz et al 2003).

Family carers of chronically ill and disabled people often have to provide physical care over many years, as the older person’s health and physical function gradually deteriorate. Carers of people with cancer frequently have to provide intense care, although the duration may be shorter due to the rapid progression of many cancers (Redinbaugh et al 2003). During the final few months of an older person’s life, their care needs will increase, as will the demands on their carers. Consequently, carers may experience cumulative effects that reduce their health and wellbeing, as well as their employment, leisure and socialisation (Brazil et al 2003a, Goldstein et al 2004).

Many older people would prefer to die at home because this allows them to stay connected with their community, have family and loved ones present, and maintain a sense of normality. Family carers play a pivotal role in helping to achieve a home death when that is the desired option (Brazil et al 2005b). Good support is also essential to sustain end-of-life care in the home (Visser et al 2004). However, death in hospital or another inpatient setting is more suitable for some older adults, particularly when they need continuous or complex nursing care to manage their symptoms (Brazil et al 2005b). Also, residential aged care may be the only option if the carer’s health prevents ongoing home care or community services are inadequate (Brazil et al 2005b). For example, when an older adult has dementia, the decision to place them in residential care is mainly associated with the carer’s health and their burden of care. Such decisions are rarely made lightly and may follow years of consideration (Rudd et al 1999).

Whereas enabling a family member to die at home can be very satisfying for the family carer (Singer et al 2005), this is not always desired, desirable or feasible.

4.1.3 What are the benefits of being a carer?

Taking on the role of carer can give people feelings of achievement and satisfaction. Research suggests that caring is rewarding for both the carer and the recipient, with each receiving support from the other (Wolff et al 2007). Research also shows that most family carers believe that satisfaction outweighs drawbacks (Osse et al 2006). As many as 70% of carers in one study claimed that their role made them feel good about themselves, allowed them to appreciate life more, and made them feel both useful and needed (Wolff et al 2007).

Other benefits of being a carer include developing a better quality of relationship with the person who needs care (Meuser and Marwit 2001), a sense of mastery in learning new skills (Meuser and Marwit 2001, Wolff et al 2007), finding the experience meaningful (Kesselring et al 2001, Fromme et al 2005) and experiencing stronger family relationships (Wolff et al 2007).

4.1.4 What are the drawbacks of being a carer?

Unfortunately, the benefits of being a carer do not protect the carer from some of the drawbacks of providing care (Beery et al 1997).

Caring has social, economic, emotional and physical costs (Brazil et al 2005a). Stressors affect everyone differently (Walker and Pomeroy 1997) and it is not unusual for carers to focus on care needs at the expense of their own health (Grunfeld et al 2004). Older carers, in particular, are affected by more illness (Wolff et al 2007) and face a higher risk of death when they are under strain from providing care (Visser et al 2004, Papastavrou et al 2007). Younger carers are also vulnerable and experience an altered role that can disrupt daily activities (Goldstein et al 2004, Grunfeld et al 2004, Osse et al 2006), limit personal freedom and require them to put future plans on hold (Meuser and Marwit 2001). The amount of psychological distress that family carers experience may initially decrease over time (Beery et al 1997, Walker and Pomeroy 1997). However, as the older person's mobility declines and symptoms increase, carers experience more distress, depression and anxiety (Given et al 2004, Dumont et al 2006).

Making the decision to change from home care to residential care is often triggered by carer depression (Bookwala et al 2004). However, depression frequently persists after this change, and even after the older person dies (Schulz et al 2003, Grov et al 2006, Papastavrou et al 2007). An American study found that up to 32% of family carers suffer from clinical depression and that many others have depressive symptoms (Covinsky et al 2003). The rate of depression among the family carers of people with dementia is higher, possibly because people who have dementia need more demanding care (Nordberg et al 2005). Carer exhaustion is a particular concern in these family carers (Almberg et al 1997), and is more likely to occur in the first three months of care and later when care is difficult and protracted (Raveis et al 1998). Overall, however, family carers who provide home care report less strain than those who support family members admitted to inpatient settings, such as residential care or hospitals (Gaugler et al 2004, Fromme et al 2005).

Whatever the setting, the severity of the older person's symptoms during their illness (particularly at the end of life) can have a powerful effect on family carers. The resulting strain affects them long after the person dies (Fromme et al 2005, Dumont et al 2006).

Carer strain can be manifested as (Grov et al 2006):

- sleep disorders
- fatigue
- headaches
- feelings of uncertainty, hopelessness and helplessness.

Financial hardship is another significant strain on carers. Family carers may need to reduce their work hours or stop working when adopting the carer role; they may also use up their savings (Covinsky et al 2001, Tilden et al 2004). Some government financial benefits are available for vital support (Banerjee et al 2003).

In the longer term, some carers' health and financial problems persist after caring ceases (Lee et al 2007). Other carers, including elderly family carers of people who have dementia, usually experience improved physical health once caring ceases and they can attend to their own physical and medical needs (Grasel 2002).

4.1.5 Assessing carers' needs

Assessing carers' needs and providing them with timely support is critically important for the health and wellbeing of vulnerable family carers. Community aged care professionals can assess carers' needs to target, refine and tailor the content, structure and delivery of care, and provide flexible and effective strategies to support the family carer (Gaugler et al 2004).

The following list summarises risk factors that can predispose carers to stress or ill health. The health care team can use these risk factors to screen carers for their likelihood of becoming stressed, and use them to help prioritise strategies for providing care. The risk factors are:

- providing live-in care (Visser et al 2004), especially when the care recipient has dementia (Banerjee et al 2003)
- having difficulty with managing the person's symptoms, medications and self-care needs (Redinbaugh et al 2003)
- looking after older people with higher levels of dependency (Ferrario et al 2004b), including a higher risk of falls (Kuzuya et al 2006)
- experiencing a disrupted lifestyle; for example, needing to be absent from work or to abandon work activities (Ferrario et al 2004b)
- having a low level of education (Lee et al 2001)
- having two or more health conditions (Lee et al 2001)
- looking after someone whose physical or psychological symptoms are causing them distress (Redinbaugh et al 2003, Tilden et al 2004)
- having difficulty communicating with the care recipient (Fried et al 2003)
- experiencing losses in social life, family relationships and leisure activities (Kesselring et al 2001)
- experiencing uncertainty about the illness (Redinbaugh et al 2003, Tilden et al 2004)
- reducing healthy behaviours, such as exercising or eating well (Ferrario et al 2004b)
- feeling a heavy or intense emotional burden (Ferrario et al 2004b).

Assessment of carers' needs is a holistic and comprehensive process. Social networks and the willingness of friends and relatives to help are resources that need to be considered; spiritual and cultural aspects are also important.

An assessment of the older person's symptoms can form a starting point for educating family carers about symptom assessment and management (Kristjanson et al 1998). Tailoring assessments to an individual carer is also likely to be important.

Male carers report less carer strain than women. This has been attributed to the different ways in which they express their emotions and to their reluctance to make voluntary disclosures about their suffering (Fromme et al 2005).

Male carers respond best to direct questions, such as the following (Fromme et al 2005):

- Have you needed to miss work to care for your family member?

- Do you have financial concerns about caring?
- How are you sleeping?
- What works really well when you provide care?
- What is the most difficult aspect of providing care?
- How do you get rest and time-out?

The aged care team can use a number of tools to work out family carers’ needs (see Table 4.1). Online access to these tools will increase over time, as tool developers respond to the needs of practitioners.

The CareSearch website provides links to useful sites, as well as information on selecting the best tool.

See http://www.caresearch.com.au

Table 4.1 Family carer assessment tools

Tool	Features	Reference
The Caregiver Quality of Life Index — Cancer scale	Takes 10 minutes to complete Has been validated in a palliative setting Identifies changes in the family carer's health status Has good internal consistency reliability	Weitzner et al (1999)
Family Strain Questionnaire	Takes 20 minutes to complete Identifies burden of caregivers Validated in Italy Can be used on its own for a general assessment of the problems that are related to providing care Can identify family carers at risk of not coping with bereavement	Ferrario et al (2004a)
The Caregiving at Life's End Questionnaire	Has good validity and reliability Information can be used to identify the benefits of care giving and impact of palliative care interventions	Salmon et al (2005)
Family Carers' of Alzheimer's Disease Problems Scale	Identifies predictors of mental health symptoms and depression Identifies family carers who are vulnerable and most in need of practical help, psychoeducation, emotional support or psychological treatment	Livingston et al (2005)
Marwit-Meuser Caregiver Grief Inventory	Measures burden of care giving and grief in carers of Alzheimer's patients Can be used to monitor carers over time	Marwit and Meuser (2002)
Bereavement Risk Index	Validated in the Australian community Short and easy to use Requires approximately four hours of training to use it efficiently, as well as to put in place protocols for bereavement support Identifies family members who need help coping with bereavement	Kristjanson et al (2005)

4.1.6 Supporting carers

Most carers do not feel prepared for their caring role (Redinbaugh et al 2003). Yet family carers do not often ask for help from formal services (Diwan et al 2004). Instead, they tend to seek help from family and friends (informal support) (Cohen et al 2001, Wolff et al 2007).

Informal support for carers has good outcomes. For example, carers of people with dementia who experience good social and emotional support from family and friends are less likely to feel overwhelmed or trapped. They are also more likely to feel that they still have someone with whom they can share close moments (Gaugler et al 2004).

When someone is new to the role of carer, as well as when care needs intensify, they may need formal services to help manage any negative consequences of caring experiences (Gaugler et al 2005). Support that may be useful includes information or education, respite care, or social and emotional support. These types of support can help protect the carer's health (Brazil et al 2003b, Fromme et al 2005) and prevent an early end to home caring (Ducharme et al 2007).

What are the barriers to accessing support?

Some family carers do not use support services, even when they need them. Their reasons for not using services include:

- concerns about privacy and confidentiality, especially in rural and remote areas (Li 2006)
- difficulty in accessing services because of the distance and travelling required; for example, to take an older person to a day respite centre (Li 2006)
- lack of awareness of community services or finding them inadequate (Strain and Blandford 2002, Teno et al 2004)
- the belief that it is inappropriate to use services (this belief may be cultural) (Brazil et al 2005a)
- a wish to maintain their relationship with the older person (Brazil et al 2005a)
- expense of services, or the lack of availability of local services, especially in rural or remote areas (Cravens et al 2005, Li 2006)
- challenges experienced with managing a change in routine because of service delivery, especially if the older person has cognitive impairment (Strain and Blandford 2002).

Additionally, male carers may resist using services to avoid appearing unfamiliar with their role. As mentioned in Section 4.1.5, they may also be reluctant to share personal feelings in support groups because there are few other men, the benefits of sharing are not concrete or they feel a need to be independent and strong (Fromme et al 2005).

What does carer support need to include?

Practical approach

Support for carers should be practical — that is, it should be easy to access, clearly defined and effective. When recommending programs or services to family carers, the aged care team should make sure that (Montgomery et al 2002):

- the family carer has clear and accurate expectations of the support that the program or service provides
- the family carer receives information about the program or service, including times and availability
- the family carer understands, and can meet, any transport needs
- there is not too much 'red tape' involved.

Information

Support in the form of information can help family carers understand what is required of them, how to use the resources and knowledge that can help them in their role, and how to cope with the challenges of being a carer. The information provided needs to be sensitive to individual carers' wishes and needs; this helps to avoid distress or misunderstanding about cultural preferences (Ingleton et al 2004). As a general guide, family carers of people who have life-limiting illness would like information about:

- the caring role and its boundaries (Lee et al 2001)
- diagnosis and likely outcomes (the 'prognosis') (Wolff et al 2007)
- the cause of the disease (Osse et al 2006)
- physical problems that can be expected (Osse et al 2006)
- possibilities of treatment and side effects (Osse et al 2006)
- alternative healing methods (Osse et al 2006)
- skills needed to meet the daily demands of caring (Osse et al 2006)
- how to provide nourishment (Osse et al 2006)
- behavioural management and functional issues, when the care recipient has dementia (Gonzalez-Salvador et al 1999)
- what will happen in the future (ie life expectancy and service availability) (Casarett et al 2003, Osse et al 2006)
- symptoms and how they can be managed (Casarett et al 2003)
- death (Casarett et al 2003).

Carers of people with neurological diseases need information on how to access services and equipment, as well as how to find reliable, ongoing support workers (Kristjanson et al 2005). These carers are particularly vulnerable due to their demanding role. Therefore, showing them how to navigate the support system is a priority, because they will need this help at a time when they are under the most pressure.

In Australia, the most appropriate initial point of contact for carers to access information about support is Carers Australia http://www.carersaustralia.com.au, or the state-based branches of this organisation.

Alzheimer's Australia is also an excellent resource for family carers of people who have dementia http://www.alzheimers.org.au. Again, this organisation has state-based branches.

Education and training

Education and training of family carers may improve the way in which information is provided. For example, family carers may be educated about the possible causes of symptoms and how to assess the intensity of symptoms. Carers can also be educated about the importance of looking after their own health. This form of education, sometimes called self care or psychoeducation, concentrates on how to cope with problems or stresses in caring. For example, the feelings of anger sometimes experienced by carers may be addressed by anger-management strategies (Meuser and Marwit 2001). Information and education are often offered by support groups and self-help organisations (Brazil et al 2005a).

Counselling and respite care

Social and emotional support are also offered by the support groups that provide information and education (Robertson et al 2007). Many disease associations, for example, run their own support groups. Counselling may be available via these groups or accessed via a referral from a general practitioner (GP).

Respite care helps carers to take a break or holiday, devote time to other family members, attend to their own health, or do anything else that they choose; it can extend for just a few hours or for a few weeks (Braithwaite 1998). However, family carers may have mixed feelings about using respite care (van Exel et al 2006). Therefore, family carers who have another family member or a friend who can help care for the older person are less likely to use respite services (Kosloski et al 2001).

Some barriers to using respite care are not easily resolved. For example, a Dutch study found that about half the family carers who failed to use respite care did need this service, but were prevented from using it because of resistance from the person they were looking after (van Exel et al 2006). Sometimes, the family carer’s sense of duty and responsibility, along with a fear that the care recipient will be unhappy, will prevent them accessing respite care. A wish to maintain privacy and lifestyle control may also mean that in-home respite, in particular, is avoided (Braithwaite 1998). Finally, some family carers do not recognise themselves as carers and therefore do not seek information about respite services (van Exel et al 2006) or they may believe that the service is not accessible (Kosloski et al 2001).

Family carers in most need of respite care include those who:

- provide high levels of support with personal care, and are unable to access blocks of free time (Braithwaite 1998, Kosloski et al 2001)
- are in dysfunctional caring relationships (which often involve a history of conflict between the carer and the care recipient) (Braithwaite 1998)
- experience increasing distress, for whatever reason (Kosloski et al 2001).

Most commonly, respite is provided as in-home respite, day care, short-stay respite (in a residential facility or hospital), or special holiday arrangements (van Exel et al 2006). Sometimes, programs are exclusive to people who have dementia. During respite, the emphasis for the care recipient can be on routine care, outdoor mobility, social visits (van Exel et al 2006), treatment or rehabilitation (Montgomery et al 2002).

4.1.7 Family carers’ experiences of loss, grief and bereavement

Grief includes a range of responses to loss that can be experienced as longing for whatever has been lost, pain, guilt, anger or sadness. Bereavement is the reaction to loss and includes healing from that loss. Healing requires working through the emotional, cognitive and social changes that relate to the loss until a satisfying conclusion is reached, even though the person may never feel fully recovered (DoHA 2006). Bereavement can, therefore, be a time of personal growth (Aneshensel et al 2004). However, everyone experiences grief, bereavement and healing differently (DoHA 2006).

Before death

End-of-life care requires family members to provide intensive care while simultaneously coping with escalating grief and loss (Carr et al 2001, Redinbaugh et al 2003). Carers experience losses caused by taking on the role of carer; for example, losses of social or work interactions (Meuser and Marwit 2001). Significant grief is likely when these losses are compounded by the deterioration of the person who is dying, when the final loss of a life-long companion is imminent (Walker and Pomeroy 1997).

This anticipatory grief may be associated with physical symptoms such as anxiety and sleep disturbance (Chentsova-Dutton et al 2002). On a more positive note, families that are anticipating death can become closer to their dying relative, at the same time making practical plans for the survivor and resolving unfinished business. In other words, they respond in advance to the loss and start the process of bereavement (Carr et al 2001).

Family carers of people who have dementia tend to suffer grief earlier, as the older person's cognitive functioning deteriorates. Some carers find this loss more significant than when death occurs (Rudd et al 1999, Meuser and Marwit 2001). Meuser and Marwit (2001) found the following two key differences between spouses and adult children who were providing care for people who had dementia:

- sons and daughters who provided care tended to experience intense grief, anger and frustration when the dementia was moderate, and sadness plus concern for others when the dementia was severe
- spouses, however, were found to have a continual increase in grief throughout the disease progression, with anger and frustration mainly being experienced in the severe stage and a strong focus on their own loss at that time.

Other research has indicated that carers of people with dementia who are not prepared for the death are likely to suffer more depression, anxiety and complicated grief. A simple screening question to detect those who may be at particular risk may therefore be helpful, asking the carer whether they are prepared for the death (Hebert et al 2006).

After death

People can respond in many ways to the death of a relative (Aneshensel et al 2004). Although individual reactions are unique, symptoms such as crying or becoming upset when thinking about the person, and feeling preoccupied with thoughts about the person tend to diminish during the first year; whereas being reminded frequently about the person during everyday life and missing the person may remain constant during that time. Reactions to grief are characterised by sleep disturbance, loss of appetite and general distress (Brazil et al 2003b).

Bereavement can be experienced as pain and other physical symptoms, especially in older adults. These symptoms can affect the physical function of the bereaved carer, and education strategies to address bereavement risks and prevent symptoms (eg depression, anxiety, other psychiatric disorders) ideally need to begin during the care-giving period (Williams 2005)

Bereavement is not just a series of stages leading to resolution. It is a complex process that does not always depend on how much time has passed since death, although the overall intensity of grief does decrease as time passes for most people (Chentsova-Dutton et al 2002, Schulz et al 2006). Sometimes, however, overall recovery may be incomplete (Brazil et al 2003a).

Bereavement is partly a social process, with family and friends playing an important role in recovery (Brazil et al 2003a). Therefore, family carers who have become socially isolated during care and have difficulty reconnecting with their social networks may be particularly vulnerable to poorer wellbeing (Valdimarsdottir et al 2002, Burton et al 2006). The end of the carer role also involves additional losses at this time, including the carer's sense of purpose and mastery (Prokos and Keene 2005) and the withdrawal of support services (Gaugler et al 2004).

Despite the extensive losses associated with both the bereavement and the ending of the carer role, most family carers are supported adequately at this time by family and friends (Schulz et al 2003). Community-based bereavement programs may include counselling and support groups that help people to deal with loss and grief, learn new skills (previously undertaken by the deceased person), look after their own health and meet others to make new friends (Caserta et al 2004). Overtreating people during bereavement, however, can have negative effects. The GP or other member of the aged care team should assess the carer to see whether they need more intensive therapy (Kristjanson et al 2005).

Signs of complex grief include (Schulz et al 2006):

- a sense of disbelief that the person has died
- anger and bitterness about the death
- recurring pangs of painful emotion, intense yearning and longing for the dead person
- preoccupation with thoughts about the dead person
- avoiding activities that are reminders of the loss.

Such grief may result in depression, anxiety and symptoms similar to those experienced in post-traumatic stress disorder; the risk of cardiovascular disease and cancer may also be increased. However, in most instances, even complex grief resolves spontaneously (Schulz et al 2006).

Bereavement resources

A bereavement risk index has been developed by Kristjanson and colleagues and may be used to detect those who are in need of intensive therapy:

- Kristjanson LJ, Cousins K, Smith J and Lewin G (2005). Evaluation of the Bereavement Risk Index (BRI): a community hospice care protocol. *International Journal of Palliative Nursing* 11(12):610–618.

Some extensive resources relevant to bereavement care and support are also available via the CareSearch website (http://www.caresearch.com.au)

Guidelines have been produced for bereavement risk assessments:

- Aranda S and Milne D (2000). *Guidelines for the Assessment of Complicated Bereavement Risk in Family Members of People Receiving Palliative Care*, Centre for Palliative Care, Melbourne. Available from the University of Melbourne: http://www.pallcare.unimelb.edu.au/ via links to research and resources.

There are also guidelines for diagnosing and treating complicated bereavement:

- Zhang B, El-Jawahri A and Prigerson HG (2006). Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *Journal of Palliative Medicine* 9(5):1188–1203.

4.2 Assessing the effectiveness of carer support programs

This section presents the evidence of the effectiveness of key types of carer support programs for older adults in a community setting. These types of carer support include respite care, disease-specific education for carers and end-of-life care education for carers. The evidence is derived from a systematic review of the literature, the full details of which are provided in Appendix A.

The literature review was based on the following specific research questions:

- Does a model of care that includes respite care improve physical and/or psychological health in older people and/or family carers compared with a model of care that does not include this respite care?
- Does education for family carers in disease-specific areas (dementia care, heart failure, chronic obstructive pulmonary disease, cancer care, Parkinson's disease) improve family carer confidence, competence, physical, psychological and spiritual health compared with a lack of this education?
- Does education for family carers in end-of-life care improve their experience of the death of their family member and their post-bereavement health compared with a lack of this education?

These questions were used to identify key words to guide the search, as well as to develop criteria for including or excluding from further review the studies identified by the searches.

Evidence-based recommendations were developed from the included studies. Summary tables of the methods and results of these included studies are shown at the end of this chapter. Excluded studies are shown in Appendix C with reasons for their exclusion. Data-extraction forms for the included studies are shown in Appendix D. Evidence matrixes are based on the NHMRC levels of evidence (NHMRC 2007; see Table 1.3). Appendix E contains full summary forms underpinning evidence decisions for each guideline.

4.2.1 Respite care

Respite care is care provided for an older person over a period of hours, days or weeks to provide the family carer a break. Respite care can be provided in the home, in another person's home or in a care facility.

Systematic review

Table 4.2 shows the research question and the inclusion criteria for the effectiveness of respite care.

Table 4.2 Review of the effectiveness of respite care

Research question

Does a model of care that includes respite care improve physical and/or psychological health in older people and/or family carers as compared with a model of care that does not include this respite care?

Selection criteria	Inclusion criteria
Population	Community-dwelling older adults in need of a palliative approach to care and their family carers
Intervention	Respite care
Comparator	Any
Outcome	Any aspects of physical or psychological health, including time to residential placement
Study design	Systematic review, randomised controlled trials, pseudo-randomised controlled trials, nonrandomised controlled trials, prospective cohort studies (at least 200 participants and relevant question set a priori)
Search period	1997 until 2007
Language	English

Eight primary studies and 14 systematic reviews were included for the effectiveness of respite care (see Appendix B). Most studies were generalised for the target population and setting, and applicable for Australian conditions. Evidence statements are shown below for respite care in the community setting for the following groups of older people and their carers:[5]

- older adults with severe chronic heart failure or other advanced disease or condition
- older adults with moderate or severe dementia
- carers of older adults with moderate or severe dementia
- carers of generally frail or unwell older adults.[6]

Evidence grading matrixes are shown in Table 4.3. Tables 4.7–4.12 (which are presented together at the end of this chapter) show a summary of the methods and results of the included studies. In these tables, systematic reviews are shown in italics for ease of reference.

Evidence statements

Effects of respite care on older adults with severe chronic heart failure or other advanced disease or condition (other than moderate or severe dementia; see next heading)

No studies were identified that addressed respite care for people with severe chronic heart failure or any other advanced disease or condition identified by the authors as being common in older adults needing a palliative approach to care (other than moderate or severe dementia). One review was included that investigated day care for people who have cancer

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[5] For further definition of these conditions, see Appendix A (Section A.3).

[6] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

(Davies and Higginson 2005), but included studies for relevant groups were not of high enough quality to form the basis of a recommendation.

Effects of respite care on older adults with moderate or severe dementia

- There is some level I/III-2[7] evidence relating to the impact of respite care on the behavioural symptoms of older adults with moderate or severe dementia. However, the studies had a high risk of bias, and gave inconsistent (contradictory) results. More research is needed before the effect (if any) of respite care on the behavioural symptoms of older people with dementia is known.
- There is some level I/III-2 evidence relating to the effect of respite care on function (eg physical and mental skills) of people with moderate or severe dementia. However, the results were inconsistent and more studies are needed before the effects (if any) of respite care on function are known.
- There is some level I/III-2 and level II evidence that respite care can increase the length of time older people with dementia spend at home before being admitted into residential care. However, the studies had a high risk of bias and the results were inconsistent. More research is needed to see whether respite care affects the time before placement into residential care.

Details of the included studies are given in Tables 4.7 and 4.8.

Effects of respite care for carers of older adults with moderate or severe dementia

- There is level I and II evidence of the effect of respite care on a variety of carer outcomes, including burden, depression, wellbeing, stress, sleep, coping, worry, depression, anger and adrenalin levels. The studies had a low risk of bias but the results were inconsistent, possibly because different types of respite care were compared for varying periods of time. However, on balance, respite care had benefits for carers of older people with moderate or severe dementia (but this had only a limited clinical impact).

Details of the included studies are given in Tables 4.9 and 4.10.

Effects of respite care for carers of generally frail or unwell older adults

- There is level I evidence with a low risk of bias of the effect of respite care on depression in carers of generally frail or unwell older adults. The results showed consistently that respite care had a moderate positive and clinically meaningful effect on depression.

- There are several systematic reviews (level I evidence) of the effect of respite care on carers' sense of burden. These reviews had a low risk of bias and showed that respite care slightly improved the sense of burden at best, or had no effect. The results were largely consistent, and any inconsistencies were due to respite care being supplemented by other support (larger effect) as opposed to delivered alone.

Details of the included studies are given in Tables 4.11 and 4.12.

Table 4.3 Evidence matrix for respite care

Outcome	Component	Rating	Description

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[7] A systematic review will only be assigned a level of evidence as high as the studies it contains, excepting where those studies are of level II evidence.

Older adults with moderate or severe dementia			
Residential placement	Evidence base	D	Level IV studies or level II to III studies with high risk of bias
	Consistency	D	Evidence is inconsistent
	Clinical impact	n/a	–
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Behavioural symptoms	Evidence base	D	Level IV studies or level II to III studies with high risk of bias
	Consistency	D	Evidence is inconsistent
	Clinical impact	n/a	–
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Function (physical and/or cognitive)	Evidence base	D	Level IV studies or level II to III studies with high risk of bias
	Consistency	D	Evidence is inconsistent
	Clinical impact	n/a	–
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Carers of older adults			
Health of carers of older adults moderate or severe dementia	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	D	Evidence is inconsistent
	Clinical impact	D	Restricted
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Depression in carers of generally frail or unwell	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	A	All studies consistent
	Clinical impact	B	Moderate

older adults	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Burden of carers of generally frail or unwell older adults	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	B	Most studies consistent and inconsistency can be explained
	Clinical impact	C	Slight
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context

n/a = not applicable

Evidence-based guidelines

Guideline 4.1 Respite care	**Grade**
Support for family carers	
Respite care should be available to support family carers of people with moderate or severe dementia.	D
Respite care should be routinely available to support family carers of generally frail or unwell older adults.[a]	A
There is currently insufficient evidence to indicate whether respite care should be made available to support family carers of older adults with advanced cancer, severe chronic heart failure or other specific advanced disease or condition.	n/a
Outcomes for older people	n/a
There is currently insufficient consistent evidence about the effects of respite care on any health or quality-of-life outcomes for older adults to warrant making any recommendations on these grounds.	

n/a = not applicable

[a] This category refers to older people who are frail or unwell with advanced life-limiting illness that is nonspecific or due to multiple comorbidities, plus people who are frail because of extreme old age.

4.2.2 Disease-specific education for carers

Disease-specific education for carers is education about the disease and its symptoms rather than just about how to deal with the stresses of providing care. Active education is a combination of education and skills training.

Systematic review

Table 4.4 shows the research question addressed and the inclusion criteria for the effectiveness of disease-specific education for carers.

Table 4.4 Review of the effectiveness of disease-specific education for carers

Research question
Does education for family carers in disease-specific areas (dementia care, heart failure, chronic obstructive pulmonary disease, cancer care, Parkinson's disease) improve family carer confidence, competence, physical, psychological and spiritual health when compared with a lack of this education?

Selection criteria	**Inclusion criteria**
Population	Family carers of community-dwelling older adults in need of a palliative approach to care
Intervention	Disease-specific education
Comparator	Any
Outcome	As the question states plus: for health or anything related to health, including wellbeing, burden, quality of life or depression
Study design	Systematic review, randomised controlled trials, pseudorandomised controlled trials, nonrandomised controlled trials, prospective cohort studies (at least 200 participants and relevant question set a priori)
Search period	1997 until 2007
Language	English

Thirty-six primary studies and 16 systematic reviews were included for disease-specific education for carers (see Appendix B). Most studies were generalisable to the target population and setting, and applicable for Australian conditions. Evidence statements are shown below for disease-specific education for carers of older adults with dementia, advanced cancer, stroke and other illnesses.

Disease-specific education may involve only the provision of information, or an approach that also shows or explains to the carer how to apply that information (active education). Skills training or counselling are two of the approaches that may help carers apply disease-specific information when they are providing care.

Evidence grading matrixes are shown in Table 4.5. Tables 4.13–4.18 (which are presented together at the end of this chapter) show a summary of the methods and results of the included studies.

Evidence statements

Disease-specific education for carers of older adults with advanced cancer

There is level II evidence from one study of the effect of active education on the health of carers of older adults with cancer. The study results showed a benefit from active education for these carers. The study had a low risk of bias and the benefits were clinically meaningful.

Details of the included studies are given in Tables 4.13 and 4.14.

Disease-specific education for carers of older adults who have moderate or severe dementia

There is level I and II evidence for the effect of active education on the health of carers of older adults with moderate or severe dementia. The results showed improved carer health (burden or depression). These studies had a low risk of bias and the effect was clinically important.

Details of the included studies are given in Tables 4.15 and 4.16.

Disease-specific education for carers of older adults who have advanced frailty or disability due to stroke

There is some level I evidence with low risk of bias, and some level II evidence with a higher risk of bias of the impact of active education on the health of carers of older adults who have advanced frailty or disability due to stroke. The studies looked for outcomes such as burden, depression, stress, quality of life, wellbeing, perceived health and function. Although the results were inconsistent, on balance, they showed that active education improved the health of this group of carers in a clinically meaningful way.

Details of the included studies are given in Tables 4.17 and 4.18.

Disease-specific education for carers of older adults with other advanced diseases

No studies were found for other relevant groups of carers (eg those caring for older adults with severe chronic heart failure).

Table 4.5 Evidence matrix for disease-specific education for carers

Disease	Component	Rating	Description
Advanced cancer	Evidence base	B	One or two level II studies with low risk of bias or SR/multiple level III studies with low risk of bias
	Consistency	n/a	
	Clinical impact	C	Slight
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Moderate or severe dementia	Evidence base	A	Several level I or II studies with low risk of bias
	Consistency	B	Most studies consistent and inconsistency can be explained
	Clinical impact	B	Moderate
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context
Advanced frailty or disability due to stroke	Evidence base	B	One or two level II studies with low risk of bias or SR/multiple level III studies with low risk of bias
	Consistency	C	Some inconsistency, reflecting genuine uncertainty around the question
	Clinical impact	C	Slight
	Generalisability	A	Evidence is directly generalisable to target population
	Applicability	A	Evidence is directly applicable to Australian health care context

n/a = not applicable

Evidence-based guidelines

Guideline 4.2 Disease-specific education for carers	**Grade**
Cancer	C
Active education[a] in the area of cancer care should be made available for family carers of older adults who have advanced cancer.	
Dementia	A
Active education[a] in the area of dementia care should be made available for family carers of older adults with moderate or severe dementia.	
Stroke	C
Active education[a] in the area of post-stroke care should be made available for family carers of older adults who have advanced frailty or disability due to stroke.	
Other advanced diseases	n/a
There is currently insufficient evidence to indicate whether disease specific education should be made available routinely for family carers of older adults with other advanced diseases (eg severe chronic heart failure).	

n/a = not applicable

[a] Active education is a combination of education and skills training.

4.2.3 End-of-life care education for carers

End-of-life care education for carers is as any form of education relating to end-of-life care provided for the family carer.

Systematic review

Table 4.6 shows the research question addressed and the inclusion criteria for effectiveness of end-of-life care education for carers.

Table 4.6 Review of the effectiveness of end-of-life care education for the carer

Research question	
Does education for family carers in end-of-life care improve their experience of the death of their family member and their postbereavement health as compared with a lack of this education?	
Selection criteria	**Inclusion criteria**
Population	Family carers of community-dwelling older adults in need of a palliative approach to care
Intervention	End-of-life care education
Comparator	Any
Outcome	As the question states
Study design	Systematic review, randomised controlled trials, pseudorandomised controlled trials, nonrandomised controlled trials, prospective cohort studies (at least 200 participants and relevant question set a priori)
Search period	1997 until 2007
Language	English

No studies met inclusion criteria, so this research question could not be answered. More research is therefore needed to see whether end-of-life education has an effect on carers.

4.3 What else may help family carers?

Compared with respite care and disease-specific education, less research has been done on other ways of supporting family carers of older people. Some of the existing studies have looked at managing stress, depression and burden during the overall caring period. Studies have also looked at mental health during end-of-life care, as well as bereavement care. These areas are discussed in the following sections. Appendix L contains the studies included in this review.

4.3.1 Support during the caring trajectory

A Canadian study looked at a group of carers of older adults who were at risk of stress (Ducharme et al 2006). The carers were taught coping strategies by trained social workers, who showed them how to fit these strategies to the stresses they were experiencing. Carers reported using more problem-solving approaches and feeling more in control of the situation, although they felt no change in their sense of burden.

Similarly, a United States study used counselling that was tailored to the needs of carers of people with dementia (Mittelman et al 2004). The counselling included a problem-solving approach (eg how to communicate with the family), as well as support group participation and additional counselling as needed. Participants were followed until two years after the death of the care recipients, and those who took part experienced gradually lowering rates of depression. The difference between the intervention and control groups lasted for more than three years.

Finally, problem-solving nurse counselling was found to be helpful by carers of people with dementia in 92% of participants. Also, problem-solving approaches were more common six months after the counselling ceased (Roberts et al 1999).

Therefore, there are indications that helping carers adopt problem-solving approaches has lasting benefits for them. Furthermore, bolstering these approaches with other components of support may increase their effectiveness. In addition, a study testing the effectiveness of telephone support groups for female carers of people who had dementia showed that the telephone support did not change the carers' sense of burden or depression overall, although older women did experience reduced depression (Winter and Gitlin 2006). Technological approaches were more effective when both computer and telephone links strengthened carer networks after family therapy (Eisdorfer et al 2003). Again, this shows that care consisting of several components or types of approaches might be the best option.

4.3.2 Support during end-of-life care

Support for family carers during end-of-life care can be provided in different ways. In an Australian study (Hudson et al 2005), nurses educated carers of people dying from cancer (not specifically older people). These dying people were already receiving specialist palliative care, as were those whose carers were in the control group. The education taught carers how to care for a dying person, how to care for themselves, how to make meaning of the situation and other issues. Despite the usual attrition problems experienced in studies involving carers of people who are dying, at eight weeks after the patient died, carers remaining in the study reported a positive impact on carer rewards (the rewards or benefits that people obtain from providing care). This finding was echoed by a United States study that had no comparison group but trained more than 2000 carers in a similar program (Kwak et al 2007). About half the carers completed surveys over a few weeks and reported greater comfort with caregiving, more satisfaction and an improved sense of closure. The results from this study are not relevant to carers of people with advanced dementia (because it involved the carer and care recipient prioritising issues together); neither was the program tested specifically with carers of older adults. Therefore, further research is needed to see whether education during end-of-life care can be applied to carers of older people with dementia and of other older people. Finally, a study with distressed carers of older adults receiving specialist palliative care services that only used supportive visits supplemented with information was found to have no effect. However, the extent to which this finding was affected by loss of carers from the study is not clear (Walsh et al 2007).

4.3.3 Support in bereavement

Support at the time of bereavement (as opposed to support during end-of-life care that addresses future bereavement needs) is not well studied in family carers of older people. A study without a control group looked at older, recently bereaved spouses (although younger women — aged at least 50 — who were widowed were also accepted) (Caserta et al 2004). The program involved 11 weekly classes in self-care, health education, and how to find resources for building new networks and coping with tasks that were the responsibility of the partner who had died. The classes improved participants' coping strategies, household management and home safety (making sure that the home is a safe environment).

Other studies have looked at broader groups of bereaved adults. For example, one study (Shear et al 2005) compared standard psychotherapy with treatment for complicated grief (grief that occurs when a person experiences intense symptoms that do not ease over time, preventing them from resuming their normal activities). People who completed the program experienced reduced symptoms of complicated grief and depression and improved adjustment to their new situation. Although this study included a diverse group of people, it showed that useful treatments are available even for those most severely affected.

4.3.4 Support for family carers — summary

Overall, there are promising interventions that support family carers in terms of counselling or family therapy. These interventions may be especially helpful when combined with other components, such as support groups. Teaching carers coping strategies during end-of-life care seems to have benefits, but more research is needed on whether this works for carers of older adults who do not receive specialist palliative care.

Also, bereavement programs specially designed for carers of older adults have not yet been well researched.

It is important to consider the family carer's needs in the context of their culture.

See Chapter 9 ('A palliative approach to care for Aboriginal and Torres Strait Islander people') and Chapter 10 ('A palliative approach to care for older people from diverse cultural and language groups').

4.4 Conclusion

A palliative approach to care includes the care and support of the older adult and their family carer. The family carer is a key member of the care team, and has their own, specific support needs. Important strategies to help family carers include education, counselling and support groups, and respite care.

Studies show that respite care and education strategies are helpful for some groups of carers, and evidence-based recommendations for these types of support are included in this chapter. However, relatively little is known about the effectiveness of education during end-of-life care in this group of carers. There are indications that counselling and support are likely to be helpful support strategies, and it is also likely that bereavement strategies that work in other groups will be helpful for carers who have looked after an older person who has died.

4.5 Good practice points — family carers

Supporting carers before and throughout the care process

The preferences and needs of the carers and family of the older person need to be considered before and during the care process to ensure they are supported, both mentally and physically (see Sections 4.1.3, 4.1.5, 4.1.6, 4.3.1).

4.1 It is important for the aged care team to consider the family's cultural preferences when supporting the family carer.

4.2 Assessing and monitoring carers' needs is crucial for effective and sustainable support. Support mechanisms need to be responsive and flexible because needs change over time.

4.3 Sensitive exploration of the older person's wishes and those of the family is needed to determine the goal of care. Although a home death is the preferred option for many people if appropriate support is available, this is a very individual preference that is determined by the older person's and the family's choices and feasibility in terms of meeting care needs.

4.4 Helping a family carer to provide effective care is one way to help them find meaning in the caring experience; also, it may help to improve the way in which they cope with bereavement.

4.5 Emphasising the benefits of good health for sustaining their role as carers may be the best incentive for encouraging family carers to look after their own health.

4.6 Providing practical support and information in ways that are easily accessible and culturally sensitive is likely to encourage their use by busy carers who have limitations because of their caring commitments.

Supporting carers as death draws near

The final stages of caring for an older person near the end of their life can be particularly stressful. Preparing carers early and making sure support strategies are in place for this stage help to minimise the trauma for carers (see Sections 4.1.7, 4.3.2, 4.3.3).

4.7 Considering end-of-life care needs in advance can allow the carer to access support quickly when they need it. This helps to ensure the best possible opportunity for a period of end-of-life caring that is meaningful and not excessively traumatic.

4.8 Supporting family carers as death approaches by helping them understand what to expect and helping them to use strategies to cope may improve carers' experiences at the time of the death and their experiences of bereavement.

Types of support strategies

Respite care and other support strategies can help carers to manage their care burden (see Section 4.2).

4.9 Flexibility in arrangements for respite care is likely to increase its effectiveness. In particular, respite care should be readily available in the case of an emergency, such as if a carer becomes sick.

4.10 Respite care needs to be made available at frequent intervals because its benefits are likely to be short lived.

4.11 Offering a range of support strategies for family carers of people who have dementia is likely to help more than offering just one option. This flexibility will allow the carer to choose an option or combination of options most suitable to their needs.

4.6 Recommendations for further research

- Australian national and population based studies are needed about family carers providing care to chronically ill and disabled people in their last year of life (Wolff et al 2007). The findings of such studies can then inform the development of health and community systems to respond to and support their needs.
- Studies are needed on anticipatory grief, or on the challenges of dealing with the impending death of a family member (Chentsova-Dutton et al 2002).
- The effectiveness of bereavement interventions needs testing in those who have been providing care for an older adult who has died.
- When considering what interventions are still to be tested, the specific needs of carers of older adults dying with nonmalignant disease are yet to be addressed adequately. In particular, the impact of providing respite care for people with advanced cancer, heart failure and other relevant specific chronic conditions or illnesses, such as chronic obstructive pulmonary disease, needs to be investigated.
- More studies are needed to investigate behavioural symptoms as an outcome of respite care, especially given their likely impact on the carer.
- Further studies are needed to determine the extent to which perceptions of respite care, in terms of anxiety about its impact on the care recipient, influence the effect of respite on the carer. Further investigation of the impact of respite on the care recipient’s function will also help to determine the extent to which the carer’s anxiety is well founded.
- Additional studies are needed to examine wellbeing and quality of life as outcomes of education for family carers of people with dementia.
- More studies are needed to investigate outcomes of carer education for carers of older adults with advanced cancer, stroke and and other advanced diseases, such as chronic heart failure and chronic obstructive pulmonary disease.
- Outcomes of education in end-of-life care need to be investigated across carers of all older adults needing a palliative approach to care.
- As a result of the ageing population, instances when carers of older adults also have dementia or other illness or disability are likely to increase. Therefore, further investigation is needed of the additional support that may be required in this situation.

4.7 Key to terms and abbreviations in Tables 4.7–4.18

Terms	
Applicability	the extent to which the study findings can be applied in the Australian community aged care context
Clinical importance	how important the effect is in clinical terms (based on NHMRC-recommended terminology when confidence intervals are reported)
Comparator	comparison or control group (in review papers, the nature of comparators was often not defined; instead presence or absence was noted)
Generalisability	the extent to which the study sample has the same characteristics of the population of interest for the review
Intervention	a brief description of the program or strategy being tested in the study
Italic font	systematic reviews
Level of evidence	as determined by NHMRC criteria (see Table 1.3)
Quality	an indication of the confidence that the reviewers have in study findings

Abbreviations	
ADL	activities of daily living
ANOVA	analysis of variance
CBT	cognitive behavioural therapy
CG	comparison or control group
CI	confidence interval
CVA	cerebral vascular accident
d	day
HF	heart failure
HR-QOL	heath related quality of life
IG	intervention group
MWE	mean weighted effect
n/a	not applicable
nCG	number in the control/comparison group
NH	nursing home
nIG	number in the intervention group
NK-cell	natural killer cell

NS	not statistically significant
OR	odds ratio
QOL	quality of life
R	outcomes directly relevant to patients or their carers (not surrogate outcomes, see Glossary)
RCT	randomised controlled trial
SD	standard deviation
VA	Veterans’ Affairs

Table 4.7 Summary of included studies (methodology): effects of respite on people with moderate or severe dementia

Reference	Type of study	Level of evidence	n IG	n CG	Applicability	Generalisability	Quality
Arksey et al 2004	*SR*	*I/III-2* *52 studies, mixture of RCTs, down to descriptive work*	*n/a*	*n/a*	*High*	*Stage of dementia often unclear but seems appropriate, age of care recipients often unclear*	*No list of excluded studies, otherwise good*
Doody et al 2001	*SR*	*I/III-2* *Approximately 175 studies, including a wide variety of designs*	*n/a*	*n/a*	*High*	*Stage of dementia unclear but seems appropriate, age of care recipients often unclear*	*Methodology appropriate. Display of results not helpful*
Neville and Byrne 2007	*SR*	*III-2* *6 studies — no RCTs*	*n/a*	*n/a*	*High*	*Stage of dementia unclear but appears appropriate*	*Good, but most studies without controls*
Pinquart and Sorensen 2006	*SR*	*I/III-1* *127 studies with untreated controls*	*n/a*	*n/a*	*High*	*Stage of dementia often unclear but seems to be appropriate, age of care recipients often unclear*	*Good. Meta-analysis*
Roberts et al 2000	*SR*	*I/III-2* *20 studies with a variety of designs*	*n/a*	*n/a*	*High*	*Stage of dementia unclear but seems to be appropriate*	*Good, although few databases searched*
Cucinotta et al 2004	RCT	II	66	61	High	Age appropriate. All had cognitive decline and physical disability, were frail and chronically ill. Italian — post-hospital discharge	Moderate/poor

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability**	**Generalisability**	**Quality**
McCann et al 2005	Cohort	III-2	218	298	High	Age-appropriate and dementia-specific but sample of United States population	Non-equivalent groups at baseline

Key to terms and abbreviations: see Section 4.7.

Table 4.8 Summary of included studies (findings): effects of respite on people with moderate or severe dementia

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Arksey et al 2004	*Respite care or short-term breaks for carers*	*Not all studies had a comparator*	*Carers of people with dementia and care recipients*	*Long-term care entry, function, mood, behaviour, agitation*	*Inconsistent for day care. Institutional respite — some indications of poorer health. Combined with carer support — behavioural improvements and delays to placement. Overall inconsistent effects on function. No effect sizes*	*Clinical importance cannot be evaluated using effect size. However, indications of benefit for respite plus carer support and negative impacts for residential respite without carer support/R*
Doody et al 2001	*Respite*	*All studies were RCTs*	*Carers of people with dementia and care recipients*	*Placement, behaviour*	*Improvements in both (small numbers of studies)*	*Clinical importance cannot be evaluated using effect size but indications of benefits/R*
Neville and Byrne 2007	*Residential respite*	*Most studies had no control*	*Older people with dementia receiving residential respite*	*Behaviour*	*Six studies — two with greatest rigour showed fewer adverse behaviours. One showed an increase in adverse behaviours in people with mild dementia*	*Clinical importance cannot be evaluated using effect size and findings are inconsistent (may differ according to stage of dementia)/R*
Pinquart and Sorensen 2006	*All carer interventions, including respite*	*All studies had untreated control*	*Carers of people with dementia and care recipients*	*Placement*	*Only multicomponent interventions were effective; also, longer interventions were more likely to be effective. Females and spouses more likely to respond*	*Clinical importance cannot be evaluated using effect size but positive impact from indicated for respite plus support and or other components/R*
Roberts et al 2000	*Programs for people with dementia including respite*	*Control or comparison for all*	*Carers of older people with dementia and care recipients*	*Placement, symptoms*	*'Child' carers maintain the parent in the community for longer with respite — indicated to be 22 d, no CI. No effect on symptoms*	*Clinical importance appears to be limited given the small effect/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Cucinotta et al 2004	Home-care support.	Usual care	Chronically ill older people, mean age 84 years, moderate or severe comorbidity. All had cognitive decline	Re-admission	IG=6.1%, CG=13.1% $P \leq 0.05$	Statistically significant impact on death and hospital re-admission, but no confidence intervals to indicate likely range of effects
				Placement	IG=3.3%, CG=3.1.1%, NS	
				Death	IG=12.0%, CG=19.7% $P \leq 0.05$	
McCann et al 2005	Day care at one centre. Variable additional support for carer	No day care at that centre	Older adults with dementia	Placement	Risk of placement higher in day care group — hazard ratio=1.3, *P*=0.001, no CI	Negative impact indicated in this study but no confidence intervals are shown to indicate likely range of effects

Key to terms and abbreviations: see Section 4.7.

Table 4.9 Summary of included studies (methodology): effects of respite on family carers of people with moderate or severe dementia

Reference	Type of study	Level of evidence	n IG	n CG	Applicability	Generalisability	Quality
Acton and Kang 2001	*SR*	*I/III-2* *24 studies, RCTs, quasi, and pre and post-test evaluations*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Large review and meta-analysis. Multiple interventions including education alone. Good quality/R*
Acton and Winter 2002	*SR*	*I/III-2* *73 studies, RCTs and others including pre and post-test evaluations*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear. Not all studies dementia specific*	*Large review of multiple interventions — 23 studies of education alone, 14 support and education*
Arksey et al 2004	*SR*	*I/III-2* *52 studies, mixture of RCTs, down to descriptive work*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*No list of excluded studies, otherwise good*
Doody et al 2001	*SR*	*I/III-2* *Approximately 175 studies including a wide variety of designs*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Methodology appropriate. Display of results not helpful*
Lee and Cameron 2004	*SR*	*3 RCTs*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Good*

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability**	**Generalisability**	**Quality**
Pinquart and Sorensen 2006	*SR*	*I/III-1* *127 studies with untreated controls*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Good. Meta-analysis*
Roberts et al 2000	*SR*	*I/III-2* *20 studies with a variety of designs*	*n/a*	*n/a*	*High*	*Stage of dementia unclear*	*Good, although few databases searched*
Gaugler et al 2003a	Cohort	III-2	248	289	High	Age appropriate and dementia specific	High attrition over a year but 87 and 140 per group still at final time point. Nonequivalent groups so regression modelling used
Gaugler et al 2003b	Cohort	III-2	248	289	High	Age appropriate and dementia specific	High attrition over a year but 87 and 140 per group still at final time point. Nonequivalent groups so regression modelling used
Grant et al 2003	RCT	II	32	23	Probably high but surrogate outcome requires further investigation of relevance	Age appropriate and dementia specific	Small sample, no power calculations
Zarit et al 1998	Cohort	III-2	121	303	High	Age appropriate and dementia specific	High attrition. Otherwise good

Key to terms and abbreviations: see Section 4.7.

Table 4.10 Summary of included studies (findings): effects of respite on carers of people with moderate or severe dementia

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/relevance**
Acton and Kang 2001	*Interventions to reduce burden, including respite*	*Some studies had no comparison*	*Carers of people with dementia*	*Burden*	*Weighted pooled effect size= –0.02 (–0.20 to 0.16), NS. A multi-component intervention made a significant difference*	*For combined effects — the range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect or a harmful effect — also the effect is not statistically significant*
Acton and Winter 2002	*Interventions for carers including respite*	*Some studies had no comparison*	*Family carers — at least some care recipients with dementia*	*Burden* *Stress* *Depression*	*Increased burden in one study, decreased stress in two, decreased depression in one, some other benefits also reported*	*Clinical importance cannot be evaluated using effect size but impact appears to be positive overall/R*
Arksey et al 2004	*Respite care or short-term breaks for carers*	*Not all studies had a comparator*	*Carers of people with dementia and care recipients*	*Stress, strain, depression, wellbeing, burden, sleep, coping*	*Day care — some evidence of mental health benefits. Institutional care — improved sleep and coping*	*Clinical importance cannot be evaluated using effect size although impacts are positive rather than negative/R*
Doody et al 2001	*Respite*	*All studies were RCTs*	*Carers of people with dementia*	*Carer health* *Wellbeing* *Coping*	*Inconsistent results.*	*Clinical importance is not evident/R*
Lee and Cameron 2004	*Respite*	*All studies were RCTs*	*Carers of people with dementia*	*Social support, burden, depression, anxiety,*	*No effect (from two RCTs)*	*No indication of clinically important effects/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
				symptoms		
Pinquart and Sorensen 2006	*All carer interventions including respite*	*All studies had untreated control*	*Carers of people with dementia and care recipients*	*Burden* *Depression* *Wellbeing*	*Burden (d=–0.26 [–0.39 to –0.12])* *Depression (d=–0.12, [–0.24 to 0.00])* *Wellbeing (d=0.27 [0.03 to 0.51])*	*Burden — clinically important benefit for full range of impacts — otherwise confidence interval includes clinically important benefits and/or estimates consistent with no effect/R*

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Roberts et al 2000	*Programs for people with dementia, including respite*	*Control or comparison for all*	*Carers of older people with dementia and care recipients*	*Burden*	*Very small reduction*	*Clinical importance cannot be evaluated using effect size but it seems likely to be unimportant/R*
Gaugler et al 2003a	Day care	No day care	Carers of people with dementia	Role overload Role captivity Worry Depression Anger	Interaction effects in regression models indicate that users experience greater reduction in role overload when memory problems diminish, but that non-users experience greater reduction in worry when ADLs improve	Clinical importance cannot be evaluated using effect size and findings provide little indication of overall clinical effect/R
Gaugler et al 2003b	Day care	No day care	Carers of people with dementia	Caregiving hours Perceived care demands At 3 months	Regression models indicate that users perceive problem behaviours and time spent on these to diminish more than nonusers $P \leq 0.05$	Clinical importance cannot be evaluated using effect size, but there is an indication of a benefit in the intervention group/R
Grant et al 2003	Ten days of in-home respite for up to 6 hours per day	No respite care	Carers of people with dementia (vulnerable because of high care needs and low respite and nonvulnerable in each group)	Epinephrine, norepinephrine, depression, anxiety, symptoms	Only significant effect was in circulating epinephrine level — significantly lowered in vulnerable carers receiving respite (ANOVA)	Clinical importance cannot be evaluated using effect size and effect difficult to assess for clinical importance as it is a surrogate outcome

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/relevance**
Zarit et al 1998	Day care centre visits at least twice weekly	No day care but small amounts of other respite	Carers of people with dementia	Captivity Overload Worry and strain Depression Anger Positive effect	Adjusting for T1 scores, overload ($P \leq 0.01$) and depression ($P \leq 0.05$) lower in IG at 3 and 12 months. Also worry ($P \leq 0.05$) and anger ($P \leq 0.05$) at 3 months	Clinical importance cannot be evaluated using effect size but there is an indication of benefits in the intervention group/R

Key to terms and abbreviations: see Section 4.7.

Table 4.11 Summary of included studies (methodology): effects of respite on carers of generally frail or unwell older adults

Reference	**Type of study**	**Level of evidence**	**n** **IG**	**n** **CG**	**Applicability**	**Generalisability**	**Quality**
Mason et al 2007	*SR*	*I/III-2 20 reviews, 22 studies (16 RCTs)*	*n/a*	*n/a*	*High*	*Older adults with cancer and frailty and those with dementia (stage unclear)*	*A very strong review* *Meta-analysis*
McNally 1999	*SR*	*I/III-2* *29 studies, 12 with comparators*	*n/a*	*n/a*	*High*	*Included all kinds of informal carers/recipients*	*Moderate*
Sorensen et al 2002	*SR*	*I/III-1* *78 studies, all with controls*	*n/a*	*n/a*	*High*	*Age appropriate. Included a variety of carers/recipients. Level of disability of care recipients often unknown*	*Good. Meta-analysis included*
Stoltz et al 2004	*SR*	*I/III-2* *26 studies with a variety of designs*	*n/a*	*n/a*	*High*	*Age appropriate. Variety of carers/recipients. Level of disability of care recipients unknown*	*Moderate*
Yin et al 2002	*SR*	*I/III-1 26 studies, RCTs and quasi*	*n/a*	*n/a*	*High — but education always mixed with other components*	*Age appropriate. Carers of frail elderly. Level of disability of care recipients unknown*	*Good. Meta-analysis included*
Baumgarten et al 2002	RCT	II	108	104	High	Very good	Good

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability**	**Generalisability**	**Quality**
Zank and Schacke 2002	Comparative study concurrent control	III-2	83	65	High	Age-appropriate sample from German population. Mean of four or more comorbidities. Dementia in 79% of IG and 63% of CG	High attrition, no power calculations

Key to terms and abbreviations: see Section 4.7.

Table 4.12 Summary of included studies (findings): effects of respite on carers of generally frail or unwell older adults

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Mason et al 2007	*Respite – day care, in home, host family, institutional, video, multidimensional*	*SRs and studies – uncontrolled studies included when controlled unavailable*	*Carers of people with frailty, cancer, or dementia, and care recipients*	*Carer burden, distress, physical & mental health, QOL, depression*	*Possible small effect on burden & carer mental or physical health. No robust evidence that respite helps care recipients. No evidence that it delays residential care placement*	*Burden: The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect, or a (slightly) harmful effect. Benefits were not statistically significant/R*
					From meta-analysis:	
					Burden, –0.03 (–0.19, 0.13) P=0.14 *Depression, –0.32 (–0.62, –0.02) P=0.04*	*Depression: clinically important benefits for the full range of estimates (but one end of the range is very close to no effect)/R*
McNally 1999	*Respite care*	*Only 12/29 studies had a comparison group*	*Broad range of carers*	*Wellbeing* *Stress/burden* *Symptoms* *Depression*	*Wellbeing and stress/burden — overall either no change or improvement. Symptoms — no change in population of interest. Depression and burden improved for a short period in one study*	*Clinical importance cannot be evaluated using effect size. Some indication that respite may help carers in terms of burden and depression sometimes/R*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/relevance**
Sorensen et al 2002	*Any intervention to improve carer health*	*Always untreated control*	*Family carers of older adults*	*Burden, depression, wellbeing*	*Burden (g= –0.30, –0.40 to –0.20, P<0.001), depression (g= –0.23, -0.36 to –0.10) P<0.001), wellbeing (g= 0.20, 0.06 to 0.34, P<0.01)* *Multicomponent approach augments effect on burden and wellbeing. RCTs show no impact from respite alone*	*Clinically important benefit for full range of impacts/R*
Stoltz et al 2004	*Support for carers (respite reported separately)*	*Single respite study seems to have involved no comparison*	*Family carers of elders sharing the same home*	*Stress, sleep, sense of freedom*	*Significant positive impact on all outcomes but stress returned to baseline after 2 weeks*	*Clinical importance cannot be evaluated using effect size but indications of a positive, short term, impact/R*
Yin et al 2002	*Interventions for family carers of frail elders*	*Always untreated control*	*Family carers of frail elders*	*Burden*	*Positive effect — mean effect sizes 0.842, 0.067, and 1.152 — no CIs*	*Clinically important benefit in three studies/R*
Baumgarten et al 2002	Day care centre visits at one or two days a week for 3 months	Waitlist	Family carers of frail elders	Burden	No effect	No effect detected/R
Zank and Schacke 2002	Day care centre visits at least twice weekly plus community service help in the home	Community service help only	Carers of older adults	Wellbeing Burden	Effect size 0.03 NS, no CIs 0.16 NS, no CIs	No effect detected/R No effect detected/R

Key to terms and abbreviations: see Section 4.7.

Table 4.13 Summary of included studies (methodology): disease-specific family carer education (cancer)

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability**	**Generalisability**	**Quality**
Harding and Higginson 2003	*SR*	*III-2* *22 studies, few RCTs*	*n/a*	*n/a*	*High*	*Age unknown. Stage of disease probably advanced — not explicitly stated*	*Process details limited. Limited keywords. Limited studies*
McMillan et al 2006	RCT	II	111	109/109	High	Population completely appropriate	Good, although attrition high and no power calculations

Key to terms and abbreviations: see Section 4.7.

Table 4.14 Summary of included studies (findings): disease-specific family carer education (cancer)

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Harding & Higginson 2003	*Interventions for informal carers of cancer and palliative care patients*	*Prospective comparators lacking in many studies*	*Carers of cancer and palliative care patients*	*No consistently examined outcomes*	*A few indications of positive benefits for some carers*	*No indication of effect size and very few findings/R*
McMillan et al. 2006	Hospice-standard care plus three visits to teach a coping skills intervention	One untreated control and one standard care plus three supportive visits	Family carers of patients with advanced cancer in the community	QOL	Effect –0.16 Improvement from intervention P=0.03	Clinically meaningful changes detected/R
				Burden of patient symptoms	0.28 improvement from intervention P=0.001	
				Caregiving task burden	–0.01 improvement from intervention P=0.04	
				Mastery	NS	
				Coping	NS	

Key to terms and abbreviations: see Section 4.7.

Table 4.15 Summary of included studies (methodology): family carer disease-specific education (dementia)

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Acton and Kang 2001	*SR*	*I/III-2* *24 studies, RCTs, quasi, and pre and post-test evaluations*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Large review and meta-analysis. Multiple interventions including education alone. Good quality*
Acton and Winter 2002	*SR*	*I/III-2* *73 studies, RCTs and others including pre and post-test evaluations*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear. Not all studies dementia specific*	*Large review of multiple interventions — 23 studies of education alone, 14 support and education*
Brodaty et al 2003	*SR*	*I/ III-2* *45 studies and 21 RCTs*	*n/a*	*n/a*	*Very high (Australian study)*	*Stage of dementia and age of care recipients often unclear*	*High quality with meta-analysis*
Cooke et al 2001	*SR*	*I/ III-2* *40 studies, 21 with control*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*High quality*
Doody et al 2001	*SR*	*I/III-2* *Approximately 175 studies including a wide variety of designs*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Methodology appropriate. Display of results not helpful*

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability in Australian system**	**Generalisability**	**Quality**
NCCMH 2006	*SR*	*I-III-2* *2 reviews and 25 trials*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Good*
Pinquart and Sorensen 2006	*SR*	*I/III-1* *127 studies with untreated controls*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Good. Meta-analysis*
Schulz et al 2005	*SR*	*51 RCTs*	*n/a*	*n/a*	*High*	*Stage of dementia of care recipients often unclear (age >60 years)*	*Good*
Selwood et al 2007	*SR*	*I/III-2* *62 studies with at least 27 RCTs*	*n/a*	*n/a*	*High*	*Stage of dementia and age of care recipients often unclear*	*Good*
Sorensen et al 2002	*SR*	*I/III-1* *78 studies, all with controls*	*n/a*	*n/a*	*High*	*Age appropriate. Included a variety of carers/recipients. Level of disability of care recipients often unknown*	*Good*
Stoltz et al 2004	*SR*	*I/III-2* *26 studies with a variety of designs*	*n/a*	*n/a*	*High*	*Age appropriate. Variety of carers/recipients. Level of disability of care recipients unknown.*	*Moderate*

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Belle et al 2006	RCT	II	323	319	High	Limited owing to population cultural group mix	Good
Bourgeois et al 1997	Concurrent control study	III-2	7	7	High	Apparently, but a very small study	Very low sample size, no baseline comparisons
Bourgeois et al 2002	RCT	II	22/21	20	High	Good when patients have behaviour problems	No power calculations, small sample
Buckwalter et al 1999	RCT	II	132	108	High	Good	Randomisation not specified
Burgio et al 2003	RCT	II	70	70	High	May be limited due to cultural differences	Control group had information materials, no details of power calculations or randomisation
Burns et al 2003	RCT	II	82	85	High	Good	No untreated control, high drop-out but 2-year intervention, no power calculations
Callahan et al 2006	RCT	II	84	69	High but intervention not only education	Good	Loss to follow up was 30%, no power calculations
Chang 1999	RCT	II	31	34	High	Good (but all carers female)	Good

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Davis et al 2004	RCT	II	23/24	24	High	Good when patients have behaviour problems	High loss at follow up especially in one group
Done and Thomas 2001	RCT	II	26	15	High	Good	No power calculations, small sample, unknown baseline equivalence
Garand et al 2002	RCT	II	Not found	Not found	Uncertain	Good	Small sample, no power calculations, baseline differences, group numbers lacking
Gerdner et al 2002	RCT	II	132	102	High	Good	54% attrition over 12 months. Assessors were blinded to group Randomisation not specified
Gitlin et al 2001 (short-term outcomes)	RCT	II	100	102	High	Good	Control situation not described. No power analysis. Randomisation not specified. Otherwise good
Gitlin et al 2005 (long-term outcomes	RCT	II	100	102	High	Good	Control situation not described. No power analysis. Randomisation not specified. Otherwise good

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Gitlin et al 2003	Meta-analysis of multisite intervention effects in six RCTs	II	780	442	This huge program would be costly to implement	Addresses cultural groups in the United States but still seems reasonable to generalise given large sample and diversity	High
Hébert et al 2003	RCT	II	72	72	High	Good when carer has moderate to severe burden	Drop-out over 4 months approximately 20%, so probably underpowered
Hepburn et al 2007	RCT	II	30	22	High	Good	Small sample and no power analysis. Randomisation not specified
Hepburn et al 2001	RCT	II	72	45	High	Good	Good
Huang et al 2003	Pseudo-RCT	III-1	24	24	High	Taiwanese study in similar population. Patients have behaviour problems	Small sample, otherwise good
Marriott et al 2000	RCT	II	14	14/14	High	Good when carer has psychological morbidity	Method of assignment not detailed, otherwise good
Martin-Cook et al 2003	RCT	II	19	18	High	Good when patients have behaviour problems	Small sample, no power calculations, method of assignment unclear

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
McCurry et al 1998	RCT	II	7	5	High	Only to carers with sleep problems — also numbers so small this is hard to judge	Tiny sample and power calculations not discussed. Randomisation not explained
Nobili et al 2004	RCT	II	34	35	High	Good when patients have behaviour problems	Very high drop-out rate, no power calculations. Randomisation not explained
Riordan and Bennett 1998	Nonrandomised trial	III-2	19	19	High	Good	No power calculations and small sample
Ripich et al 1998	Nonrandomised trial	III-2	19	18	High	Good	No power calculations and small sample
Stolley et al 2002	RCT	II	133	108	High	Moderate — some unknown diagnoses	Probably underpowered due to attrition
Teri et al 1997	RCT	II	23/19	10/20	High	Good	Small group sizes, randomisation not specified
Teri et al 2005	RCT	II	47	48	High	Good	Quite a high drop-out rate
Wright et al 2001	RCT	II	68	25	High	Good	Good but no power calculations, quite small sample, high drop-out rate

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Zanetti et al 1998	Comparative study	III-2	12	11	High	Italian — study in similar population	Very small study without effect size comparisons between groups, no randomisation, preliminary indications only

Key to terms and abbreviations: see Section 4.7.

Table 4.16 Summary pf included studies (findings): family carer disease-specific education (dementia)

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Acton and Kang 2001	*Education and psycho-education (and others)*	*Mainly usual care*	*Carers of people with dementia*	*Burden*	*No effect on burden. Effect size from –0.08 to –0.52 NS*	*Minimal clinical impact upon burden, not statistically significant/R*
Acton and Winter 2002	*Education ± support (and others)*	*Only some studies had a control- mainly usual care*	*Family carers – at least some care recipients with dementia*	*Burden* *Stress* *Coping*	*Inconsistent – including an increase in burden (one pre-post study)*	*No consistent impact determined – one indication of possible harm/R*
Brodaty et al 2003	*Education and training – with other components on 18/19 occasions*	*All studies had a control – details not provided*	*Family carers of people diagnosed with advanced dementia*	*Psychological morbidity, burden, mood*	*Positive overall effect on most outcomes (no impact on burden)* *Weighted average 0.31 and 0.32 (low) for psychological morbidity, mood. Involvement of the patient and the carer predicted a positive outcome*	*Indication of clinically important benefits particularly when patient and carer both involved/R*
Cooke et al 2001	*General education, social skills training, practical skills & other psychosocial*	*Only some studies had a control*	*Carers of people with dementia*	*Wellbeing burden* *Social outcomes*	*Improved knowledge only led to improved burden in 3/11 studies (one with a control group*	*Effect limited, not quantified/R*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Doody et al 2001	*Education and training (and other strategies)*	*All studies were RCTs – comparator unclear*	*Carers of people with dementia*	*Placement* *Carer health* *Wellbeing* *Coping*	*Some short term benefits in coping, education + support delayed placement (6 studies)improved wellbeing (4)*	*Effect not quantified/R*
NCCMH 2006	*Education relevant to dementia*	*Generally no education*	*Carers of people with dementia*	*Variety of health outcomes including burden and depression*	*Findings from reviews said to indicate at least a small intervention effect. Variety of effect sizes reported*	*Certainly overall indications of a clinically important effect/R*
Pinquart and Sorensen 2006	*Information and/or education about dementia(and other strategies)*	*All studies had untreated control*	*Carers of people with dementia*	*Burden, depression, wellbeing*	*Positive impact on all except when only information provision*	*A clinically important benefit for the full range of plausible estimates/R*
					Active education effect: *burden, –0.20 (–0.32, –0.07) P<0.01*	*As above*
					depression, –0.36 (–0.58, –0.15) P<0.001	*As above*
					wellbeing, 0.21 (0.00, 0.43) P<0.05	*The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no*

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
						effect/R
Schulz et al 2005	*Education/counselling/skills training*	*All studies were RCTs*	*Carers of older adults with dementia from multiple causes including stroke*	*Depression* *Burden* *Anxiety hostility* *Anger* *Stress*	*Consistent positive benefits*	*Effect not quantified/R*
Selwood et al 2007	*Education about dementia plus behaviour management (and other strategies)*	*Most studies were RCTs (44 studies overall)- comparators unclear*	*Carers of people with dementia*	*Psychological health, burden, stress, depression, distress*	*Information only and group teaching of behaviour management – no benefits and some harms*	*Effect not quantified but some indication of harms as well as no effect – few indications of benefits/R*
					Individual behaviour management – reduced depression for longer interventions. One impact on burden	
Sorensen et al 2002	*Any intervention to improve carer health – education identified*	*Always untreated control*	*Family carers of older adults*	*Burden, depression, wellbeing, uplifts, coping*	*Improved burden, depression, wellbeing. RCTs alone failed to show this effect for wellbeing*	*A clinically important benefit for the full range of plausible estimates/R*
					Heterogeneity of effect sizes ranged from 0.12	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
					to 0.53 SD units	
Stoltz et al 2004	*Education plus support (and other support interventions)*	*Only controlled studies reported for education (no details)*	*Family carers of elders sharing the same home*	*Depression* *Anxiety* *QOL* *Coping* *Caregiving competence* *Preparedness for caregiving*	*From one RCT and two other controlled studies, no change in depression, anxiety, QOL in RCT. Positive findings in other studies for other outcomes*	*Effect not quantified/R*
Belle et al 2006	Carer education in home and per phone	Educational materials and check in phone calls	Family carer of person with dementia (Latino, African American, Caucasian)	Depression Burden Self-care	Positive effects across all these domains of QOL, except in African Americans (some domains)	Clinically meaningful drop in at least depression, as described by author/R

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/ relevance**
Bourgeois et al 1997	Behaviour focused skills training workshop + 11 home visits	Caregiver focused affective self management training	Primary carers living with person with dementia with behavioural issues	Self-efficacy	Positive effect at follow-up	Not quantified (*n*=14)/R
Bourgeois et al 2002	IG1- training to change pt behaviour IG2 – training to change coping behaviours	Weekly support visit	Carers of people with dementia and behavioural issues	Mood Strain Anger Anxiety Self-efficacy Stress	IG1 led to improvements in all areas except anger and anxiety IG2 led to improvements in mood and strain	Effect size not reported/R
Buckwalter et al 1999	Training in the home with follow up phone calls	Routine information	Carers of people with dementia/memory problems	Depression and mood state	Positive impact on both	Effect size not reported/R
Burgio et al 2003	Shill training w/shop then home training in behaviour management	Informational materials	Carers of people with dementia	Wellbeing Care giver appraisal	No significant difference	No effect detected/R
Burns et al 2003	Education in behaviour care plus stress reduction and phone calls	Education in behaviour care only and phone calls	Carers living with person with dementia	Wellbeing Depression Bothered by behaviour	Significant improvement in wellbeing, otherwise no effect	No effect size reported but indications of benefit/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Callahan et al 2006	Carer and patient education (plus medication for patient and carer support)	Augmented usual care	Carers of people with dementia	Carer stress	Lower in IG than in CG at 12 months but not at 18 months. Drop in stress 0–12 months for IG, rise in CG	No effect size reported but indications of benefit/R
Chang 1999	Video training + CBT+ phone support	Attention only phone calls	Carers of people with dementia	Depression Anxiety Emotional health	Reduction in depression	Interaction effect reported so effect size not indicated/R
Davis et al 2004	IG1+ telephone training IG2 = in home training (high attrition in I1)	One friendly home visit + 12 phone calls	Carers of people with dementia and behavioural issues	Burden Distress Depression	Most consistent reduction in burden and distress IG2 but some impact from both control and IG1 No change for depression. Effect size 0.58 for burden and 0.47 for distress in IG1	Clinically important effect size but confidence intervals not reported/R
Done and Thomas 2001	Carer training in communication with person with dementia	Booklet training	Home carer of person with dementia Note: age of care recipient NOT indicated –almost certain to be mean of 70+ years	Stress	No significant difference	No evidence of effect detected/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Garand et al 2002	Carer education	No carer education – otherwise same	Home carer of person with dementia (medication and alcohol restrictions)	Distress NK-cell activity T-cell activity	Impact upon T-cell immune function but not on NK-cell activity or distress reports	No effect size reported/Evidence of effect on proven surrogate outcome for IG
Gerdner et al 2002	In home training (4 hours) plus referrals	In home visits, information, referrals	Carers of people with dementia/memory problems	Response to behaviours Response to ADL	Trend in benefits over time in terms of response to behaviours. Only spouses responded better to ADL	No effect size reported/R
Gitlin et al 2001	Carer education and skills building	Usual care	Primary carers living with person with dementia	Self-efficacy and upset	No effect for either	No effect detected/R
Gitlin et al 2005	Carer education and skills building	Usual care	Primary carers living with person with dementia	Upset Perceived affect change Task strategy use	6 months + impact on upset, not at 12 months. Affect improvement at 6 months, sustained at 12. Task strategy only improved in subgroup	‘Meaningful’ effect according to author/R
Gitlin et al 2003	Six interventions, most including carer education	Varies – usually minimal support	Family carer of person with dementia in diverse sites in the United States	Burden Depression	6-month findings: Burden reduced, no effect on depression. Burden – small effect (1.40)	Clinically meaningful effect detected/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Hébert et al 2003	Education program of 2 hours per week for 15 weeks	Referred to existing support group program	Family carer of person with dementia with mod–severe burden; age of care recipient NOT indicated –almost certain to be mean of 70+ years	Reactions to behaviours Burden Anxiety Psychiatric symptoms Support perceptions Desire to institutionalise	Positive significant impact on reactions to behaviours only. No impact on others including burden	No effect size reported/R
Hepburn et al 2007	Education supported by video and manual	Not explained	Family carers of older adults with dementia	Role deprivation and captivity Carer competence and mastery. Loss of self. Carer distress	Improved carer mastery, loss of self, and distress	No effect size reported/R
Hepburn et al 2001	Weekly carer training for 7 weeks in workshop	Waitlist control	Family carer of person with dementia	Carer beliefs, depression, burden, reaction to problems	Burden and depression decreased, also response to behaviour improved	No effect size reported/R
Huang et al 2003	Two sessions of in home training plus 2 follow up phone calls	Information leaflets plus 2 social phone calls	Family carer of person with dementia who had agitation	Self-efficacy	Significant improvement	No effect size reported/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Marriott et al 2000	Carer education, stress management, coping skills training, cathartic interview	Cathartic interview only OR No interview or other elements	Family carer of person with dementia – carer has psychological morbidity	General health Depression	Intervention group improved at post test and follow up on both measures. General health 'caseness' was lower in IG. For reduction in 'cases' no needed to treat = 2	Clinically meaningful effect reported/R
Martin-Cook et al 2003	Two group education sessions	Usual care	Family carers of people with dementia who had behavioural disturbance	Resentment Depression	No significant change	No effect detected/R
McCurry et al 1998	Six weekly group education sessions related to sleep and caring for a person with dementia	Wait list control	Family carer of older person with dementia. Carer had sleep problems	Sleep Mood Reaction to behaviours	Sleep improved post test and at 3 months – no other changes.	No effect size reported/R
Nobili et al 2004	Psychologist and occupational therapist visit plus info manual	Contact numbers and limited information	Family carer of person with dementia who had behavioural issues	Stress score Time spent caring	No effect	No effect detected/R
Riordan and Bennett 1998	One year of tailored help including education	Regular domiciliary services	Family carer of person with dementia	Stress, problems	No gains for carers	No effect detected/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Ripich et al 1998	Eight hours of group training over 4 weeks	Usual care	Carers of people with dementia	Wellbeing Depression Health Hassles	Improvement in communication hassles. Otherwise no significant difference	Small clinically important benefit/R
Stolley et al 2002	Two weekly educational/training sessions, written materials, referrals	Two home visits with information	Carers of people with dementia	Burden Caregiver appraisal Mastery	Impact of caregiving decreased, burden increased and then dropped below control, mastery showed no difference	No effect size reported/R
Teri et al 1997	I1: Teaching behavioural strategies I2: teaching problem solving	CG1:info, advice, support CG2: no contact	Carers of people with dementia	Depression	Improvement in carer depression retained for at least 6 months	No effect size reported/R
Teri et al 2005	Weekly education sessions x 8 plus 4 monthly phone calls	Routine care, advice, support	Carers of people with dementia who had behavioural disturbance	Burden	–4.2 (–7.6, 0)	The range of estimates defined by the confidence interval includes clinically important effects but this range is also compatible with no effect in some instances/R
				Depression	–2.3 (–0.6, 0)	
				Reaction to behaviour	–3.2 (–6.1, –0.2)	
				Sleep	–1.1 (–2.2, –0.1)	

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/ relevance
Wright et al 2001	Education with counselling – 5 sessions via visits and phone over 12 months	Phone calls only	Family carers of people with dementia	Stress Depression Physical health	No change	No effect detected/R
Zanetti et al 1998	Education about dementia and prevention of behavioural disturbance	No education	Carers of people with dementia who had behavioural disturbance	Depression, stress, QOL	Improvement in stress and QOL, not depression	Very small study providing preliminary indications/R

Key to terms and abbreviations: see Section 4.7.

Table 4.17 Summary of included studies (methodology): disease-specific family education (stroke)

Reference	**Type of study**	**Level of evidence**	**n IG**	**n CG**	**Applicability in Australian system**	**Generalisability**	**Quality**
Bhogal et al 2003	*SR*	*I/III-2* *10 RCTs for this topic (other designs for other topics)*	*n/a*	*n/a*	*High*	*Stroke specific. Age and level of disability not always identified*	*Good*
Forster et al 2001	*SR*	*I/III-1* *9 RCT and quasi*	*n/a*	*n/a*	*High*	*Stroke specific. Age and level of disability not always identified*	*Good*
Lee et al 2007	*SR*	*3 RCTs*	*n/a*	*n/a*	*High*	*Age appropriate but likely to include wide range of disability in care recipients*	*Good. Meta-analysis included*
Visser-Meily et al 2005	*SR*	*I/III-2* *22 studies, 18 RCTs*	*n/a*	*n/a*	*High*	*Age appropriate. Stroke specific. Level of disability often unknown*	*Limited search strategy*
Clark et al 2003	RCT	II	32	30	High — but education mixed with other components	Yes. Stroke specific. No cognitive or severe language problem	Control group not described and no blinding. Otherwise good but small sample, probably underpowered
Hartke and King 2003	RCT	II	43	45	High — but education mixed with other components	Yes. Stroke specific	Lack of baseline equivalence. No power calculation. Probably underpowered

Reference	Type of study	Level of evidence	n IG	n CG	Applicability in Australian system	Generalisability	Quality
Mant et al 2000	RCT	II	258	262	High — but information mixed with other components	Yes. Stroke specific	Treatment individualised by manager — replication problematic
Rodgers et al 1999	RCT	II	107	69	Probably not feasible due to attendance issues	Yes. Stroke specific	Extremely high drop-out rate. Underpowered. Intervention attendance poor
Smith et al 2004	RCT	II	49	48	High but significant resource issues	Yes. Stroke specific	Unclear difference in education between groups

Key to terms and abbreviations: see Section 4.7.

Table 4.18 Summary of included studies (findings): disease-specific family education (stroke)

Reference	**Intervention**	**Comparator**	**Participants**	**Relevant outcomes**	**Results**	**Clinical importance/relevance**
Bhogal et al 2003	*Family carer education relevant to community reintegration after stroke*	*Various although usual care in most instances*	*Family carers of adults with radiologically confirmed CVA*	*Carer health*	*Benefits for education plus counselling (4/5 RCTs). None for information packages/workbooks alone (2/2 RCTs)*	*Effect sizes not reported but clear indications of benefits for education with counselling/R*
Forster et al 2001	*Information/education to improve outcomes — not part of rehabilitation program*	*Generally usual care*	*Family carers of stroke patients (also patients)*	*Carer health*	*Some benefits but inconsistent. Perceived health, QOL, use of services consistently unchanged. No impact from information alone*	*Effect sizes not reported but clear indications of benefits for education when this is not just information provision/R*
Lee et al 2007	*Any intervention to improve carer health — education identified*	*Generally usual care*	*Family carers of stroke patients — older patients in studies referred to here*	*Carer wellbeing*	*Data pooling showed benefits from education. MWEs=0.35 (0.09, 0.61) P<0.01*	*Clinically important benefit for full range of plausible impacts — small to moderate effect size/R*
Visser-Meily et al 2005	*Any intervention to improve carer health — education identified*	*Uncontrolled trials as well as RCTs*	*Family carers of stroke patients — patients aged at least 60 years*	*Carer health*	*Three of 22 studies reported varied health benefits. One reported a negative impact on social function*	*Effect sizes not reported and most findings indicate no effect/R*
Clark et al 2003	Information pack and three visits from counsellor	No information or counselling	Spousal carers of stroke patients	Family functioning and carer health	Family functioning improved at 6 month. No impact on carer health	Shows no effect on carer health/R

Reference	Intervention	Comparator	Participants	Relevant outcomes	Results	Clinical importance/relevance
Hartke and King 2003	Manual plus meetings to discuss patient progress for dyads	Usual care including stroke leaflets	Family carers of stroke patients	Burden, depression, loneliness, competence, stress	Positive impact on burden ($P<0.05$) and carer competence ($P<0.05$) (comparison of change scores). Otherwise no impact	Effect size not shown and range of likely impacts not indicated by confidence intervals but benefits were found in this study/R
Mant et al 2000	Information leaflets plus support.	Usual care — not described	Family carers of stroke patients	Emotional health, social activity, QOL	Positive impact on social activity, energy, mental health, pain, physical function, health perception, QOL as identified by comparison of 6 month scores between the groups	Clinical importance cannot be evaluated using effect size/R
Rodgers et al 1999	Stroke education for patient/family dyads. Poorly attended	Usual care including information sheets and hotline access	Family carers of stroke patients	Perceived health and function	Only difference at Time 2 was poorer social functioning in IG. Comparisons seem to be of post-test scores only	Clinical importance cannot be evaluated using effect size. Negative effect detected/R
Smith et al 2004	Stroke manual plus support meetings	Usual care including information sheets	Family carers of stroke patients	General health	No difference between groups	No effect detected/R

Key to terms and abbreviations: see Section 4.7.

4.8 References

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Chapter 5 Advance health care planning and advance health care directives

An important ideal of a palliative approach to care for older people in the community is to provide care that matches each person’s wishes. When an older person has been able to express their wishes about future health care and medical treatment, their doctors, community care providers and family members can all feel more confident that they will be able to meet the person’s needs in the way that they would prefer.

This chapter defines advance health care plans and advance health care directives, explores some of the barriers to their use, and determines the best ways to promote them. The chapter is based on an examination of reviews of research (see Appendix M for included studies) but also incorporates information about the current situation in Australia.

5.1 What are advance health care plans and advance health care directives?

Advance health care directives are designed to be used when people are unable to make decisions for themselves (Wilkinson et al 2007); they extend the person’s autonomy, allowing them to continue to stipulate their wishes and direct the type of care that they would prefer (Baker 2002). People often express wishes about treatments, such as cardiopulmonary resuscitation, mechanical ventilation, artificial feeding and hydration, the use of medications (eg antibiotics), and surgical procedures. However, older adults sometimes prefer to address issues such as where their care may be provided towards the end of life (AF Street, Austin Health Clinical School of Nursing, pers comm, 8 May 2008).

An advance health care directive is underpinned by an advance health care plan and this, in turn, is based on discussions about the person’s values, beliefs and preferences with respect to possible future health care options (Wilkinson et al 2007). Each step of this process, outlined below, is valuable (Allen and Shuster 2002):

- Discussions promote important communication on salient issues and facilitate an awareness of the person’s perspective regarding their care and treatment.
- Plans resulting from such discussions communicate decisions that have been made.
- Advance health care directives then formalise these plans.

> ‘Advance health care planning is the process by which people can consider their values and goals in discussion with their family members and the health professionals providing their care and treatment; preferences for future health care are then made known.’ (Tulsky 2005)

In Australia, health care professionals should always be aware of their local situation regarding the legally binding nature of advance health care directives because of the likely relevance of state and territory legislation.

An advance health care directive is only valid when it is made voluntarily and with clear and definite knowledge and understanding of the options available (Wilkinson et al 2007). People may make these directives when they are young and healthy. However, for frail or unwell older adults, the range of likely health driven scenarios is more limited and discussion can be more focused. People need to be fully informed about their diagnosis and the likely course of their disease or illness; they also need to understand possible choices between different types of care and treatments (Allen and Shuster 2002). The health care team should explain the risks and benefits of all options, including options for palliative and supportive care (Wilkinson et al 2007). The directive should also be completed when the person is determined to be competent to make relevant decisions in both legal and medical terms (Allen and Shuster 2002). Determining competence is a complex issue. Many older adults may not be able to express their wishes about complex medical treatment but can still express their desires for health and social care (AF Street, Austin Health Clinical School of Nursing, pers comm, 8 May 2008).

The Capacity Toolkit, a resource for those assessing the capacity of people to make decisions, is available from the New South Wales Attorney General's Department:
Website: http://wwwlawlink.nsw.gov.au (Lawlink agencies >Diversity services>Capacity toolkit)

Please be aware, however, that state laws may vary in this area.

An older person making an advance health care directive can nominate a proxy decision maker to advocate for medical or care decisions on their behalf. This advocacy may be particularly useful if it is not clear what issues may arise in the future or when an event is not covered by the directive (Lyness 2004). Wilkinson et al (2007) report evidence showing that proxy decision makers are more accurate than doctors when predicting people's choices. Also, a study by Beer (2004) developed Australian recommendations from a review of end-of-life care for older adults in hospitals. This author found that older adults, in particular, need proxy decision makers because they are often unable to express their preferences when seriously ill in a hospital setting. However, appointing a proxy is not essential and may not always be acceptable. For example, in an American study that looked at issues related to advance health care planning that affected minority groups, some people were reluctant to appoint a proxy because they felt that it was culturally inappropriate (Baker 2002).

5.2 Barriers to implementation

Many people with a life-limiting illness prefer to be given honest information about end-of-life issues early in the course of their illness (Siegler and Levin 2000, Ramsaroop et al 2007). Also, many others wish to avoid 'inappropriate prolongation of dying' (Singer et al 1999, cited in Rutledge et al 2001, p 2) and to maintain some sense of control at this time (Rutledge et al 2001). Yet, despite this need for communication about the end of life, such discussions are difficult (Riley et al 1999) and take place only rarely (Wilkinson et al 2007). Health care providers and their clients can both be reluctant to broach the topic of death and aspects of end-of-life care. Older adults may assume that their families or health care providers will know their preferences without this discussion taking place. Older adults may also perceive completing an advance health care directive to be difficult, or to be a step that should be initiated only by a health care professional (Wilkinson et al 2007). In fact, some studies suggest that the reluctance of health care professionals to discuss advance health care planning is the main barrier to writing an advance health care directive (Street and Ottmann 2006). However, people may welcome discussions about treatment options but not wish to complete advance health care directives, preferring informed family members and providers to make decisions for them when the time comes (Wilkinson et al 2007).

‘Advance care planning facilitates ethical decision making and helps patients to maintain their autonomy and doctors to make better decisions for individuals they do not know’ (Clarnette 2000, p 19).

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a key end-of-life communication study from the United States, was designed to encourage people to complete advance health care directives. However, as Street and Ottmann (2006) note, it failed to meet its goal. The failure of such a well-resourced initiative caused researchers to examine people’s basic assumptions underpinning their decisions to use advance health care directives. Researchers found that there was generally poor-quality communication around advance health care planning and a need for better staff education (Street and Ottmann 2006).

Additionally, research has shown that patients’ preferences change over time, often as their situation changes. If advance health care directives are seen as failing to take account of the person’s health and social situation at any given time, this perception becomes a barrier to their completion (Wilkinson et al 2007). Studies have also reported administrative issues in the application of advance health care directives, including a lack of continuity in care, plans not being made available when needed, a lack of understanding of directives across settings, and a lack of routine reviewing to make sure plans take into account changes in the patient’s situation (Street and Ottmann 2006, Wilkinson et al 2007).

Other barriers to completing advance health care directives may include the following issues or beliefs:

- people need to be literate and have good eyesight to complete the paperwork (Baker 2002)
- many people think that costly legal and medical advice is needed, making them less likely to complete an advance health care directive (Brown 2003)
- advance health care directives provide guidance for only a limited set of future medical possibilities, which may or may not apply to the patient’s situation (Wilkinson et al 2007)
- the health care professionals responsible for implementing advance health care directives need additional education, support and guidelines (Mahoney et al 1999, Riley et al 1999, Wilkinson et al 2007) because they share the responsibility of ensuring that people’s preferences are formulated, communicated and honoured (Riley et al 1999).

Consistent with at least some of these findings, after 20 years of intervention research in the United States, most people still do not complete advance health care directives (Wilkinson et al 2007). Furthermore, in the United States, advance health care directives are not easy to use when they are completed, and therefore have a limited impact (Wilkinson et al 2007).

5.3 Overcoming these barriers

Ideally, advance health care directives are the product of a comprehensive interactive process between the person, their family and health care professionals that help to determine the course of the patient’s care (Wilkinson et al 2007).

Street and Ottmann (2006) describe a number of successful initiatives for implementing advance health care plans and advance health care directives in recent years in the United more focused. People need to be fully informed about their diagnosis and the likely course of their disease or illness; they also need to understand possible choices between different types of care and treatments (Allen and Shuster 2002). The health care team should explain the risks and benefits of all options, including options for palliative and supportive care (Wilkinson et al 2007). The directive should also be completed when the person is determined to be competent to make relevant decisions in both legal and medical terms (Allen and Shuster 2002). Determining competence is a complex issue. Many older adults may not be able to express their wishes about complex medical treatment but can still express their desires for health and social care (AF Street, Austin Health Clinical School of Nursing, pers comm, 8 May 2008).

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Additionally, research has shown that patients’ preferences change over time, often as their situation changes. If advance health care directives are seen as failing to take account of the person’s health and social situation at any given time, this perception becomes a barrier to their completion (Wilkinson et al 2007). Studies have also reported administrative issues in the application of advance health care directives, including a lack of continuity in care, plans not being made available when needed, a lack of understanding of directives across settings, and a lack of routine reviewing to make sure plans take into account changes in the patient’s situation (Street and Ottmann 2006, Wilkinson et al 2007).

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5.3 Overcoming these barriers

Ideally, advance health care directives are the product of a comprehensive interactive process between the person, their family and health care professionals that help to determine the course of the patient’s care (Wilkinson et al 2007).

Street and Ottmann (2006) describe a number of successful initiatives for implementing advance health care plans and advance health care directives in recent years in the United

States. Factors that appeared to contribute to the success of these initiatives included community involvement, a coherent approach across services and settings, and the provision of a set of tools to increase the accessibility of health care professionals to patients' wishes (although the initiatives were evaluated in a way that made it difficult to see exactly what factors were most helpful). Street and Ottmann (2006) also identified five prerequisites that need to be in place to ensure advance health care planning is implemented:

- ongoing discussions about advance health care planning among health care professionals, older people and families
- systemic processes to support advance health care planning across settings
- the normalisation of advance health care planning within clinical practice
- the involvement of particular cultural groups and of the wider community
- education and research to guide the process.

Other review findings emphasise acknowledging the uniqueness of each discussion about future care options, not just because of the person's health status but because of their background and perspective. For example, people with limited trust in the medical system may be less inclined to take part in advance health care planning, and some cultural groups may have particular difficulties (Wilkinson et al 2007). Cultural experiences affect preferences (Riley et al 1999), as does the degree of the person's adoption of their resident society (Kwak and Haley 2005). In some cases, it may be culturally inappropriate to discuss end-of-life issues (Ersek et al 1998). Therefore, an understanding of relevant cultural perspectives is a prerequisite for any discussions on this topic (Ersek et al 1998, Ott 1999, Haley et al 2002).

Specific considerations are needed for advance health care planning with Aboriginal and Torres Strait Islander people. Health care providers need to be mindful of confusion or conflict in differing values, consider respect and decency, and take into account cultural protocols and customs (Nayler 2006).

The Australian Government Department of Health and Ageing (DoHA) has developed a useful resource for palliative care for Aboriginal and Torres Strait Islander peoples. This resource provides information relevant to advance health care planning:

DoHA (2004). *Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander Peoples — Resource*. Wodonga TAFE, Mungabareena Aboriginal Corporation and Mercy Health Service, DoHA, Canberra.
Available from the CareSearch website at: http://www.caresearch.com.au (What is Palliative Care>National Palliative Care Program>Indigenous Palliative Care Project)

The Respecting Patient Choices Program has also produced a document to guide health care professionals in advance health care planning with Aboriginal and Torres Strait Islander peoples:

Nayler D (2006). *Respecting Patient Choices: Advance Care Planning with Aboriginals and Torres Strait Islanders*, Respecting Patient Choices Program and Austin Health.
Available from the CareSearch website at: http://www.caresearch.com.au (What is Palliative Care>National Palliative Care Program>Respecting Patient Choices)

Currently in Australia, there is growing interest in the topics of advance health care planning and advance health care directives; however, according to Cartwright (2007), a good deal of confusion remains. At least two programs from overseas have been used to guide practice in recent years: ‘Let Me Decide’ (described in Caplan et al 2006) and ‘Respecting Patient Choices’. The Respecting Patient Choices program has a range of resources available via its website (see below). Evaluations of both programs within Australia are somewhat limited but do indicate benefits (Lee et al 2003, Caplan 2006).

A number of websites have links that are particularly helpful when attempting to navigate the current situation regarding advance health care planning and advance health care directives across Australia. For example:

Alzheimer’s Australia website:
http://www.alzheimers.org.au (Legal Planning and Dementia)

Australian General Practice Network website:
via the Aged Care Panels Initiative’s Aged Care Resources Directory
http://www.agpn.com.au (Programs>Aged Care Initiative>GPs working in residential aged care: a guide>Aged Care Resource Directory>Advance Care Directives)

Royal Australian College of General Practice website:
http://www.racgp.org.au (Clinical resources>Guidelines)

One of the most widely known relevant initiatives in progress in this area at present is ‘Respecting Patient Choices’:
http://www.respectingpatientchoices.org.au

5.4 Conclusion

In summary, advance health care planning involves the person’s discussion about their future health care options with their family and doctor so that their wishes are known in the event that health care is needed when they are no longer able to express these themselves. Advance health care directives are tools to formalise and document advance health care plans so that they are more likely to be implemented. A proxy decision maker may also be appointed to provide guidance on issues that are not explicitly covered in the advance health care directive. A number of barriers to completing advance health care plans and directives have been identified from the literature, including:

- health care professionals’ reluctance to discuss advance health care directives
- poor communication about advance health care directives
- administration difficulties
- lack of flexibility in advance health care directives (to adapt to people’s changes in circumstance or preferences)
- lack of education and support for health care professionals.

Overcoming these barriers so that advance health care directives are adopted widely relies on support within the health care system, as well as making it a habit to address barriers during routine clinical practice. In Australia, at least two programs from overseas have been used in recent years, with some success. Although some confusion still exists about advance health care directives, the extent to which older adults might expect to be supported in developing advance health care plans and/or directives, with all the potential benefits that this entails, is improving. Furthermore, community health care professionals can each play their part in providing such support by remaining aware of legislation and practice initiatives and actively promoting organisational policies that advocate for advance health care planning.

5.5 Good practice points — advance health care planning and advance health care directives

Discussing plans and directives

Discussion about end-of-life care is appreciated by many older people and their families and is generally best early in the palliative care process (see Sections 5.1 and 5.3).

5.1 An understanding of cultural and individual perspectives is necessary before initiating discussions relating to advance health care planning.

5.2 Discussion about end-of-life care is likely to be appreciated by many older adults, depending on their individual perspectives. There is more opportunity to develop a comprehensive advance health care plan and/or directive when discussion occurs earlier rather than later (ie before the matter is urgent).

5.3 A prompt to initiate a conversation around health care plans and directives may be when a life-limiting illness is diagnosed or when the older adult is becoming frail. Ideally, a health care professional who knows the older person and their health issues well (eg the GP) will take on this role so that care and treatment options can be explained in a way that is sensitive to the situation of the older adult.

5.4 Palliative care options should be included in discussions with all older adults because advance health care planning is an ongoing communication process about goals, values and treatment options tailored to each person’s health care needs and life circumstances. Options may also include ‘time-limited trials’, in which treatments are discontinued if ineffective within a limited period (Wilkinson et al 2007).

5.5 In the case of older adults with dementia, discussions about future care and treatment early in the illness that are approached with extreme sensitivity can empower the older person. Alzheimer’s Australia provides resources that can help in this instance.

5.6 Older adults should have the opportunity to have a family member or friend with them when discussing advance health care plans and/or directives.

Developing plans and directives

Developing advance health care plans and directives uses the information from discussions with the older person and their family or carer to communicate decisions that have been made (see Section 5.3).

5.7 Information provided when preparing an advance health care plan or advance health care directive needs to be explained in plain English and provision should be made for older adults with literacy, vision, or hearing limitations, or for whom English is not their first language, to make sure they completely understand all information.

5.8 Advance health care planning should include:

receiving appropriate information
reflecting on personal goals, values and choices
consulting and discussing with health care providers, family members and important others
understanding current and future choices that are available
appointing a proxy (substitute) decision maker
communicating wishes and values.

5.9 Refer to specialist resources for initiating advance health care planning with people from culturally and linguistically diverse backgrounds (see Chapter 10) and Aboriginal and Torres Strait Islander people (see Chapter 9).

5.10 Additional education in advance health care planning may be needed by some health care professionals. This education can help to make sure that health care professionals have adequate skills and sensibilities, plus confidence, when addressing advance health care planning issues and developing advance health care directives.

Using and reviewing plans and directives

Patients' preferences may change over time; therefore, plans and directives should be reviewed, and the existence and content of up-to-date plans communicated to all those involved in the older person's care (see Section 5.2).

5.11 An advance health care directive needs to be reviewed while the person remains competent, either annually or when there is a significant change in the person's health or circumstances. This will help to maintain the directive's validity.

5.12 One key issue to be addressed with an advance health care plan or directive is the likelihood of successful treatment for acute illness (eg chest infection) given the current health status of the person. When a health care plan or directive is current and known to providers, hospitalisation for aggressive treatments that are likely to be futile can be avoided and plans for successful symptom management can be discussed in advance.

5.13 Advance health care plans and their documentation should be known and understood by the family and/or other advocates to ensure their more effective implementation. It is also important that health care providers know about advance health care plans because they need to document their existence and pass on the information when the older adult is transferred to the care of another health care provider.

5.14 When an older adult is too unwell to provide a copy of their advance health care directive to a health care provider, their advocate should provide one on their behalf.

5.15 Health care professionals should respect current and valid advance health care plans because these are an indication of the older person's wishes.

5.6 Recommendations for further research

More research is needed to provide evidence about the stability of decisions made regarding end-of-life care when these decisions are made by people in good health (Song 2004). More work testing adherence to advance health care directives by health care providers that also determines key barriers to this adherence is also appropriate. Thereafter, interventions to overcome these barriers need to be tested rigorously.

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Siegler EL and Levin BW (2000). Physician-older patient communication at the end of life. *Clinics in Geriatric Medicine* 16(1):175.

Song MK (2004). Effects of end-of-life discussions on patients' affective outcomes. *Nursing Outlook* 52(3):118–125.

Street AF and Ottmann G (2006). *State of the Science Review of Advance Care Planning Models*, Respecting Patient Choices Program and the Palliative Care Branch, Australian Government Department of Health and Ageing, La Trobe University (Bundoora), Melbourne.

Tulsky JA (2005). Beyond advance directives: importance of communication skills at the end of life. *Journal of the American Medical Association* 294(3):359–365.

Wilkinson A, Wenger N and Shugarman LR (2007). *Literature Review on Advance Directives*, prepared for Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services, RAND Corporation, Washington, DC (contract #HHS-100-03-0023).

Chapter 6 Physical symptom assessment and management

The most important aim of a palliative approach to care is to provide relief for distressing symptoms. There is now an extensive body of research to support physical symptom management — far more than could be reviewed in these guidelines. Therefore, this chapter provides a list of other guidelines that summarise the research in a way that is useful for health care professionals. This chapter focuses on physical symptoms; the management of psychosocial and spiritual symptoms are covered elsewhere in these guidelines (see Chapters 7 and 8). Guidelines that are listed here address:

- pain
- fatigue
- nutrition and hydration
- oral symptoms and dysphagia
- anorexia
- cachexia
- nausea and vomiting
- respiratory problems
- skin integrity
- continence
- constipation
- falls
- delirium.

Medication management and the use of complementary and alternative medicine are also briefly addressed, as is symptom management for three common conditions: chronic heart failure, chronic obstructive pulmonary disease and chronic renal failure.

Although the following sections of these guidelines address some individual symptoms or disease processes, three key documents provide more general guidance for health care professionals in this area. These three key documents are listed in the box below.

Key documents

Australian Government Department of Health and Ageing (2003). *Evidenced Based Clinical Practice Guidelines in Palliative Care for the Multi-Disciplinary Team*, National Palliative Care Program, DoHA, Canberra.
Available from the archives of the National Library of Australia: http://www.nla.gov.au/

Therapeutic Guidelines (2010). *Palliative Care*, version 3, Therapeutic Guidelines Ltd, Melbourne.
Available from the Therapeutic Guidelines website at: http://www.tg.com.au

Institute for Clinical Systems Improvement (2008). *Guideline: Palliative Care*. National Guideline Clearinghouse (NGC), Rockville (MD). NGC:006526.
Available from http://www.guideline.gov Search for NGC:006526

These documents cover the assessment and management of additional symptoms and conditions seen in older adults that include:

- cough
- intestinal obstruction

- ascites (excess fluid in the space between the tissues lining the abdominal cavity and the organs)
- convulsions
- hypercalcaemia (high levels of calcium in the blood)
- fungating (breaking through the skin) and bleeding tumours
- spinal cord compression
- complications associated with treatments, including radiotherapy and chemotherapy.

Also, much information from the Guidelines for a Palliative Approach in Residential Aged Care (DoHA 2006) is applicable in the community setting. Finally, if symptoms are too complex to be managed by the team delivering a palliative approach, networking with specialist palliative care services is essential so that specialist knowledge and experience can provide the best possible outcome for the older adult.

This chapter also discusses how to assess symptoms. Community health care providers need to be sensitive to worsening and newly developing symptoms so that they make the older person as comfortable as possible. They also need to evaluate strategies for managing symptoms. Therefore, symptom assessment is a vital part of care provision. However, as well as assessing individual symptoms, an overall assessment is useful for determining how comfortable the older person is in general, and for identifying symptoms that need more in-depth assessment. The box below lists tools that are used to help to provide a palliative approach to care. These tools are comprehensive symptom assessment tools that have acceptable psychometric properties. Other tools that assess individual symptoms are explained in many of the presented guidelines.

Comprehensive symptom assessment tools

Bruera E, Kuehn N, Miller MJ, Selmser P and Macmillan K (1991). The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. *Journal of Palliative Care* 7(2):6–9.
Tool available via Cancer Care, Ontario, Canada at: http://www.cancercare.on.ca/

Kristjanson LJ, Pickstock S, Yuen K, Davis S, Blight J, Cummins A, Dean AA, Tinnelly K and Cousins K (1999). *Development and Testing of the Revised Symptom Assessment Scale (SAS): Final Report*, Edith Cowan University, Perth.

Managing symptoms in the community presents many unique challenges to health care professionals. Barriers that may be encountered include the environment in which care is provided, and limited access to other health care professionals, equipment, and medications. In particular, those working in rural or remote areas may experience significant access issues. Also, some older adults may not be able to afford costs of medications or equipment, meaning that health care professionals need to source alternatives. Moreover, community service provision needs to be flexible to meet individual and family needs, but supporting community care workers in home environments can be problematic at times.

The CareSearch website is a useful resource to source equipment and links to information about financial support: http://www.caresearch.com.au/ (Finding services).

Centrelink:
Website: http://www.centrelink.gov.au/
Telephone: 13 27 17

Despite the large body of literature relating to symptom management, it is rare for guidelines to be specific to both community aged care and a palliative approach. However, many guidelines provide recommendations that can, nonetheless, be useful in this context.

Cultural perspectives and individual experiences are important to consider when symptoms are being assessed and managed (see Chapters 9–11). Chapter 11 also provides information about how some symptoms may be addressed in older adults with motor neurone disease and Parkinson's disease.

Appendix F documents the search strategy and guidelines that were found. As always, health care professionals need to use their judgment about the extent to which they implement these guidelines in any given clinical situation. Also, although guidelines provide a systematic approach to specific situations (Keeley 2003), managing complex symptoms requires knowledge and understanding of pathophysiology, disease progression and clinical manifestations.

6.1 Pain

Pain is an 'unpleasant sensory and emotional experience associated with actual or potential tissue damage' (IASP Task Force on Taxonomy 1994, p 212). It is also defined as a subjective feeling and as 'whatever a person says it is and existing where ever the person says it does' (McCaffery 1979, p 11). The inability to verbally communicate pain does not negate the possibility that a person is experiencing pain (ANZCA 2005). Pain in older people is also often under-reported, under-recognised and undertreated (AGS 1997, RCP 2007). Types of pain can be classified as acute (of rapid onset and short duration), chronic (pain of long duration, often lasting for longer than three months) or incident (pain experienced during a specific activity, especially movement) (APS 2005).

There are three main types of pain:

- nociceptive pain (tissue pain)
- neuropathic pain (nerve pain)
- pain related to psychological or psychiatric factors.

Table 6.1 summarises these types of pain.

Table 6.1 Classification of pain types

Pain	Characteristics
Nociceptive pain	Caused by stimulation of pain receptors in somatic (body) and visceral (organ) structures, including skin, bone, muscles, joints and internal organs. Visceral pain is sometimes referred. Musculoskeletal pain is often described as an ache, and visceral pain as squeezing or pressure.
Neuropathic pain	Caused by damage to the central or peripheral nervous systems, and is often described as involving sensations such as shooting, burning, pins and needles, numbness or extreme sensitivity to touch.
Pain related to psychological or psychiatric factors	This type of pain can present as part of a psychological or psychiatric problem or can be worsened by such a problem. In this instance, treating the underlying problem is appropriate to relieve the pain.

Source: Ferrell and Whiteman (2003), APS (2005)

This kind of classification also helps with determining treatment, as is clearly indicated in the Australian Pain Society's *Guidelines for Pain Assessment and Management in Residential Aged Care* (APS 2005). Readers are strongly advised to refer to these guidelines and apply recommendations for the residential setting to older people who live in the community. These guidelines were specifically developed for use with the kinds of older people who are in need of a palliative approach to care and for the Australian setting. An accompanying tool kit is available that might also be helpful for community care providers.

Although pain is not part of the normal ageing process, older people are more likely to experience musculoskeletal disorders, malignancy and other chronic health problems that are associated with pain (AGS 1998ab). The treatment of chronic pain is likely to involve the use of pharmacological and nonpharmacological treatments. Medications usually need to be used regularly, with additional provision for 'breakthrough' pain (APS 2005).

The consequences of pain that is treated inadequately are well documented and affect psychosocial and physical status, including function, mood and quality of life (Horgas and Dunn 2001). The high likelihood of sensory and cognitive impairment among older people in the community complicates the accurate assessment of pain (Herr 2002, Clark et al 2004). Many older adults may discount symptoms or be fearful about indicating the extent of their pain because of misunderstandings about the effects of analgesia, concerns about the side effects of treatment, acceptance of pain as a normal part of ageing or fear of what pain may represent (Gartrell 2005). Older people receiving a palliative approach may also rely heavily on carers reporting pain on their behalf.

Relevant Australian guidelines are listed below. Other guidelines for pain management are shown in Table 6.2 (acute pain) and Table 6.3 (chronic, nonmalignant pain).

Relevant Australian guidelines

Australian Pain Society (2005). *Pain in Residential Aged Care Facilities — Management Strategies,* APS, North Sydney.
This document provides useful pain-assessment tools and addresses the key issue of pain assessment in people who have dementia.

A related toolkit — the PMG (Pain Management Guide) Toolkit — is also available.

Both documents are available from the Caresearch website:
http://www.caresearch.com.au (Clinical practice>Specific populations>Aged care facilities).

Table 6.2 Acute pain-management guidelines

Country	**Reference**	**Purpose**	**Symptom**	**Type of guideline**	**Target population**	**Intended users**	**Access**
United Kingdom	*The Assessment of Pain in Older People: National Guidelines* (RCP 2007)	To provide simple and pragmatic advice for clinicians with regard to screening and assessment of pain in older adults	Pain management	Evidence-based guidelines	Older people, all settings	Health care professionals[a]	http://www.bgs.org.uk
Australia	*Acute Pain Management: Scientific Evidence* (ANZCA 2005)	To combine the best available evidence for acute pain management with current expert practice	Acute pain	Evidence and consensus-based guidelines	Acute setting	Medical professionals	http://www.anzca.edu.au
Australia	*Evidenced-based Management of Acute Musculoskeletal Pain: A Guide for Clinicians* (Australian Acute Musculoskeletal Pain Guidelines Group 2004)	To inform practice in the management of acute musculoskeletal pain and promote partnership between patients and clinicians in decision making	Acute pain	Evidence-based guidelines	All settings	Health care professionals[a]	http://www.nhmrc.gov.au
Canada	*Assessment and Management of Pain* (RNAO 2002)	To provide recommendation for the assessment and management of pain in people of all ages	Pain management	Evidence and consensus-based guidelines	People of all ages and various settings	Medical and nursing professionals	http://www.guideline.gov

a Health care professionals refers to medical, nursing and allied health professionals. Health care providers refers to all paid caregivers including care workers and volunteers.

Table 6.3 Chronic nonmalignant pain-management guidelines

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
United States	*Assessment and Management of Chronic Pain* (ICSI 2005)	To provide guidance on managing chronic pain	Pain management — chronic pain	Evidence-based and consensus guidelines	Adults with chronic pain excluding migraine, cancer pain, or in the context of end-of-life management, all settings	Health care professionals and consumers	http://www.guideline.gov
United States	*Opioid Guidelines in the Management of Chronic Non-cancer Pain* (Trescot et al 2006)	To provide guidance on the use of opioids for treating chronic noncancer pain and to reduce the incidence of drug diversion	Pain management — opioid use	Evidence-based guidelines	People with chronic noncancer pain, all settings	Physicians and other health care professionals	http://www.guideline.gov
United States	*Persistent Pain Management* (University of Iowa Gerontological Nursing Interventions Research Center 2005)	To help health care providers manage persistent pain in older adults through assessment and treatment strategies	Pain management — persistent nociceptive pain	Evidence-based guidelines	Older adults' persistent nociceptive pain due to chronic musculoskeletal conditions and neuropathic conditions of the peripheral/ central nervous system, all settings	Health care professionals	http://www.guideline.gov

6.2 Fatigue

Fatigue is a frequent symptom that has major implications for a person’s quality of life. Defined as a persistent, subjective sense of tiredness, fatigue is a common problem in end-of-life care and may include or overlap with other symptoms (McKinnon 2002). Fatigue may manifest as decreased physical energy, decreased concentration, poor memory and lack of motivation (McKinnon 2002, Therapeutic Guidelines 2010). These manifestations can be distressing to the person as well as their family, and may be interpreted as ‘giving up’ (Paolini 2001, Therapeutic Guidelines 2010). Fatigue can have many different causes and can result from pre-existing conditions, comorbidities, disease processes or side effects of treatment (Therapeutic Guidelines 2010). Fatigue is associated with many other disease states and symptoms, including (Tyler and Lipman 2000, McKinnon 2002):

- anaemia
- electrolyte imbalance
- dehydration
- malnutrition
- infection
- altered metabolism
- depression
- insomnia.

Importantly, medications may cause or exacerbate fatigue (Tyler and Lipman 2000, Therapeutic Guidelines 2010). Identifying and managing fatigue needs to be in accordance with the wishes of the individual and family. Guidelines on fatigue assessment and management for people with advanced cancer have been developed (see Table 6.4). Although these guidelines are not specific to a palliative approach in older adults, they may provide useful strategies.

Table 6.4 Guidelines for fatigue management

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
United States	*Clinical Practice Guidelines in Oncology: Cancer Related Fatigue, Version 1* (NCCN 2003) (An updated guideline is now available on the same site)	To ensure that cancer patients with fatigue are identified and treated promptly and effectively	Fatigue — cancer related	Evidence-based and consensus guidelines	People with cancer, all settings	Health care professionals	http://www.nccn.org

6.3 Poor nutrition and dehydration

Nutrition and hydration can be complex issues to address. This is because they are associated with more than physical need; also, psychosocial and cultural beliefs strongly influence people's preferences and the meanings that they attribute to meals and drinks.

6.3.1 Malnutrition and undernutrition

Older adults are at an increased risk of malnutrition or undernutrition (these terms are used interchangeably) (AMDA 2001). Malnutrition is a state of deficiency in energy, protein or nutrients, which causes measurable adverse effects in the body in terms of composition and function (NCCAC 2006). Malnutrition is also a common medical condition that is both the cause and consequence of ill health (NCCAC 2006). The causes of malnutrition in older people in the community are often multifaceted and can be associated with the ageing process, increased morbidity, increased functional dependence, and environmental and social factors (NCCAC 2006).

Indications for nutritional support using dietary supplementation, tube feeding or parenteral nutrition (eg intravenous) are complex (NCCAC 2006). Adequate discussion with the older person and family about nutritional needs and wishes are important in the early phases of a palliative approach (see Chapter 5 for more information on advance care planning and directives). Although some people prefer artificial nutrition in the terminal phases of care, it does not improve weight loss, lethargy or survival (Therapeutic Guidelines 2010). Artificial nutrition can also impair quality of life by causing discomfort due to the body's limited capacity to tolerate food intake in this end-of-life phase (Therapeutic Guidelines 2010). Issues related to nutrition and hydration can be particularly difficult for people in the late stages of dementia (Abbey 2006). See Chapter 7 for further information on care for people with dementia.

Resources

Visvanathan R (2007). *Under-Nutrition and the Older Person,* Position Statement 6 (Revised 2007), Australian and New Zealand Society for Geriatric Medicine (ANZSGM), Sydney.
Available from the ANZSGM website at: http://www.anzsgm.org (Position statements)

Meals on Wheels:
Website: http://www.mealsonwheels.org.au/
Telephone: 08 82718700 for information in each state or territory.

Potentially useful guidelines are shown in Table 6.5.

6.3.2 Dehydration

Dehydration is common at the end of life, and is defined as an overall reduction in water content in the body that results from reduced intake or from fluid loss (Kuebler and McKinnon 2002). Dehydration should not be confused with thirst. Older people have an increased risk of dehydration, because a reduced sense of thirst is part of the normal ageing process (Kuebler and McKinnon 2002). Dehydration precipitates electrolyte imbalance, which causes symptoms such as headaches, confusion, restlessness, irritability, nausea and vomiting, and the feeling of thirst (Kuebler and McKinnon 2002). Other clinical manifestations include dry skin and mucous membranes, thickened secretions, poor skin turgor (elasticity), decreased urine output, orthostatic hypotension (drop in blood pressure when moving into a more upright position) and constipation (DoHA 2006). The primary aim in the management of dehydration may sometimes be relieving discomfort rather than providing optimal hydration. A guideline relating to hydration in older people is shown in Table 6.6.

Table 6.5 Guidelines for nutrition in older adults

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
United Kingdom	*Nutrition Support in Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition* (NCCAC 2006)	To improve the practice of nutrition support by providing evidence and information for all healthcare professionals, patients and their carers so that malnutrition is identified and treated appropriately	Nutritional support	Evidence and consensus-based guidelines and good practice points	Adults (>18 years) who are either malnourished or are at risk of malnutrition; all settings	Health care professionals	http://www.nice.org.uk
Europe	*ESPEN Guidelines on Enteral Nutrition: Geriatrics* (Volkert et al 2006) An updated guideline is now available on the same site	Developed to give evidence-based recommendations for the use of ONS and TF in geriatric patients	Nutrition — enteral	Evidence-based recommendations	Older people; all settings	Health care professionals	http://www.espen.org/

ONS = oral nutritional supplement; TF = tube feeding

Table 6.6 Guidelines for hydration in older adults

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Australia	*Maintaining Oral Hydration in Older People* (Jones et al 2001)	To describe risk factors commonly identified for dehydration or decreased fluid intake in older people, and how best to identify and manage older people at risk of dehydration or inadequate fluid intake	Hydration	Evidence-based recommendations	Older people, all settings	Health care providers	http://www.joannabriggs.edu.au

6.3.3 Oral symptoms

Oral symptoms can severely impact on quality of life (Therapeutic Guidelines 2010). Age can sometimes be characterised by poor dental and denture hygiene, few functional teeth, and a dry mouth — all of which can contribute to more serious oral complications (Gil-Montoya et al 2006). Poor oral health of older adults can affect management of medical problems, nutrition and social interactions (Gil-Montoya et al 2006). Possible risk factors for poor oral or dental health include (Pearson and Chalmers 2004):

- salivary dysfunction
- polypharmacy
- comorbid conditions
- swallowing and dietary problems
- increased functional dependence
- poor access to and use of dental care.

Simple management strategies that are tailored to the older person's needs to promote oral hygiene in terminally ill older people can provide benefits, such as increased appetite, easier eating, adequate salivation and overall improved wellbeing (Therapeutic Guidelines 2010). The guideline listed in Table 6.7 provides guidance on assessing and managing oral hygiene.

6.3.4 Swallowing difficulties

Dysphagia (swallowing difficulty) is a common problem and major cause of weight loss in older adults (Therapeutic Guidelines 2010, DoHA 2006). The prevalence of dysphagia increases with age (Mitchell and Finlayson 2000). The cause may be neurological, mechanical or infective (Therapeutic Guidelines 2010). Dysphagia is associated with a number of neurological conditions that are common in older people, including dementia, cerebrovascular accidents and Parkinson's disease. Risk factors include neurological conditions, altered level of consciousness, decreased cognitive ability, reduced alertness, increased impulsiveness or agitation, some medications and advanced age (Mitchell and Finlayson 2000). Dysphagia may occur in otherwise healthy older adults due to changes in the oropharynx (the area of the throat at the back of the mouth) associated with the ageing process (Mitchell and Finlayson 2000). General signs and symptoms include (Mitchell and Finlayson 2000):

- difficulty managing oral secretions or drooling
- absence or weakness of voluntary cough or swallow
- decreased mouth and tongue movements
- frequent throat clearing
- changes in eating patterns
- weight loss
- dehydration.

When eating or drinking, signs and symptoms include (Mitchell and Finlayson 2000):

- delayed swallowing reflex (greater than five seconds)
- uncoordinated chewing or swallowing
- multiple swallowing for each mouthful
- extended time eating or drinking
- coughing or sneezing during or following eating or drinking.

The guidelines in Table 6.8 provide recommendations relevant to the assessment and management of dysphagia.

Recommended reading

Chan D, Phoon S and Yeoh E (2004). *Dysphagia and Aspiration in Older People*, Position Statement 12, Australian and New Zealand Society for Geriatric Medicine (ANZSGM), Sydney.

Available from the ANZSGM website at: http://www.anzsgm.org (Position statements)

Table 6.7 Guidelines for assessing and managing oral hygiene

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Australia	*Oral Hygiene Care for Adults with Dementia in Residential Aged Care Facilities* (Pearson and Chalmers 2004)	To provide best practice for oral hygiene in adults with dementia in residential care	Oral hygiene	Evidence-based recommendations	Older adults with dementia in RACFs	Health care providers	http://www.joannabriggs.edu.au

RACF=residential aged care facility

Table 6.8 Guidelines for assessing and managing dysphagia

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Australia	*Identification and Nursing Management of Dysphagia in Adults with Neurological Impairment* (Mitchell and Finlayson 2000)	To summarise best evidence on identification and nursing management of dysphagia in adults with neurological impairment	Dysphagia	Evidence-based recommendations	Adults with neurological impairment in institutional or home setting	Health care professionals	http://www.joannabriggs.edu.au
Scotland	*Management of Patients with Stroke: Identification and Management of Dysphagia* (SIGN 2004b)	To promote early detection of swallowing disorders in stroke patients and appropriate methods for food and fluid intake	Dysphagia/ stroke	Evidence-based guidelines	Stroke patients in all settings with emphasis on acute care	Health care providers	http://www.sign.ac.uk (An updated guideline is now available on the same site)

6.3.5 Anorexia, weight loss and cachexia

Anorexia, weight loss and cachexia are common symptoms in advanced disease (Therapeutic Guidelines 2010). Anorexia and cachexia are often associated with cancer, but are also sometimes present in people with chronic diseases, including chronic heart failure, chronic renal failure and dementia.

Anorexia is a lack of appetite and can be intermittent and associated with infection, constipation, depression or treatment (DoHA 2006). Anorexia can also be chronic and lead to severe problems, including cachexia.

Cachexia is a complex syndrome of weight loss, lipolysis (breakdown of fat), loss of muscle, anorexia, chronic nausea and weakness (Bauer et al 2006).

The causes of weight loss may relate to symptoms such as anorexia, depression, fatigue, pain, dysphagia or cachexia. Consequences of malnutrition caused by these conditions may include the risk of complicating illness, decreased tolerance to treatment and lower quality of life (Bauer et al 2006). Older adults receiving a palliative approach to care need comprehensive nutritional assessment. Management needs to focus on the goals of care and meet the preferences of the older person and family. A relevant guideline is shown in Table 6.9.

6.3.6 Nausea and vomiting

Nausea and vomiting can be debilitating in people with advanced disease (ICSI 2007). Nausea is the unpleasant feeling of needing to vomit. Nausea and vomiting can occur together but can be separate conditions (NCCN and ACS 2007). Both symptoms are common in people with advanced illness or disease (Griffie and McKinnon 2002) and have a profound impact on quality of life, including physical and psychological functioning (ICSI 2007). The negative consequences of nausea and vomiting are substantial, especially when the symptoms are long lasting. Nausea and vomiting can lead to dehydration, fatigue, loss of appetite and impaired healing (NCCN and ACS 2007). There are multiple causes of nausea and vomiting that can be related to the comorbidities experienced by older adults, medications, gastrointestinal problems or psychological distress (ICSI 2007). Thorough clinical assessment is therefore essential (Griffie and McKinnon 2002, DoHA 2006).

The treatment of nausea and vomiting in the end stages of life depends on the selection of appropriate medications and interventions. Drugs used to control these symptoms are referred to as antiemetics. However, the potential benefits of treatment must outweigh the burden (eg side effects). No guidelines could be included for this section.

Table 6.9 Guidelines for managing anorexia and cachexia

Country	**Reference**	**Purpose**	**Symptom**	**Type of guideline**	**Target population**	**Intended users**	**Access**
United States	*Unintentional Weight Loss in the Elderly* (University of Texas at Austin School of Nursing 2006)	To provide guidance on the early identification, screening/management of unintended weight loss in the elderly	Nutrition/weight loss	Consensus guidelines	Older people in all settings	Health care providers	http://www.guideline.gov

6.4 Respiratory symptoms

Respiratory problems in older adults can be particularly distressing (Therapeutic Guidelines 2010). These symptoms can impact on both function and comfort, also causing anxiety and distress.

6.4.1 Dyspnoea

Dyspnoea is a subjective symptom that is defined as an awareness or sensation of uncomfortable breathing (Thomas and von Gunten 2003, Therapeutic Guidelines 2010). Symptoms may be described as a shortness of breath, air hunger or suffocation (Thomas and von Gunten 2003). Dyspnoea is common in advanced disease states and affects 50–70% of people at the end of life (Kuebler 2002). There are many factors that contribute to the experience of dyspnoea, including physiological, psychological, social and environmental factors (Therapeutic Guidelines 2010, DoHA 2006). Dyspnoea affects all aspects of a person's activities of daily living, restricts mobility and increases anxiety. Dyspnoea frequently worsens as death approaches and may therefore be a sign of a deteriorating condition in people receiving a palliative approach.

Dyspnoea is a distressing and frightening symptom for both individuals and their families (Therapeutic Guidelines 2010, DoHA 2006). In the terminal phases, the older person's fear and their family's anxiety associated with dyspnoea can affect the end-of-life experience (DoHA 2006). The assessment and management of dyspnoea aims to minimise the symptom and relieve suffering and distress.

Older adults with chronic obstructive pulmonary disease (COPD) have dyspnoea as a predominant symptom. Older adults with chronic heart failure also experience dyspnoea. Table 6.10 lists a guideline recommending management strategies for dyspnoea in these people. See Table 6.19 for guidelines for the overall management of chronic heart failure, and Table 6.20 for guidelines for the overall management of COPD.

6.4.2 Changes in respiratory pattern

During the final hours of life, abnormal breathing patterns can occur. The rhythm and rate may change (Therapeutic Guidelines 2010). Noisy breathing and the sounds of secretions may be unsettling for caregivers. Secretions can accumulate in the oropharynx and airways for multiple reasons, including weakness, decreased responsiveness, loss of reflexes and swallowing difficulties (Bennett et al 2002). Managing noisy breathing includes reducing salivary and bronchial secretions, breathing rate and airway resistance (Bennett et al 2002). Guidelines have been developed for managing respiratory secretions. The guidelines in Table 6.11 relate to the pharmacological management of respiratory secretions in end-of-life care.

Recommended reading

Findeisen M (2001). Long-term oxygen therapy in the home. *Home Healthcare Nurse* 19(11):692–700.

Table 6.10 Guidelines for assessing and managing dyspnoea in chronic obstructive pulmonary disease

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Canada	*Nursing Care of Dyspnea: The 6th Vital Sign in Individuals with Chronic Obstructive Pulmonary Disease (COPD)* (RNAO 2005c)	To address the nursing assessment and management of stable, unstable and acute dyspnoea associated with COPD	Respiratory — dyspnoea	Evidence and consensus-based guidelines	Clients with dyspnoea associated with COPD and adults with dyspnoea who have a history of smoking and who are aged >40 years	Nurses	http://www.rnao.org

COPD=chronic obstructive pulmonary disease
See Table 6.20 for COPD management

Table 6.11 Guidelines for managing secretions in end-of-life care

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
United Kingdom	*Using Anti-muscarinic Drugs in the Management of Death Rattle: Evidence-based Guidelines for Palliative Care* (Bennett et al 2002)	To develop clinical guidelines on the effectiveness of various anti-muscarinic drugs in drying oropharyngeal and bronchial secretions in dying patients	Respiratory — secretions	Evidence-based guidelines	People receiving end-of-life care, all settings	Health care professionals	No web address (see References)

6.5 Skin integrity issues

Skin problems in older adults requiring a palliative approach to care may include abnormal sweating, pruritus (persistent itching), oedema (fluid retention), wounds and ulcers (DoHA 2006). Maintaining skin integrity requires a multidisciplinary care team with a strong focus on supporting the family carer.

No published data in Australia on the prevalence of pressure ulcers among older people cared for in the community setting have been found. However, international research suggests that rates in the community are high (Murray et al 2001). Pressure ulcers, also known as pressure sores, bed sores, decubiti or decubitus ulcers (Murray et al 2001) are localised damage to skin and underlying tissue caused by pressure, shear or friction (Wiechula 1997a). There are multiple risk factors for the development of pressure ulcers and wounds, and some of the most common are (Murray et al 2001):

- immobility
- poor nutritional status
- sensory impairments
- incontinence
- trauma.

Chronic illness and malignancy are also risk factors for pressure ulcers (Murray et al 2001). Several risk-assessment tools have been developed and are well validated in this population. These tools use a numerical scoring system to weight the severity of risk and to help the health care professional to identify people at high risk of developing pressure ulcers (Murray et al 2001). The most frequently used tools are (Murray et al 2001):

- the Norton Risk Assessment Score
- the Braden Scale
- the Waterlow Pressure Sore Prevention Scale.

Early assessment is fundamental for both preventing and treating pressure ulcers. Managing pressure ulcers and wounds in a palliative approach also needs to take into account the preferences of the older person and family. See Table 6.12 for relevant guidelines.

Table 6.12 Guidelines for preventing, assessing and managing pressure ulcers

Country	**Reference**	**Purpose**	**Symptom**	**Type of guideline**	**Target population**	**Intended users**	**Access**
Australia	*Clinical Practice Guidelines for the Prediction and Prevention of Pressure Ulcers* (AWMA 2001)	To present current research on the prediction and prevention of pressure ulcers in the Australian context	Skin integrity	Evidence and consensus-based guidelines	Adults >14 years old, acute, postacute, extended care, RACFs and the community	Health care professionals	http://www.awma.com.au
United Kingdom	*The Management of Pressure Ulcers in Primary and Secondary Care — A Clinical Practice Guideline* (RCN 2005)	To provide recommendations for early identification of patients at risk of pressure ulcers, preventive interventions and to highlight harmful or ineffectual practice	Skin integrity — pressure ulcers	Evidence-based guidelines	Adults, all settings	Health care providers	http://www.nice.org.uk
United Kingdom	*The Use of Pressure-relieving Devices (Beds, Mattresses and Overlays) for the Prevention of Pressure Ulcers in Primary and Secondary Care* (NCC-NSC 2004a)	To establish the most clinically and cost-effective beds, mattresses or overlays for preventing pressure ulcers	Skin integrity — pressure ulcers	Evidence-based guidelines	Adults, all settings	Health care providers and consumers	http://www.nice.org.uk

Australia	*Pressure Sores — Part 1: Prevention of Pressure Related Damage* (Wiechula 1997a)	To provide clinicians with evidence-based recommendation related to the *prevention* of pressure sores	Skin integrity	Evidence and consensus-based guidelines	All ages, acute and community setting	Health care providers	http://www.joannabriggs.edu.au (An updated guideline is now available on the same site)
Australia	*Pressure Sores — Part II: Management of Pressure Related Tissue Damage* (Wiechula 1997b)	To provide clinicians with evidence-based recommendation related to the *treatment* of pressure sores	Skin integrity	Evidence and consensus-based guidelines	All ages, acute and community setting	Health care providers	http://www.joannabriggs.edu.au
Australia	*Pressure Ulcer Prevention and Treatment: Transforming Research Findings into Consensus Based Clinical Guidelines* (Lewis et al 2003)	To develop plain language guidelines relating to the prevention and treatment of pressure ulcers	Skin integrity — pressure ulcers	Consensus guidelines	Adults, all settings	Health care providers	No web address (see References)
United Kingdom	*Nutritional Guidelines for Pressure Ulcer Prevention and Treatment* (European Pressure Ulcer Advisory Panel 2003)	To provide guidance of the role of nutrition in pressure ulcer prevention and treatment	Skin integrity — pressure ulcers	Evidence and consensus-based guidelines	Adults, all settings	Health care providers	http://www.epuap.org (An updated guideline is now available on the same site)
United States	*Guidelines for the Treatment of Pressure Ulcers* (Whitney et al 2006)	The guidelines provide recommendations for treatment of pressure ulcers supported by current evidence	Skin integrity — pressure ulcers	Evidence-based guidelines	Adults, all settings	Health care providers	http://www.woundheal.org

Canada	*Risk Assessment and Prevention of Pressure Ulcers* (RNAO 2005a)	To assist nurses with the provision of evidence-based quality care to those adults at risk for developing pressure ulcers	Skin integrity—pressure ulcers	Evidence and consensus-based guidelines	Adults at risk of pressure ulcers, all settings	Nurses	http://www.rnao.org

RACF=residential aged care facility

6.6 Incontinence

Incontinence is the inability to control urination or defecation (AIHW 2006). Increasing with age in both males and females, the estimates of how common urinary and fecal incontinence is vary considerably (AIHW 2006). Continence problems have serious social, psychological and financial repercussions. Continence care is a fundamental component of a palliative approach to care for older adults and includes assessment and the prompt implementation of individually tailored strategies to maximise comfort and minimise loss of dignity (DoHA 2006).

6.6.1 Urinary incontinence

Urinary incontinence, an involuntary leakage of urine, is a symptom of underlying abnormalities or one occurring as a result of illness or environmental factors (NICE 2006). There are different types of urinary incontinence, including stress, urgency and other forms relating to the specific cause. Urinary incontinence is associated with adverse effects on quality of life, such as social isolation, loneliness, depression and embarrassment that affect activities of daily living, relationships and sleep patterns (SIGN 2004a). Evidence also suggests that urinary incontinence is associated with increased risk of falls and fractures. Risk factors for urinary incontinence include age, prostate surgery for men, and pregnancy problems and obesity in women (SIGN 2004a). Older adults and their carers may be reluctant to seek help for urinary incontinence and health professionals need to be proactive and sensitive in the approach to continence and its positive management (SIGN 2004a). See Table 6.13 for guidelines.

Continence Foundation of Australia:
Website: http://www.continence.org.au

National Continence Helpline:
Telephone: **1800 33 00 66**

6.6.2 Fecal incontinence, diarrhoea and constipation

Fecal incontinence causes embarrassment, discomfort and skin problems. Fecal incontinence may also relate to changes in consciousness or awareness, and is usual in the late stages of some neurological diseases, such as Alzheimer’s disease. If neurological damage or other advanced disease is the cause of this symptom, management generally only involves maintaining a soft-formed stool with appropriate dietary modification and/or medication, predicting bowel motion patterns wherever possible so that appropriate preparations can be made and ensuring prompt postdefecation hygiene. In the community setting, a person’s fecal elimination pattern needs to be considered when arranging the timing of care worker visits. However, educating and supporting the carer to manage toileting issues may be an appropriate option if the carer and the older adult find this acceptable in the context of their cultural background and ongoing relationship. Psychosocial aspects of care also need to be considered, in that passing a bowel motion is generally accepted to be a time when a person requires privacy. Dignity (as well as skin hygiene) is affected if hygiene is not attended immediately afterwards, with due respect and understanding of the care recipient’s feelings.

Fecal incontinence may also relate to diarrhoea, which is an increase in stool volume and liquidity resulting in the passage of several loose or unformed stools per day and is often associated with abdominal cramping and urgency (Heidrich 2002). Diarrhoea can be caused by numerous factors, but common causes in end-of-life care include medication or laxative overdose, fecal impaction with overflow, and bowel obstruction (Heidrich 2002).

Constipation refers to difficulty or straining in defecation and infrequent bowel motions over an extended period. There are variations in what are considered ‘normal’ bowel habits among older people. A person’s usual bowel habits need to be determined as part of any assessment of possible constipation. Symptoms associated with constipation are hard or dry stool, bloating and abdominal pain. Fecal incontinence is most likely when a person is constipated when fluid stool bypasses the hard, dry, fecal matter (overflow incontinence).

About 20% of elderly people in the community experience symptoms of constipation as a result of contributing factors, such as fluid intake, diet, mobility and other factors, including medications. Normal defecation requires adequate fluid, fibre intake and peristalsis (the wave-like movements in the walls of the intestines that propel food through the digestive tract). Often, older people approaching the end of life are deficient in these areas and therefore constipation is more frequent (JBI 1999). Medications used in end-of-life care, such as analgesics and anticholinergics, increase the risk of constipation (Therapeutic Guidelines 2010).

Bowel care is a key component of a palliative approach and there have been several guidelines and recommendations published that address best practice relating to bowel care for older adults (see Table 6.14).

6.7 Falls

Falls are common and present a major problem for older adults (AGS Panel on Falls in Older Persons 2001, Moreland et al 2003, NCC-NSC 2004b). Falls are associated with significant economic and social costs (Feder et al 2000), including morbidity, reduced functioning, hospital admissions, premature residential care admission and mortality (AGS Panel on Falls in Older Persons 2001). Although many falls do not result in injury, the consequences of falls or not being able to get up can include (NCC-NSC 2004b):

- psychological problems, such as loss of confidence and anxiety
- loss of mobility
- increased dependency and disability
- hypothermia
- pressure-related injury
- infection.

Falls have multifaceted causes. Risk factors include age, disease, loss of balance, muscle weakness, polypharmacy and environmental hazards (AGS Panel on Falls in Older Persons 2001, NCC-NSC 2004b). Many of these risk factors can be modified (NCC-NSC 2004b). Falls risk assessment is fundamental for preventing falls. Several guidelines have been published in the area of fall prevention and management (see Table 6.15).

Table 6.13 Guidelines for preventing, assessing and managing urinary incontinence

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Scotland	*Management of Urinary Incontinence in Primary Care* (SIGN 2004a)	To provide guidance relating to assessment and treatment of urinary incontinence in adults	Continence — urinary	Evidence and consensus-based guidelines	Adults with urinary incontinence in primary care	Health care providers and consumers	http://www.sign.ac.uk
United Kingdom	*Urinary Incontinence: The Management of Urinary Incontinence in Women* (NICE 2006)	To provide best practice recommendations for managing urinary incontinence in women	Urinary incontinence in women	Evidence and consensus-based guidelines	All settings, women only	Health care professionals	http://www.nice.org.uk
Canada	*Canadian Urological Association Guidelines on Urinary Incontinence* (Corcos et al 2006)	To provide guidance on the management of urinary incontinence in adults	Continence — urinary	Consensus guidelines	Adults, all settings	Health care professionals	No web address (see References)
Canada	*Conservative Management of Urinary Incontinence* (Robert and Ross 2006)	To outline the evidence for conservative management options for treating urinary incontinence	Continence — urinary (female)	Evidence-based guidelines	Adult females with urinary incontinence, all settings	Health care professionals	No web address (see References)

Table 6.14 Guidelines for preventing, assessing and managing constipation

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Australia	*Management of Constipation in Older Adults* (JBI 1999)	To present the best available evidence on the prevention and management of constipation in the older adult	Continence — constipation	Evidence-based and consensus recommend-dations	Older adult, any setting	Health care providers	http://www.joannabriggs.edu.au
United States	*An Evidence-based Approach to the Management of Chronic Constipation in North America* (American College of Gastroenterology Chronic Constipation Task Force 2005)	To produce data on chronic constipation and provide recommendations for management	Continence — chronic constipation	Evidence-based recommend-dations	Adults, all settings	Health care providers	No web address (see References)
Canada	*Prevention of Constipation in the Older Adult Population* (RNAO 2005b)	To present evidence-based nursing best practice guidelines for preventing constipation in older adults	Continence — constipation	Evidence-based guidelines	Older adults in all settings (excluding those with medical conditions restricting intake or enternal nutrition, palliative or narcotic analgesics)	Nurses	http://www.rnao.org

Table 6.15 Guidelines for preventing or reducing falls

Country	**Reference**	**Purpose**	**Symptom**	**Type of guideline**	**Target population**	**Intended users**	**Access**
Canada	*Evidence-based Guidelines for the Secondary Prevention of Falls in Older Adults* (Moreland et al 2003)	To provide evidence-based assessment and treatment to prevent falls in older adults. To provide researchers with risk factor studies and randomised controlled studies of fall prevention	Falls	Evidenced-based guidelines	Older adults, community and institution dwelling	Health professionals	No web address (see References)
United Kingdom	*Guidelines for the Prevention of Falls in People Over 65. The Guidelines' Development Group* (Feder et al 2000)	To translate trial evidence on prevention of falls into recommendations for implementation, with the aim of reducing the rate of falls in people aged >65 years	Falls	Evidence-based guidelines	Older adults, all settings	Health care providers	http://www.bmj.com
United Kingdom	*Clinical Practice Guideline for the Assessment and Prevention of Falls in Older People* (NCC-NSC 2004b)	To formulate evidence-based and, where possible, clinical-practice recommendations on the assessment and prevention of falls in older people	Falls	Evidence-based guidelines	Older people in the community or extended care, who are at risk of falling or who have fallen	Health care professionals and consumers	http://www.nice.org.uk

Country	**Reference**	**Purpose**	**Symptom**	**Type of guideline**	**Target population**	**Intended users**	**Access**
United States, United Kingdom	*Guideline for the Prevention of Falls in Older Persons. American Geriatrics Society, British Geriatrics Society, and American Academy of Orthopaedic Surgeons Panel on Falls Prevention* (AGS Panel on Falls in Older Persons 2001)	To help health care professionals to assess fall risk and manage older patients who are at risk of falling and those who have fallen	Falls	Evidence and consensus-based guidelines	Older persons who had not fallen, those at risk for falls, and those experiencing single or frequent falls in the community; acute or long-term care facilities	Health care providers	http://www.americangeriatrics.org

6.8 Delirium

Delirium is a disturbance of consciousness that is characterised by ‘impaired function and reduced ability to focus, sustain or shift attention’ (Melbourne Health 2006, p 25). Delirium is a common symptom in older adults who are unwell. The symptom generally develops in a relatively short period of time (hours or days) and the severity fluctuates over the course of a day (APA 1999, Melbourne Health 2006). Although delirium generally lasts for a few days, it may persist for weeks or months (Melbourne Health 2006). The causes of delirium are complex and multifactorial. The underlying conditions or disorders that are commonly associated with delirium include (APA 1999, Melbourne Health 2006):

- a general medical condition (eg pneumonia, urinary tract infections)
- disorders of the central nervous system (eg stroke)
- substance use or withdrawal (including medications)
- a combination of causes (eg at the very end of life).

A number of risk factors predispose people to delirium. Having dementia, being older than 70 years and having severe medical conditions are leading risk factors (Melbourne Health 2006). Most research in the area of delirium in older people has focused on acute hospital settings, where approximately 10–15% of older people admitted to hospital are delirious at the time of admission and a further 5–40% are estimated to develop delirium while hospitalised (Britton and Russell 2001). Signs and symptoms of delirium may include the following (APA 1999, Melbourne Health 2006):

- difficulty focusing, sustaining or shifting attention
- disorientation to place or time
- memory impairment (commonly recent memory)
- speech or language disturbances
- emotional disturbances, such as mood swings
- disturbance of the sleep–wake cycle
- misinterpretations, illusions or hallucinations, such as seeing, hearing or feeling things that are not there.

Delirium in older adults is often under-recognised and misdiagnosed (Melbourne Health 2006). Consequences of delirium include high morbidity and mortality, hospital admission, increased length of hospital stays, and other complications (Melbourne Health 2006). The prevention or early detection and treatment of delirium can reduce these adverse events. It is therefore important the aged care providers have a good understanding of delirium.

Tools for assessing delirium include the following:

- Confusion Assessment Method — is a valid and reliable diagnostic tool for delirium. It was specifically designed for use with the hospitalised older person, to improve delirium identification and recognition (Inouye et al 1990).

- Delirium Symptom Interview (DSI) — The DSI is an interview protocol for assessing the seven symptom domains delineated by the DSM-III criteria for delirium. It was designed to be administered (on a daily basis) to hospitalised older people by nonclinicians (Albert et al 1992).

Both the above tools are available from the Positive Aging Resource Center at **Error! Hyperlink reference not valid.** (Health and social service providers>Screening and assessment tools).

- Delirium Rating Scale (DRS) — Although the DRS was originally developed to rate the symptoms of delirium, not as a diagnostic instrument, it has been assessed for its ability to accurately diagnose delirium (Trzepacz et al 1988).

Managing delirium includes identifying and addressing the cause, managing the symptoms with pharmacological and nonpharmacological strategies, and educating and supporting the older adult and their family. Nonpharmacological strategies to manage delirium are aimed at reorientating and reassuring the person with delirium and may include (Therapeutic Guidelines 2010, Melbourne Health 2006):

- using a support person who has been trained in how to care for people with delirium
- using validation and reality-orientation strategies
- providing relaxation strategies (eg music) to help people to sleep.

Medications are useful for treating behavioural or emotional disturbances associated with delirium. See the guidelines in Table 6.16 for pharmacological and nonpharmacological management of delirium.

Recommended reading

Maher S (2005). *Delirium in Older People,* Position Statement 13, Australian and New Zealand Society for Geriatric Medicine (ANZSGM), Sydney.

Available from the ANZSGM website at: http://www.anzsgm.org (Position statements)

Table 6.16 Guidelines for assessing and managing delirium

Country	Reference	Purpose	Symptom	Type of guideline	Target population	Intended users	Access
Australia	*Clinical Practice Guidelines for the Management of Delirium in Older People* (Melbourne Health 2006)	To provide a series of recommendations to guide clinical assessment and management of delirium in older Australians in hospital and across health care settings	Delirium	Evidence and consensus based-guidelines	Older people in all settings (excluding alcohol-withdrawal delirium and terminal delirium)	Health care providers	http://www.health.vic.gov.au/acute-agedcare
Canada	*Screening for Delirium, Dementia and Depression in the Older Adult* (RNAO 2003)	To improve screening assessments for older adults for delirium, dementia and depression	Delirium, dementia, depression	Evidence and consensus-based guidelines	Older adults in all settings	Nurses	http://www.rnao.org
Canada	*Caregiving Strategies for Older Adults with Delirium, Dementia and Depression* (RNAO 2004)	To present nursing best-practice guidelines for caregiving strategies for older adults with delirium, dementia and depression	Delirium	Evidence and consensus-based guidelines	Older adults with delirium, dementia and/or depression	Nurses	http://www.guideline.gov

6.9 Medication management

Medication use in older people in the community is high. One of the problems encountered with elderly people and medications in the community is the excessive or unnecessary use of medication — often referred to as polypharmacy. Polypharmacy increases the risk of drug interactions, adverse drug reactions and financial expense. Medications are important for managing symptoms at the end of life; however, they can also cause harm. Quality use of medicines (QUM) means selecting management options wisely, choosing suitable medicines, and using medicines safely and effectively. The QUM can have a positive impact on health and can improve quality of life (Australian Pharmaceutical Advisory Council 2006). Health care professionals need to work in consultation with local pharmacists to ensure that optimal health outcomes and economic objectives are achieved for older adults. Relevant resources such as *Therapeutic Guidelines — Palliative Care* (Therapeutic Guidelines 2010) and the *Australian Medicines Handbook* (http://www.amh.net.au/) should be consulted for specific information such as dosage levels. Australian guiding principles for medication management have been developed and should be referred to as needed (see Table 6.17).

Australia's National Prescribing Service provides a service called RADAR (Rational Assessment of Drugs and Research). This service provides medication information for all health care professionals. Website: http://www.npsradar.org.au/

6.9.1 Complementary and alternative medicines

Complementary and alternative medicines (CAM) are a group of diverse medical and health care systems, practices and products that are not presently considered to be part of conventional medicine (NCCAM 2007). Complementary medicines are used to augment conventional medicine, and alternative medicines are used in place of conventional medicine (NCCAM 2007). Complementary and alternative medicines are commonly used in the community, but this use is controversial. In 2004, estimates suggested that approximately 52% of the population used CAM (MacLennan et al 2006). Among these people, 57% did not tell their doctor about their CAM use (MacLennan et al 2006). CAM is commonly integrated into palliative care (Kellehear 2003). People requiring a palliative approach may use CAM for various reasons. Health care providers need to encourage open communication with older people and their families and provide them with information about CAM that will help their informed choices and judgments. There is a lack of guidelines published in this area other than the Australian Government's regulatory guidelines (DoHA 2005) and these should be consulted as necessary (see Table 6.18).

Table 6.17 Guidelines for managing medication

Country	Reference	Purpose	Issue	Type of guideline	Target population	Intended users	Access
Australia	*Guiding Principles for Medication Management in the Community* (Australian Pharmaceutical Advisory Council 2006)	To promote the quality use of medicines and better medication management in the community	Medication management	Consensus guidelines	All ages, community setting	Health care providers and consumers	http://www.health.gov.au
Australia	*Guiding Principles to Achieve Continuity in Medication Management* (Australian Pharmaceutical Advisory Council 2005)	To guide the quality use of medicines in achieving continuity in medication management	Medication management	Consensus guidelines	All ages, all settings	Health care providers and consumers	http://www.health.gov.au

RACF=residential aged care facility

Table 6.18 Regulatory guidelines for the use of complementary medicines

Country	Reference	Purpose	Issue	Type of guideline	Intended users	Access
Australia	*Australian Regulatory Guidelines for Complementary Medicines (ARGCM) Part I Registration of Complementary Medicines* (DoHA 2005)	To provide guidance for complementary therapies in Australia	Complementary therapies	Evidence-based guidelines	Complementary therapists, health care professionals and consumers	http://www.tga.health.gov.au http://www.tga.health.gov.au/

6.10 Chronic conditions

Symptoms experienced in older people with chronic conditions can be specific to disease states (Lipman 2000). Chronic conditions occur commonly in older adults and include dementia, chronic heart failure, chronic renal failure, chronic obstructive pulmonary disease, Parkinson’s disease and other neurodegenerative diseases. This chapter presents guidelines relating to the specific management of chronic heart failure, chronic renal failure and chronic pulmonary disease (guidelines available for other chronic conditions are addressed in other chapters; see Chapter 11 for guidelines on Parkinson’s disease and dementia).

6.10.1 Chronic heart failure

Chronic heart failure (CHF) is a complex syndrome that can result from a structural or functional heart disorder (NCCCC 2003). Chronic heart failure usually includes systolic or diastolic dysfunction of the ventricles (the large chambers of the heart) or both (Hunt et al 2005, NCCCC 2003). Chronic heart failure affects 1.5–2.0% of Australians and is a growing concern, because the incidence and prevalence increases markedly with age (NHFA and CSANZ 2006), affecting about 10% of people aged 65 years or older and more than 50% of people aged over 85 years (NHFA and CSANZ 2006). Common causes include coronary heart disease, prior myocardial infarction and essential hypertension (NHFA and CSANZ 2006). In elderly people, accurate diagnosis is more difficult because of comorbidity. Hypertrophy (increase in size) and myocardial fibrosis may be other important causes of heart failure in the elderly (National Heart Foundation of New Zealand 2001). The guidelines listed in Table 6.19 should be useful for health care professionals providing care for people with CHF. However, health care professionals should remember that these guidelines could apply equally to the beginning or end of the course of the illness, and care therefore needs to be taken when deciding how applicable some guidelines are to each stage of the disease.

Table 6.19 Guidelines for managing chronic heart failure

Country	Reference	Purpose	Diagnosis	Type of guideline	Target population	Intended users	Access
United Kingdom	*Guidelines for the Diagnosis and Treatment of Chronic Heart Failure (update 2005)* (European Society of Cardiology 2001)	To provide updated practical guidelines for diagnosing, assessing and treating CHF for use in clinical practice, as well as for epidemiological surveys and clinical trials	CHF	Evidence and consensus-based guidelines	People with CHF	Health care providers	http://www.guideline.gov (An updated guideline is now available on the same site)
United Kingdom	*Management of Chronic Heart Failure in Adults in Primary and Secondary Care* (NCCCC 2003*)*	To provide guidance for the diagnosis and management of CHF	CHF	Evidence and consensus-based guidelines	People with CHF	Health care providers and consumers	http://www.nice.org.uk.
Australia	*Guidelines for the Prevention, Detection and Management of People with Chronic Heart Failure in Australia, 2006* (NHFA and CSANZ 2006)	To provide best practice for the management of CHF	CHF	Evidence and consensus-based guidelines	People with, or at risk, of developing, CHF	Health care professionals	http://www.heartfoundation.org.au
United States	*ACC/AHA 2005 Guideline Update for the Diagnosis and Management of Chronic Heart Failure in the Adult: A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines* (Hunt et al	To assist health care providers in clinical decision making by describing a range of generally acceptable approaches for preventing, diagnosing and managing HF	CHF	Evidence and consensus-based guidelines	People with CHF	Health care providers	http://www.americanheart.org

Country	Reference	Purpose	Diagnosis	Type of guideline	Target population	Intended users	Access
	2005)						
New Zealand	*A Guideline for the Management of Heart Failure: Health Professionals Guide* (National Heart Foundation of New Zealand 2001)	To provide recommendations for management of patients with a diagnosis of congestive HF due to systolic ventricular dysfunction	Congestive HF	Evidence and consensus-based guidelines	People with diagnosis of congestive HF due to systolic ventricular dysfunction. Excludes diastolic dysfunction	Health care professionals	http://www.nzgg.org.nz

CHF = chronic heart failure; HF = heart failure; NF = nursing facility

6.10.2 Chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a common, progressive disorder that increases in prevalence with age (NCCCC 2004b). The disorder is characterised by airflow obstruction, which can be accompanied by airway hyperactivity and can be partially reversible (ICSI 2001). Chronic obstructive pulmonary disease produces symptoms that disable and impair the older person's quality of life (NCCCC 2004b). Signs and symptoms include (ICSI 2001):

- wheezing
- a prolonged expiratory phase
- dyspnoea
- chronic sputum production
- hyperinflation of the chest
- use of accessory muscles.

Chronic bronchitis and emphysema, often caused by cigarette smoking, are common conditions resulting in COPD (McKenzie et al 2003, ICSI 2001). Chronic obstructive pulmonary disease has serious complications and exacerbations that have specific requirements at the end of life. The guidelines in Table 6.20 offer recommendations for the specific needs of people with COPD, including for those with advanced disease.

6.10.3 Chronic kidney disease

Chronic kidney disease (CKD), otherwise known as chronic renal failure, is a common condition that reduces people's quality of life and use of health services, and increases mortality (AIHW 2005). Chronic kidney disease progresses to end-stage renal failure at a rapid rate (Mathew 2005). Although dialysis or transplantation are sometimes treatment options, many older adults are not suitable candidates for such aggressive treatment. Diagnosis is usually made by glomerular filtration rate (60 mL/min/1.73 m^2 for three months or more) or evidence of kidney damage (microalbuminuria, proteinuria, glomerular haematuria, pathological abnormalities and anatomical abnormalities) (National Kidney Foundation 2002, Mathew 2005). Early stages of the disease do not have specific symptoms; therefore, a diagnosis of CKD is often delayed or missed (AIHW 2005). Multiple factors increase the risk of CKD, including diabetes, high blood pressure (hypertension) and smoking (AIHW 2005).

Aboriginal and Torres Strait Islander people, particularly those who live in remote communities, have a high prevalence of chronic disease (including CKD) with resultant morbidity and mortality. End-stage kidney damage is common among Indigenous Australians, and rates of treated end-stage kidney disease in some communities are 30 times the rate among other Australians (AIHW 2005). Many Aboriginal and Torres Strait Islander people also experience barriers to accessing health care. For example, treatment for CKD is a particular problem for Australians living in remote communities. To receive treatment with the necessary equipment for dialysis often requires families to travel long distances. Cost may be an issue but also the cultural importance of family and place to Aboriginal and Torres Strait Islander people may mean that leaving their home and moving to a hospital or satellite dialysis facility is not appropriate (AIHW 2005). However, similar issues may occur in relation to palliative care. Mainstream care providers may have only limited awareness of the palliative care needs existing in Australian Indigenous communities, and people living in these communities and providing health care in these settings may be unaware of the extent of service availability (Maddocks and Rayner 2003). Without proactive approaches, access to a palliative approach to care may be delayed (see Chapter 9 for more information on a palliative approach to care for Aboriginal and Torres Strait Islander people). Table 6.21 lists guidelines specific to the assessment and management of CKD.

Table 6.20 Guidelines for the management of chronic obstructive pulmonary disease

Country	**Reference**	**Purpose**	**Diagnosis**	**Type of guideline**	**Target population**	**Intended users**	**Access**
United States	*Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease* (GOLD 2001)	To increase awareness of COPD and decrease morbidity and mortality from the disease by improving prevention and management	COPD	Evidence and consensus-based guidelines	People with COPD	Health care professionals	http://www.guideline.gov Update available from http://www.goldcopd.com/
Singapore	*Chronic Obstructive Pulmonary Disease* (SMH 2006)	To give physicians a practical guide to the care of COPD patients	COPD	Evidence and consensus-based guidelines	People with known or suspected COPD	Physicians	http://www.guideline.gov
Australia and New Zealand	*The COPDX Plan: Australian and New Zealand Guidelines for the Management of Chronic Obstructive Pulmonary Disease 2003* (McKenzie et al 2003)	To change reliance on pharmacological treatment to a range of other options	COPD	Evidence and consensus-based guidelines	People with COPD and exacerbations	Health care professionals	http://www.nzgg.org.nz Update available from http://www.copdx.org.au/
United Kingdom	*Chronic Obstructive Pulmonary Disease. National Clinical Guideline on Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care* (NCCCC 2004a)	To provide guidance for the diagnosis and management of COPD	COPD	Evidence and consensus-based guidelines	People with COPD	Health care professionals and consumers	http://www.guideline.gov

COPD = chronic obstructive pulmonary disease
See also Table 6.10 for management of dyspnoea in COPD

Table 6.21 Guidelines for managing chronic kidney disease

Country	Reference	Purpose	Diagnosis	Type of guideline	Target population	Intended users	Access
United Kingdom	*Chronic Kidney Disease in Adults: UK Guidelines for Identification, Management and Referral* (Joint Specialty Committee on Renal Medicine 2006)	To promote the optimal management of patients with CKD	CKD	Evidence and consensus-based guidelines	Adults in all settings	General practitioners and other health professionals	http://www.nice.org.uk. (An updated guideline is now available on the same site)
United States	*K/DOQI Clinical Practice Guidelines for Chronic Kidney Disease: Evaluation, Classification, and Stratification* (National Kidney Foundation 2002)	To provide classification of stages as well as evaluation and treatment of kidney disease	Renal disease	Evidence and consensus-based guidelines	People with kidney disease	Health care providers	http://www.kidney.org
United States	*Diagnosis and Management of Adults with Chronic Kidney Disease* (Michigan Quality Improvement Consortium 2006)	To provide guidance on the diagnosis and management of CKD	CKD	Evidence and consensus-based guidelines	People with or at risk of CKD	Health care professionals	http://www.guideline.gov

Country	Reference	Purpose	Diagnosis	Type of guideline	Target population	Intended users	Access
United States	*Detection of Chronic Kidney Disease in Patients with or at Increased Risk of Cardiovascular Disease: A Science Advisory from the American Heart Association Kidney and Cardiovascular Disease Council [trunc]* (American Heart Association and National Kidney Foundation 2006)	To provide recommendations for the detection of CKD in patients with CVD	Renal disease	Evidence and consensus-based guidelines	People with or at risk of CVD	Health care providers	http://www.guideline.gov

CKD = chronic kidney disease; CVD = cardiovascular disease

6.11 Conclusion

A palliative approach to care embraces the care of older adults with many symptoms and underlying disease states. A growing body of knowledge now underpins best practice in symptom assessment and management. Although many of the clinical practice guidelines available are not specific to older adults or to advanced disease, many include relevant information for health care professionals working in this area. Health care professionals are therefore advised to access this information, using appropriate clinical judgment, to allow them to develop a framework for high-quality care for older adults living in the community.

6.12 Good practice points — physical symptom assessment and management

Using action plans and checklists

Checklists of tasks, medications charts, and action plans of daily activities can help family carers to keep track of aspects of care (see Section 6.9).

6.1	Family carers are often stressed and sleep deprived; this can cause them to lose track of aspects of providing care. Providing them with a form to record events relevant to care, such as food and fluid intake, and sleep and bowel patterns, may be helpful. Similarly, a notepad on which to record their questions may be useful. Also, a written record of information from the care provider may help. If there is more than one carer, they can all access this record (as appropriate) to facilitate more coordinated care and to minimise any confusion.
6.2	Polypharmacy is common in older people with comorbid illness. To minimise error and help older people and their carers manage their medication, the family carer can use a medication chart. Health care professionals need to make sure the older person and their family carers are taught about the effective use of medication charts and that these people understand requirements for the safe use and storage of medications.
6.3	During end-of-life care, older adults and their carers are required to make many decisions regarding symptom control. An action plan can be helpful that details what to do if something unexpected or an emergency occurs (eg because of an incorrect medication dose).

Promoting open and honest communication

Good communication between the older adult and their carer(s), and the health care professional is needed for effective care; this includes disclosure about any alternative medicines the older person might be taking, and respect for the older person's cultural beliefs and preferences (see the introduction to this chapter and Section 6.9).

6.4	Complementary and alternative therapies are commonly used in the community, without notification to health care professionals. Health care providers need to promote open, honest communication with the older person and family to encourage them to tell about their use of other therapies (Chan and McConigley 2006).
6.5	Health care providers need to consider specific needs relating to symptom assessment and management for people from culturally and linguistically diverse groups (see Chapter 10), and Aboriginal and Torres Strait Islander people (see Chapter 9).

6.13 Further research

Clinical guidelines are increasingly being used to form standards of care. Despite the extensive amount of literature and guidelines published in the area of palliative care, there are few clinical practice guidelines for the management of some specific symptoms during end-of-life care for nonmalignant conditions. Symptoms such as fatigue, nausea, vomiting and cachexia, in particular, require future research and guideline development.

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Chapter 7 Psychosocial care

Psychosocial care incorporates support both of a psychological nature (eg counselling) and a social nature (eg improved social support). A person's psychosocial wellbeing may be harmed by physical illness and ageing; conversely, psychosocial factors affect physical and mental health, the outcomes of illness, and overall wellbeing. Although the mechanisms by which psychosocial interventions can modify the course of a disease, or even a disease itself, still remain unknown, a multidisciplinary approach, including psychosocial treatment, is obviously more effective than medical treatment alone (Rehse and Pukrop 2003). As with physical factors that affect health, psychosocial factors alter with age (Ballantyne 2004).

This chapter is based mainly on reviews of research (see Appendix N for included reviews), but some additional material is referred to when reviews failed to address key issues. The chapter addresses the following topics:

- the overall needs of older adults for psychosocial care and how a palliative approach can be used to address these needs (Section 7.1)
- psychosocial care and treatment options for specific conditions common in older adults (Section 7.2), with references to clinical practice guidelines and other readings that may be particularly useful
- psychosocial care and treatment for older adults in declining health in general (Section 7.3).

7.1 Psychosocial needs and a palliative approach

Any change in the psychosocial environment that is associated with ageing may affect both quality of life and the outcomes of illness that are more common in old age (Rehse and Pukrop 2003). A person's social network and support are important predictors of their wellbeing and having an inadequate social network also increases the risk of depression, poor health and even death (Luskin et al 2000). Therefore, social support should be considered as an integral dimension in the provision of 'basic care' for frail older people living in the community.

A person's social network can include both extended family and friends (Jordan-Marsh and Harden 2005). Friends of older adults have been shown to be more important than family for emotional wellbeing, possibly because friends are in a similar age group with comparable lifestyles, experiences and values; also, interactions with friends may be more likely to be voluntary and occur in social settings (Rehse and Pukrop 2003). In addition, the quality rather than the number of relationships is important (Pinquart and Sorensen 2000) and how satisfied the person is with support from their family and friends is more important than the actual amount of support, with people having different needs (DoHA 2006). Gender and cultural background, in particular, may be key factors in determining the amount of social contact and types of ties that might be adequate (Jordan-Marsh and Harden 2005).

Providing older adults with appropriate psychosocial care may reduce the need for medical treatment, improve clinical outcomes and increase longevity. Psychosocial interventions can be simple; for example, when addressing loneliness with tailored interventions that strengthen social networks (Cattan et al 2005). These interventions can also sometimes be as effective as pharmacological treatments in specific illnesses, such as depression (Mohlman 2004).

Older adults are more likely to suffer multiple medical conditions; therefore, using effective psychosocial interventions can reduce the risk of side effects from medications and adverse drug interactions (Mohlman 2004). Psychosocial interventions are also often more cost-effective than other forms of treatment (Rehse and Pukrop 2003, Vachon 2006).

Because of its holistic nature, a palliative approach to care addresses the psychological and social needs of older adults and acknowledges that these needs can be best addressed by a multidisciplinary team. In a North American review, the role of the community nurse was emphasised as being of particular importance (Markle-Reid et al 2006). Many types of interventions and programs that rely on community nursing reduce hospitalisation, use of residential aged care and cost. A greater role of the community nurse in psychosocial programs has also been associated with improved effectiveness (Markle-Reid et al 2006). In the Australian context, the community-based nurse might coordinate care packages for older Australians, liaising with the general practitioner (GP) when any referrals are needed. General practitioners, therefore, also need to be able to recognise psychosocial needs and recommend appropriate strategies. Also, in the context of ongoing service provision, nurses might direct rather than provide care in some instances, relying on information provided by care workers. Therefore, care workers also need to be aware of key indicators of psychosocial need. This kind of interdisciplinary team approach is essential to provide the best possible outcomes (Skultety and Zeiss 2006).

The delivery of psychosocial care should also take into account considerations raised in Chapter 9 (‘A palliative approach to care for Aboriginal and Torres Strait Islander people’) and Chapter 10 (‘A palliative approach to care for older people from diverse cultural and language groups’).

7.2 Psychosocial care and treatments for specific conditions common in older adults

Specific psychosocial needs have been documented in people who are experiencing anxiety, depression, dementia, cancer and chronic illnesses. This section addresses psychosocial treatments and management strategies that are likely to be useful for these conditions.

Some of these conditions have overlapping symptoms, leading to the risk of misdiagnosis. For example, anxiety and depression occur quite commonly in people who have dementia and there is overlap in the symptoms of depression and dementia (Pachana et al 2006). Additionally, delirium can have similar symptoms to depression and dementia. Guidelines relevant to delirium management are listed in Chapter 6 (‘Physical symptom assessment and management’).

The **Registered Nurses Association of Ontario** (RNAO) has also published useful guidelines: RNAO (2003). Screening for Delirium, Dementia and Depression in the Older Adult, RNAO, Toronto.

Available from the RNAO website at: http://www.rnao.org/ (Nursing best practice> guidelines>Clinical practice guidelines program>Guidelines and fact sheets)

7.2.1 Anxiety

Anxiety is a common reaction in people who have life-limiting illnesses. It may arise from fear of death or because of separation and loss and the impact on the family. Anxiety is characterised by feelings of apprehension, fear and dread. Anxiety may also manifest in physical symptoms such as nausea, dizziness, complaints of shortness of breath and diarrhoea (Mohlman 2004). Older adults may present with symptoms that are different from those of younger adults (eg anxiety of decreased emotional intensity or with symptoms similar to those of depression), and this can lead to difficulty in diagnosis. Older adults with symptoms of anxiety tend to prefer to see a GP rather than a mental health specialist (Mohlman 2004), and to make longer and more frequent visits to a GP than older adults without anxiety (Wetherell et al 2005). Older adults may also use different coping strategies from those used by younger people (Mohlman 2004). Anxiety ranges in severity, from a mild state to severe panic.

Pharmacological intervention may be required for severe acute anxiety and the following guidelines may be helpful:

- Therapeutic Guidelines (2010). Palliative Care, version 3, Therapeutic Guidelines Ltd, Melbourne.

Available from the TG website at: http://www.tg.com.au

- Therapeutic Guidelines (2003). Psychotropic, version 5, Therapeutic Guidelines Ltd, Melbourne.

Available from the TG website at: http://www.tg.com.au

Swinson RP (2006). Clinical practice guidelines. Management of anxiety disorders. *Canadian Journal of Psychiatry* 51(8 Supp 2):1S–91S.

For subjective anxiety symptoms, relaxation training may be the most effective psychosocial treatment (Wetherell et al 2005, Ayers et al 2007) and the most cost-effective (Ayers et al 2007). Imagining muscle tensing and relaxing may be as effective as actual tensing and relaxing and is therefore of particular benefit to some subgroups of older adults (eg those with musculoskeletal conditions) (Ayers et al 2007). Relaxation training can also help to reduce anxiety in older adults who have dementia (Wetherell et al 2005). Other management strategies include identifying concerns and needs, addressing specific fears and using distraction (eg visits from family, friends, volunteers).

For generalised anxiety disorder, cognitive–behavioural therapy (CBT), which alters behaviour by modifying thinking processes (Luskin et al 2000), is the most effective psychosocial treatment (Mohlman 2004, Wetherell et al 2005, Ayers et al 2007). In younger adults, CBT can be more effective than anti-anxiety medications (Mohlman 2004). However, CBT is less effective in older adults and older adults are less likely to complete treatments.

CBT protocols may need adapting for older adults, and for the problems they are facing, for them to be optimally effective (Wetherell et al 2005, Ayers et al 2007). Tailoring the treatment to each person, and to the particular problem the person wants to resolve (eg sleep disturbances), is the most effective approach (Wetherell et al 2005).

7.2.2 Depression

Depression has a substantial impact on older adults, affecting both quality of life and mortality (Cuijpers et al 2006). Loss and separation are common in older people experiencing life-limiting illness and are common triggers for depression. Between 10% and 15% of older adults not living in residential aged care are estimated to have depression (Hill and Brettle 2006), and almost 60% of medically ill older adults are reported to be depressed (Pachana 1999). Episodes of depression before the age of 65 years (Freudenstein et al 2001) and a high number of recent negative life events (Kraaij et al 2002) increase the risk of depression.

Bipolar disorder is a disabling illness that includes symptoms of depression. However, its prevalence rates are lower and there are additional symptoms of periods of mania or hypomania (RANZCP 2004).

The **Royal Australian and New Zealand College of Psychiatrists** (RANZCP) has published guidelines that may be helpful for managing bipolar disorder (although these guidelines are not specific to older adults):

RANZCP (2004). Australian and New Zealand clinical practice guidelines for the treatment of bipolar disorder. *Australian and New Zealand Journal of Psychiatry* 38(5):280–305.

Depressive symptoms in older adults are associated with (Skultety and Zeiss 2006):

- worsened physical symptoms, including pain
- delayed recovery from illness
- increased functional disability
- higher rates of use of the health care system
- increased risk of mortality from cardiovascular disease.

Physical health problems are also more likely to result in new or worsened depression (Pachana 1999, Freudenstein et al 2001, Skultety and Zeiss 2006).

A thorough assessment of the factors that contribute to depression is required to determine appropriate management. Management strategies can include pharmacological and nonpharmacological treatments.

As well as the therapeutic guidelines listed under ‘Anxiety’, the following guidelines may be useful for managing depression:

- Baldwin RC, Anderson D, Black S, Evans S, Jones R, Wilson K and Iliffe S (2003). Guideline for the management of late-life depression in primary care. *International Journal of Geriatric Psychiatry* 18(9):829–838.

- Faculty of Psychiatry of Old Age (New South Wales Branch) RANZCP (2001). *Consensus Guidelines for Assessment and Management of Depression in the Elderly*. Centre for Mental Health in the New South Wales Health Department, North Sydney.

Additional guidelines for the treatment of depression are also available; however, these guidelines are not specific to the treatment of older adults:

- RANZCP (Royal Australian and New Zealand College of Psychiatrists) (2004). Australian and New Zealand clinical practice guidelines for the treatment of depression. *Australian and New Zealand Journal of Psychiatry* 38:389–407.

Nonpharmacological treatments that have been used for depression include CBT, other behavioural therapies, reminiscence and life review, psychotherapy, problem-solving therapy, and improving social support and coping strategies. Psychological therapies may be used as a first-line option for depression, particularly in older people wishing to avoid medication, because they can sometimes be at least as effective (Cuijpers et al 2006). There is no indication that any one of the psychological treatments is more effective than another, so a program can be tailored to the preferences of the older person and practitioner (Hill and Brettle 2006) and a flexible approach by the care team is the most effective (Freudenstein et al 2001). Fostering social support and network building is also an effective preventive approach to depression in older adults (Jane-Llopis et al 2003).

Early diagnosis is important because psychosocial interventions are most effective when implemented early in the treatment of anxiety and depression in older adults and using an interdisciplinary team approach (Huibers et al 2007).

A number of tools can be used to screen quickly for anxiety and depression but health care professionals need to be aware of their accuracy. For example, Mitchell (2008) reports that asking two questions (one about mood and one about loss of interest) can correctly detect depression in 91% of cases and an absence of depression in 86% of cases.

7.2.3 Dementia

People with dementia sometimes show behavioural symptoms as the underlying disease process progresses. At this time, wandering, agitation and aggression may be manifested (Opie et al 1999), making it less likely the person can continue to live in the community (Pachana 1999). Often these symptoms may result from frustration because of communication difficulties. Family carers may find coping on a day-to-day basis at this time more problematic than coping in later stages of the disease. Therefore, providing adequate support at this time may facilitate home care throughout the course of the disease, when this is desired. This support may be regarded as part of a palliative approach to care. Pain and other symptoms also need to be considered as possible causes of these behavioural symptoms and treated appropriately if this is the case (see Chapter 6 for more information on assessing and managing symptoms). Depression and anxiety may also be implicated, a fact that presents particular assessment challenges. Multidimensional programs that include behavioural, psychological and social components are effective approaches for depression in dementia and these programs can be tailored to each person (Teri et al 2005).

Common treatments for behavioural symptoms may involve the use of psychotropic medications (medications that affect the mind, emotions or behaviour) (Opie et al 1999, Abbey et al 2008). However, psychosocial interventions can also be effective, one aim being to address the triggers for these symptoms. In particular, activity programs that provide diversion, stimulation and exercise are known to help reduce anxiety, boredom and wandering (Opie et al 1999). Activities are also important for encouraging socialisation and friendship, enjoyment, maintaining self-esteem and improving psychological wellbeing (Marshall and Hutchinson 2001). Addressing effective communication may reduce agitation (Opie et al 1999). Wellbeing may be improved and apathy reduced by stimulating smell, taste, touch and hearing (Verkaik et al 2005). Minor changes to the physical environment aimed at reducing disorientation can improve wellbeing and decrease behavioural symptoms (Verkaik et al 2005, Torrington and Tregenza 2007). Music and art therapy may also help the exploration of identity and self expression in people with dementia (Marshall and Hutchinson 2001), as well as providing stimulation, addressing behavioural symptoms in a different way. Qualitative evidence also suggests that animal-assisted therapy can help. Animal-assisted therapy may decrease agitation, wandering and distress (Pachana 1999); decrease verbal aggression; and increase social interaction (Filan and Llewellyn-Jones 2006).

The following guidelines may be useful when addressing behavioural symptoms and responses in people who have dementia:

- Expert Consensus Panel for agitation in dementia (1998). Treatment of agitation in older persons with dementia. *Postgrad Med Spec* No.: 1–88.
- NCCMH (National Collaborating Centre for Mental Health) (2006). *Dementia: Supporting People with Dementia and their Carers in Health and Social Care*, National Institute for Health and Clinical Excellence, NCCMH, London, United Kingdom, National Clinical Practice Guideline Number 42. http://www.nice.org.uk/ (search for CG42)

In later stages of dementia, as the person becomes bedfast and unable to use language to communicate, psychosocial approaches remain important, although at this time physical symptoms may also become more prominent (see Chapter 6 for more information on assessing and managing symptoms). In late-stage dementia, those providing care need to try to understand the unspoken communication of the person who has dementia to detect any distress or discomfort, and address them appropriately (DoHA 2006) and use improved communication strategies to promote wellbeing. Other strategies, such as playing music the older person enjoys, are also useful. Many more suggestions for supporting older adults with dementia in the community are available from state branches of Alzheimer’s Australia, an organisation that also provides psychosocial support for people who have dementia and their carers, and education in this area for staff.

Alzheimer’s Australia

http://www.alzheimers.org.au

7.2.4 Cancer

Cancer has significant psychological consequences. In particular, better psychological outcomes can be achieved by using techniques to help the person with cancer to understand their condition better or to prepare them for procedures (Luxford and Fletcher 2006). In older adults, special issues arising from cancer treatment and its associated psychosocial consequences include decreased reporting of depression, more co-occurring illnesses, polypharmacy and decreased social support. From a psychosocial perspective, cancer is a complex stressor with effects that alter throughout the disease course and may also vary with the environmental setting (Kua 2005).

Recent trials have failed to detect evidence that psychosocial interventions increase survival in people with cancer (Chow et al 2004) but there are other clear benefits for individuals; for example, psychosocial support leads to better coping and improved quality of life (Graves 2003, Rehse and Pukrop 2003). Multifaceted psychosocial interventions, of a minimum of 12 weeks' duration, are recommended as routine treatment for people diagnosed with cancer (Rehse and Pukrop 2003). Increased rates of psychosocial distress and depression also occur after cancer survival, especially in people aged over 70 years (Vachon 2006). Depression is linked to worse health outcomes and psychosocial interventions can decrease distress and improve quality of life (see the section on depression, above, for more information).

7.2.5 Chronic conditions

The seven most common chronic conditions affecting adults older than 70 years living in the community are arthritis, hypertension, heart disease, diabetes mellitus, respiratory disease, stroke and cancer (Pachana 1999). Arthritis is the most common of these conditions, affecting approximately half of those aged over 70 years. In Australia, at least 50% of adults aged over 65 years have at least one chronic illness (Pachana 1999). This rate increases with increasing age (Pachana et al 2006). Physical illness has multiple effects on social status, interactions and psychological functioning, and — at the same time — psychological and social factors affect the course of the disease and life expectancy (Furr 1998).

In general, chronic conditions are best managed by a program that is tailored to each person, with individualised feedback and review, and an emphasis on psychological interventions (Chodosh et al 2005). Promoting an understanding of how the older person can have some control over their health status (eg using self-management strategies) plus the provision of adequate social support are key factors in reducing depression and medical complications, and improving quality of life (Furr 1998). In particular, education about lifestyle and diet can improve coping and the physical symptoms of many chronic illnesses (Luskin et al 2000). Targeting psychosocial wellbeing, even when the person's health is deteriorating, can still improve psychological factors at that time (DoHA 2006).

7.3 Psychosocial care and treatment for older adults in declining health in general

7.3.1 Reminiscence and life review

Reminiscence can benefit older adults who need to adapt to difficult circumstances as they age, perhaps because they can reflect on how they were able to cope with previous life challenges. This strategy also allows the person to observe a sense of continuity and meaning in their lives, and use this reflective process as a prompt to seek reconciliation when appropriate (eg when there has been family discord) (Bohlmeijer et al 2007). Whatever the mechanism, reminiscence can improve life satisfaction and wellbeing. Moreover, a structured approach to life review in which the older person considers the impact of major life events and turning points, resolves past conflicts, and develops a coherent life story is more beneficial than the less structured approach of reminiscence (Bohlmeijer et al 2007).

7.3.2 Music therapy

Music therapy may include playing music and singing, as well as listening to music. It can also be useful in conjunction with other treatments, such as reminiscence (Luskin et al 2000). Many music therapists use music therapy specifically for pain reduction, particularly in older adults, and the use of relaxation therapy in conjunction with music therapy has also been found to have benefits in this area (Luskin et al 2000).

7.3.3 Computer resources

Computer resources can be useful for older adults who are unable to leave their homes because of illness or disability; they have the potential to reduce social isolation and provide support in terms of information and social interaction (eg with family or via support groups). In this way, computers may also improve mental health (Alexy 2000). Also, specific computer-based interventions called interactive health communication applications include a computerised CBT component and can significantly improve knowledge about one's illness, perceived social support, health behaviours and clinical outcomes (Murray et al 2005). Computers may also be used for relaxation.

7.3.4 Health-promotion programs

Components of health-promotion programs vary, but may include education about diet and exercise, self-management programs, meditation and relaxation (Luskin et al 2000). These programs both provide psychosocial support and help to manage effects of physical and psychological conditions. Community-based programs targeting a range of illnesses reduce mortality, improve depressive symptoms and delay admittance to residential care (Verkaik et al 2005).

7.3.5 Relaxation therapy

Relaxation therapy or some form of meditation is often included as part of a CBT program. These programs appear to help restructure behaviour, but it is difficult to isolate the effects of relaxation from other components of the program. Imagery-based relaxation, in which imagination is used to create or recreate a situation that promotes relaxation, can reduce stress, increase pain tolerance and help to reduce depression and anxiety (Luskin et al 2000).

7.3.6 Mind–body therapies

Mind–body therapies, which involve developing both mental and physical skills, include yoga, tai chi and qigong. These therapies can provide mild exercise suitable for older people, and may reduce stress and help with chronic illness management. All these benefits can potentially improve health outcomes via the combination of psychological and physical impacts. Yoga seems to decrease pain and increase the range of movement in arthritis sufferers; tai chi reduces frailty and may also help with pain management. However, much more research is needed to comprehensively test and evaluate the effectiveness of these therapies (Luskin et al 2000).

7.3.7 Animal-assisted therapy

Companion animals are currently used in some Australian hospitals and residential care facilities to improve psychological wellbeing and quality of life in older adults (Steed and Smith 2002, May 2007). In the home situation, many older adults will have their own pets but some will be too frail to care for a pet any longer and could benefit from visits from a companion animal. Anecdotal evidence indicates that interaction with companion animals may improve depression, anxiety, loneliness and stress, and increase social competence, interest and life satisfaction. However, more research is needed in this field; for example, to distinguish between the effect of interacting with the animal and interacting with the handler (Filan and Llewellyn-Jones 2006, May 2007).

7.3.8 Environmental modification

Environmental modification can be viewed as a psychosocial intervention, because features such as appropriate lighting and use of space can improve psychosocial wellbeing for older adults (Torrington and Tregenza 2007). For example, lighting can improve wellbeing (eg by minimising falls and increasing mobility) if it is appropriate for the ageing eye, reduces glare and areas of darkness, increases light and contrast within the main area of focus, and uses the red–yellow spectrum (Torrington and Tregenza 2007).

7.4 Conclusion

Psychosocial care, treatments and support have many potential benefits for older adults in community settings who are in failing health. In some instances, these options can be as beneficial as pharmacological therapies. They may also minimise adverse treatment effects and be more in keeping with the preferences of the older adult. In other instances, psychosocial interventions can be used to increase the effectiveness of treatments, minimise disease symptoms or simply to improve overall wellbeing. The diversity of options available also allows people’s needs and preferences to be incorporated into decision-making processes around care planning. In this way, the increasing array of psychosocial therapies empowers the older adult by offering them choice.

7.5 Good practice points — psychosocial care

Assessing and screening

Accurate detection of conditions that may be particularly helped with psychosocial care is important so that a palliative approach to care can be tailored appropriately (see Section 7.2.2).

7.1 Psychosocial assessment should be included as routine in the care of older adults living in the community so that needs for psychosocial support can be identified and addressed.

7.2 Screening older adults for depression who have had a previous major depression or who have recently experienced major life events, such as bereavement, is appropriate; these people may be at risk.

7.3 Screening older adults for depression who have severe physical illness is appropriate even when the older adult is significantly debilitated. Depression is likely to be treatable even when it occurs in conjunction with severe physical illness.

7.4 Care providers need to consider that depression may be a contributing factor for a person with dementia who behaves in an agitated or aggressive manner, as well as when withdrawal and apathy are observed. However, other considerations are also appropriate. For example, is the person experiencing pain or are they frustrated because they are having difficulties with communication?

7.5 Although depression needs to be considered, older adults with life-limiting illnesses and their family may feel sad and be experiencing adjustment problems rather than depression.

Using interventions and support

Choosing the right psychosocial intervention relies on an understanding of the older person's individual symptoms and preferences (see Sections 7.2 and 7.3).

7.6 Psychological support and reassurance may be needed in older adults who are experiencing anger. Anger may be part of grief reaction from having an incurable disease and/or related to other losses; it can present in many forms (eg verbal and physical aggression, noncompliance, withdrawal). Careful assessment is required to determine the extent to which anger is appropriate and proportionate, and to identify possible causes (Chan and McConigley 2006).

7.7 Consideration of psychological and social reasons for symptoms is appropriate. For example, symptoms related to anxiety may include hyperventilation, which may be confused with dyspnoea from a physical problem.

7.8 An understanding of the overlap in symptoms of depression and dementia will minimise misdiagnosis in this area and, therefore, facilitate appropriate treatment. Similarly, how symptoms of delirium differ also needs to be understood.

7.9 A person's psychological and social situation needs to be assessed at an individual level with consideration for culture, gender and beliefs when planning for care and support. No assumptions can be made about experiences of older people due to the diversity of these experiences. Treatable illness (eg depression) may also be missed if it is assumed that symptoms are caused by ageing.

7.10 Effective psychosocial interventions are most likely when a collaborative, integrated, team approach to treatment is taken, with a focus on communication and shared information.

7.11 Tailoring an intervention to the older person's preferences is likely to increase its effectiveness because compliance is more likely; this should be possible because of the many psychosocial therapies that are available.

7.12 Psychosocial treatment options should be considered to minimise problems from polypharmacy and medication side effects. For example, the use of a combination of relaxation and music therapy merits consideration in pain management. The decision needs to take into account the older adult's specific needs and preferences as well as the potential effectiveness of treatments.

7.13 Psychological interventions for older people living in the community, particularly for those living alone or recently bereaved, may be improved by strategies to promote social support (eg volunteer visits), if this approach is acceptable to the older person.

7.14 Minor modifications to the physical environment (positioning chairs to face natural external views, etc) can improve physical and mental wellbeing, and may reduce effects of confusion and disorientation associated with dementia.

7.15 Using strategies to alleviate boredom or possible distress for older adults with advancing dementia may minimise behavioural symptoms, such as agitation or wandering. Social activities are also likely to improve quality of life in most older adults.

7.16 Effective communication with people who have dementia includes using simple, clear language (Pachana 1999). Simple strategies, such as promoting communication effectiveness by educating caregivers to give only one instruction at a time, may significantly reduce agitation (Opie et al 1999).

7.17 For people who have dementia, lighting can be organised to help them to recognise their surroundings (eg to highlight the dining area when it is time to eat). Overall, increasing environmental lighting, ensuring some time is spent outside, or — for housebound people — a diurnal lighting pattern, may lessen sleep disturbances and depression (Torrington and Tregenza 2007).

7.6 Recommendations for further research

Areas requiring more research include:

- effects of individual interventions versus effects of combined interventions
- dose-specific effects
- distinction between effects of individual and group interventions
- the mechanisms underlying benefits of psychosocial interventions
- currently underinvestigated areas, such as art therapy.

Recommended readings

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Chapter 8 Spiritual support

Many people experience a sense of spirituality (Pronk 2005). Spirituality is described as ‘that which lies at the core of each person’s being, an essential dimension which brings meaning to life’ (MacKinlay 2001, cited in MacKinlay and Trevitt 2007). This spiritual dimension may be reflected in beliefs, attitudes and behaviours. Participation in organised religion is one way in which spirituality may be expressed (Lindberg 2005).

‘Religion is an extrinsic organised faith system, grounded in institutional standards, practices and core beliefs, while spirituality is personal beliefs and practices that can be experienced within or without formal religion.’ (Phillips 2003, p 249)

Older people may become more interested in spiritual issues as they age, possibly in response to the new challenges that ageing may introduce (Lindberg 2005, Moberg 2005, Dalby 2006). In particular, mortality becomes a more confronting issue and it is sometimes difficult to come to terms with the life that one has lived (Dalby 2006). A palliative approach allows for spiritual care to be a key practice component (DoHA 2006).

A person’s spiritual dimension determines what is sacred to them; what provides meaning, purpose and fulfilment in their life; and how they can come to feel at peace (Pronk 2005, Dalby 2006). Spiritual care begins with understanding the person’s spirituality, supporting them in the life practices that are, therefore, important to them (Dalby 2006). This element of care requires an appreciation of the person as they are defined by their past roles and relationships, hopes and dreams, inner creativity, and how they find meaning in life (Pronk 2005). If a person identifies with religious beliefs, understanding these beliefs will provide a basis for spiritual care.

In Australia, from 2006 figures, Christianity was the most common religious affiliation of people who were aged 65 years and over (approximately two million people). However, there were many other religious affiliations in this age group, including Buddhism (approximately 26 000 people), Hinduism (approximately 5500 people) and Islam (approximately 10 000 people). With growing numbers of migrants from sub-Saharan Africa, southern Asia and the Middle East, and given the ageing of the current population, a gradually increasing proportion of older people will identify with Buddhism, Hinduism, Islam and Judaism (ABS 2006). Service providers need to develop an awareness of the key tenets of religious and spiritual beliefs, and perceptions and practices that are relevant to the community in which they deliver care (Moberg 2005).

This chapter is underpinned by reviews of relevant research (see Appendix O for the included articles). The topic areas of spirituality and health, spiritual needs towards the end of life, and how to incorporate spiritual care into a palliative approach for the older adult in the community are addressed.

8.1 Spirituality and health

Spirituality or religion can influence physical health (Luskin et al 2000). However, spirituality and religion are best recognised for their contribution to psychosocial health in terms of:

- contributing to a sense of wellbeing among older adults in the final years of their lives (Van Ness and Larson 2002, Moberg 2005, Chi 2007)
- helping people who are coping with crises and problems (Ano and Vasconcelles 2005)
- allowing the person to experience psychological growth, rather than to be overwhelmed by their health experiences (Koenig et al 2001).

8.1.1 Family carers

Family carers of people with illness and disability sometimes use religious coping and may benefit in terms of a lower likelihood of depression and greater spiritual growth (Pearce 2005). Having spiritual and religious beliefs has also been associated with better bereavement experiences (Pearce 2005). Moreover, members of religious organisations are reported to obtain social benefits that include bereavement support and relief from social isolation (Musick et al 2000). However, carers who use negative forms of religious coping, such as blaming their god for their misfortune, have been found to manifest emotional distress, and poor physical health and quality of life (Pearce 2005).

8.1.2 People receiving care

Research has tended to focus on the health effects of spirituality in people receiving care, rather than in carers (Pearce 2005). For people receiving care, hope appears to be the key element. Importantly, hope correlates with the degree to which people cope with disease (Chi 2007).

A positive relationship with health care professionals can foster hope for people (Chi 2007). Religion can also provide hope during progressive disease, disability and emotional difficulties (Van Ness and Larson 2002). Moreover, religious beliefs are associated with decreased rates of depression and suicide (Van Ness and Larson 2002).

Overall, benefits for psychological health tend to accrue from embracing a spiritual or religious dimension to life. However, a brief review by Hilleras et al (2001) of how religion affects wellbeing notes that being religious is sometimes associated with negative outcomes because it can worsen some stressors. Although the review did not provide examples, it may refer to a need to adhere to religious rules or codes of conduct and the sense of guilt experienced when these rules or codes are broken.

8.2 Spiritual needs toward the end of life

The older person's perception of dying, their acceptance of death and their family's acceptance of death may be influenced by spiritual comfort or religion (Gruenewald and White 2006). People may have numerous spiritual needs near the end of life, such as a need to (Gruenewald and White 2006):

- complete life tasks
- share experiences with families
- resolve feelings
- make practical preparations
- make peace with their god.

Criteria have been identified that help care workers to recognise older people with life-limiting illness who need additional spiritual support (Meraviglia et al 2006). These criteria include:

- an inability to engage in spiritual or religious practices
- frustration, fear, hurt or doubt
- feelings of loneliness and isolation
- a lack of hope or a feeling that life is not worthwhile
- feelings of losing control
- verbalising questions about faith or loss of faith
- emotional suffering, such as experiencing a lack of meaning, guilt or anger
- anxiety or depression
- exhibiting a desire for death.

8.3 Incorporating spiritual care into a palliative approach to care

A rapidly growing body of resources can help health care professionals to incorporate spiritual care that is not belief specific into care provision (Moberg 2005).

Effective interventions for relieving spiritual distress in older adults focus on the core feelings of loneliness, social isolation, hopelessness, and anxiety and depression by easing loneliness, promoting connection with others and encouraging hope (Meraviglia et al 2006).

The challenge for community services is to make sure that community care workers are sensitive to people's spiritual or religious needs and understand how their own beliefs impact on their practice. Community care workers also need to know how they can sensitively and respectfully offer spiritual interventions with the older person's permission (Moberg 2005).

8.3.1 Spiritual care in aged care

Although spiritual care is a responsibility of palliative care providers, literature suggests that even palliative care specialist teams may be more skilled at alleviating physical rather than spiritual symptoms (Francke 2000). However, aged care providers tend to have one key advantage over hospice care providers in that their relationships with individuals often exist over a longer time. Spiritual care is an integral part of a palliative approach to care, but one that needs to be individualised according to the person's needs (Pronk 2005). For example, interventions targeting religious beliefs are beneficial primarily for those who look to their religion for support (Gruenewald and White 2006).

8.3.2 Spiritual assessment

Spiritual assessment begins by recognising the person's need for spiritual comfort (Phillips 2003). To create open, nonjudgmental communication relating to the spiritual needs of an older adult, care workers need to cultivate attentive listening skills and 'being present' as well as taking the time to talk to people (Gaskamp et al 2006). They need to demonstrate caring behaviours, show that they are genuine and value what the person is saying (Chi 2007).

Spiritual assessment is also a continuing process (DoHA 2006). Assessments do not need to include religion, but a person's religious views should not be excluded (Pronk 2005). Recognition of the person's and their family's beliefs, practices and experiences is essential to understand their spiritual needs, as well as to implement interventions to address spiritual distress (Phillips 2003, DoHA 2006). When taking a spiritual history or performing a spiritual assessment, either an open-ended discussion or one of several existing tools should be used (Phillips 2003).

Health care providers also need to consider cultural practices, because spiritual beliefs and practices are often tied to culture (see Chapter 9 for more information on providing care for Aboriginal and Torres Strait Islander people, and Chapter 10 for providing care for older adults from culturally and linguistically diverse groups).

Few spiritual assessment tools have been validated; however, the Brief Assessment of Spiritual Resources and Concerns[8] is an example of a tool that community care providers can use to open the conversation about spiritual needs with the individual (Koenig 2002, Meyer 2003, both cited in Gaskamp et al 2006). Also, a number of valid assessment tools (listed in the box below) are useful for evaluating spiritual dimensions of a person's quality of life or other relevant aspects.

Pronk (2005) indicates that health care professionals should be careful when using assessment tools, so that the person is not disempowered by the process. Instead, the person should be allowed to guide the pace and timing of such discussions, and the health care professional needs to seek their permission for them to occur.

Relevant assessment tools

The following two tools are cited in Hearn and Higginson (1997). The McGill Quality of Life Questionnaire (MQOL) is currently on a number of websites accessed via a web search, although none of these websites seem to be permanent, so a web address is not provided. The McMaster Quality of Life Scale (MQLS) has not been found on the web.

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[8] The Brief Assessment of Spiritual Resources and Concerns is available in Gaskamp C, Sutter R, Meraviglia M, Adams S and Titler MG (2006). Evidence-based guideline: promoting spirituality in the older adult. *Journal of Gerontological Nursing* 32(11):8–13.

- The McGill Quality of Life Questionnaire (MQOL) (Cohen et al 1995)
- The McMaster Quality of Life Scale (MQLS) (Sterkenburg et al 1996)

The following tools are cited in Meraviglia (2006):

- Functional Assessment of Chronic Illness Therapy (FACIT) — Spiritual (Cella 1997)

Available from: http://www.facit.org

- Loneliness Scale (Hughes et al 2006)

Available from the University of Chicago website http://www.uchicago.edu using the search option

- Herth Hope Index (Herth 1992)

Available from the author at (email): kaye.herth@mnsu.edu

The following tool is cited by Moberg (2005):

- Spiritual Well-Being Scale (SWB) (Paloutzian and Ellison 1982, Paloutzian and Ellison 1991)

Available from: http://www.lifeadvance.com/

8.3.3 Staff education

Everyone in the multidisciplinary team should be sensitive to the spiritual care of older adults and their families (Pronk 2005). Staff education and training related to meeting spiritual needs and recognising the importance of spirituality to a person's health is therefore important (Phillips 2003). The team also needs to include chaplains and/or pastoral care workers and, where appropriate, traditional healers, who are able to provide spiritual care in a variety of settings. These workers need to understand the different spiritual issues that may arise (DoHA 2006). For example, people providing care and the older adults receiving care may have different views of spirituality and religion. This may lead to misunderstandings if carers fail to understand the language used by older adults when referring to spiritual issues (Phillips 2003).

8.3.4 Staff sensitivity

Good spiritual care includes an awareness of the spiritual dimension of a person's life, the use of sensitivity, a trusting relationship, common sense and maturity (Pronk 2005). Carers or health care professionals do not need to share the same beliefs as the person to be able to recognise that person's needs. However, it is important that carers do not impose their own views (DoHA 2006). Moreover, carers need to recognise the spirituality of people who cannot communicate their perspectives in the usual way because of disability or illness.

People with dementia can have rich spiritual lives and inner resources, as well as spiritual needs. Providing spiritual care for these people recognises that the language of the spirit is much more than words, is often symbolic and expressed in music, story, art, dance, touch, beauty, tears, laughter and so on. People with dementia may understand, respond to and 'speak' this language more clearly than those who depend more on verbal language.

8.3.5 Resources

Health care professionals and carer workers also need to know of the spiritual support resources that are available within the community (Gaskamp et al 2006). For example, many religious organisations provide home-visiting services and could also help people with transport to churches or other religious centres.

8.3.6 Interventions

Interventions can include requesting home visits by pastoral care workers or chaplains and, where appropriate, traditional healers, providing information about community services such as support groups, or referring the person to healers, chaplains, pastoral care workers, or for other spiritual or religious counselling (Moberg 2005). Some people may prefer different spiritual pursuits, such as listening to music, doing artwork, engaging with nature or other activities.

Respecting the person’s need for prayer, meditation and other practices may entail timing home visits so that they do not interrupt spiritual and religious practices. It may also include physically helping the person to take part in spiritual activities (Gaskamp et al 2006).

Regular reviews of spiritual strengths and needs are essential because the older person’s and the family members’ requirements may change throughout the progression of their illness and care, particularly as death draws near (DoHA 2006). The purpose is generally not to necessarily resolve the person’s spiritual or religious issues, but to create an environment that promotes spiritual expression (Phillips 2003).

8.4 Conclusion

Spiritual support may be an important component of a palliative approach to community care for older adults. Spiritual and religious needs, and the extent to which these are met, can have important implications for the quality of life of those facing old age in ill health and drawing close to death, and for the experiences of their families. Health care providers can therefore help people and their families by making sure that spiritual and religious care needs are identified and addressed.

8.5 Good practice points — spiritual support

Recognising older people's spiritual needs near the end of life

People may become more interested in spiritual issues near the end of their life and recognising their spiritual needs can allow this key dimension of wellbeing to be addressed (see Section 8.2)

8.1 Facing old age, increasing illness or disability, and the end of life can bring about multiple losses and challenges for older people. Coping with these challenges can be improved by recognising spiritual strengths and needs.

8.2 Maintaining hope is one way of supporting spiritual wellbeing. When the likelihood of a cure or renewed health is limited, sustaining hope for relief from pain and symptoms, a peaceful death, and being with family and friends when one is dying may be supportive (Chan and McConigley 2006).

8.3 The care team needs to be spiritually sensitive because spiritual perspectives and needs evolve over time and may become more important as death draws nearer. For family carers and others, spiritual needs may continue into the postbereavement period. Showing sensitivity will ensure a responsive approach to spiritual support and care.

8.4 Recognising signs of spiritual need, such as distress seemingly out of proportion to symptoms, insomnia that is resistant to medication, and over-reacting to trivial events will allow hidden support needs to be addressed (Chan and McConigley 2006).

Incorporating spiritual needs into a palliative approach to care

The older person's spiritual beliefs can be incorporated into a palliative approach to care in different ways, depending on what is best for the individual older person (see Section 8.3).

8.5 Making sure that spirituality is included in care assessment, planning and delivery will improve the older person's quality of care. It is also likely to improve the wellbeing of the older person and their family. Spiritual care and support may be a key dimension of providing a palliative approach to care.

8.6 For many older people, spirituality is manifested, in part, through religion. When providing care for these people, an understanding of their core religious beliefs and practices will help to make sure that care is congruent with, and respectful of, their religion.

8.7 Including chaplains or pastoral care workers and, where appropriate, traditional healers, as part of the care team can help to deliver flexible and adaptable spiritual care for people and their families.

8.8 Affiliations with relevant religious and other organisations that may address spiritual issues can help in the delivery of spiritual care.

8.9 Supporting older people who struggle with spiritual or religious issues until death is one aspect of implementing a palliative approach to care. When the older person understands that they are dying, it may be appropriate to ask sensitively about things they want to do before they die, and any fears they may have, so the older person has an opportunity to explore these issues if they wish to do so. Equally, any indication that such a conversation is not desired should be respected; the person may instead prefer someone to provide companionship in silence (Chan and McConigley 2006), or to spend time alone.

8.10 Facilitating worship, rituals, customs, human relationships and life review may help to alleviate spiritual distress, and may even help the older person or their family to find meaning in suffering (Pronk 2005).

8.11 Recognising that medication does not fix emotional or spiritual pain is important. The older person’s distress may be helping them to work through spiritual pain and this should not be stopped by medication. However, if anxiety is preventing them from sorting through their issues, a gentle anxiolytic (anti-anxiety medication) may be appropriate to reduce panic to a manageable level (Chan and McConigley 2006).

8.6 Recommendations for further research

Research on spirituality is still in its infancy and most investigations are not age specific. Much of the literature in this field comprises qualitative studies with small samples of similar people. North American studies predominate; there is little work relevant to cultural groups within Australia and there are no reviews relevant to Aboriginal and Torres Strait Islander people. Future research should include an exploration of strategies for carers and health care professionals to provide spiritual support. Studies should include samples of older adults from a variety of under investigated cultural groups’. The rigorous testing of interventions using appropriate, valid and reliable tools is also essential.

Recommended reading

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Notes:

[1] This wide-ranging review, which addresses a variety of aspects of care, is not included in our review for this chapter because spiritual issues are generally integrated throughout rather than addressed in one section. The document includes reference to additional useful spiritual assessment tools on p 40.

[2] This book is a compilation of lessons learned from patients, research and clinical work. It is based not only in scholarly study but also in experiences of clinicians, chaplains, clergy, caregivers and educators. It is a practical guide for clinicians, clergy, patients and family alike, as well as educators.

8.7 References

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Chapter 9 A palliative approach to care for Aboriginal and Torres Strait Islander people

There are approximately 500 000 Aboriginal and Torres Strait Islander people in Australia (ABS 2006) who live in diverse communities with their own unique characteristics (DoHA 2004, 2006), including:

- languages
- customs
- beliefs
- healing practices
- diets
- cultural practices.

A common characteristic of Aboriginal and Torres Strait Islander peoples is their strong connection with the land (or sea), their community and obligation to their family (DoHA 2004).

Delivering a palliative approach to care for older people in the community context is highly relevant to Aboriginal and Torres Strait Islander people. However, because a palliative approach originated from a non-Indigenous cultural perspective (DoHA 2006), the health care team needs to take many things into account when tailoring care appropriately for Indigenous people. In particular, Aboriginal and Torres Strait Islander perceptions of, and attitudes towards, illness, death and dying differ from those of non-Indigenous people, and the idea of palliative care is not a commonly understood concept among Aboriginal and Torres Strait Islander peoples (Sullivan et al 2003, DoHA 2004, McGrath and Holewa 2006a). Recognising the unique cultural values of Indigenous Australians receiving care and their families, as well as the historical, social, economic and geographical context of the care, is clearly essential.

This chapter explores key issues relevant to health care delivery for Indigenous Australians and addresses the delivery of a palliative approach to care for this population.

9.1 The context of care

Australia is one of a number of countries in which there is a legacy from ‘white settlement’ that is generally accepted to have affected the health of its Indigenous peoples. The history of the dispossession of Aboriginal and Torres Strait Islander peoples and its impact on their current status is well documented (Sullivan et al 2003). The forced relocation from traditional lands, the taking of mixed-race children (the ‘Stolen Generation’[9]) and the long-standing

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[9] People of the Stolen Generation are Aboriginal and Torres Strait Islander peoples forcibly separated from their families and communities as a result of past governments’ laws, policies and practices. Reunification of families separated by past government policies provides the first step towards healing the transgenerational trauma. Facilitating family reunions is fundamental to better mental health outcomes as it provides the individual and family with opportunities to incorporate spiritual, cultural and traditional methods into the care process.

restrictions on the rights of Indigenous Australians have all had important implications for their health status (DoHA 2004, McGrath and Holewa 2006ab).

Australia’s Aboriginal and Torres Strait Islander peoples are some of the most socially and economically disadvantaged people in the world and their health problems are considerable (Trewin and Madden 2005, Warburton and Chambers 2007). Heart disease, renal problems, diabetes-related issues and injuries are particularly prevalent (Cunningham and Beneforte 2000, cited in Stein 2004). Long-term eye and ear disease is also common (Trewin and Madden 2005). Additionally, life expectancies are almost 20 years less than those of non-Indigenous people (OATSIH 2001, Trewin and Madden 2005, Warburton and Chambers 2007). Consequently, Indigenous Australians who require a palliative approach to care are likely to be younger than non-Indigenous people (ABS 2006, DoHA 2006). Because of this, planning for aged care takes into account the population of Aboriginal and Torres Stait Islander people aged 50 years and over.

Few services in Australia provide palliative care that is specific to Indigenous Australians (Sullivan et al 2003). Aged care community services specifically designed to meet the needs of local Aboriginal and Torres Strait Islander people are also limited. Therefore, Indigenous Australians have little choice but to use mainstream aged care or palliative care services that are generally designed to meet the needs of older, non-Indigenous people. Indigenous Australians may also have problems communicating their needs (eg English may be a second or third language) and accessing services when this involves financial outlay (eg for transport).

Only 31% of Indigenous Australians live in cities; most live in regional and remote areas (ABS 2006). Providing health services in rural and remote areas is difficult and costly; therefore, services are often scarce. In addition, many practical problems need to be overcome when providing a palliative approach for Aboriginal and Torres Strait Islander people in rural and remote areas (Lindeman and Newman 2006, McGrath et al 2007). These include (Bailie et al 2002, McGrath et al 2007):

- equipment problems (eg wheelchairs, hoists and other equipment with wheels may not work well on sandy soil)
- unreliable and expensive power supplies
- problems with transport
- a lack of telephone access.

The distance to health care facilities and availability of health professionals also limit access to health care in rural and remote areas (Bailie et al 2002). Moreover, some Aboriginal and Torres Strait Islander people move often, further complicating continuity of health care.

Whether living in the city or in remote areas, Aboriginal and Torres Strait Islander people may choose to live in an extended family, within a single house (Trewin and Madden 2005). In some situations, housing may be inadequate, leading to overcrowding. Providing health services in these situations will affect everyone in the household (Sullivan et al 2003). Therefore, the aged care team needs to provide care that is innovative and tailored to each person or family. However, understanding of care and treatment issues may be minimal, both for the older person and their extended family. There are several hundred Indigenous Australian languages (Sullivan et al 2003, DoHA 2004) and some Aboriginal and Torres

Strait Islander people may be unfamiliar with the terminology commonly used in palliative care when discussed only in English (Sullivan et al 2003).

Communicating information effectively to Aboriginal and Torres Strait Islander people is particularly important in relation to end-of-life issues, because Indigenous Australian beliefs about health and illness are different from western biomedical views (McGrath et al 2005). Sullivan et al (2003) suggested that all palliative care services should have the capacity to engage Indigenous Australian language interpreters. However, these authors also noted that this would not always be easy because there is a severe shortage of Indigenous Australian language interpreters, both in remote areas and cities. Indigenous language interpreters and cultural brokers (Aboriginal and/or Torres Strait Islander people with cultural knowledge and skill who help the aged care team and the Indigenous older person communicate effectively) need to be taught about the objectives and methods of palliative care, as well as the general medical and care culture in which they will be working. They will also need access to appropriate counselling or debriefing services (Sullivan et al 2003).

In summary, Australia's Aboriginal and Torres Strait Islander peoples form a minority population that is exceptionally diverse. This population has been historically disadvantaged, which influences social, economic and health characteristics. Aboriginal and/or Torres Strait Islander people who need a palliative approach to care are likely to need it at an earlier age via services that are primarily designed for non-Indigenous older people. Moreover, Aboriginal and/or Torres Strait Islander people may have difficulty accessing services and service providers, and may experience practical, economic and communication challenges.

9.2 Key community health care issues

Traditional health beliefs and practices, issues around death and dying, and the impact of grief and bereavement are areas that affect the need to provide care to Aboriginal and Torres Strait Islander people. Health care providers need to understand the preferences of each person they are caring for, because of the diverse perspectives of Aboriginal and Torres Strait Islander people. The information provided in the following sections may improve health care practitioners' understanding of these individual perspectives.

9.2.1 Traditional health beliefs and practices

Traditionally, many Indigenous Australian religious frameworks are based on the notion of being 'spiritual beings'. In addition, Christianity has been adopted widely by many communities and has also had a profound impact (DoHA 2004). Traditional beliefs are based in the cyclical concept of life–death–life (DoHA 2004), and beliefs about health and sickness differ from western views (McGrath and Holewa 2006a, McGrath et al 2006). For many, the cause of illness or disease is embedded in the spiritual world or is perceived as payback for misdeeds (McGrath et al 2006). Traditional medicine continues to be practised among Aboriginal and Torres Strait Islander communities and traditional healers are often involved in care, although healing practices are often performed discreetly. Traditional healing may be viewed as an adjunct to care in this context (Sullivan et al 2003).

9.2.2 Kinship, status and relationships

The most appropriate person(s) to make decisions and to provide care may be dictated by family and kinship relationships. For example, in some communities, some family members may be in ‘avoidance relationships’, and therefore can only provide a limited amount of care (Sullivan et al 2003, DoHA 2004).

When an aged care team provides a palliative approach for an older Aboriginal and/or Torres Strait Islander person, they need to consider the person’s role within their community.

In many Aboriginal and Torres Strait Islander societies, concepts of power and authority are based on a combination of factors, including age, relationship, gender, status and community contribution. People of high standing (according to these factors) are regarded as ‘Elders’ and have crucial roles in the community (Warburton and Chambers 2007, p 3).

Providing care for older Aboriginal and Torres Strait Islander people requires considering how illness and a palliative approach will affect their role. The aged care team needs to also consider who may be involved in care. Service providers often assume that the main carer is also the key decision maker or the next of kin. However, this is not a safe assumption, because there are complex individual roles, responsibilities and rules that govern who can know and make decisions about certain issues for particular people (Sullivan et al 2003, DoHA 2004). Not involving appropriate people in care can have serious cultural repercussions in some communities, which may result in ‘blaming’ or ‘payback’ (Sullivan et al 2003, DoHA 2004). Not only is it critical that the right person is spoken to, but the right people need to also be present for all relevant care (McGrath et al 2005). Health care providers need to ask ‘who is the right person for me to speak with?’ as this is often the most important first step in providing culturally safe care. This concern has widespread implications; for example, in relation to support people (eg cultural brokers) who are sent with people to provide support and advocacy when relocating for specialist services (McGrath and Patton 2006).

9.2.3 Issues around death and dying

Traditional health beliefs and practices around death and dying are often particularly sensitive areas for Aboriginal and Torres Strait Islander people, and end-of-life issues are often discussed indirectly, rather than directly (Sullivan et al 2003). Local preferences need to be ascertained; for example, from local Aboriginal or Torres Strait Islander health workers.

Indigenous health care workers, included as members of the multidisciplinary team, are essential for providing culturally appropriate palliative care (Sullivan et al 2003).

Including an Indigenous liaison officer or an Aboriginal and/or Torres Strait Islander nurse who can speak the language of the older person can also facilitate the explanation of medical issues and client advocacy. See Chapter 5 (‘Advance care planning and advance health care directives’) for information specific to advance care planning with Aboriginal and Torres Strait Islander people.

A variety of ceremonies may be held and cultural practices may apply during death and dying (Sullivan et al 2003, DoHA 2004); service providers need to be aware of issues about place of death, who should be present and care of the deceased person. Each community has its own practices and particular rules are followed to prevent repercussions. Place of death is a vitally important issue for Indigenous Australians and many people desire to return ‘home to their country’. Also, although many families are committed to caring for the dying person at home, there may be cultural reasons why some families do not want the person to die at home (or not in the house), or they may not have the capacity to provide the appropriate care (Sullivan et al 2003).

9.2.4 Grief and bereavement

Research suggests that there is a large burden of unresolved grief, trauma and loss inherent in Aboriginal and Torres Strait Islander communities. Historical assaults have damaged traditional culture and affected the numbers of surviving Indigenous Australian people. High rates of disease and death continue to the present day (Dunn 2001, DoHA 2004). In many communities, multiple experiences of death can lead to cumulative grief (Fried 2000, DoHA 2004), which can have implications for the dying and bereavement experience for family, community members and staff (Sullivan et al 2003).

Funerals are an important part of bereavement; as an opportunity to express grief, they are central to the healing process (DoHA 2004). Grieving can be complicated and intensified by the short period of time between one funeral and the next. Traditional practices vary across Australia and include periods of wailing, periods of absence from the community and ‘sorry camps’, where bereaved people gather for extended periods (Sullivan et al 2003, DoHA 2004, McGrath and Holewa 2006a). The appropriate role of service providers is to provide support and practical assistance. Starting culturally appropriate counselling early for families involved in care is also recommended (Sullivan et al 2003). Indigenous staff may need to attend ceremonies and practices and may also need debriefing and counselling because of their exposure to death on a regular basis, sometimes within their own families (Sullivan et al 2003, McGrath and Holewa 2006a).

9.3 Delivering a palliative approach to care

The issues discussed in this chapter show how complex and challenging it is to provide a palliative approach to care for older Aboriginal and Torres Strait Islander Australians. Delivering care is also affected by service-related issues, such as:

- a lack of rapport between Indigenous Australian people and health care providers (Sullivan et al 2003)
- a lack of cultural understanding among health care professionals (Sinnott and Wittmann 2001)
- inflexible health services (Sullivan et al 2003, DoHA 2004)
- minimal inclusion of Aboriginal and Torres Strait Islander staff (Sullivan et al 2003, DoHA 2004)
- a lack of acceptance of social and cultural differences (Sullivan et al 2003, DoHA 2004)
- poor continuity of care (Sullivan et al 2003, DoHA 2004)
- lack of awareness of existing services (OATSIH 2001)
- a lack of services in rural and remote communities (OATSIH 2001).

These issues need to be overcome before health services can be delivered effectively.

Before providing care, the aged care team needs to find out whether an older person identifies as an Aboriginal and/or Torres Strait Islander person and, if so, not make any cultural assumptions. A personalised approach to care for each person should be underpinned by knowledge of contextual issues, the significance of traditional customs and beliefs to this particular person, issues that may apply around death and dying, and sensitivity to potential bereavement issues.

Culturally safe assessment strategies also need to be used when developing the best approach to care for older Aboriginal and Torres Strait Islander people (Fenwick 2006). Many assessment tools used in Aboriginal and Torres Strait Islander populations are not properly validated and provide false positive results or outcomes. This leads to unnecessary or inappropriate treatment and therapy. Using assessment tools validated in the relevant Indigenous Australian context is appropriate. For example, the Kimberly Indigenous Cognitive Assessment (KICA) tool can be used for cognitive assessment with some Aboriginal populations, although it is not considered appropriate in others. The KICA tool may also be used to assess emotional wellbeing, activities of daily living and to help obtain a medical history (LoGiudice et al 2006).

The Kimberly Indigenous Cognitive Assessment (KICA) Tool is available from the Western Australian Centre for Health and Ageing (WACHA) at http://www.wacha.org.au from the home page.

McGrath and Holewa (2006b) identify seven key principles important for health care providers who are working with Indigenous Australians during end-of-life care. These principles are not specific to Aboriginal and Torres Strait Islander people, although they provide useful guidance to non-Indigenous practitioners working with this population group. For example, these principles provide a useful reminder that value systems tend to be culturally bound. Recognising and setting aside your own value system is sometimes a prerequisite for providing nonjudgmental care. The seven principles are (McGrath and Holewa 2006b):

- equity
- autonomy/empowerment
- trust
- humane, nonjudgmental care
- seamless continuity of care
- emphasis on living
- cultural respect.

To apply these principles, the health care team needs to be flexible, innovative and inclusive. Including Indigenous staff as active members of the community aged care team is vital (DoHA 2004). Indigenous volunteers may also be available. These staff or volunteers may act as cultural brokers and interpreters (Sullivan et al 2003, McGrath and Holewa 2006a). However, their own special needs also require consideration; for example, they may fear repercussions associated with ‘blame’ and ‘payback’ following illness or death and this can have implications for work practice. Their own kin or relationship with the patient may also affect their cultural ability to care for the person. Staff may need to be involved in ceremonial practices that may cause conflict between their cultural obligations and professional duty of care (DoHA 2004). Health service management needs to understand these issues;

management should also make sure that ongoing professional support is provided for Aboriginal and Torres Strait Islander health care workers.

Indigenous workers need to be provided with education and training in a palliative approach to care before they join the health care team. Furthermore, cultural awareness training, tailored specifically for mainstream aged and palliative care service providers, is necessary for cross-cultural competence (Sinnott and Wittmann 2001, Sullivan et al 2003, McGrath and Holewa 2006a). Health care providers delivering care at home also need particular skills in building good rapport with Aboriginal and Torres Strait Islander people and communities (Sullivan et al 2003), because setting up good communication strategies is essential for understanding people's needs and wishes.

Continuity of care and of staff is also particularly important. Holding case-management meetings involving members of the community service and palliative care team, as well as the family, is an effective way of coordinating care and allowing family to clarify roles and reduce the number of 'strangers' visiting the home (Sullivan et al 2003).

9.4 Conclusion

Identifying the best way to provide a palliative approach to care for older Aboriginal and Torres Strait Islander Australians experiencing life-limiting illness is vital, given the poor health of the population. However, the context of care provides challenges that are unique, and traditional beliefs and cultural practices associated with death, dying and bereavement need special consideration. Because no assumptions can be made about an individual's cultural needs, including local, appropriately trained, Indigenous Australian people in the health care team is essential. Furthermore, education in cultural sensitivity and communication issues is necessary for other members of the health care team, and issues of staff continuity need to be addressed. In this way, an acceptable and appropriate approach to care may be achievable, despite the practical difficulties.

Recommended reading

Sullivan K, Johnston L, Colyer C, Beale J, Willis J, Harrison J and Welsh K (2003). *National Indigenous Palliative Care Needs Study*, Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing (DoHA), Canberra, publication approval number: 3370.

Available via link from CareSearch website at http://www.caresearch.com.au (What is Palliative Care>National Palliative Care Program>Indigenous Palliative Care Project)

McGrath P and Holewa H (2006). *The 'Living Model' — A Resource Manual For Indigenous Palliative Care Service Delivery*, Researchman, Brisbane.

DoHA (2004). *Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander peoples: Resource Kit*, Wodonga TAFE, Mungabareena Aboriginal Corporation and Mercy Health Service, Albury, Victoria for the National Palliative Care Program, DoHA, Canberra.

Available from the CareSearch website at: http://www.caresearch.com.au (What is Palliative Care>National Palliative Care Program>Indigenous Palliative Care Project)

DoHA (2007). Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities, DoHA, Canberra.

Available from the **Alzheimer's Australia** website at: http://www.alzheimers.org.au/ (Use the search facility)

9.5 Good practice points — providing a palliative approach to care for Aboriginal and Torres Strait Islander people

The following good practice points have been developed with reference to the key studies on palliative care in Australia's Indigenous population (Sullivan et al 2003, DoHA 2004, McGrath and Holewa 2006a), recommendations from the *Guidelines for a Palliative Approach in Residential Aged Care* (DoHA 2006) and the discussion in this chapter.

Understanding important community health care issues

Being aware of traditional beliefs and customs regarding health, kinship, and death and dying helps the aged care team to deliver the best-quality palliative care (see Section 9.2).

9.1 When Aboriginal and/or Torres Strait identity is confirmed, service providers need to consider the context and special needs of Indigenous Australians. However, service providers should not make assumptions about cultural needs.

9.2 Communication and decision making needs to be sensitive to circumstances and should involve the appropriate people, and show respect for family and kinship rules and responsibilities. If unsure, ask the patient, accompanying person or Aboriginal liaison person, ‘Who is the right person for me to speak with?’

9.3 Traditional healing can be used as an adjunct to care, as appropriate.

9.4 Culturally appropriate respite services can help to sustain families during their caregiving roles.

9.5 Effective communication strategies should include honest information sharing, and use language interpreters, cultural and medical interpreters, support, and other forms of communication (eg pamphlets in plain English or computer programs). Pictorial story boards may also be useful.

9.6 Service providers need to establish relationships with Aboriginal and Torres Strait Islander communities. Health care professionals undertaking home visits should be accompanied by Indigenous staff or other cultural brokers or advocates, once invited and welcomed into the home. In some cases, being ‘invited in’ will involve joining the person at the (outside) fireplace; this being the equivalent of a lounge room.

9.7 Employing trained Aboriginal and/or Torres Strait Islander staff or brokers who can act as cultural advocates (eg Indigenous health workers or nurses) can help the aged care team to understand the health care needs of older Indigenous people.

Delivering a palliative approach to care

Specific issues need to be taken into account when delivering a palliative approach to care for Aboriginal and Torres Strait Islander people (see Section 9.3).

9.8 Health care professionals need to show cultural sensitivity and culturally safe practices. Respectful attention is required from the attending community care staff with regard to the older person’s individual cultural beliefs and values regarding choice of care, importance of place of care, death and needs after bereavement.

9.9 Mainstream services need to work with Aboriginal and Torres Strait Islander services to provide integrated care.

9.10 Using appropriate assessment tools that have been validated within the relevant community context may provide helpful information. Tools that have not been validated in that context may provide inaccurate results and may lead to the use of inappropriate treatment or therapy.

9.11 Clear care coordination should be managed by an appropriate person who can facilitate continuity of staff and care and organise regular case conferences among all service providers.

9.12 Service providers need to recognise stressors for Aboriginal and/or Torres Strait Islander health workers, such as conflicting cultural and professional obligations and grief from (many) deaths within their own community.

9.13 Service providers need cultural awareness education and training for effective and sensitive cultural practice in this area.

9.14 Indigenous health workers need education and training in a palliative approach to care so that they can perform effectively in this role.

9.15 Health care providers should be proactive in recognising the need for, and providing, bereavement support. Practical assistance is a valuable form of bereavement support. Aboriginal and Torres Strait Islander staff may require additional support because of cultural requirements and community responsibilities.

9.16 Experienced remote and rural community nurses are likely to have extensive knowledge of local Indigenous communities and may be useful contacts, along with Aboriginal community members.

9.6 Recommendations for further research

Palliative care for older Aboriginal and Torres Strait Islander Australians remains an under-researched area. Overall, there are few studies that examine the health or care needs of older Indigenous Australians. The studies that have been done look at the reasons why palliative care is limited, rather than assessing how many services exist or are used. Data that are specific to Aboriginal and Torres Strait Islander people's use of health services are limited and service use across Australia needs to be better reported. Future research needs to include larger, quantitative, descriptive studies, and studies trialling interventions. Local Indigenous Australian people need to be included in the research teams to ensure that such studies are run with appropriate cultural sensitivity.

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Chapter 10 A palliative approach to care for older people from diverse cultural and language groups

Australia has a richly diverse population in which many groups of people coexist (eg Lickiss 2003, DoHA 2006). Differences include:

- languages
- ages
- sex and sexual orientations
- capabilities
- occupations
- socioeconomic status
- ethnic origins
- migrant experiences
- religious or spiritual beliefs
- health status.

This chapter addresses issues related to cultural and linguistic diversity in older adults who need a palliative approach to care. First, the health care needs of older adults from culturally and linguistically diverse (CALD) backgrounds are addressed, then service access issues are outlined. Finally, planning and delivering a palliative approach to care for older adults from CALD backgrounds is discussed.

10.1 Cultural diversity

Approximately 24% of Australians were born overseas (ABS 2006) and the 2002 Census showed that an additional 26% of the population had one parent who fell into this category. Migrants mainly came from English-speaking backgrounds (United Kingdom 23% and New Zealand 10%), but significant groups were non-English speaking (eg migrants from Italy 4%, China 4% and Vietnam 4%). By 2011, 23% of people older than 65 years will be from CALD backgrounds (that is, about 653 800 people) (Rowland and Karmel 2004).

10.1.1 Changes over time

Cultural diversity tends to change over time, as indicated by a recent increase in the number of people migrating to Australia from the Sudan, Afghanistan and Iraq (Rao et al 2006). From 2006 data (AIHW 2007):

- older adults from Poland were more strongly represented in the 75–84-year-old age group
- older adults from Greece were more strongly represented in the 65–74-year-old age group
- people from Vietnam were more strongly represented in the 50–64-year-old age group.

Although this dynamic picture gives only a slight indication of changes occurring, the implications for service providers working with people from CALD groups are clear: they will need to be flexible in their approach to the provision of care for older adults as needs change over time.

10.1.2 Distribution

The distribution of older adults from the various cultural groups varies. From 1996 data, overseas-born people aged 55 and older tended to be over-represented in cities and under-represented in rural areas (Benham et al 2000). A higher proportion of people in this age group from Greece, Italy, Ukraine, Hungary, Poland, Cyprus, Lebanon and Egypt were concentrated in Melbourne (21%) and Sydney (16%) than in other capital cities (Benham et al 2000). This means that providing care for culturally diverse groups becomes ‘core business’ for service providers in some metropolitan areas.

10.1.3 Variation within groups

Most importantly, among and within the ethnic groups, there are variations across a range of beliefs and practices, including those related to illness, death and bereavement. Community health service providers need to be sensitive to these variations to provide a tailored and appropriate service (Lickiss 2003, DoHA 2006).

10.2 Health care needs

Health care needs are shaped by a blend of life experience and cultural perspectives that make the needs of each person unique. This section explores some of the complexity of this situation.

10.2.1 The cultural and experiential perspective

Cultural differences can change over time, and cultural perspectives vary within cultural groups as well as among them.

First-generation migrants, in particular, may have specific needs and concerns as they grow old. A variety of reasons may prompt people to migrate to another country. Some people choose a new homeland for a better lifestyle, some seek family reunion and others (who have less choice) seek refuge in Australia (Stevens 2001, Rao et al 2006). The circumstances that prompted their migration, as well as their language and communication skills, can have a lasting impact (Rao et al 2006). This is especially the case when people have experienced war, torture, trauma, economic unrest, poverty, hunger and political oppression. Regardless of their reasons for migration, many people from CALD backgrounds may have experienced discrimination or feelings that they do not belong or are unwanted (Rao et al 2006). They may also experience geographic or social isolation, particularly because they might not have familiar social networks (Stevens 2001, Rao et al 2006, Warburton and McLaughlin 2007).

Migrants who are not refugees tend to have comparatively good health because of migrant-screening programs (AIHW 2006). However, problems with language and communication may affect diagnosis and treatment of diseases or conditions (Comino et al 2001). Also, some symptoms, such as pain, may be experienced differently in different cultural groups (Rabow and Dibble 2005). Symptoms that are severe can sometimes go undetected until a person has a check-up for a more pressing health problem (Stevens 2001). For example, there is a high incidence of depression among Asian migrants but a much lower rate (around 50%) of detection and treatment than for Australian-born people (Comino et al 2001).

Cultural differences are important considerations in delivering care and these differences can change over time. Moreover, cultural perspectives vary within cultural groups as well as among them.

Types of support used

Overall, CALD groups are more likely to turn to the family for support rather than use formal community services (Craw and Gilchrist 1998). Despite this, the tradition of in-home caring for older people with disabilities and chronic illness is changing. An example of this is seen in some Chinese families (both in China and Australia), in which elders have traditionally been the responsibility of their children. Many modern, nontraditional Chinese children either do not want to or cannot undertake caring responsibilities for their ageing parents. These younger people experience difficulties when trying to reconcile responsibilities to parents with commitments to their own children and a need to continue to work to earn enough money (Yan et al 2002).

Sharing cultures

When different cultures are exposed to each other, they may swap ideas or modify ways of doing things. This is called ‘acculturation’ and it can lead to changes in obligations and expectations. In some ethnic communities in Australia (eg the Greek community), first-generation migrants may expect their children to provide home care for them but their children may not feel supported in meeting this obligation. The family integration, social support and religious affiliations that are available to carers in their country of origin are less available or structurally different in their adopted country, or the carer may not know how to negotiate the Australian system (Morse and Messimeri-Kianidis 2001, Stevens 2001). Subsequent generations may not experience such strongly conflicting obligations but may still experience family pressures because of the more traditional expectations of their parents and grandparents (Morse and Messimeri-Kianidis 2001).

Variations in health status between migrants and nonmigrants may also be diminished as the lifestyle of the new country is adopted. For example, although migrants are generally less likely to die from cardiovascular disease or to be hospitalised with skin cancer than people born in Australia (AIHW 2006), it is highly likely that migrants who adopt the Australian lifestyle early in their lives will have a pattern of health that is more similar to people born in this country than people who retain a traditional lifestyle.

Making decisions about care

People rely on beliefs, tradition and cultural norms when making decisions about care and treatment (Kwak and Haley 2005). Acculturation, therefore, also affects health care decision making. These issues, in conjunction with previous experiences with health systems, are of particular relevance when providing care for older adults with life-limiting illness. In particular, they influence attitudes to making advance health care directives and the choice of aggressive life support options (that is, intensive treatments that can sometimes be uncomfortable). For example, although some groups of Chinese people tend to believe that aggressive end-of-life treatment will bring suffering on themselves, their family and society, Japanese people may be more likely to choose aggressive treatments, such as enteral feeding (supplying food directly into the stomach via a tube) (Kwak and Haley 2005). The aged care team needs relevant cultural knowledge and sensitivity when discussing questions about end-of-life care for older adults with non-Australian cultural backgrounds.

10.2.2 Challenges for the formal system

Overall, based on the complexity of the issues summarised in the previous section, providing a palliative approach to older people from CALD populations who are living in Australia has unique challenges that relate to the following issues:

- whether these older adults are migrants or were born in Australia
- migration experiences and personal experience before arrival in Australia
- degree of acculturation
- earlier experience of palliative care services, if any, as these services do not exist in many countries, meaning that some people from CALD backgrounds may not understand the concept of palliative care
- reluctance or impaired ability to report symptoms, or a different perception of symptoms
- prevailing family care or other practices within the cultural group
- a need to consider people from CALD backgrounds as individuals within a particular cultural group, with all the consequent implications for diversity of needs, values and goals of care.

These factors all require consideration by health care providers if the needs of older adults from CALD backgrounds are to be met adequately.

10.3 Accessing community health care

Even if community health services exist, people from CALD backgrounds may not use them. This section looks at the reasons why people may not use these services, as well as how use can be encouraged.

10.3.1 Reasons for low levels of access

Studies consistently report low levels of community care service use in CALD groups (McDonald and Steel 1997, cited in Comino et al 2001, Lister and Benson 2006). However, this does not mean that CALD groups do not need these services (Jack et al 2001, Morse and Messimeri-Kianidis 2001, Yan et al 2002). Families from CALD backgrounds have much the same need for formal care as non-CALD families (Jack et al 2001, Morse and Messimeri-Kianidis 2001, Yan et al 2002). Yet, carers in CALD families may continue to struggle to cope alone, even when services are available.

People from CALD backgrounds may be reluctant to seek help for a variety of reasons. They may experience stigma and shame associated with illness, lack knowledge of the Australian health system (Comino et al 2001, Rao et al 2006) or be worried about the expected cost of such assistance. Differing beliefs and customs may also stop them from using care services.

For example, Islamic people may fear that service providers will discuss death, dying, how bad the illness is or how long a person is likely to live — topics that some Islamic people believe should be avoided. In other cultural groups, such as in some Japanese families, discussion about prognosis is considered to be appropriate with the family rather than the person themselves (Ahmed et al 2004).

Providing home care for long periods, even when cognitive and behavioural needs make this difficult, may also reflect a fear that residential care will be the recommended option, should services be requested. Some cultural groups are known to abhor residential placement for an older family member, experiencing not only guilt but also a sense of public shame (Fitzgerald et al 2001).

Finally, the idea of community service provision may also be an alien one within some migrant groups. People from CALD backgrounds may be totally unfamiliar with voluntary organisations, or churches may have filled the roles of formal nonprofit organisations for migrants from traditional Hispanic countries, some Asian countries and from the Eastern block (Warburton and McLaughlin 2007).

10.3.2 Promoting access

One way of encouraging CALD people to use health services is to provide culturally appropriate materials that explain what services exist (Lorenz et al 2004). Native language papers and radio programs are good resources for distributing such materials (Eyles and Xsateroulis 1995). However, although these two options address the need for information about services, they do not address cultural norms and related expectations.

Providing health services that are tailored for specific ethnic groups is another way of meeting the needs of family carers who require more support than is available from any informal community source, in a more culturally appropriate way (Stein 2004). One example of this is the Partners in Culturally Appropriate Care initiative, which helps to address the needs of older adults from CALD backgrounds by encouraging partnerships among aged care providers, CALD communities and the Australian Government Department of Health and Ageing. In conjunction with this initiative, the Community Partners Program aims to promote access to aged care services by older people from CALD backgrounds.

The Centre for Cultural Diversity in Ageing is funded via the Partners in Culturally Appropriate Care initiative, details of which are available from the centre's website at: http://www.culturaldiversity.com.au/

The website also has links to many helpful resources.

10.4 Planning and delivering appropriate care

Health services for CALD clients clearly need to be provided in an appropriate way, whether they are services tailored to specific cultural groups or included within mainstream services. To achieve this, the aged care team needs to promote understanding of, and respect for, different cultures ('cultural safety'), use translation services as needed, use the most appropriate resources and provide ongoing education for staff. These issues are discussed in the following sections.

10.4.1 Cultural safety

To provide culturally safe care, staff need to understand and respect the cultural perspective of the older person and their carers. Recognition of this fact needs to be the central principle of the care service and all those who work in it (Jack et al 2001). To increase staff commitment to this principle, they need to be aware of how their own feelings and thoughts are influenced by their cultural background and the environment in which they live (Jack et al 2001). General practitioners (GPs) who speak the same language and are of the same ethnic group as the older people being cared for are valuable resources and team members. They can help to provide culturally appropriate care, particularly when they often have prolonged relationships with the older person and their family.

10.4.2 Translation

The main resource needs for aged care team members is for language and cultural translation. Using qualified language interpreter services will help to make sure culturally sensitive and acceptable care is provided to these groups of older people (Jack et al 2001). The Australian Translation and Interpreting Service (TIS) is available 24 hours a day and can provide on-the-spot translation by telephone, as well as face-to-face interpreters by booking. This service is free for approved service providers. Organisations, including general practices, can apply to be fee exempt. Local translating services are also likely to be available and may be preferred in some instances. Contact state or territory health departments to find local services.

Interpreter services

Telephone Interpreter Service (24 hours, 7 days per week)
Telephone: 131 450

On-site Interpreter Enquiry Line (business hours)
Telephone: 1300 655 082

On-site Interpreter Bookings
Email: tis@immi.gov.au
Ph: 1300 655 082
On-line booking form:
http://www.immi.gov.au/living-in-australia/help-with-english/help_with_translating/booking.htm

Doctor's Priority Line
Telephone: 1300 131 450

Document Translation Enquiries
Your local adult migrant English program — see local directories

Translating and Interpreting Service (TIS)
Client Liaison and Promotions
Telephone: 1300 655 820
Email: tispromo@immi.gov.au

High-quality and appropriate care depends on community care staff who are skilled in using translation services to discuss sensitive issues with people from different backgrounds (Hsu et al 2005). Even when people from CALD groups cope with spoken English for everyday use, they may feel that their skills are insufficient to discuss medical conditions or end-of-life care. They might also be worried about being misunderstood by community support workers

(Field et al 2002). Members of the care team can improve care outcomes by being sensitive to these concerns. For example, a Sydney day respite facility used bilingual staff to explain an assessment tool to older clients and their family carers, finding that staff could then better identify and meet the older people's needs (Kilstoff and Chenoweth 1998).

Interpreter services may help people to share information; discuss hopes, fears and end-of-life expectations, and clarify their expectations of the community service. Interpreters, however, may also need information about the particular cultural group for whom they are providing services; they also need adequate support.

Cultural translators or brokers can also be particularly useful, especially when services are first offered and the older person is being assessed for the most appropriate care (NCCC 2004). Cultural translators are trusted members of the cultural group that they represent; they can understand and interpret the cultural values and norms of that cultural group. Using cultural translators alongside qualified interpreters can help to successfully provide a palliative approach to care for older adults from CALD backgrounds (DoHA 2006) because language interpreters cannot address the barriers arising from differences in health beliefs and illness behaviours. Working closely with specific ethnic and multicultural services will also provide networks that can be called on to help cultural translation. Before using cultural brokers or translators, the aged care team need to consider whether the older person or their family will be comfortable; for example, in some small communities, people may choose not to use local translators because they already know the translator well.

10.4.3 Assessment tools and resources

Culturally appropriate assessment tools can be useful resources. For example, although there is no gold standard for cognitive testing within culturally diverse populations, a tool such as the Rowland Universal Dementia Assessment Scale (RUDAS) may be a good option. This tool does not appear to be influenced by language, education or gender, and its accuracy has been demonstrated (Rowland et al 2006). These kinds of tools, however, need to be used in the context of the unique cultural factors of the person being assessed.[10]

10.4.4 Staff education

Staff education needs to address knowledge of, and sensitivity to, particular cultural needs, such as the understanding of taboos relating to touch, clothing and other issues (eg care from male versus female support workers). When staff members show they understand these needs, people's confidence in the assessment process and acceptance of services will be improved (Rao et al 2006). Staff members also need to know with whom to communicate within the family and to have a respectful understanding of cultural rituals and traditions (Hsu et al 2005). For example, it may be considered inappropriate to discuss cancer in direct terms within Chinese, Jewish, Greek or Italian communities (Field et al 2002). However, as discussed earlier, it is always important for staff to also understand that assumptions should not be made about cultural issues as cultures continually evolve and individuals also develop

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[10] The RUDAS can be used without cultural adaptation.Rowland JT, Basic D, Storey JE and Conforti DA (2006). The Rowland Universal Dementia Assessment Scale (RUDAS) and the Folstein MMSE in a multicultural cohort of elderly persons. I*nternational Psychogeriatrics* /IPA 18(1):111–120.

their own perspective (Lickiss 2003, Kwak and Haley 2005). Each person is an individual as well as a member of a cultural group.

A useful resource is **The Multicultural Palliative Care Guidelines** (Taylor and Box 1999).

These guidelines provide information and practice recommendations relevant to many cultural groups living in Australia (Lickiss 2003).

See http://www.pallcare.asn.au (Resources for sale)

10.5 Conclusion

In conclusion, older adults from CALD groups who live in Australia, especially those born overseas, have special needs for culturally appropriate, accessible care. Their care also needs to be personalised for each individual, because there is variation within as well as among cultural perspectives. Cultural safety, access to services and resources and education will all help the aged care team to provide a culturally competent service that improves a palliative approach to care for these older adults.

Recommended reading

Taylor A and Box M (1999). *Multicultural Palliative Care Guidelines*, Palliative Care Australia, Palliative Care Council of South Australia (PCCSA) and Palliative Care Victoria, Eastwood, South Australia.

Available from the PCCSA website at: http://www.pallcare.asn.au (Resources for sale)

NCCC (National Center for Cultural Competence) (2004). *Bridging the Cultural Divide in Health Care Settings: The Essential Role of Cultural Broker Programs*. Georgetown University Center for Child and Human Development, Rockville, Maryland, USA.

10.6 Good practice points — A palliative approach to care for older adults from diverse cultural and language groups

Promoting access to community health services **Providing information about the community health services that are available can encourage people in culturally and linguistically diverse (CALD) groups to use them (see Section 10.3).**	
10.1	Promote access to services within CALD groups by targeted strategies using media such as radio, television and ethnic newspapers. This can inform people about relevant services available within their local community (Lorenz et al 2004).
10.2	Community health care providers need to establish networks with culturally specific services that can offer advice and help as needed. This will improve the care provided to older adults from CALD backgrounds.
Planning and delivering appropriate care **Providing an appropriate palliative approach to care for older people from CALD groups requires taking into account specific issues, which are discussed in Section 10.4.**	
10.3	Whenever possible, include in the aged care team staff and volunteers whose background or language skills reflect the main cultural group of the area (Lorenz et al 2004, Hsu et al 2005, Rao et al 2006).
10.4	Use services tailored to specific ethnic groups to provide culturally appropriate care. For example, Italian in-home and centre-based respite care may be both viable and highly regarded in areas with large groups of Italian-speaking older people.
10.5	When appropriate, use professional interpreter services and cultural brokers. These services form part of the basis of culturally appropriate care.
10.6	When delivering care to older adults from CALD groups, prepare staff and provide ongoing education to maintain their cultural competence and cultural sensitivity.
10.7	Use information fact sheets about services and treatments, written in the languages of target groups, to provide more accessible health care information for older adults from CALD backgrounds.
10.8	When reviewing how happy older people from CALD groups or their carers are with the care provided, consider asking questions through an interpreter in a verbal, rather than written, format. In this way, the aged care team can check that people understand what is being asked.
10.9	Use culturally appropriate assessment tools to improve cognitive assessments of older adults from CALD groups.
10.10	Include on the aged care team a GP who speaks the same language or is from the same ethnic group as the older person. This GP can help to provide culturally appropriate care, especially when they have had a prolonged relationship with the older person and family.
10.11	Obtain appropriate religious or spiritual support for older adults from CALD groups, as desired by individual older people.

10.7 Recommendations for further research

There is limited research into the needs of frail or unwell older adults from CALD groups in Australia, and more research is needed to inform practice development. Studies developing and testing culturally appropriate assessment tools are also needed. Finally, interventions designed to improve access to and the provision of culturally appropriate care in the Australian context need to be tested in robust studies. Often, CALD groups are excluded from research on the basis of a need to understand and speak English to take part; helping to include groups of older adults in research so that samples are more representative of the population being investigated clearly needs to be a priority area.

10.8 References

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Chapter 11 Other older people with special needs or perspectives

This chapter discusses the needs for a palliative approach to care for groups of older adults who live in the community and who have special needs or perspectives relevant to providing this approach to care. The groups include those older people who:

- live alone without nearby family support, or with long-distance support
- have a mental illness
- live with post-traumatic stress disorder
- are gay, lesbian, bisexual, transsexual or intersex
- have an intellectual disability
- have one of two neurodegenerative diseases that cause symptoms that can be difficult to manage, especially in the advanced stages (motor neurone disease or Parkinson's disease)
- are experiencing dementia.

This chapter emphasises the importance of providing a holistic palliative approach to care that is tailored to the needs and perspective of each person. Good practice points (GPPs) specific to each context or condition are listed at the end of each section, rather than at the end of the chapter.

11.1 Living alone without nearby family support

Increasing numbers of older adults live alone without family carers, or live alone with a long-distance carer (eg with family living interstate). Projections indicate that there could be as many as 2.8 to 3.7 million people living alone by the year 2026 (Trewin 2004). The projected increase in the number of people living alone reflects likely changes in the size and age structure of the population and trends in living arrangements over time (Trewin 2004).

Studies have found that people who live with others tend to remain healthier and have better financial circumstances than those who live alone (Koskinen et al 2007). In particular, older people who live alone without support from family and friends are at greater risk of depression (Wilson et al 2007). An English study found that 21% of people who lived alone and were aged between 80 and 90 years experienced depression. This result was supported by other similar studies (Osborn et al 2002, Stek et al 2004 and Bergdhalet et al 2005 — all cited in Wilson et al 2007). Nevertheless, there is considerable variation within this group of people. Some people who live alone enjoy their freedom and independence (Lloyd-Williams et al 2007, Aoun et al 2008). Others may feel distressed by their living circumstances (Koskinen et al 2007). For those who live alone because they choose to do so, a goal may be to die in their own home, maintaining control of end-of-life decisions (Lloyd-Williams et al 2007).

At any one point in time, there is extreme diversity in the care needs of older adults who live alone. At one end of the health spectrum, there are physically and mentally fit older people. Some of these individuals fear becoming debilitated and a burden on others, or suffering terminal illness and dying without being found. It is not uncommon for these people to prepare for their death, including making a will, arranging their funeral and sorting out their belongings to minimise any burden on others. The older person is likely to make these preparations without help, possibly because discussing death and dying can be emotionally difficult (Lloyd-Williams et al 2007). However, it is likely that their care needs may change over time.

At the other end of the spectrum are older people with significant care needs, who will eventually need to move into residential aged care because they need a carer to be constantly present. However, this is a difficult move, given that it may reduce privacy and independence, and may not match the older person's preference for the setting for their end-of-life care (Lloyd-Williams et al 2007). Therefore, there may be a period during which time the frail older adult tries to manage with community-based care alone. There may also be an interim period during which the person is hospitalised or receives care elsewhere (eg transition care).

Of the remaining group of older adults (those who live alone with more moderate care needs), some will have stable needs because of permanent disability. However, many will be in transition between good health and poor health. People with dementia are likely to quickly lose the capacity to manage safely alone at home, needing a residential care placement early in their pattern of illness. Whatever the cause, when a person loses the functional ability required for them to remain independent during the course of a progressive, life-limiting illness, they may become increasingly isolated. The effects of treatments can impose further restrictions, with side effects such as fatigue. Some people are able to alleviate their isolation with, for example, the television and telephone (Aoun et al 2008).

A recent study of specialist palliative care for people living alone without a family carer in three Australian states (average age 70 years) found that 35% died at home compared with 57% of those with a family carer (Aoun et al 2007). Therefore, even when people are entitled to specialist palliative care services, older people who live alone without a family carer might be disadvantaged if they want to be able to die in their own home. However, an alternative explanation for this study's results might be that fewer of those living at home alone want to die at home.

11.1.1 Differences in care needs

Additional support

As well as raising the issue of place of death, Aoun et al (2007) noted the exceptionally high care needs of older people living alone. More than 60% of the health care professionals involved in the study reported spending at least 15–30 minutes of extra time per visit providing symptom control, medications, mobility, transport and social support when the person lived alone. Moreover, more than 20% of these professionals reported spending at least an hour of additional time per visit on helping with activities of daily living, symptom control, housekeeping and social support (Aoun et al 2007).

Medication concerns

Older adults living alone are at particular risk of problems related to medication use. For example, there may be unintentional noncompliance involving confusion, missed doses or double dosing of medications. This risk can be reduced by a coordinated approach among doctors, pharmacists and the older person.

An established example of this coordinated approach is the Dose Administration Aid (DAA) Service, which is provided by the Australian Government Department of Veterans' Affairs. The DAA Service helps coordinate effective medication management in the veteran community. Following referral from a general practitioner (GP) to an accredited pharmacist for a home medicine review, the veteran is placed on a trial in which they collect packed medicine weekly from the pharmacist. The pharmacist takes this opportunity to advise the veteran on the use of the DAA service and medication management. The pharmacist also liaises with the GP about regular reviews of the veteran's progress. The DAA can be changed if the condition of the veteran changes and a change of medication is required.

More details are available on the **Department of Veterans' Affairs** website at: http://www.dva.gov.au (Health and well being>Self management)

The **Home Medicines Review** program for other older adults is described on the **Pharmacy Guild of Australia** website at: http://www.guild.org.au (Medication management review program)

Falls and other emergencies

People who live alone and who have a life-limiting illness can be concerned that they have no one to call in emergencies (Shih et al 2000). Also, some people in this population have a fear of falling (Aoun et al 2008). Although some people can obtain assistance from willing neighbours and friends, they may be worried about the durability of this kind of support and about burdening these people (Aoun et al 2008). Also, people living in rural or remote areas may have no one living nearby. Community health care providers have echoed concerns about safety in this population (Aoun et al 2007). Although older adults with increasing care needs can be referred by the GP to the aged care assessment team so their eligibility for care can be reassessed, another option is to arrange a personal alarm, which can be activated in emergency situations (although there is a cost involved with this) (see also Chapter 3). Staff involved in the Australian study conducted by Aoun et al (2007) prioritised the following strategies:

- access to a 24-hour service, including 'night sitting' and after hours support
- the use of a pool of volunteers and paid caregivers to provide a flexible response to care needs
- in-house respite
- (home care for brief periods to avoid a hospital admission)
- funded alert link (emergency call) systems.

11.1.2 Good practice points

Older people living alone without nearby family support	
11.1	To address the particular fears and concerns of older adults living alone without nearby support, discuss their goals of care (eg dying at home) and fears (eg dying and not being found) when developing a plan of care.
11.2	Help the older person to develop a formal advance health care plan to communicate their end-of-life wishes. Help the older person to keep this plan up to date and known to health care professionals (see Chapter 5). Providing a copy for the GP, who can then inform hospital staff of its existence if there is an emergency admission, for example, may be appropriate.
11.3	Recommend an emergency call system as a simple and effective intervention that may support an older adult who lives alone to remain in their own home for longer.
11.4	Arrange regular and frequent reviews of the level and type of care provided to an older adult with progressive health deterioration. This can help to make sure that the response to care needs is flexible.
11.5	Because of the high likelihood of depression in older adults who live alone, arrange routine screening to help prevent needless distress.
11.6	To alleviate loneliness, consider arranging psychosocial interventions, such as volunteer community visits from members of local churches or other organisations.

11.2 Living with a mental illness

Mental illness can potentially lead to premature functional decline and death among older people (Kilbourne et al 2005). Mental illness can also cause behavioural symptoms (McKay 2007). Although older adults who have a mental illness and also require a palliative approach to care are a comparatively small group, significant numbers of people are affected because some mental illness is more common in older adults (Jeon et al 2007). A Canadian study reported that 50% of people aged over 80 years had some kind of mental illness or disorder (Martens et al 2007). In particular, dementia and mental illness are often experienced together, people with dementia being especially likely to also experience depression or anxiety (Ganguli 2002, Reisberg et al 2002, McKay 2007). Mental illnesses affecting older adults include anxiety, depression, addiction, substance abuse, psychosis, schizophrenia, bipolar disorder and personality disorders (Jeon et al 2007, Martens et al 2007). However, substance abuse is less prevalent in older adults than in younger people.

11.2.1 Differences in care needs

Exacerbated symptoms

Physical and mental disorders are known to affect one another, making symptoms worse. For example, depression can dramatically worsen the experience of chronic (long-term) pain (Kilbourne et al 2005, McKay 2007). Also, older people receiving mental health care often have coexisting medical conditions, such as cardiovascular, endocrine and lung conditions, or cancer. This high rate of comorbidity may be related to side effects from long-tem use of medication for mental function. Also, chronic overactivity of physiological systems triggered by mental illness may be implicated (Kilbourne et al 2005).

Altered cognition

Recent research has found that altered levels of cognition further compound the challenges of providing care to older people with psychiatric illness. Cognitive deficits include problems with memory, learning, attention and executive functioning. These problems are evident in older people who have schizophrenia, schizophrenia-like psychosis, depression and bipolar disorder; they affect day-to-day functioning and learning abilities (Twamley and Harvey 2006). For example, older people with schizophrenia often need help with activities of daily living (eg bathing and dressing), even though they are mobile and self-sufficient in other areas (eg feeding themselves) (Lariviere et al 2002). Older adults with schizophrenia may also have problems with social functioning. This can show up as impaired relationships with people, or as social withdrawal and dependency on others (Lariviere et al 2002).

Behavioural issues

Most people with chronic mental illness have well-controlled mental health symptoms, and their needs can be met by mainstream community aged care with occasional specialist input. However, in a small number of instances, severe mental health conditions and behavioural symptoms challenge both family carers and community care providers. In particular, family carers may experience a high burden of care and stress (Bartels 2003, Bartels et al 2004).

When there is mental illness in conjunction with declining physical health, the aged care team may need to coordinate the services with those provided by the mental health team (Bartels et al 2004, Martens et al 2007) in a way that also takes into account the preferences of the person who has the mental illness and any family carers (Jeon et al 2007). For example, when the aged care service provider liaises with the mental health team, joint consideration of the older person’s mental and physical illness and treatment can be the starting point for a coordinated approach (Kilbourne et al 2005, Bedard et al 2007). Although this kind of approach may need to be modified in areas that have different types of service provision (eg in remote communities), it may still be possible to use a coordinated approach to care. Discomfort (because of being uncertain or unclear about what is required) may occur in either the aged care team or the mental health team if inadequate collaboration has occurred to ensure that all team members are confident in addressing the holistic needs of the older adult.

In an effective collaboration between aged care providers and the mental health team, key issues of access to crisis care, staff education and training, and how to respond in emergencies will all have been covered.

Carer burden

Some family carers are involved in caring for a relative who has a severe mental illness, and older carers are particularly vulnerable to the unpredictable and aggressive nature of some severe mental illnesses (Tedman-Jones et al 2003). These carers are likely to be concerned about their safety as well as that of their relative (Jeon et al 2007) and they therefore require more support (Bedard et al 2007). The most difficult care burden for these carers is the behavioural symptoms of mentally ill family members, including violence and verbal aggression. Also, they may need to deal with threats, destructive behaviour, manipulation, lack of motivation, noncompliance with treatments, psychotic behaviour, suicide attempts, paranoia, hallucinations and other manifestations (Tedman-Jones et al 2003). The community care service can ask the mental health team to assess the family carer's risks and develop a management plan that reflects their needs (Tedman-Jones et al 2003).

An Australian study identified that family carers of mentally ill relatives need respite care and that health professionals can help them by providing information about service availability and accessibility (Jeon et al 2007). This can be problematic, because behavioural symptoms that are difficult to tolerate may mean that the person is excluded from respite care. In such instances, the aged care team should liaise with mental health services to identify appropriate respite services (Jeon et al 2007).

11.2.2 Differences in planning care

Expert advice and consultation needs to be sought when undertaking risk assessment and management plans for older adults with mental illness, their families and carers. Mental health care plans can outline any known risks related to the mental illness, and community care staff can then monitor these risks and report any changes to the mental health team for management advice. It is helpful for the mental health assessor to have access to records from community care providers, with the consent of the older person. All people involved in care can then share risk management and crises plans, according to the information they need (OMH 2001).

These plans need to be reviewed when there is (OMH 2001):

- a major change in the older person's condition or symptoms
- a change to medication or care provision
- a change in the care provider or the location of care.

11.2.3 Good practice points

Older people living with a mental illness	
11.7	Aged care services and mental health care services or consultancies should develop relationships with each other to help plan effective collaborative care for older people who live with a mental illness.
11.8	Use case conferences, where appropriate, as an effective way of encouraging collaborative care planning.
11.9	For a holistic care plan, the aged care team needs to make sure that staff are educated in relevant areas, staff understand crisis management, and relevant staff have access to supports such as peer mentors or supervisors (OMH 2001).
11.10	Support family carers of these older adults by providing emotional, informational and other support. In particular, crisis-management plans need to be in place and access to respite care provided. Crisis-management plans should be clearly documented, known to all family carers and service providers, and show processes to be followed in acute situations (eg who to contact first and who will be available if the first person cannot be contacted).
11.11	When caring for older people with behavioural symptoms, make sure that care has a focus on occupational health and safety for staff. This helps to provide safe and effective care for the older person, and minimises risks for staff and families (McKay 2007).
11.12	Include family carers in decision making about how to provide care (with the older person's consent).

11.3 Living with acute stress disorder or post-traumatic stress disorder

Acute stress disorder (ASD) and post-traumatic stress disorder (PTSD) are psychological reactions that develop in some people after traumatic events, such as major disaster, war, sexual or physical assault, motor vehicle accidents and torture. For war veterans, ASD/PTSD has sometimes been referred to as ‘shell shock’ or ‘combat neurosis’ (Markowitz 2007). Exposure to a traumatic event is not an uncommon experience (ACPMH 2007).

11.3.1 ASD and PTSD core symptoms

People with ASD or PTSD may re-experience the event. This involves some or all of the following symptoms when faced with remainders of the event:

- intrusive and distressing recollections of the traumatic event
- flashbacks
- nightmares
- intense psychological distress
- physical reactions such as sweating, heart palpations or panic.

Avoidance and emotional numbing are other core symptoms that entail avoidance of activities, places, thoughts, feelings or conversations related to the event; restricted emotions; loss of interest in normal activities; and feeling detached from others.

Further symptoms include hyperarousal, which shows up as difficulty sleeping, irritability, difficulty concentrating, hypervigilance (being excessively wary or watchful) or an exaggerated startle response (ACPMH 2007).

Dissociative symptoms may also be experienced in ASD. These symptoms include feelings of detachment, reduced awareness of surroundings, derealisation, depersonalisation and dissociative amnesia (ACPMH 2007).

11.3.2 People most at risk

Epidemiological studies (eg NCPTSD 2007) reveal that 50–65% of people experience at least one traumatic event during their lives and 5–10% experience PTSD.

PTSD is relatively common among people who have been involved in war, including veterans, refugees and asylum seekers (NCCMH 2005, ACPMH 2007).

Veterans’ mental health problems are as varied as the conflicts in which they served. For example, health practitioners may treat an ex-prisoner of war from World War II, or a Vietnam veteran who served in Rwanda, Iraq or East Timor. Although their problems and the treatment they receive may be unique, veterans share a military culture. This culture is dynamic, and therefore not experienced in exactly the same way by all veterans; however, a broad understanding of the culture will greatly help health practitioners to provide the most appropriate treatment for veterans.

11.3.3 Resources

The following questions might be useful to ask when screening an older person for possible PTSD (Feldman and Periyakoil 2006, p 215):

In your life, have you ever had any experience that was so frightening, horrible or upsetting that in the past months you have:

- had nightmares about it or thought about it when you did not want to?
- tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
- were constantly on guard, watchful or easily startled?
- felt numb or detached from others, activities or your surroundings?

A person answering yes to two or more questions is likely to need to be referred to a PTSD expert.[11]

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[11] Mental health practitioner

11.3.4 Care needs

Health care professionals can be reassured that they can help veterans with mental health problems with much the same approach used to help older adults in the general community. Anxiety, depression, panic and substance use are often observed in people with ASD or PTSD (Otis et al 2003). Psychosis and agitation are also sometimes shown (Laramie 2007). Additional symptoms may include anger and rage (Kennedy and Duff 2001, Otis et al 2003). ASD/PTSD was previously thought to be transient, healed by time and avoidance was not considered to be a symptom but a way of managing the illness (Watson and Daniels 2008). Some people may recover from ASD/PTSD with no or little treatment; however, others develop long-term problems (NCCMH 2005).

Symptoms of ASD/PTSD can also be heightened in later life. In particular, symptoms can re-emerge in older adults when the person becomes less distracted by daily responsibilities, such as work and family, and when friends become ill and die (Markowitz 2007).

Family members of those with ASD/PTSD may have coped with withdrawal, verbal abuse, anger, jealousy and hypersensitivity over many years. Sometimes, these family members also exhibit some of the symptoms exhibited by the person with ASD/PTSD; for example hypervigilance, neglect of their appearance, hostility, withdrawal, lack of concentration and indecisiveness, with a number of theories being proposed to explain this manifestation (Lyons 2001). The literature also suggests that some partners may have married the person with ASD/PTSD with the intent of providing care for them (Lyons 2001). However, other people with PTSD are without family because they have chosen to sever all family ties (Feldman and Periyakoil 2006).

Health care providers are most likely to encounter older adults who have ASD/PTSD when providing a palliative approach to care for veterans or those who have entered Australia as refugees. Knowledge of how to manage symptoms and responses to ASD/PTSD, and how to activate necessary resources, is therefore essential (Laramie 2007). Encouraging access to care may also be an issue because distrust of authority can lead people with PTSD to have difficulty communicating with health professionals and to refuse offers of care (Feldman and Periyakoil 2006).

11.3.5 Treatments and therapies

Some therapies, such as cognitive–behavioural therapy, are helpful for people with ASD/PTSD. Some medications also improve symptoms (Bisson 2007). However, for people who have a short life expectancy, care is generally focused on minimising distress. The GP or psychiatric consultant may consider prescribing quick-acting medication to relieve the person’s symptoms (Feldman and Periyakoil 2006). A client-centred and client-controlled approach to care is the most appropriate care in these situations. The care team should also provide relevant information and support to the family (Feldman and Periyakoil 2006).

Understanding the kinds of triggers that cause symptoms in the person will also help care providers to modify care to avoid causing distress. Also, a plan of care underpinned by staff education and support resources can help when providing care to these older adults who may present as highly anxious, agitated or even aggressive.

11.3.6 Good practice points

Older people living with acute stress disorder or post-traumatic stress disorder	
11.13	Screen older adults at risk of ASD/PTSD, especially those exhibiting depression, anxiety or symptoms such as agitation. This may help the aged care team to provide appropriate care for these people.
11.14	When older adults are known to have ASD/PTSD, check whether the family needs additional support. This can help the aged care team deliver appropriate care and assess what resources are appropriate.
11.15	Provide appropriate information and education for health care providers who deliver care to older adults who have ASD/PTSD. This will maximise quality of care, and family carer support.
11.16	Accessing specialist support from the mental health team will also help to facilitate appropriate care and support for the family carer of the older person.
11.17	Make sure that only competent and appropriately qualified practitioners provide psychosocial interventions for ASD/PTSD, such as cognitive–behavioural therapy. Also, some interventions may be inappropriate; see the guidelines for managing ASD and PTSD under 'Recommended readings' for this chapter.
11.18	Help the older adult to participate in health care decision making. This is particularly appropriate for older adults with ASD/PTSD, who may be anxious and distrustful of authority.
11.19	Be aware of possible triggers for flashbacks or other adverse reactions in the older person receiving care. This awareness will allow people providing care and support to avoid inadvertently causing distress or provoking a hostile reaction. An understanding in care providers that pain and any perception of restraint may cause distress in this way can also help to inform the plan of care.
11.20	Because older adults with ASD/PTSD can be at risk of self-harm and of harming others, the aged care team (in conjunction with the mental health team) should prioritise the management of these concerns (NCCMH 2005).
11.21	Debriefing can support care staff who are facing challenging situations when providing care for the older adult with ASD/PTSD and their family carers.
11.22	The Department of Veterans' Affairs is a good resource for those providing care for veterans and can provide additional services such as counselling and support. More information is available at http://www.dva.gov.au.

Recommended reading

ACPMH (Australian Centre for Posttraumatic Mental Health) (2007). *Australian Guidelines for the Treatment of Adults with Acute Stress Disorder and Posttraumatic Stress Disorder*, ACPMH, Melbourne.

Available from: http://www.acpmh.unimelb.edu.au or http://www.nhmrc.gov.au

NCCMH (National Collaborating Centre for Mental Health) (2008). *Post-Traumatic Stress Disorder. The Management of PTSD in Adults and Children in Primary and Secondary Care*, National Institute for Clinical Excellence (NICE), London.

Available from the National Guideline Clearinghouse at: http://www.guideline.gov

11.4 Being an older gay, lesbian, bisexual, transsexual or intersex person

People who identify as being gay, lesbian, bisexual, transsexual or intersex (GLBTI) may need special consideration of their perspectives when they are being cared for. However, the issues that relate to their sexual and gender identity may be invisible to mainstream health and community care services (MacDonnell and Andrews 2006). This group may also have experienced anticipatory or actual discrimination and be reluctant to seek help. Many older GLBTI people have hidden or avoided disclosing their sexuality or relationships throughout their lives to protect themselves from discrimination. Others have disclosed this information to friends and families, some of whom provide support and others who have withdrawn from their lives (Brotman et al 2007). In general, GLBTI people are more likely to be connected to the gay community than the broader community, although many live alone and have no social connections (Brotman et al 2007, Hyde et al 2007). Those older adults with no social connections may have no sense of belonging or of feeling supported within the community (WACHPR 2007).

11.4.1 Differences in care needs and access

Even though an older GLBTI person may be in a long-term relationship, older lesbian couples, in particular, tend to be invisible in Australian society (Hyde et al 2007). Many of these couples are cautious about homophobic attitudes among health care providers and some do not disclose their relationship because they may feel it is irrelevant to their care needs (MacDonnell and Andrews 2006). Lesbian and bisexual women are less likely to use health services and preventative programs compared with heterosexual women. Therefore, these women may have poorer general health, with a greater prevalence of obesity, recreational drug use, smoking and mental illness than the wider community (Hyde et al 2007).

Older gay men may not have disclosed their sexuality before they need care, and doing so may cause them discomfort. Some of these men may refuse home care services for fear that their living arrangement with a same-sex partner will be revealed (O'Neill et al 2003). Gay men also tend to avoid health service use and preventative programs. These men may face a variety of health issues, including human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), smoking-related problems, problems related to recreational drug use, depression, sexually transmitted disease, and anal cancer and hepatitis to a greater degree than the general population (Ferri 2004).

A recent Australian study revealed that 23% of GLBTI people reported being discriminated against (Victorian Gay and Lesbian Rights Lobby 2000, cited in Hyde et al 2007). Mainstream services tend to reflect the majority views of society (Nicholson and Turner 2000) and are, therefore, often perceived to be unsafe for minority groups who frequently experience discrimination. In response to this perception, many GLBTI people seek alternate therapy (MacDonnell and Andrews 2006). When mainstream services are accessed, the quality of care provided may be reduced by misunderstandings brought about because care recipients and people around them avoid disclosing their GLBTI status. For example, to protect their relationship, an older person may introduce their partner as a friend or housemate. Complexities and difficulties then arise as family carers support their sick parent, friend or partner to maintain their privacy (Brotman et al 2007). Community care providers need to provide an environment of care for this group that is perceived by its members to be safe. Ideally, sexual preference will be established routinely during assessment to avoid false assumptions being made about a person's sexuality (Hyde et al 2007).

11.4.2 Providing care

Many community support workers have not been educated about gay, lesbian and bisexual issues, and even fewer have received information about transgender and transsexual people (Hyde et al 2007). A lack of understanding of this group of older people may foster fears about coping with the person's disclosure of their sexuality and managing challenges to personal beliefs and values.

GLBTI people may consider safe care environments to be those provided by organisations that have explicit policies about sexual discrimination and confidentiality, and provide anonymity when required. Acceptance of GLBTI people needs to be obvious in the attitude of individual support workers and the community-service organisation as a whole; sensitivity and respect need to be conveyed so that a trusting relationship may be established (MacDonnell and Andrews 2006).

Recent history has identified some aspects of safe care for GLBTI people. The emergence of HIV/AIDS in the 1980s created an increased awareness of the style of care that gay men preferred. Gay men wanted to reduce discrimination and ensure care would be provided regardless of race or sexual orientation (Nicholson and Turner 2000). As a group of activists, they strove to obtain patient-centred treatment, confidentiality, acceptance of their lifestyle and control of information (Nicholson and Turner 2000). Ensuring that these issues are included in organisational policies and practice is likely to improve community services as inviting places of care for GLBTI people.

When care is provided for any older adults who have HIV/AIDS, staff may fear becoming infected themselves if they are not provided with education to explain the precautions that need to be taken. This diagnosis is rare in older adults in the Australian context, and care providers are far more likely to encounter GLBTI people who have cancer or deteriorating chronic health conditions, such as heart failure. However, when a palliative approach to care is provided for people who have HIV/AIDS, demands on community health care providers increase dramatically (Nicholson and Turner 2000). Features of pain, physical disability and psychosocial needs in people who have HIV/AIDS are similar to those experienced by cancer patents, but there can be additional issues, including mental illness, multiple medications, acute treatments and lengthy dying periods (Nicholson and Turner 2000).

Community support workers need to be aware of the unique family structures of GLBTI people to target information, education, support and services to them, as well as to facilitate their support for the older person. The term 'family' may be rejected in this population and replaced with 'chosen kin'. However they are defined, identifying people who are significant to the older person requiring care is necessary to support carers and provide bereavement care (Carlisle 2000).

11.4.3 Chosen kin

Family carers (chosen kin) of GLBTI people may have unique stressors. They may face stigmatisation, fear of infection and isolation from usual support networks. They may also have problems accessing insurance, housing and survivor benefits after bereavement because of a lack of recognition of their relationship with the person who has died (Stajduhar and Davies 1998, Brotman et al 2007). They may be reluctant to join carer support groups and are less likely to be offered bereavement support (Brotman et al 2007). When service providers recognise the carer’s role and form a partnership of care, this can improve carer confidence and provide enormous support. Conversely, carers who experience unsupportive or unsuitable care may reject service provision because they perceive that the system will not meet their needs (Stajduhar and Davies 1998).

11.4.4 Advance care plans

Many GLBTI people have not been able to discuss their feelings and thoughts about relationships or end-of-life wishes. In addition to encouraging the older person to prepare an advance health care plan (see Chapter 5), advising them to delegate enduring power of attorney may be particularly helpful. This delegation will clarify roles and help to ensure that the same-sex partner or chosen kin has legal rights to participate in decision making and access to managing finances on behalf of the client (Brotman et al 2007). It will also help identify to whom carer support and bereavement care should be targeted by the community support workers.

11.4.5 Good practice points

Older people who are gay, lesbian, bisexual, transsexual or intersex	
11.23	Actively demonstrating a nondiscriminatory policy and targeting information about services to the GLBTI community will support the accessing of services by this group of people.
11.24	Education for health care providers about the issues facing GLBTI older adults, the particular importance of confidentiality and how to best support this vulnerable group of older people will help to ensure that a ‘safe’ care environment is provided for them.
11.25	Individual health care workers can promote the acceptance of care and support by establishing relationships with clients that demonstrate respect and sensitivity.
11.26	GLBTI clients can gain support by networking with GLBTI support groups and by accessing telephone support from these groups. The aged care team can provide GLBTI clients with information to help them do this.
11.27	To allow the implementation of the client’s preferences, community health care providers are advised to seek the client’s guidance about with whom they should discuss care, when and if an advocate is required.
11.28	Developing advance health care directives and delegating enduring power of attorney take on particular importance with this client group and should therefore be encouraged actively.
11.29	The chosen kin of GLBTI clients are at risk of being overlooked when carer support or bereavement care is provided. To avoid unnecessary distress in this group, service providers need to take steps to identify these kin and provide support as they would to other family carers.
11.30	A partnership in care with the chosen kin of the care recipient has the potential to improve care for GLBTI clients.
11.31	It may be appropriate for the aged care team to provide information about volunteer home care services for GLBTI clients when such services exist.

Recommended reading

Further information on aged care services for older GLBTI people, as well as a glossary of relevant terms, can be found in the following publication:

Matrix Guild Victoria Inc and Vintage Men Inc (2008). *My People: A Project Exploring the Experiences of Gay, Lesbian, Bisexual, Transgender and Intersex Seniors in Aged-Care Services*, Matrix Guild Victoria Inc, Melbourne.

Available at: http://www.matrixguildvic.org.au/ or http://www.glhv.org.au

11.5 Living with an intellectual disability

Within the global population, severely intellectually disabled people (manifesting an IQ of less than 50 plus deficits in adaptive behaviour) represent 0.3%–0.5% of all children born. Mildly intellectually disabled people (IQ 50–70) represent 0.2%–4.0%. In Australia, intellectual disability is estimated to affect between 1.7% and 1.9% of the population (Bittles et al 2002). People who have a severe intellectual disability are 20% more likely to die before they are 30 years of age and very unlikely to reach old age (Patja et al 2000). The average survival of people with an intellectual disability overall is 68.6 years and those with a mild disability are likely to have similar lifespans to those who do not have intellectual disability (Patja et al 2000, Bittles et al 2002). People with genetically determined intellectual disability have a slightly lower median survival of 60.1 years (Bittles et al 2002).

Some people with an intellectual disability live in the community and are serviced by the mainstream health care system. People who have a mild disability are unlikely to require community care unless or until they become unwell or disabled (Patja et al 2000). Many people with intellectual disabilities are likely to be able to direct their own care, manage their budgets, and pursue their own goals (Botsford and King 2005).

11.5.1 Differences in care needs

Older adults with intellectual disability may have poor dentition, motor impairment or neurological anomalies, and are more prone to seizures and sensory impairment than others (Janicki et al 2002). In addition, people with Down syndrome have a high risk of eventually developing Alzheimer’s disease. People with intellectual disabilities also have a relatively high rate of behavioural symptoms and many have trouble communicating (Botsford 2000, Janicki et al 2002). Sensory impairment in older adults may contribute to behavioural symptoms (Janicki et al 2002). Disease progression in this client group is largely unknown (Tuffrey-Wijne et al 2007).

As in other client groups, when a person with an intellectual disability has a progressive, life-limiting illness, a palliative approach to care requires consideration. The basis for decision making in this event is to take into account the person’s ability to understand information, involving them to the extent that is possible. Often, decisions are made late in the course of the illness for people with a disability so severe that they cannot participate in discussion (DADHC 2004). A decision to stop futile curative treatments is more clearly justifiable when this is known to reflect the client’s wishes; therefore, it is appropriate to organise advance heath care directives early, when the person is able to take part in discussions (DADHC 2004). See also Chapter 5 for more information on advance health care directives and planning.

Many people with an intellectual disability can participate in decision making, express their preferences about end-of-life care, and participate fully in developing advance health care plans (Botsford and King 2005, Tuffrey-Wijne et al 2007).

When the older adult is deemed incompetent to make decisions about care or treatment, a guardian will need to be appointed. This appointment is made via the state or territory guardianship board or tribunal.

Family relationships and remaining in a familiar environment are particularly important to people who have an intellectual disability. Therefore, providing a palliative approach within the community may be the best option (Tuffrey-Wijne et al 2007). However, when a person is dying in a group home, the needs of other residents and staff need careful consideration (DADHC 2004) because they are essentially part of the person's family.

11.5.2 Differences in care provision

Staff liaison with specialist palliative care services is an important component of a palliative approach to care. Liaison is particularly important for managing symptoms, planning care, and providing bereavement support for the person's family and for staff, and — if appropriate — for other group home residents (Tuffrey-Wijne et al 2007). Managing symptoms might be problematic because of the client's communication disability, emphasising the importance of consulting with palliative care specialists. Also, bereavement care for other group home residents may be challenging because of their disabilities.

Medical and specialist staff may be worried about their own lack of understanding of responses to symptoms and treatment in people with intellectual disability. People with an intellectual disability can respond to pain in different ways, ranging from an increase in activity and behaviour to a dramatic decrease, with the person remaining still. Therefore, people who know the person well can help to interpret their responses. Using coloured pain analogue scales and photographs can sometimes help to assess pain; however, little is known about how to assess other types of symptoms within this population (Tuffrey-Wijne et al 2007). Despite this, an approach that applies knowledge and experience gained with other patient groups, together with an understanding of the person and their disability, is likely to provide good outcomes.

Even when the person with an intellectual disability is older than 65 years, a parent or sibling may still be involved in care. This has implications for the support that needs to be provided.

Whoever the family carer is, they may not want their relative to be admitted into residential care for end-of-life treatment because they (the family carer) has been resisting institutional care for many years (Tuffrey-Wijne et al 2007). However, the death of a parent may lead to an abrupt end to home support and prior planning is required to prepare for this eventuality as the family carer grows old or frail. Respite care may provide a much needed break for the carer and also allow them to see that other care options can be enjoyed by the person who has the disability (Bigby et al 2002).

11.5.3 Loss and grief

An older person with an intellectual disability may experience bereavement while they are also receiving care for life-limiting illness. In particular, this may occur when their aged parent dies. Whereas a response to loss and grief is not different for people with an intellectual disability, their expression of grief is influenced by their communication and intellectual capacity (Botsford 2000). A person with an intellectual disability whose carer dies is at a high risk of extreme grief, because such a loss may also include their home, community, income and personal belongings (Botsford 2000). It is important to provide appropriate bereavement support in such a situation, and inappropriate to assume that the person does not understand the death or that they will soon forget the event (Botsford and King 2005). Full participation in social rituals and support related to death and dying by the person with the intellectual disability is generally appropriate (Botsford 2000).

Equally, family members, other residents in group homes and care staff need to be acknowledged and supported when the person with an intellectual disability dies (Botsford and King 2005, Tuffrey-Wijne et al 2007). In addition, group home residents may need support to accept a new resident soon after the death (Botsford and King 2005). Staff training in end-of-life care and bereavement support can help them to continue to respond sensitively and effectively to other residents (Botsford 2000). Anticipatory bereavement care can help to identify any disagreements among residents, families and staff about the dying person's choices, begin to resolve these issues, and contribute to a more peaceful death (Botsford 2000).

The **Disability Advocacy and Information Service Inc** provides support for carers of people with a disability:

Website: http://www.dais.org.au

11.5.4 Good practice points

Older people with an intellectual disability	
11.32	A collaborative approach to care among family carers, social care providers, the GP and the aged care team that also aims to identify and respect the wishes of the older adult with an intellectual disability is likely to benefit that older adult.
11.33	Because intellectual disability is also associated with communication difficulties, specialist palliative care advice may be especially useful for these people, particularly when the care team is assessing symptoms and identifying the older person's wishes regarding advance health care planning.
11.34	Bereavement care may also be more complex for these older adults, so specialist input may be helpful.
11.35	This group of older adults is likely to derive particular benefits from early advance health care planning. Additional time may be needed to identify and articulate their wishes to allow for any communication difficulties.
11.36	Health care providers who do not know the person with the disability may be reluctant to value their advance health care plans. Therefore, health care providers who have been involved in the development of these plans may need to adopt an advocacy role or support the family carer in this role, explaining the rigorous process underpinning the plan.
11.37	When someone close to the person with a disability dies, it may be helpful to involve the person with the intellectual disability in rituals, such as the funeral. Other helpful strategies include using nonverbal rituals, respecting cherished mementos and trying to minimise any major changes for 12 months.
11.38	During bereavement, behavioural changes such as development of aggression, regression, mutism (not speaking), self-harm, wandering and long-standing tearfulness may indicate that additional specialist support is required (Botsford 2000).

11.39 An older adult with an intellectual disability whose family carer dies when they are already unwell or frail themselves will be at particular risk of extreme grief, partly because this will usually result in relocation and consequent further loss. Because of this crisis in their lives, health and social care teams need to provide a high level of emotional support for the person and try to maintain as much stability as possible.

11.40 Educational and resource support for people who work for aged care services or palliative care services and provide care for people with intellectual disabilities is essential. As well as addressing skills such as symptom assessment, education and resources should explore issues around myths and stereotyping of people with intellectual disability.

Recommended reading and resources

Center for Excellence in Aging & Community Wellness, University at Albany website: http://ceacw.org/ (Learning centre>Intellectual disabilities, Aging and dementia resources>Intellectual disabilities)

and

Understanding Intellectual Disability & Health website: http://www.intellectualdisability.info/

11.6 Experiencing motor neurone disease

Motor neurone disease (MND) is a progressive and incurable degenerative process of motor neurons leading to muscle wasting that ultimately ends in death from respiratory failure. The disease most commonly starts with weakness and clumsiness of the skeletal muscles in the limbs, and progresses to involve the tongue, pharynx, larynx and muscles of respiration. Speech becomes slurred and slow (‘dysarthric’) and cough is impaired, causing the person to inhale food and saliva (Glaetzer and Allcroft 2004). Motor neurone disease has no known cause and no known cure (Clarke et al 2005). The only treatment, riluzole, slows the progression of the disease only marginally. Riluzole is an antiglutamatergic agent that increases survival by an average of three months if it is taken for 18 months (Morrison 2005). Palliative care is therefore fundamental to ensuring the best outcomes for the person with MND and their carers.

There are four main clinical categories of MND:

- *Amyotrophic lateral sclerosis* (most common), in which the pyramidal (corticospinal) tracts as well as the anterior horn cells of the spinal column are involved. This results in wasting of the muscles in the limbs, with speech and swallowing problems appearing later.
- *Progressive bulbar palsy*, which involves the cranial nerve nuclei. This predominately affects the muscles of speech and swallowing.
- *Progressive muscular atrophy*, which is characterised by degeneration of the anterior horn cells of the spinal column. This results in wasting of the muscles of arms and legs, but does not affect swallowing and speech (Robbins et al 1981).

- *Primary lateral sclerosis* (uncommon) is characterised by muscle spasticity, slowed recruitment of voluntary muscle strength, pseudobulbar palsy and weakness (Tomik et al 2008).

People with MND usually remain continent, because sensory neurons and tracts are not normally affected by the disease (Oliver 1994). Frontotemporal dementia is detected in less than 5% of people with MND and is more common in progressive bulbar palsy (Mitsumoto and Munsat 2001).

11.6.1 Diagnosis

Motor neurone disease is diagnosed on the basis of clinical examination, with progression over time and the absence of any other cause for the symptoms. The presence of widespread fasciculations (muscle twitches) with weakness is highly suggestive of MND (Morrison 2005). Electrophysiology studies are required to confirm the diagnosis; these will show evidence of acute denervation (loss of nerve supply to a muscle) and reinnervation (replacement of a dead nerve by an adjacent, living nerve) without nerves losing their ability to conduct signals (Howard and Orrell 2002). If a diagnosis of MND is suspected, the health care professional should refer the person to a neurologist (preferably in the public health system) or to a neuromuscular clinic. Motor neurone disease should only be diagnosed if it is definite or probable (after the investigations discussed above). As a general rule, people and their families should be informed gently and in stages (depending on the person’s background and personality).

Often, people with MND express frustration at the length of time it takes for a diagnosis to be confirmed. Despite clear explanations of the difficulty in making a diagnosis based solely on progression of clinical signs, this remains a source of frustration for many people and often causes them to be dissatisfied with how the diagnosis was conveyed, despite the greatest care and sensitivity.

11.6.2 Prevalence

Approximately five people in 100 000 have MND. Half of the people with MND will die within 36 months of their first symptom (Polkey et al 1999). Most people with MND present between the ages of 50 and 70 years. The disease is usually sporadic (not inherited), but around 10% of people will have a family history of the disease (Morrison 2005). This is compatible with an autosomal dominant inheritance.

11.6.3 Advance health care planning

The pattern and rate of disease progression is unique to each person. This makes it difficult to pre-empt the exact needs in a timely manner. Regardless, the health care team should introduce the concept of advance health care plans and directives early in the disease process, so people with MND have the opportunity to document their preferences before the disease progresses (see Chapter 5 for more information on advance care planning and directives). However, discussing end-stage care early in the disease process needs to be done with caution. For example, it may not be appropriate to start talking about tracheostomy (opening the wind pipe to help breathing) and gastrostomy (placing a feeding tube into the stomach) options as soon as the diagnosis is confirmed. But, at the same time, these issues should be discussed well before there is severe dysphagia (swallowing difficulties), weight loss and respiratory muscle weakness. The health care team needs to consider the overall benefits versus drawbacks of any treatments when they are discussing options. If treatment options are considered early and all their implications are understood, an advance health care plan or directive that is also understood by the family and well communicated to relevant health care professionals will be invaluable.

11.6.4 Care and support

The essence of care for people with MND is good management of symptoms, which involves coordinating multidisciplinary care (Howard and Orrell 2002). Many people with MND prefer to be cared for in their own homes. In this setting, people can focus on normality, maintaining control and freedom, and achieve better quality of life (Eng 2006). The essential components of successful home care include skilled medical supervision, adequate home care nursing and support for the family (Maddocks 1997). There is also a need for ready access to equipment, allied health services and medical supplies when required (Glaetzer and Allcroft 2004). Specialist palliative care services have an important role in the care of people with MND and early referral should be encouraged.

11.6.5 Resources

Caring for people with MND is resource intensive because of the high level of dependence as the disease progresses. Often, a hoist (a lifting machine), operated by two assistants, is needed to transfer people from bed to chair. This may require coordination among a number of different support agencies, such as care package providers and community nurses. Communication difficulties can also add to the time required to help a person with MND because speech is often slow, or they may rely on alternative communication methods. The period of total dependence may be prolonged for some people with MND; therefore, respite care may be important for easing the burden on the family or carer. Regular respite should be offered in the home. If the illness is prolonged, alternative care arrangements should be offered for regular periods in a facility, such as a palliative care unit, hospital or residential aged care facility.

Motor neurone disease associations throughout Australia can offer many resources and support to people with MND and their families. MND Australia offers resources and is able to direct people to other appropriate sources of support and assistance in relevant states and territories.

MND Australia:
Website: http://www.mndaust.asn.au

See ‘Motor Neurone Disease Australia’ in the White Pages

11.6.6 The family

Particular attention should be paid to the family and friends providing care at home. The health care team should ask family carers how they are managing, and whether they are getting enough sleep, receiving adequate support, and attending to their own medical care.

Many people with MND believe that the disease is harder on their family than on them and are comforted to know that the family's needs are also being considered (Oliver et al 2006).

11.6.7 Education

Educating the person with MND and their family carers is fundamental for making sure that they are better equipped to cope with each stage of the disease. People are more likely to accept recommendations if they understand the reasoning behind certain interventions or treatments. The health care team should explain any suggestions in simple terms and in a timely way so people have enough time to consider the options before making a decision (Oliver et al 2006). This is particularly important when discussing options for managing nutrition and respiratory interventions. Staff should be aware of cultural preferences so they can communicate with the older person in an appropriate way.

11.6.8 Symptoms

The major symptoms experienced by people with MND may include:

- emotional difficulties
- communication problems
- dysphagia or choking
- saliva problems
- dyspnoea (breathing difficulties) and respiratory failure
- loss of mobility and increased physical dependence
- pain and discomfort
- constipation.

Many of these symptoms are similar to those experienced by people with any life-limiting illness; this is where a palliative approach has much to offer (Kristjanson et al 2003). The sections below explain these major symptoms in more detail.

Emotional difficulties

Neurodegenerative diseases are commonly accompanied by mood disturbances (Kristjanson et al 2003). The way a person reacts to a diagnosis of a life-limiting illness such as MND depends on a number of factors, including life experience, personality, support systems, culture, frame of reference, education, beliefs, values, attitudes and emotional stability (Glaetzer and Allcroft 2004). Counselling is commonly offered to people to help them to adapt to their deterioration and increasing physical dependence. The person's capability of participating in counselling becomes problematic as they become less able to communicate. This may add to the emotional distress. Depression is common in people with MND, but can be alleviated by antidepressants. Mood swings are common, particularly in progressive bulbar palsy where corticobulbar fibres are affected. This causes uncontrollable laughing or crying for no apparent reason, which requires careful explanation to both the person with MND and their family carer (Glaetzer and Allcroft 2004) and can be controlled by dextromethorphan/quinidine (Brooks et al 2004).

Communication problems

Up to 80% of people with MND will have varying degrees of speech problems (O'Brien et al 1992). Speech may vary from mildly slurred to unintelligible or absent. Early introduction to a speech pathologist is essential to allow continual adaptation of communication methods as the disease progresses. Communication devices may include voice amplifiers, picture boards, LiteWriters and devices with speech synthesis. The challenge is to ensure the person with MND continues to be able to communicate needs, make informed decisions and maintain control over their lives (Glaetzer and Allcroft 2004).

Dysphagia

Most people with MND will have difficulty swallowing at some stage. Involving a speech pathologist in dysphagia assessment and management is crucial. Initial swallowing problems may be managed by changes in consistency of food and fluids. Referral to a dietician will ensure that the person and their carer are given advice about how to maintain adequate nutrition. As the disease progresses, everyone involved needs to consider the option of tube feeding. A percutaneous endoscopic gastrostomy (PEG) tube insertion (which transfers food directly into the stomach) is the preferred approach. The gastrostomy may be used to supply all nutrition, supplement reduced intake, maintain hydration and administer medications. Some people with MND may choose not to opt for intervention and prefer to continue eating while they are able and to stop when they are no longer able — well aware this will lead to their demise. Fear of choking is common for people with MND, and a plan should be in place for managing these episodes when they arise (both to minimise risk and reduce anxiety). Commonly, clonazepam sublingual drops can be used to reduce the cough reflex during episodes and further reduce anxiety.

Saliva problems

People with MND may be troubled by a change in their saliva production. This change, combined with swallowing problems, may cause them to dribble and drool, which is socially embarrassing. The health care team needs to establish the nature of the problem by asking questions such as ‘Is the saliva thick and sticky or thin and runny?’ Thick saliva may be caused by dehydration, and can be helped by giving the person saline via a nebuliser (which produces a mist to be breathed in), or mucolytic agents like dark grape juice or papaya enzyme (these break down mucous). If the person has thin saliva, they may need to be prompted to consciously collect and swallow saliva. Alternatively, they can take medications such as glycopyrrolate (which reduces saliva production) or small doses of amitriptyline (an antidepressant that has the side effect of causing dry mouth). The use of atropine tablets and botulinum infections — which dry secretions and block the nerves that stimulate salivary glands, respectively — can also be helpful to reduce secretions to a normal level. Some people might also find suction to be useful.

Dyspnoea and respiratory failure

Respiratory failure (causing low blood oxygen with or without high blood carbon dioxide) is the cause of death in most people with MND (Glaetzer and Allcroft 2004). Respiratory function should be monitored using simple tests such as measuring forced vital capacity (the amount of air that can be breathed out after taking in a deep breath) and blood gas analysis. The person with MND should also be asked whether they have morning headaches, unrefreshed sleep, fatigue, poor concentration and memory, and breathing difficulties when lying down (Glaetzer and Allcroft 2004). There are two possible approaches to managing respiratory failure in MND: palliation of symptoms with medication, or with physical measures including mechanical ventilation. Palliative measures to consider include simple physiotherapy to help coughing up or spitting out saliva, providing suction equipment, and administering medications such as opioids, benzodiazepines and anticholinergics (Polkey et al 1999). Mechanical ventilation is usually administered via noninvasive positive pressure ventilation.

Discussions about respiratory failure should be held early in the course of the illness. Treatment options should be discussed in detail, including the limitations and exclusion criteria for respiratory interventions. This allows people with MND to make an informed decision, helps them to develop a plan of action for acute episodes of dyspnoea, and hopefully prevents an unplanned crisis hospital admission.

Loss of mobility and increased physical dependence

People with MND need to have ready access to a range of equipment and mobility aids as their physical condition deteriorates. This may include a hospital bed, lifting machine, wheelchair and showering equipment. The home environment will have to be considered when such equipment is supplied so that it is practicable to use. Foot splints (eg ankle–foot orthotics for foot drop) may also be needed to help with moving around, and hand splints may be needed to maintain hand function and stop joints from stiffening. The family or carer will need to be taught manual handling techniques to prevent injury to themselves and to maximise comfort for the person with MND.

Pain and discomfort

Motor neurone disease is often referred to as a painless disease, but pain has been reported in up to 57% of patients with MND (O'Brien et al 1992). The causes of pain can range from generalised discomfort, to musculoskeletal pain caused by altered muscle tone and restricted movement, to painful muscle cramps. Analgesics (pain medication), including opioids, should be considered, as well as nonsteroidal anti-inflammatory medications. Particular attention should be paid to the head and a soft collar may be useful to support the neck. Subluxation (complete or partial dislocation) of the shoulders is common and, if pain is not improved by analgesia, an intra-articular steroid injection should be considered. For muscle cramps, medications such as baclofen and benzodiazepines may be helpful options (Glaetzer and Allcroft 2004).

Constipation

Constipation in MND can be attributed to a combination of immobility, weakness of the abdominal muscles, reduced or altered food or fluid intake, and side effects from medications such as opioids and medications to reduce saliva (Glaetzer and Allcroft 2004). Constipation may also be worsened by the person’s reduced ability to access a toilet as they become more dependent. Ensure the person has adequate fluid intake (this is much easier to achieve if a PEG is in place) and mild laxatives. It is best to avoid increasing fibre when constipation is caused by immobility.

11.6.9 Good practice points

Older people with motor neurone disease (MND)	
11.41	A collaborative multidisciplinary approach that provides support for the family carer is essential in MND. Successful home care depends on the availability of a committed family carer, and coordinated and accessible home support services.
11.42	The level of help and support needed will vary from one situation to the next.
11.43	Contingency plans are essential for acute situations that may arise and all care providers should be aware of the wishes of the person with MND and their family carers.
11.44	All people with MND should be encouraged to complete an advance health care directive — ideally, early in the disease process (see Chapter 5). Sensitivity is essential. For example, it may not be appropriate to discuss tracheostomy and gastrostomy options immediately after diagnosis but they should be broached well before there is severe dysphagia, weight loss and respiratory muscle weakness.
11.45	Specialist palliative care services should be introduced soon after diagnosis so specialists can provide consultative advice throughout the course of the illness.
11.46	Practical aids and equipment are essential resources.

Recommended reading

Kiernan M (2007). *The Motor Neurone Disease Handbook*, Australasian Medical Publishing Co, Strawberry Hills, New South Wales.

11.7 Experiencing advanced Parkinson’s disease

Parkinson’s disease (PD) is a progressive neurological disorder of unknown cause. It primarily affects the dopamine-producing neurones within the substantia nigra of the basal ganglia (the part of the brain responsible for motor control, thinking, emotions and memory) in the midbrain (Hauser et al 2006). This can result in a variety of symptoms affecting all aspects of daily living. There is currently no cure and the pharmaceutical treatment can cause side effects that may, in the long term, be as disabling as the symptoms it aims to control.

11.7.1 Diagnosis

Diagnosis is based on the presence of the following major symptoms:

- tremor
- bradykinesia (slowness of movement)
- rigidity (increased muscle tone)
- postural instability, which can lead to falls.

The onset of these symptoms is often insidious and a clinical diagnosis is possible only when 70–80% of dopamine neurons have been lost.

In the absence of a definitive test for PD and the lack of changes seen on a magnetic resonance image (MRI), a positive response to levodopa (which is transformed into dopamine in the brain) is regarded as confirmation of a diagnosis. Typically, disease progression is gradual so longevity of disease and treatment combined with the aging process can result in multifaceted challenges in the area of palliative care. Parkinson’s disease can be described as a life-altering condition rather than a life-threatening disease.

11.7.2 Prevalence

Parkinson’s disease is a worldwide phenomenon and is slightly more common in males than in females. A recent study conservatively predicts that the Parkinson’s population in Australia will reach 98300 people by 2025 (Access Economics 2007). Prevalence increases with age: one in 1000 people aged over 65 years; one in 100 people aged over 75 years. Young-onset PD is defined as PD diagnosed under the age of 40 years and juvenile-onset PD is PD diagnosed before the age of 21 years.

11.7.3 Parkinson’s plus

Over time, some people with presumed PD may develop additional symptoms, which suggests they have a condition known as ‘Parkinson’s plus’. Such conditions include multiple system atrophy, progressive supranuclear palsy and corticobasal degeneration. The shift in diagnosis from PD to any of the Parkinson’s plus conditions often adds frustration and emotional suffering. These conditions have a limited response to levodopa and a more rapid rate of progression, and palliative care becomes a vital part of management much earlier than in idiopathic PD.

11.7.4 Symptoms and support

In PD, there is often no single point when the disease becomes terminal. Therefore, it is vital to use a palliative approach to care in its broadest sense — that is, to provide the best possible symptomatic treatment in combination with psychological support and coping strategies (Gonsalkorale 2007). Also, GPs or physicians need to provide a referral or discuss care with a neurologist or PD specialist (in a movement disorder clinic or PD speciality unit) about optimal symptomatic treatment. This treatment could include new therapies, such as intraduodenal duodopa, the apomorphine pump and deep brain stimulation.

Advanced stages of PD are accompanied by worsening mental and physical symptoms while drug response progressively decreases. Home management becomes increasingly difficult and people involved may need to make decisions about future care. Institutionalised care can be delayed or avoided with responsive and sympathetic support for the carer.

11.7.5 Side effects

The long-term medical management of PD is often limited by the side effects of the medication (levodopa) used to treat the condition. These include:

- dyskinesia (involuntary movements)
- end of dose failure (see below)
- neuropsychiatric problems, such as hallucinations, paranoia and psychosis.

Dyskinesia may become apparent as early as five years after the introduction of levodopa. Incidence figures of levodopa-induced dyskinesia vary between 20% and 80% after five to six years of treatment in various studies and a higher incidence is frequently seen in young-onset PD (Luginger et al 2000). These involuntary movements are thought to be due to pulsatile stimulation of the dopamine receptors and require careful adjustment of levodopa. In spite of this, perfect control may be impossible, and severe dyskinesia may limit the treatment options.

End-of-dose failure marks the progression of the disease and the effect of levodopa becoming less potent over time. This requires adjustments to medications to control the disease symptoms to maintain independence and quality of life.

11.7.6 Adjusting medication

In late stage PD, drug-related neuropsychiatric problems, such as hallucinations and psychosis, may limit the dosages and types of medication. A palliative approach to care in PD can involve adjusting and, in some cases, stopping PD medications to relieve the person of these side effects. Introducing atypical antipsychotic drugs will help to manage hallucinations, paranoia and psychosis if the reduction of levodopa results in an unacceptable decrease in mobility and independence.

11.7.7 Advance health care planning

The patterns of disease symptoms, disease progression and medical management are unique to each person — PD can be described as a ‘designer label disease’. The end-of-life issues also become individualised and a palliative approach needs to reflect the symptoms to be managed and the wishes of both the person with PD and their family. Introducing advance health care directives following informed discussion will help the family to make informed decisions about end-of-life issues (see Chapter 5 for more information).

In addition to the key signs of PD and side effects of medications (as listed above), there are many other aspects of daily life that are affected and impact on quality of life, particularly in the later stages of the disease process.

11.7.8 Communication

Approximately three-quarters of people living with PD experience changes with communication (Camburn et al 1998). The person’s voice may gradually become quieter, (microphonia) which makes verbal communication difficult. In extreme cases, aphasia (complete loss of voice) may occur. A mechanical aid, such as a LiteWriter, can be used. Voice amplifiers can also be used if speech therapy is not effective or appropriate. Festination of speech (similar to stuttering) may also impair communication. Decreased facial expression and loss of automatic body language add to the communication changes that frustrate both people with PD and their families.

11.7.9 Swallowing changes

Swallowing changes, such as delayed swallow and dysphagia, increases the risk of inhaling fluids, food or saliva. This can cause pneumonia, which is the most common PD-related cause of death. Review by a speech pathologist is recommended to assess people's risk of aspiration and to determine the appropriate level of thickened fluids or modified diet. Alternative ways of feeding, such as using a PEG tube, may be needed for adequate nutritional intake and to avoid pneumonia. However, before alternative feeding mechanisms can be used, the person needs to be educated so they can give their informed consent regarding both the procedure and the impact on their quality of life. Such choices are the essence of palliative care.

11.7.10 Saliva

Excessive saliva (sialorrhea) may be a problematic symptom of PD and is related to poor mouth closure, impaired posture and decreased swallowing frequency. This leads to drooling, which often means that the patient becomes socially isolated due to embarrassment. Treatment options are botulinum injections into the salivary glands (to decrease saliva production) and atropine eye drops used under the tongue to dry the saliva (although this can sometimes cause hallucinations). If saliva production is excessive and swallowing is impaired, the saliva can be accidently inhaled, increasing the risk of pneumonia.

11.7.11 Weight loss

Weight loss is a common phenomenon in end-stage PD and can be associated with tremors and dyskinesia (involuntary movement), causing increased energy use (Oxtoby et al 2002). Decreased food intake either due to swallowing difficulties or bradykinesia (slowed movement) will add to the potential for weight loss.

11.7.12 Constipation

Constipation can be both a common and a major problem throughout the disease process; it is also challenging. Constipation is caused by the disease process (which reduces the motility of the gut), as well as being a side effect of treatment (Doherty and Lyle 2007). Monitoring bowel function is essential for preventing bowel obstruction, which can become a medical emergency.

11.7.13 Mobility

Muscle rigidity, bradykinesia and postural instability can lead to frequent falls and eventual immobility. Also, the person with PD may sometimes become unable to move for a short time (ie freeze).

End-stage PD (stage five, according to Hoehn and Yahr 1967) means that the person is bedbound and requires full nursing care. This terminal stage has a high risk of pressure sores and aspiration pneumonia. Hoists, hospital beds and showering equipment can be borrowed through the local aged care assessment team (ACAT) or, in the case of a younger person, through the occupational therapy department of the local hospital. Accessing these services will require a GP referral.

11.7.14 Emotional support and bereavement care

Support for people living with this long-term condition and those caring for them is essential. Each case needs to be assessed individually and the needs of all concerned identified. End-of-life issues continue after the death of the person with PD, and grief counselling is of great importance for the family, given the long-term nature of the disease.

11.7.15 Resources

Parkinson’s associations throughout Australia are an excellent source of literature, contacts, and, in some cases, Parkinson’s-specific nursing expertise. They will direct the carer, both informal and formal, to appropriate sources of assistance in the relevant state or territory.

Parkinson’s Australia:
Telephone: 1800 644 189
Website: http://www.parkinsons.org.au

11.7.16 Good practice points

Older people with Parkinson's disease (PD)	
11.47	People with PD and their families are likely to benefit from the development of advance health care plans and directives.
11.48	Involving a speech pathologist and dietician in the care of the person with PD can help to ensure safe and adequate nutritional intake.
11.49	A bowel-management program is of key importance for people who have PD, because they are highly likely to experience constipation.
11.50	The safe mobility of people who have PD is likely to be improved if care workers are educated about people with PD 'freezing' (ie being unable to move for a short period) and how walking may best be assisted. Fact sheets are available on these and many other relevant topics from Parkinson's Australia at http://www.parkinsons.org.au (About Parkinson's).
11.51	Managing symptoms of dementia occurring in PD may require referral to a specialist in this area.

Further reading

NCCCC (National Collaborating Centre for Chronic Conditions) (2006). *Parkinson's Disease: National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care*, Clinical Guideline 35, National Institute of Health and Clinical Excellence (NICE), United Kingdom.

Available from the NICE website at: http://www.nice.org.uk (Search for Parkinson's disease CG35)

11.8 Experiencing dementia

Dementia is a syndrome in which cognitive ability and function decline (Access Economics 2003). In most cases, this decline is caused by progressive disease and death is the eventual outcome. The most common underlying causes of dementia in older adults are those of:

- Alzheimer's disease (AD), causing dementia of the Alzheimer's type (DAT)
- vascular disease of the brain, causing vascular dementia (VaD)
- Lewy body disease, causing Lewy body dementia (LBD).

Mixed or uncertain pathologies are frequent (Henderson and Jorm 2002).

Alzheimer's disease is believed to be responsible for 50%–70% of dementias. The trajectory is gradual and variable in length; living with DAT for from 7 to 10 years is common (Henderson and Jorm 2002). The affected brain has widened sulci, grossly enlarged ventricles, hippocampal atrophy, and neurone degeneration. Intracellular tau protein tangles and extracellular beta-amyloid plaques cause disintegration of transmission within and between nerve cells (NIH 2002).

Vascular dementia is believed to comprise 10%–30% of dementias. The disease pattern is variable but stepwise and often lasts for approximately 8–10 years. There is cerebrovascular disease with infarction or ischaemia on CT scan. Coexisting cardiovascular disease is to be expected (Henderson and Jorm 2002).

Lewy body dementia is reported to comprise 10%–15% of dementias. Lewy bodies are found in cortical and subcortical neurones, this being linked to dopamine deficiency. Some plaques and tangles are found in the brain, as is the case in AD. The disease pattern involves gradual deterioration over about four years (Henderson and Jorm 2002).

11.8.1 Diagnosis

When dementia is suspected, it is important to rule out health problems that can cause similar symptoms, such as delirium and depression (see Chapter 6). Treatable conditions, such as vitamin deficiencies, need to be considered also. The GP may refer the older adult to a specialist memory clinic for further investigation that may include computed tomography (CT) scanning as well as extensive psychological testing.

The Rural Health Education Foundation provides excellent materials that can be webstreamed in many instances. For example, it provides a program on assessment and diagnosis in dementia:

RHEF (Rural Health Education Foundation) (2003). *Dementia: Assessment and Diagnosis?* (Video Recording/DVD/webstreaming), RHEF, Canberra.

Available from the RHEF website at: http://www.rhef.com.au/

Early diagnosis is important because treatments can sometimes be useful for symptom delay or management. An early diagnosis can also empower the person to communicate their choices about care and treatment.

11.8.2 Prevalence

The prevalence of dementia is approximately (Henderson and Jorm 2002):

- 1% at the age of 65 years
- 5% at the age of 75 years
- 20% at the age of 85 years
- 40% at the age of 95 years.

11.8.3 Symptoms and trajectory

In AD, symptoms tend to appear in a particular order, although this does vary. In mild AD, symptoms are likely to include (Swan et al 2003):

- difficulties remembering recent events and where things are kept, repetition of stories and questions, and sometimes vague answers to avoid the embarrassment of appearing confused
- word-finding difficulties
- problems with orientation to time and place

- apathy and a loss of initiative
- irritability
- anxiety.

In moderate AD, additional symptoms may include (Swan et al 2003):

- difficulties with familiar tasks
- delusions or hallucinations
- behavioural changes
- growing difficulties with recognising familiar people.

In severe AD, the person is severely incapacitated and generally unable to (Swan et al 2003):

- provide self-care
- communicate in words
- walk
- maintain continence.

Eventually, swallowing will also be affected.

In VaD, memory impairments and difficulties with verbal communication are common, as are sensory motor deficits (eg gait problems, incontinence) and focal signs (eg unilateral weakness). Cognitive problems may be uneven and develop because of neurovascular 'events' (ie often in steps) (Henderson and Jorm 2002).

In LBD, there is variability in attention and alertness, visual hallucinations, and symptoms such as those occurring in PD. Falls and transient loss of consciousness are common. These individuals have severe reactions to neuroleptic medications.

11.8.4 Advance health care planning

The key to advance care planning and developing advance health care directives for people with dementia is to obtain a diagnosis and be able to 'work through' the issues associated with this while they are still able to communicate their care and treatment preferences (see also Chapter 5). Alzheimer's Australia provides useful resources, information and counselling.

The Australian Government **National Dementia Helpline**, which is operated by:

Alzheimer's Australia:
Website: http://www.alzheimers.org.au

Telephone: 1800 100 500

Dementia Behaviour Management Advisory Service:
Telephone: 1800 699 799

11.8.5 Care and support

The care and support needs of each person are unique, not only because of personality differences, but also because of the variation in symptoms and disease patterns, and the extent and nature of comorbidities. Probably the most important issue to address is how to communicate with, and recognise the needs of, the person when communication is so severely affected. Therefore, providing a palliative approach to care involves considerable skills in nonverbal communication and the ability to recognise and interpret cues. Knowledge and understanding of the person's background is also highly desirable to facilitate good care. In this way, the quality of life of the person with dementia may be improved significantly. Assessing the symptoms of common comorbid disease (eg pain from arthritis — see Chapter 6 — and depressive symptoms — see Chapter 7) can be challenging. Many psychosocial strategies are helpful (see Chapter 7). Family carers need particular support because of the often lengthy trajectory and communication difficulties (see Chapter 4).

11.8.6 Good practice points

Older people with dementia	
11.52	If an older person shows signs of early dementia, it is appropriate to support them to visit their GP for assessment to determine possible treatments and, as they are able, to address issues of advance care planning (see Chapter 5). However, advance care planning needs to be addressed sensitively and to take account of the degree to which the person understands and has come to terms with the diagnosis.
11.53	Alzheimer's Australia provides useful resources for supporting people who have dementia, their family carers, and staff and volunteers providing care. These resources include training and education, counselling, advice and support groups. In particular, Living with Memory Loss is a very successful program.
11.54	Expertise in the care and support of people with dementia is of primary importance in community aged care, given the high numbers of older adults who eventually develop dementia. Staff attendance at relevant training courses is highly recommended.
11.55	Developing a brief document showing the background and preferences of the person with dementia can help staff to provide appropriate care when an acute or respite care admission is required.
11.56	Skills in assessing and managing symptoms are of key importance for older adults who have advanced dementia. Special pain assessment tools are available (see Chapter 5).

11.9 Conclusion

Overall, it is important to provide older people with special needs or perspectives with a holistic palliative approach to care, tailored to each person. Although aspects of care are specific to each of the groups of people with special needs discussed in this chapter, the following key considerations are common to all groups:

- the care team needs to understand the older person's wishes and preferences regarding their end-of-life care

- care team members need to ignore cultural or disease stereotypes rather than making assumptions about an older person and their preferences
- advance care plans and directives are extremely helpful and, if possible, should be set up in the early stages of illness
- regular communication and a good relationship between the older person, their family, carers and the aged care team is essential
- collaboration with specialist services (eg mental health, palliative care) and information sharing can improve outcomes for the older person
- support and education for all those involved in providing care can improve outcomes for the older person, their family, carers and the whole aged care team
- accurate screening programs to identify specific conditions, and comprehensive symptom assessment and management can improve care and the quality of life for the older person.

11.10 References

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Glossary

Active education

The provision of information in conjunction with training or advice regarding how this information may be used in the provision of care.

Acute stress disorder and post-traumatic stress disorder

Recurrent reactions that follow the experience of traumatic events such as major disaster, war, sexual or physical assault, motor vehicle accidents and torture.

Advance care planning

A process whereby a person, in consultation with health care providers, family members, and important others, makes and communicates preferences and plans for their health care or treatment. The plan is based on the individual’s values, beliefs and preferences.

Advance health care directive

A written document designed to be used when an individual is unable to make or communicate their own decisions about care or treatment. The directive results from a health care planning process that must occur when the person is competent and fully understands the options open to them.

Bereavement

The reaction to loss, including healing from that loss. Healing requires working through the changes that relate to the loss until a satisfying conclusion is reached, even though the individual may never feel fully recovered. Bereavement can, therefore, be a time of personal growth. However, grief, bereavement and healing are experienced uniquely by every individual.

Carers

Family carers or informal carers, as opposed to paid care workers. Carers are usually family members but may also be friends. When the term ‘family carer’ is used in the guidelines it also includes friends. Carers’ work is based on a pre-existing relationship and is unpaid and often unrecognised. The ‘primary carer’ is the person who provides the most assistance to the person in relation to self-care, mobility, communication and household assistance. However, it is recognised that some family carers who are not the primary carer provide substantial support and sometimes care is shared to the extent that a primary carer cannot be identified.

Care workers

The term ‘care worker’ is used in these guidelines to refer to a range of nonprofessional workers in the community. Care workers are paid workers who provide direct help and care in the home; they work under the supervision of a health care professional, generally a nurse, although that supervision is often indirect (ie from a distance).

Community care

Care and support provided in an older person's home (including a retirement village setting but excluding a residential aged care facility). These guidelines address health-related community care.

Cultural broker or translator

Trusted members of the cultural group that they represent who have the ability to understand and interpret the cultural values and norms of that group.

Cultural safety

Promotion of culturally 'safe' care that is epitomised by an understanding of, and respect for, the clients' and carers' cultural perspective.

Crisis care

Intermittent access to services in the home that are rapidly available when needed because of exceptional circumstances.

End-of-life care

Care that is appropriate when a person is in their final weeks or days of life.

Evidence-based guidelines

Best practice recommendations based on a systematic review of the available evidence on the issue.

Family

The term 'family', as used in this document, means those who are closest to the older person in terms of affection (ie this can include friends as well as biological family).

Good practice points

Consensus-based recommendations developed with reference to any relevant literature, expert opinion and experience.

Guideline development group

The group responsible for guideline development. In the case of these guidelines, this was the project investigators and the project manager.

Life-limiting illness

A progressive condition that is expected to restrict the lifespan of a person. Life-limiting conditions include malignant and nonmalignant disease.

Multidisciplinary team

Teams consisting of a mix of aged care, health and social welfare disciplines. Team members share common goals, collaborate, and work independently in planning, problem solving, decision making, implementation and evaluation. Members of a multidisciplinary team can include general practitioners, medical specialists, nurses, Aboriginal health workers, care workers, dentists, optometrists, psychiatrists, psychologists, social workers, pharmacists, physiotherapists, pastoral care workers, volunteers, occupational therapists, speech therapists and others.

Nonpharmacological interventions

Treatments that do not use medications. Examples of nonpharmacological treatments include music or art therapy, psychotherapy, massage, aromatherapy and support groups.

Older adults

In this project, older adults are defined as those aged 65 years and over. However, in accordance with Australian Government policy for Aboriginal or Torres Strait Islander peoples, this document addresses the care of Australian Indigenous people aged 50 years or older.

Palliative approach to care

An approach to care that addresses the quality of life of individuals with life-limiting illness and their families. A palliative approach is also appropriate for those who are growing progressively more frail due to the ageing process. The approach facilitates the reduction of suffering through the early identification, assessment, and holistic treatment of physical, psychological, social, cultural and spiritual needs. Family needs are also addressed. A palliative approach is not only appropriate at the end-stage of an illness, but is a planned and proactive approach provided on a needs basis, sometimes over a period of years. It involves a multidisciplinary team and a coordinated approach to care. A palliative approach involves the older person and the family in decisions about care when this is both possible and desired by the respective individuals. Bereavement support for the family is also a component of a palliative approach.

Pharmacological interventions

Treatments that involve medications.

Psychosocial care and support

Care that incorporates support both of a psychological nature (eg counselling) and a social nature (eg improved social support).

Respite

A service that allows carers to take a break or holiday, devote time to other family members, attend to their own health, or do anything else that they choose; it can extend for just a few hours or for a few weeks.

Specialist palliative care team

A team of health care professionals that provides specialist care and practical support for people living with a life-limiting illness.

Surrogate outcome

Physiological or biochemical markers that can be relatively quickly and easily measured and that are taken as predictive of important clinical outcomes.

Transitional care

Care that supports the transfer of patients across levels of care or settings; for example, when discharged from hospital to home.

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
ACAT	aged care assessment team
ACPMH	Australian Centre for Posttraumatic Mental Health
ACS	American Cancer Society
AD	Alzheimer’s disease
ADL	activities of daily living
AGREE	Appraisal of Guidelines Research and Evaluation
AGS	American Geriatric Society
AIHW	Australian Institute of Health and Welfare
AHA	American Heart Association
AMDA	American Medical Directors Association
AMEP	Adult Migrant English Program
ANOVA	analysis of variance
ANZCA	Australia and New Zealand College of Anaesthesia
APA	American Psychiatric Association
APS	Australia Pain Society
ARGCM	Australian Regulatory Guidelines for Complementary Medicines
ASD	acute stress disorder
AWMA	Australia Wound Management Association
BPSD	behavioural and psychological symptoms of dementia
CALD	culturally and linguistically diverse
CAM	complementary and alternative medicines
CBT	cognitive–behavioural therapy
CG	control/comparison group
CHF	chronic heart failure
CI	confidence interval
CKD	chronic kidney disease

COPD	chronic obstructive pulmonary disease
CMSA	Case Management Society of Australia
CSANZ	Cardiac Society of Australia and New Zealand
CVA	cerebral vascular accident
CVD	cardiovascular disease
DAA	dose administration aid
DADHC	Department of Aged, Disability and Home Care
DAT	dementia of the Alzheimer's type
DoHA	Australian Government Department of Health and Ageing
ECCV	Ethnic Communities Council of Victoria
ED	emergency department
ESAS	Edmonton Symptom Assessment System
FACIT	Functional Assessment of Chronic Illness Therapy
GDG	guideline development group
GLBTI	gay, lesbian, bisexual, transsexual or intersex individuals
GOLD	Global Initiative for Chronic Obstructive Lung Disease
GP	general practitioner
GPP	good practice point
HF	heart failure
HIV/AIDS	human immunodeficiency virus/acquired immune deficiency syndrome
HR-QOL	health-related quality of life
IASP	International Association for the Study of Pain
ICSI	Institute of Clinical Systems Improvement
IG	intervention group
LOS	length of stay
JBI	Joanna Briggs Institute
IG	intervention group
KICA	Kimberley Indigenous Cognitive Assessment

LBD	Lewy body dementia
MND	motor neurone disease
MQLS	McMaster Quality of Life Scale
MQOL	McGill Quality of Life Questionnaire
MRI	magnetic resonance imaging
MWE	mean weighted effect
n/a	not applicable
NCCAC	National Collaborating Centre for Acute Care
NCCAM	National Centre for Complementary and Alternative Medicine
NCCC	National Centre for Cultural Competence
NCCCC	National Collaborating Centre for Chronic Conditions
NCCMH	National Collaborating Centre for Mental Health
NCCN	National Cancer Comprehensive Network
NCC-NSC	National Collaborating Centre for Nursing and Support Care
nCG	number in the control/comparison group
NCPTSD	National Centre for Post-traumatic Stress Disorder
NGC	National Guideline Clearinghouse
NH	nursing home
NHFA	National Heart Foundation of Australia
NHMRC	National Health and Medical Research Council
NICE	National Institute for Health and Clinical Excellence
nIG	number in the intervention group
NK-cell	natural killer cell
NS	not statistically significant
NYHA	New York Heart Association
OATSIH	Office for Aboriginal and Torres Strait Islander Health
OMH	Office of Mental Health
ONS	oral nutritional supplement

OR	odds ratio
PACE	Program of All-inclusive Care for the Elderly
PD	Parkinson’s disease
PEG	percutaneous endoscopic gastrostomy
PMG	Pain Management Guide
PRISMA	Program of Research to Integrate Services for the Maintenance of Autonomy
PTSD	post-traumatic stress disorder
QOL	quality of life
QUM	quality use of medicines
R	outcomes directly relevant to patients or their carers (not surrogate outcomes)
RACF	residential aged care facility
RADAR	Rational Assessment of Drugs and Research
RANZCP	Royal Australian and New Zealand College of Psychiatrists
RCN	Royal College of Nursing
RCP	Royal College of Physicians
RCT	randomised controlled trial
RHEF	Rural Health Education Foundation
RNAO	Registered Nurses Association of Ontario
RR	relative risk
RUDAS	Rowland Universal Dementia Assessment Scale
sd	standard deviation
SIGN	Scottish Intercollegiate Guidelines Network
SMH	Singapore Ministry of Health
SR	systematic review
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
SWB	spiritual well-being
SWB Scale	Spiritual Well-Being Scale
TAIS	Therapeutic Advice and Information Service

TF	tube feeding
TIS	Translation and Interpreting Service
UK	United Kingdom
USA	United States of America
VA	Veterans’ Affairs
VaD	vascular dementia
WACHPR	Western Australian Centre for Health Promotion Research
WHO	World Health Organization

Useful links for community health care professionals

Aged Care Information	1800 200 422
Aged and Community Services Australia Inc	http://www.agedcare.org.au
Aged Care Association Australia	http://www.agedcareassociation.com.au
Aged Care Australia (contact details for home and community care service providers and relevant government departments in each state and territory)	http://www.agedcareaustralia.gov.au
Aged Care Complaints Investigation Scheme	1800 550 552
Aged Rights Advocacy Service	1800 700 600 http://www.agedrights.asn.au
Australian Association of Gerontology	http://www.aag.asn.au
Australian and New Zealand Society for Geriatric Medicine	http://www.anzsgm.org
Australian Government Department of Health and Ageing	1800 020 103 http://www.health.gov.au
Australian Government Department of Veterans' Affairs	13 32 54 (or 1800 555 254 country callers) http://www.dva.gov.au
Cancer Australia — Cancer Council helpline	131120 http://www.cancer.org.au
CareSearch	http://www.caresearch.com.au To find services in your state > Finding services> State resources
Centre for Cultural Diversity in Ageing	http://www.culturaldiversity.com.au
Centrelink	Financial assistance for carers: 13 27 17 Multilingual information: 13 12 02
Continence Aids Payment Scheme	1800 330 066 (National Continence Helpline)
Council on the Ageing	http://www.cota.org.au
Dementia Behaviour Management Advisory Service	1800 699 799
Disability Advocacy and Information Service	http://www.dais.org.au
Lifeline	13 11 14

Medicines Line	1300 888 763
MND Australia (Motor Neurone Disease Australia)	1800 777 175 http://www.mndaust.asn.au
National Aboriginal Community Controlled Health Organisations	http://www.naccho.org.au
National Aged Care Advocacy Line	1800 700 600
National Carer Counselling Program (operated by Carers Australia)	1800 242 636 http://www.carersaustralia.com.au
National Continence Helpline	1800 330 066
National Dementia Helpline	1800 100 500 http://www.alzheimers.org.au
Palliative Care Australia	1800 660 055 http://www.pallcare.org.au
Parkinson’s Australia	1800 644 189 http://parkinsons.org.au
Pharmaceutical Benefits Scheme Information Line	1800 020 613
Retirement and Aged Care in Australia	http://www.ageing.com.au
Stroke Foundation	Stroke information line: 1800 787 653 http://www.strokefoundation.com.au
Translating and Interpreting Service (TIS)	13 14 50
Veterans’ Affairs Networks	1300 551 918 http://www.dva.gov.au
Volunteering Australia	http://www.volunteeringaustralia.org