



# Planning for Palliative Dementia Care

## Resource Guide

© ACH Group 2009

This resource guide was developed by the Dementia Learning and Development Unit, ACH Group.

The project was undertaken by Lenore de la Perrelle, Manager Dementia Learning and Development Unit, ACH Group, and Sandra Obst and Anne Heard, Project Officers.

The project was funded by the Australian Government, Department of Health and Ageing – Local Palliative Care Grants Program Funding Round Four.

This project has been informed by the ‘Better Palliative Care for People with Dementia Project’ (Round One), and responds to three of the recommendations:

1. To review and develop a consistent approach in the use of validated best practice care planning tools
2. To develop strategies that promote family carers being influential in service delivery
3. To explore a variety of ways to support identified palliative dementia training and development needs of staff and volunteers on palliative dementia care.

An extensive literature review of Australian and international literature on palliative dementia care and advance care planning was undertaken by Penny Roe.

The Project has developed and implemented a Planning for Palliative Dementia Care Resource Kit, including:

- Planning Ahead – an information guide for people with dementia and their families (including Advance Care Directives)
- Planning for Palliative Dementia Care Resource Guide to inform and support coordinators, Registered Nurses and care workers
- Annual Training Program for ACH Group Palliative Dementia Care Champions.

© 2009 ACH Group      ISBN 978-0-9806199-0-4

All rights reserved. Except under the conditions described in the Copyright Act 1968 of Australia and subsequent amendments, no part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior permission of the copyright owner.

Whilst every effort has been made to ensure the accuracy of this guide, the authors cannot accept or assume any responsibility or legal liability for its use, including liability for negligence, for errors or oversights in the information provided.

Many of the areas covered are such that while there are generally recognised theories and practices about a topic, the theories are evolving and we have endeavoured to cover the consequent changes.

This material is general in nature and gives an overview of palliative care for people with dementia and will not provide ALL the information needed on this topic or the carers role.

Independent professional advice should be sought about specific issues.

Produced and Printed in South Australia.

# Contents

Acknowledgements	5
Welcome	6
Target Group	7
Using this Resource	8
Continuum	9
About the Continuum	10
Palliative Approach	13
What is the palliative approach?	
Why include people with dementia?	
When should palliative care be initiated?	
Assessment	21
Why assessment is important	
4 key assessment tools	
Symptoms of end of life	
<i>Symptom Checklist: End of Life Care</i>	
Symptom Control	31
Treating pain is essential	
When to treat infections	
Skin and mouth care	
When eating and drinking becomes difficult	
Could it be delirium?	
Frequently asked questions about medications	
Future Planning and support for the family	41
Raising sensitive issues	
The 5 Advance Directives you need to know about	
How can you support people with dementia and their families?	
<i>Advance Directives, South Australia - A Summary</i>	
Team work	49
You can't do it alone	
Communication with the person with dementia	
The impact of different values and beliefs	
Taking care of yourself	
The ethical approach to interventions	
Supportive relationships with specialist palliative care services and others	57
When should specialist services be involved?	
What can specialist services offer?	
How best to work together with specialist services	

Grief Support	61
What is ambiguous loss?	
Symptoms of grief	
What you can do to help	
Glossary of Terms	63
Reference List	66
Appendices	68
Appendix 1 – Coordinators and Nurses Care Pathway for Supporting a Person with Dementia	69
Appendix 2 – Care Workers Care Pathway for Supporting a Person with Dementia	70
Appendix 3 – Coordinators and Nurses Care Pathway for Supporting a Person with Advanced Dementia	71
Appendix 4 – Care Workers Care Pathway for Supporting a Person with Advanced Dementia	72
Appendix 5 – End of Life Care Pathway for a Person with Dementia who is Actively Dying	73
Appendix 6 – Abbey Pain Scale	74
Appendix 7 – Use of the Abbey Pain Scale	75
Appendix 8 – Australia - Modified Karnofsky Performance Scale	76
Appendix 9 – SNAP Phases of Palliation	77
Appendix 10 – Gold Standards of Palliative Care	78
Appendix 11 – Dementia – Changes in the ability to live independently	79
Appendix 12 – Advance Directives, South Australia - A Summary	80
Resource List	81



# Acknowledgements

The Palliative Dementia Care Project Reference Group, consisting of representatives from partner organisations, was actively involved in the development of this Resource Guide and provided feedback and direction throughout the project.

Acknowledgement and thanks go to the members of the Reference Group.

Marie Alford	Alzheimer's Australia SA
Cathy Bennett	RDNS
Dr Michael Briffa	Central and Eastern Adelaide Palliative Care Service
Kirsty Delguste	Adelaide North East Division of General Practice
Kevin Hardy	RDNS
Peter Jenkin	RDNS
Rosie Ranford	Family Carer
Robyn Rouvray	The Palliative Care Council of SA
David Webb	Carer Support and Respite Centre
Catherine Wohling	Adelaide North East Division of General Practice
Pauleen Bond	ACH Group, Team Manager, Dementia Services West
Tracy Bryant	ACH Group, Clinical Nurse, In Home Care East
Lisa Hickson	ACH Group, Coordinator /RN, In Home Care West
Anne Higginson	ACH Group, Regional Manager, In Home Care North

Professor Jennifer Abbey, Dementia Collaborative Research Centre, Queensland University of Technology and Sue Jarrad, Dementia Services Consultant, acted as consultants to the project providing advice and feedback.

In addition, the project consulted with people with dementia, their families and carers and ACH Group Staff. Consultation mechanisms included both focus groups and individual interviews.

# Welcome

This Planning for Palliative Dementia Care Resource Guide will guide in the planning for palliative care for people with dementia and their families. It will:

- assist new and existing community care coordinators and nurses in planning a palliative approach with people with dementia and their families, with a particular focus on supporting people to remain living at home throughout their life
- assist care workers as they provide the ongoing support for people with dementia and their families
- promote consistent practice between members of the care team and across the organisation
- promote and enhance communication between the care team and specialist palliative care services, as they work together to support the person with dementia and their family.

Documents that could assist you as you use this resource include:

- A Guide to Palliative Care Service Development, Palliative Care Australia, 2005
- Better Practice Framework – Palliative Care for People with Dementia, ACH Group, 2006
- Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, Department of Health and Ageing, 2008
- Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7, 2006
- Palliative Dementia Care and Advance Care Planning – a Literature Review, ACH Group, 2008
- Planning Ahead – an information guide for people with dementia and their families, ACH Group, 2009
- Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, Department of Health and Ageing, RDNS and partners
- Standards for Providing Quality Palliative Care for All Australians, Palliative Care Australia, 2005



# Target Group

This resource kit is for:

- coordinators, nurses and care workers to support people with dementia and their families to remain living at home throughout their life
- informing coordinators and nurses in their role of providing supervision and information to care workers who support people with dementia and their families
- managers and team coordinators, or others, who have direct responsibility for supervising coordinators and nurses and who are currently working within a community care setting.

In this resource guide, the term nurses includes Registered Nurses (RNs) and Enrolled Nurses (ENs) working in the community in specialist roles, as well as those working in residential aged care facilities.

# Using This Resource

This resource guide describes the process of supporting a person with dementia from the time they commence receiving services from the program through to end of life, as a continuum.

The continuum is progressive through four stages from:

- *Admission to the Service*
- *Transitional Points*
- *Health Deterioration to*
- *End of Life*

These are shown as the horizontal continuum.

The continuum is also progressive in the:

- depth of knowledge
- care provided
- relationships
- communication

These are portrayed in the vertical columns.

Together, these describe the:

- emotional and physical support to be provided to the person with dementia and their family

*Anyone central to the support network of the person is regarded as 'family', regardless of whether or not they are related; it is the bond of affection that is important. Therefore the family carer may be either a friend or a family member - Department of Health and Ageing 2006*

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 87)

- assessment and clinical care required to meet changing needs
- support, information and education required for the staff team as they support the person with dementia and their family
- links and relationships with other services, including the General Practitioner (GP) and specialist palliative care services
- care in the dying phase
- importance of effective communication at all times between all parties.

The materials are available in this booklet, or electronically on the ACH intranet and on the CD attached to this resource, and both are colour coded.

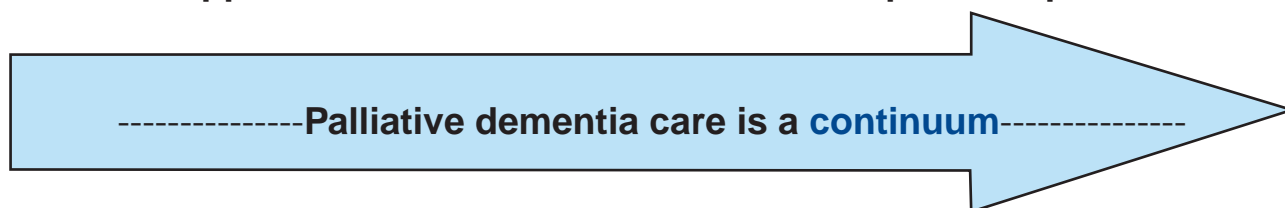
Throughout the guide, there are references to resources. In the electronic version these resources are hyperlinked. Web addresses are also listed for references.

The guide can be used sequentially, starting at the beginning and working through to the end, or staff may choose to select a specific module or section, as relevant to their needs.



# Continuum

Palliative approach ..... Specialist palliative care



	Admission to Service	Transitional Points	Health Deterioration	End of Life
Palliative approach	Palliative approach Planning to optimise quality of life	Palliative approach Supporting adjustment to change Promoting health and independence	Palliative approach Responding to health changes and spiritual needs	Palliative approach Not losing sight of the person with dementia still being a person with individual needs, desires and life preferences
Assessment	Assessment Needs, symptoms, preferences and other issues that are important to the person	Assessment Observing and identifying needs and changes to needs	Assessment Observing and responding to changing needs	Assessment Actively dying, signs of death
Symptom control	Symptom control for maximising life	Symptom control for quality of life	Symptom control for comfort	Symptom control to achieve a dignified death
Future planning	Future planning Information to make informed choices and decisions	Future planning Supporting the person and family to respond to changes	Future planning Support and information for family to continue caring role, if this is what they choose	Future planning Supporting the family
Team work	Team work Clarification of roles and boundaries	Team work Knowledge and skills	Team work Inform and support	Team work Flexible care for end of life
Supportive relationships	Supportive relationships with specialist palliative care services	Supportive relationships Consultation, advice and support	Supportive relationships Referral when needs become complex	Supportive relationships Review of care
Grief Support	Grief support Preparation	Grief support Anticipating changes	Grief support Ongoing losses	Grief support Post bereavement

## About the Continuum

The great majority of people who live with a life limiting illness such as dementia, spend most of their time not in treatment centres or in hospitals, but at home with their family and friends. As few as 10% of people over the age of 65 years in Australia live in a residential aged care facility. A significant proportion of older people with dementia live at home with support of family, friends and aged care providers.

The role of the primary care provider is key in promoting good lives and good endings for people with dementia. In this resource, the primary care provider is the aged care provider. At times the person may also be assisted by other providers, including GPs, hospital based doctors, nurses, allied health staff and staff of residential aged care facilities. To ensure that the needs of people with a life limiting illness such as dementia are appropriately met, primary care providers need to have established and supportive relationships with specialist palliative care services.

(A Guide to Palliative Care Service Development, 2005, p 29)

**The focus of the continuum** is on supporting people with dementia and their family, and the staff who provide care through community packages. The continuum focuses on the emotional and physical needs, clinical care needs, teamwork, what helps a team to function well, and other services that are available for support.

The aim is to provide high quality care for people with dementia throughout life.

The continuum is progressive, that is, through the four stages from *Admission to the Service*, *Transitional Points*, *Health Deterioration* through to *End of Life*.

This is portrayed in the horizontal continuum.

The continuum is also progressive in the depth of knowledge, ongoing assessment of needs, the required care and support to meet these needs, relationships and communication. This is portrayed in the vertical columns.

Together, these describe the:

- emotional and physical support to be provided to the person with dementia and the family
- assessment and clinical care required to meet changing needs
- support, information and education required for the staff team as they support the person with dementia and their family
- links and relationships with other services, including the General Practitioner (GP) and specialist palliative care services
- care in the dying phase
- importance of effective communication at all times and between all parties.



**Wider application of this model.** This resource is placed in the context of best practice models such as Gold Standards for Palliative Care, (Gold Standards Framework) evidence-based best practice (Evidence-based Best Practice in Community Care) and Planning Services Around the Individual (PSAI) (Delivering PSAI People in Partnerships).

It is essential that community care for people with dementia incorporates the best practice principles of:

- emphasis on capacity building or restorative care to maintain or promote a person's capacity to live as independently as possible. The overall aim is to maintain functional independence, quality of life and social participation
- an emphasis on a holistic, 'person-centred' approach to care that promotes the person's wellness and active participation in the decisions about care
- an attempt to provide more timely, flexible and targeted services that are capable of maximising the person's independence.

(Evidence-Based Best Practice in Community Care, 2008, p 6)

**Information and other supports.** Before the person with dementia starts using aged care services, they and their family may have received information and support from others. This may include the identification of symptoms which have led to the diagnosis of dementia, consulting with medical practitioners, accessing information and community supports such as through Alzheimer's Australia SA, and assessment by the Aged Care Assessment Team. Some people will have also made changes and adjustments to their lifestyle and home environment to assist them to manage their changing condition.

**Crisis often prompts a referral to services.** A crisis time in a person's life can be an opportunity to move to a new way of doing things. After a crisis or trauma, people often just get on with coping with the crisis and their current needs and don't look beyond the immediate situation. It is at this time that they need someone to stand by them, to provide information and support that will help them to not only address the immediate issues but also to think about what they would like to happen in the future.

#### **Practice Tip**

Some questions for the person and their family to ask:

- How could we do this differently?
- Might there be another way of doing this that will make it easier?
- Who could assist with some of the basic tasks to relieve you of some of the load?

Crisis and change can equal an opportunity. A crisis can be a catalyst to move to a new partnership which may be the start of a new way of doing things.

### **Practice Tip**

Be alert to changing needs. In palliative dementia care staff may notice the changes which a person with dementia may not always describe. This requires good observation and planned responses, effective communication and coordination of services, e.g. 'let's try doing it this way ...'

### **Care Pathways for Coordinators, Nurses and Care Workers**

Three Care Pathways have been developed to help coordinators, nurses and care workers focus on:

- the key requirements for supporting a person with dementia and their family
- the roles of the coordinator, nurse and care workers in supporting the person with dementia and their family, and
- the needs of the person with dementia and the needs of their family carer.

The pathways describe:

Support for a person with dementia:

- **Coordinators and Nurses Care Pathway for Supporting a Person with Dementia**
- **Care Workers Care Pathway for Supporting a Person with Dementia**

Support for a person with advanced dementia:

- **Coordinators and Nurses Care Pathway for Supporting a Person with Advanced Dementia**
- **Care Workers Care Pathway for Supporting a Person with Advanced Dementia**

End of life support:

- **End of Life Care Pathway for a Person with Dementia who is Actively Dying**





## Palliative Approach

In this section:

- What is the palliative approach?
- Why include people with dementia?
- When should palliative care be initiated?

### Admission to services Transition points

#### *What is the palliative approach?*

A palliative approach aims to promote quality of life for older adults who have a life limiting illness, or who are becoming progressively more frail during old age, without attempting to either lengthen or shorten life. This approach acknowledges that end of life is drawing near, although it may be many months, or even several years, away. The approach also recognises that a range of symptoms may need to be addressed to promote overall comfort during life and around the time of death.

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 1)

A palliative approach to dementia care is particularly relevant because it involves supporting both the older person and their family. 'It is steeped in the philosophy of holistic, compassionate care – physical, emotional and spiritual – to relieve pain and discomfort of advanced disease and invites the person and family to participate in making decisions about future care needs and where it is best delivered.

(Better Practice Framework – Palliative Care for People with Dementia, 2006, p 14)

#### **Practice Tip**

Support and care needs to relate to the whole person and not just the illness.  
Get to know the person and their family

**Palliative dementia care actively treats distressing symptoms**, for the best possible quality of life for the person facing dementia, and their family, knowing that the underlying cause cannot be cured.

Palliative Care (World Health Organisation 2006):

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of care
- offers a support system to help the family cope during the illness and in their bereavement.

## *PSAI (Planning Services Around the Individual)*

In the 1980's PSAI was developed by the ACH Group, in keeping with the values of the organisation, to provide a systematic approach for staff in planning service delivery with older people. PSAI is based on the philosophy of Social Role Valorisation (SRV) and the Strengths Based Approach.

The Principles of PSAI are based on the person centred approach, individualised needs and focusing on the person's strengths and culture. It is about working in partnership with people and focuses on supporting them to retain their roles and continue to be a contributing member of society.

(Delivering PSAI People in Partnerships)

PSAI continues to guide the way that ACH Group works with people, and at commencement of employment, all new staff undertake training in the ACH Group Values approach.

## *Enabling people to have a voice*

Developing relationship-centred connections acknowledges that care giving is a partnership based on working together and respecting choices, and values people's inter-dependence on others. The person with dementia and their family need to be supported to have a voice in planning and reviewing their care. Dementia affects many people directly and indirectly - the person with dementia, their family and the professional carers. Relationship-centred practice needs to be inclusive of the person with dementia, the family and health and social professionals. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 8)

## *Partnering with people in decision making*

The time to establish a partnering relationship is at the assessment. This is the time for coordinators to ask questions and gather information that will assist them to:

- understand the individuality of each person, where they're at and where they're coming from. Take as good a psycho/social history as you can as a starting point and build on that profile as you go along
- get an understanding of the family and community and social dynamics that impact on who the person is
- understand the language and communication that the person uses. These are dependent on the person's schooling and education, life and work experience, and their cultural, social and linguistic background
- take into consideration other health factors.

### **Practice Tip**

For focus and prompts refer to the:

**Coordinators and Nurses Care Pathway for Supporting a Person with Dementia**

**Care Workers Care Pathway for Supporting a Person with Dementia**



## Cultural attitudes and beliefs

Within the context of a palliative approach, it is especially important for service providers to understand different cultural attitudes and beliefs. Understanding that the words Death and Dying are taboo for many cultures creates immediate difficulties in discussing palliative care.



Within cultural groups there can be variations in beliefs and practices including those related to illness, death and bereavement. To be able to provide an individualised approach to care, staff need to have relevant cultural knowledge and sensitivity when discussing and planning end of life care for people with dementia from non-Australian cultural backgrounds.

### Practice Tip

Information on a range of cultural practices can be found in the *Multicultural Palliative Care Guidelines*. A copy is contained in the Planning for Palliative Dementia Care Resource Kit

## Promoting health, independence, planning for living

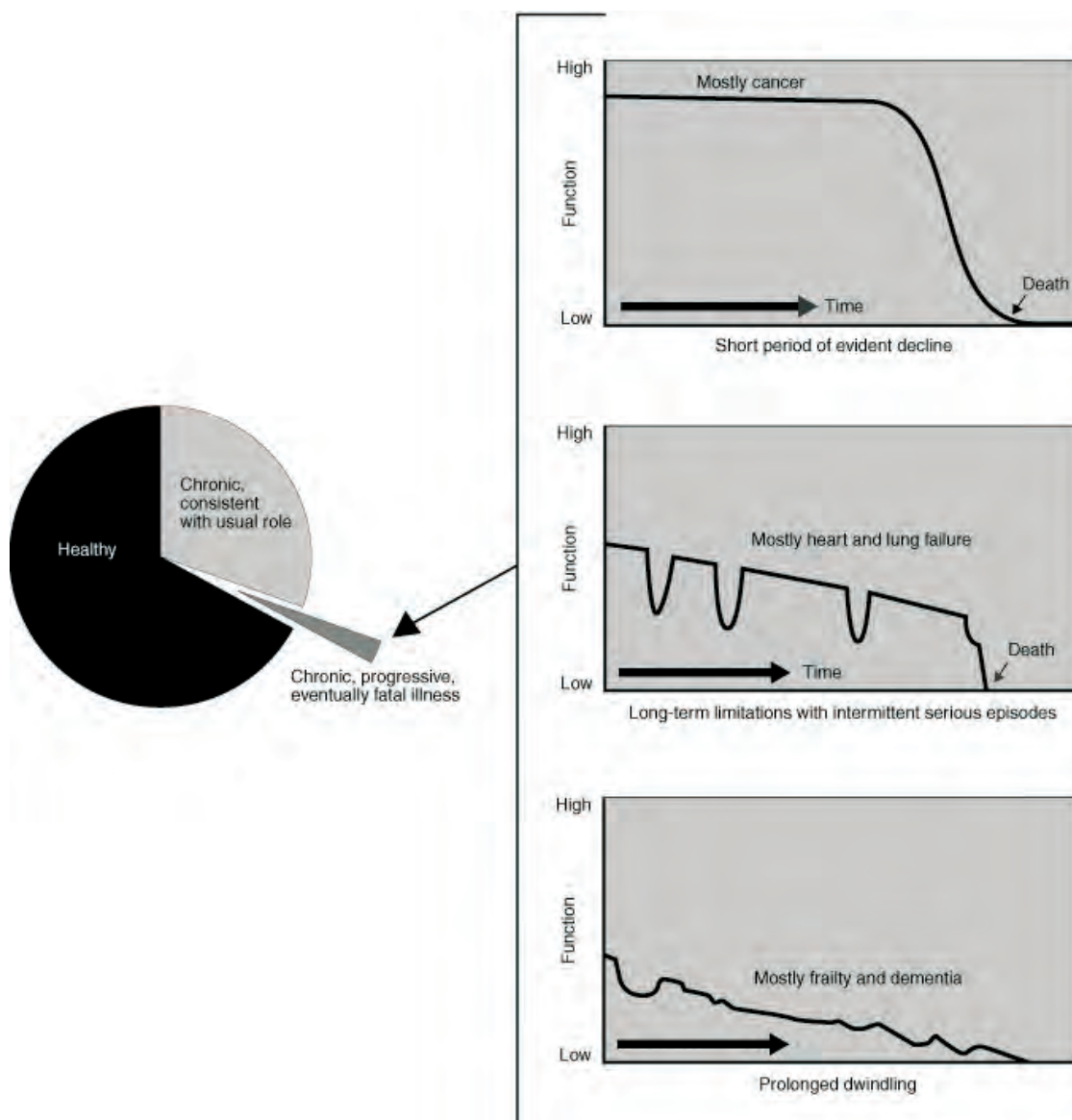
At this time the person with dementia and their family are facing a number of losses and an unknown future. Some of the challenges they face include loss of health, physical and social independence, loss of autonomy in decision making, the fear of changed relationships.

While working with the reality of the person's diagnosis, it is important that the coordinator also uses this time to assist people to plan for living, health and independence by providing advice, information and access to support.

*An understanding of the three main trajectories (courses of illness) is helpful to inform your discussions and decision making at this time:*

- *the trajectory for cancer often results in a clear change in health status in the last weeks of life. People with a diagnosis of cancer have a more predictable course and can still undertake many activities of daily living until quite late in the process of the disease*
- *In organ failure, i.e. heart failure, obstructive lung disease and cirrhosis, the trajectory tends to be of a gentle decline punctuated by exacerbations. People with these disabilities may live with them for a long time with occasional acute events that trigger fears of death but recover and then may die suddenly with little warning after a rapid deterioration*
- *In advanced dementia there tends to be a very gentle decline over a long period of time, with the person becoming increasingly dependent as they slowly decline. Knowing exactly when death will occur is difficult. When a palliative approach to care is implemented early in care, the health status of the person with dementia can be clarified and support can be provided accordingly.*

Those living with dementia may need supportive care over many years during which time they may also receive diagnosis and treatment for other conditions or co-morbidities. People who have dementia may also have other chronic life-threatening conditions, which need to be considered at the same time as the impact of dementia on their health and wellbeing.



*Figure 1: Chronic illness in the elderly typically follows one of the three trajectories*  
(Living Well at the End of Life, 2003, p 8)

These trajectories are useful to illustrate the potential scenarios for individuals. However, each individual's illness will be experienced differently and cannot be predicted with certainty. A palliative approach to care is appropriate when:

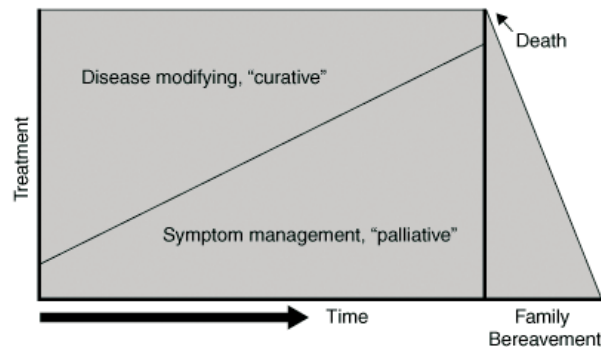
- symptoms are troublesome, particularly complex symptoms or symptoms that are difficult to assess and manage such as dementia
- there is a need for psychosocial and emotional support during a deteriorating trajectory, and/or
- there is a need for family support during that deteriorating trajectory or after the person has died (bereavement support).

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 3 and 4)



## When should palliative care be initiated?

The model of palliative care involvement over the course of a life-threatening condition suggests that palliative care should increase as death approaches.



**Figure 3:** Model of palliative care involvement over the course of the illness (Lynn & Adamson 2003)

Broadly, the **palliative approach** is appropriate from the time of diagnosis of a life-limiting condition and throughout the journey until death. It is used to improve the quality of life of people with a life-threatening condition, and families. Philosophically, it is aligned with relationship-centred care and quality dementia care and is best activated when an individual is identified as living with dementia. The palliative approach promotes advance care planning while the individual still has mental capacity to be involved in making decisions for the future.

**Specialised palliative services** are short-term and multidisciplinary in nature. Interventions are often carried out in response to a crisis event or emergency situation. Accessing specialised palliative services does not replace the palliative approach to care but complements it. The specialist will provide information and advice on complex issues like ethical dilemmas, complex family dynamics and psychological and spiritual distress and pain management strategies. People with end-stage dementia may or may not need the services of a specialist palliative care service but those with co-morbidities may benefit if specific focused interventions are required. Staff also benefit from the expert advice and consultation with specialists.

**End of life care** is activated when the individual is identified as actively dying. Predicting when someone will actually die is fraught with uncertainty as some individuals recover when they were not expected to and others die unexpectedly. None-the-less, there are signs that indicate when someone is actively dying which staff should recognise and help prepare the family. End of life care may benefit from specialist palliative care services. (Better Practice Framework – Palliative Care for people with Dementia, 2006, p 17)

A palliative approach is complemented and supported by a good working relationship between the primary care provider (aged care provider) and the specialist palliative services.

### Practice Tip

Distinguishing between the 3 forms of palliative care helps to clarify the stage of the condition, who should be involved and the overall goals of care

## Health Deterioration

### End of Life

#### *Spiritual care and emotional support around loss, bereavement and transitions*

#### *Remaining strengths*

#### *Life review*

Spirituality can mean more than religion or church. It can relate to anything that gives meaning or peace to a person's life.

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. Spiritual care begins with having an understanding of the person's spirituality and supporting them in the life practices that are important to them. This requires an appreciation of the client as a person defined by their past roles and relationships, hopes and dreams, inner creativity, and how they find meaning in life. If a person identifies with religious beliefs, understanding of these beliefs will provide a basis for spiritual care. (Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 307)

Facing old age, increasing illness or disability and the end of life can bring about multiple losses and challenges. Near the end of life people may have numerous spiritual needs, such as a need to:

- complete life tasks
- share experiences with families
- resolve feelings
- make practical preparations
- make peace with God.

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 309)

However, in later stage dementia, as people lose communication, they may not be able to express their feelings and concerns.

*People with dementia still 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 often understand, respond to, and 'speak' this language more clearly than those more dependent upon verbal language.* (Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 312)

#### **Practice Tip**

It is important when supporting older people with dementia for all staff to ensure that they respect people's spiritual and religious needs, and understand that their own beliefs may impact on their professional practice



**Some steps to assist staff to identify and address the spiritual and religious care needs of people with dementia include:**

- ensuring that spirituality is included in the assessment, planning and delivery of care. This will enhance the person's quality of care and is likely to impact on the well being of the person and their family. This conversation can be included when discussing [advance care planning](#)
- maintaining hope. At the end of the journey with dementia, sustaining hope for relief from pain and symptoms, a peaceful death, and being with family and friends may be supportive
- having an understanding of the person's core religious beliefs and practices will help to ensure that care is congruent with, and respectful of their beliefs
- the inclusion of chaplains / pastoral care workers / spiritual advisors and, where appropriate, traditional healers, as part of the care team can aid in the delivery of flexible, adaptable, spiritual care for the older person and their family
- facilitating worship, rituals, customs, relationships, and life review may help to alleviate spiritual distress and may even promote the finding of meaning in suffering
- 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
- recognising that medication does not fix emotional or spiritual pain is important. Perhaps the person's distress is allowing them to work through spiritual pain and should not be stopped by medication. (Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 314)

**Practice Tip**

Ways of exploring a statement like "I just want to die"

- "What makes you say that today?"
- "It sounds like it is hard for you today"
- "I would like to sit with you and sing your favourite song once more"

Be prepared to talk it through with the person and not just try to cheer them up

For further reading refer to the [Reference List](#) at the end of this document.





## Assessment

In this section:

- Why assessment is important
- [4 key assessment tools](#)
- [Symptoms of end of life](#)

### Admission to Service

#### *Why assessment is important*

Assessment is the beginning of a relationship. It is the time to draw the most comprehensive picture of this new person as you can. It is like doing a jigsaw puzzle where the pieces are the information you need to collect that will give you an understanding of the person, their family, community, preferences and needs – the whole picture.

Planning Services Around the Individual (PSAI) is the broad approach, the key for keeping the person as the focus while assessing their needs. Together, PSAI and the palliative approach address the holistic care needs of the older person with dementia and provide support for their family. This approach:

- aims to enhance quality of life during the period of declining health, from assessment through to the dying period
- focuses on the person's needs as well as their health needs
- is an ongoing process of negotiation between the service provider, the person and their family
- identifies and implements safeguards while acknowledging and utilising the individual's strengths.

While there are multiple pages of documentation to gather and complete at assessment, the process of assessment:

- may be more conversational than just a tick box and may take place over a number of visits. You will need to gather a lot of information about the person, such as their life style, preferences, and needs by listening to the person tell their story
- focuses on the needs of the person
- focuses on the needs of the carer. Following a newly diagnosed condition, or progression of a condition, the carer's needs may also be new or constantly changing. Refer to [Supporting Families](#) page 46
- is about observing and responding to change
- requires coordinators to make judgements at times in order to identify gaps and risks e.g. issues around housekeeping and safety.

#### **Practice Tip**

To assist the person with dementia to participate in the conversation sit on the side of the person where they have good hearing so that they can hear you, or make sure that they don't sit where they have glare in their eyes, turn off the radio or TV so that they can focus better, check for eye contact

## Transitional Points Health Deterioration

Regular and ongoing assessment is essential to match the care provided with identified needs, as symptoms for people with a life limiting illness can change frequently and rapidly. Specific assessment tools are needed to assess the changing health needs of a person with dementia as they may not be able to tell you what is changing. These tools assist to understand the impact of dementia and may be more observational than conversation.

The three trajectories (described in the Palliative Approach section) describe the fragility and likely declining health progression for older people with dementia.

This progression requires that assessment does not only take place at the commencement of the service, but is continual and ongoing throughout the time that support is provided, until death.

### Key assessment tools

Coordinators, nurses and care workers need to be aware of changes happening to the person around:

- activities of daily living
- functional status
- distressing symptoms
- quality of life
- worsening and newly developing symptoms so that they can meet the comfort needs of the person.

Refer to the section Team Work on page 50 for information on *A person in the advanced stage of dementia*.

Ongoing comprehensive assessment helps coordinators and nurses to anticipate future needs of the person and to know when to advocate for additional services like specialist palliative care services or respite care. Addressing the person's spiritual, cultural, emotional and social needs is fundamental to understanding what the person may need in order to die with dignity. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 25)

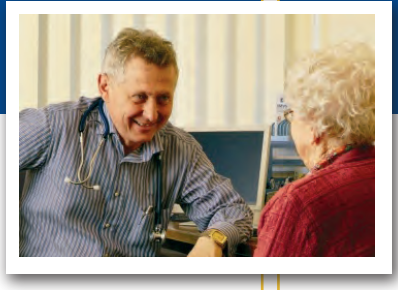
#### Practice Tip

The terminology and language in assessment tools can assist care workers to use the same language as the nurse and GP when making reports or writing in progress notes. The use of appropriate terminology is important for accurate and responsive reporting

#### Practice Tip

For focus and prompts refer to the:

- **Coordinators and Nurses Care Pathway for Supporting a Person with Advanced Dementia**
- **Care Workers Care Pathway for Supporting a Person with Advanced Dementia**



**Best practice assessment / observation tools** to assist staff include:

- [Australia-modified Karnofsky Performance Scale](#)
- [SNAP Phases of Palliation](#)
- [Abbey Pain Scale](#)
- [Use of the Abbey Pain Scale](#)
- [Dementia – Changes in the ability to live independently](#) (University of Western Sydney) – while this is not a formal assessment tool, it helps in the understanding of the stages of dementia, the person's remaining abilities and the decline of independence.

Copies of these tools are in the [Appendix](#) and can be photocopied for use.

## End of Life

### *Symptoms at end of life*

To prepare for end of life and to plan ahead, a family conference is the ideal process for discussing the situation with the person, family members, GP, and other relevant service providers. It's an opportunity for the family to ask questions and understand what might happen in the future and for care staff to clarify the goals of care with everyone present. The person with dementia may not be able to participate towards the end of life. A family conference is especially helpful if there are conflicting expectations within a family. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 26)

Through the Enhanced Primary Care (EPC) program the Australian government makes provision for GPs and other health professionals to provide more preventative care for older Australians and improve the coordination of care for people with chronic conditions and complex care needs. The program provides a framework for a multidisciplinary approach to health, including Multidisciplinary Case Conferencing and Health Assessments for which GPs and other health professionals are paid through Medicare.

A Multidisciplinary Case Conference is a meeting or discussion at which the older person's GP and at least two other health and community care providers discuss the person's care needs and look for ways to better coordinate the services that the person will be receiving. Case conferences are for people with a chronic medical condition and complex care needs, requiring care from a multidisciplinary team.

The Older Person's Health Assessment is to inform the GP of risk factors and hazards which older people face whereby they may require further health management. In addition to assessing the person's health status, a health assessment is used to identify a broad range of factors that influence the person's physical function, psychological function and social function.

For more information, visit the Department of Health and Ageing website [www.health.gov.au](http://www.health.gov.au)



The family are often unprepared for the impending death and can be upset if they are not warned in advance, even when it is obvious to the health care team that there is little time left. Care staff need to ensure that close relatives are informed that time is short so they can say their final goodbyes which can in turn ease some of the burden of grief. On the other hand, predicting when someone has little time left is extremely difficult – people can survive days when they are not expected to, or can die unexpectedly especially when co-morbidities like end-stage organ failure exist.

*Much of the emotional and spiritual support a dying person needs can best be given by the family. The family in turn needs support to continue caring at this difficult time and to know that their contribution is vital.*

(Better Practice Framework – Palliative Care for People with Dementia, 2006, p 18)

Optimal end of life care is difficult to define because individuals view it differently. For the person at the end stage of advanced disease it is dependent on the individual's cultural and spiritual beliefs, values and assumptions about life.

However there are some commonly agreed factors that are necessary for optimal end of life care. These include:

- knowing when death may happen and knowing what to expect
- having the individual's wishes respected and honoured
- retaining dignity
- good pain management and relief for distressing symptoms
- having a choice as to where death occurs
- having access to information and quality care
- having access to spiritual and cultural support
- having access to specialist palliative care, if needed
- planning care in advance of advanced illness
- not having life prolonged inappropriately
- knowing what to do and say in the last few weeks, days, hours.

(Better Practice Framework – Palliative Care for People with Dementia, 2006, p 18)

### **Practice Tip**

For focus and prompts refer to the:

- **End of Life Care Pathway for a Person with Dementia who is Actively Dying**

The following *Symptom Checklist for End of Life Care* has interventions suitable for family members, coordinators, care workers and others to use.



## Symptom checklist: End of Life care

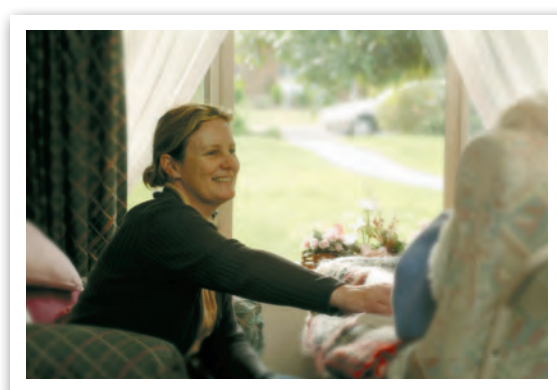
The interventions suggested here are suitable for coordinators, care workers, family carers and volunteers.

Symptom	Monitor and observe	Interventions
<b>Pain</b>	<ul style="list-style-type: none"> <li>✧ The site of pain</li> <li>✧ Duration – new or existing</li> <li>✧ Type of pain – descriptive words</li> <li>✧ Score severity (use appropriate assessment tools)</li> <li>✧ What makes it better or worse?</li> <li>✧ Associated signs and symptoms, including non-verbal signs of increased restlessness, agitation and facial grimaces</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report pain, site, duration, type and severity to GP or nurse for further assessment and follow up</li> <li>◆ Tell key people when medications are administered and when interventions are best provided, e.g. start activities of daily living (ADLs) 20 mins after pain medication is given</li> <li>◆ Offer massage, heat pack, bolster pillow or change of position</li> <li>◆ Offer the possibility of alternative therapies like massage and aromatherapy</li> </ul>
<b>Nausea and / or vomiting</b>	<ul style="list-style-type: none"> <li>✧ Any underlying causes, e.g. infection, pain, medication like morphine, constipation</li> <li>✧ What makes it better or worse?</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report possible causes to GP or nurse for further assessment and follow up</li> <li>◆ Feedback information to GP or nurse on what works or doesn't work</li> <li>◆ Offer a cool moist face washer to neck / face, and have a bowl close by if needed</li> <li>◆ Offer to lay the person slightly upright if tolerated</li> <li>◆ Offer fizzy drinks like soda or lemonade to be sipped</li> <li>◆ Offer some fresh air and reduce odours that cause distress</li> </ul>
<b>Constipation</b>	<ul style="list-style-type: none"> <li>✧ Assess what is normal for the individual</li> <li>✧ What is different now?</li> <li>✧ Medication like morphine can cause constipation</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report abnormal bowel actions to GP or nurse for further assessment and follow up</li> <li>◆ Encourage the individual to take prescribed bowel medications regularly and drink adequate fluids as tolerated</li> <li>◆ Support normal routines and offer additional hot drinks, dried fruit and mild exercise as tolerated</li> </ul>

Symptom	Monitor and observe	Interventions
<b>Dry mouth and dehydration</b>	<ul style="list-style-type: none"> <li>✧ Common when someone is actively dying</li> <li>✧ Check the state of the mouth daily</li> <li>✧ What makes it better or worse?</li> <li>✧ Signs of oral thrush</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report pain or mouth soreness to the GP or nurse</li> <li>◆ Offer mouth care every 1-2 hours as directed by GP or nurse</li> <li>◆ Offer sips of cool water or ice chips to moisten mouth as tolerated</li> <li>◆ Use soft toothbrush as tolerated</li> <li>◆ Remove dentures and soak overnight if preferred</li> <li>◆ Apply lip balm to dry lips as required</li> </ul>
<b>Agitation and restlessness</b>	<ul style="list-style-type: none"> <li>✧ Common in advanced disease</li> <li>✧ What makes it better or worse? e.g. pain, noise, being rushed</li> <li>✧ Signs of delirium</li> <li>✧ Signs of increased confusion</li> <li>✧ Signs of actively dying</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report increased incidence of symptoms to GP or nurse for review</li> <li>◆ Keep them safe from hurting themselves, e.g. falling, by sitting with them and offer reassurance</li> <li>◆ Offer relaxation techniques, e.g. massage, aromatherapy, music, therapeutic touch</li> </ul>
<b>Lethargy and weakness</b>	<ul style="list-style-type: none"> <li>✧ Common in advanced disease</li> <li>✧ Monitor the level of ability to attend to personal care regularly (use appropriate assessment tools)</li> <li>✧ Common when someone is actively dying</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report any changes to the GP or nurse</li> <li>◆ Offer support and assistance with personal care routine, e.g. showering, hair care, shaving, make-up, nail care, dressing according to personal preferences</li> <li>◆ Offer a bed bath if showering is not tolerated</li> </ul>
<b>Loss of appetite</b>	<ul style="list-style-type: none"> <li>✧ Common when someone is actively dying</li> <li>✧ Difficulty swallowing safely – monitor for choking</li> <li>✧ Signs of weight loss</li> <li>✧ Signs of pressure area soreness or redness</li> <li>✧ Signs of dry mouth</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report any changes to the GP or nurse</li> <li>◆ Offer small portions of preferred foods, e.g. ice cream, chocolate mousse – may need to modify diet by adding cream or supplements</li> <li>◆ Offer a straw with fluids as tolerated, do not force</li> <li>◆ If possible assist them to sit up</li> <li>◆ Maintain a warm environment</li> </ul>

Symptom	Monitor and observe	Interventions
<b>Reddened area on skin or sore areas</b>	<ul style="list-style-type: none"> <li>✧ Common in advanced disease when the individual is bed or chair bound</li> <li>✧ Check skin integrity daily – on back, ears, heels, elbows</li> <li>✧ Review need for continence aids regularly</li> <li>✧ As death approaches the blood circulation slows and arms and legs become cool and may look mottled or dark – there is no need for extra blankets</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report any changes in skin integrity or continence to the GP or nurse</li> <li>◆ Provide regular repositioning - as death approaches frequent turning may not be needed</li> <li>◆ Provide gentle massage but not if an area is infected or inflamed</li> <li>◆ Use scented oils, creams and lotions (as preferred) to dry skin and sore areas</li> <li>◆ Change the bed linen as much as tolerated to help the individual feel fresh</li> </ul>
<b>Breathlessness</b>	<ul style="list-style-type: none"> <li>✧ Common when someone is actively dying</li> <li>✧ There will be changes in the breathing pattern as death approaches, from gaps of several seconds to several minutes</li> <li>✧ Some individuals become distressed when they can't breathe easily</li> </ul>	<ul style="list-style-type: none"> <li>◆ Report any changes in the breathing pattern or level of distress to the GP or nurse</li> <li>◆ Provide gentle bed baths instead of a shower</li> <li>◆ Offer to raise the head of the bed if tolerated</li> </ul>

**Source:** Jo Boylan, 2006.



## **Actively dying**

At the time when a person is actively dying, palliative dementia care is designed to reduce panic and provide comfort and support for the person with dementia and their family. This time can be both distressing and peaceful for those present. For some it's a time when family and extended family members and friends can gather in the home and celebrate the achievements and strengths of the life they are witnessing. It may be a time for grandchildren and great grandchildren to be present, for pets to be near and stories to be told.

It's also a time for sadness, a time for quiet reflection on the person's life.

Some families prefer to do this reflection by themselves and others prefer company – it's respectful to ask the family what they need.

It can be a special time – when time seems to stand still because it is limited and therefore precious. People who are dying are aware that others are present.

They can hear what's being said even if they can't respond. They may want to be hugged, kissed, and touched.

Some deaths are unexpected and sudden, even though the person has lived with a life-threatening condition for many years, and some are slow. Families may panic at the thought of not managing this stage of life and will benefit from having 24 hour contact numbers for the coordinator, GP, nurse or palliative care service. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 19)

## **Indicators of when the person is actively dying**

Some or all of these indicators may be present immediately before death regardless of the cause:

- peripheral shutdown and cyanosis – purplish discolouration in extremities
- changes in breathing pattern e.g. 'Cheyne-Stokes' breathing
- drowsiness or unresponsiveness – no response to verbal and/or physical stimuli
- uncharacteristic or recent restlessness and agitation – delirium may develop in end stage dementia
- retained secretions in upper airway (death rattle)
- changes in cardiac output e.g. tachycardia or hypotension
- decreased mobility e.g. becoming bed bound
- decreased ability to swallow safely.

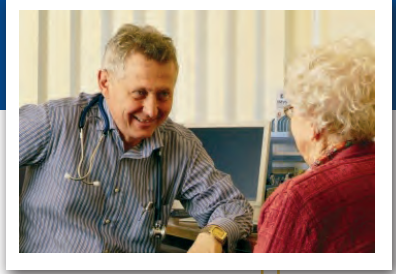
(Better Practice Framework – Palliative Care for People with Dementia, 2006, p 19)

## Signs of death

The following list is a guide to the common signs of death:

- there is an absence of a 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
- the jaw may fall open.

(Better Practice Framework – Palliative Care for People with Dementia, 2006, p 19)



## Death

If the care worker is present when the person has died, or arrives at the home shortly after, they need to inform the coordinator that the person has died.

If the family is present, they may wish to spend some time with the person and there may be no urgency to contact the GP or funeral director. Others may prefer for this to be done straight away. This is a time to be sensitive to family preferences and cultures.

At some point the GP will need to be informed of the death as a GP needs to verify death before the funeral director can remove the body. The funeral director will need to be advised when the family will be ready for the body to be removed from the home.

Coordinators and care workers can do some simple and practical things at this time which may be helpful for everyone, such as making a cup of tea for those present or making phone calls as required.

It is important that care staff care for themselves and find someone to share their grief with. When staff have been caring for someone for a long period of time, it is only natural that they will be upset, but the family have their own grief and cannot be expected to comfort staff. Seek a colleague, coordinator or friend to share your sadness with. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 67)

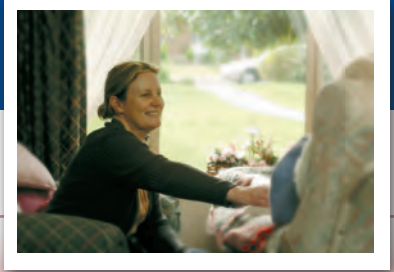
### Practice Tip

Staff across all levels of care can become overwhelmed by the experience and may need additional support to put it into perspective

Care workers who have established a meaningful relationship with the person with dementia will experience loss after the death and may benefit greatly from support from fellow workers. It's important to create a working environment where care workers can access support and stress management strategies as needed. Attending the funeral may assist

For further reading refer to the [Reference List](#) at the end of this document.





## Symptom Control

In this section:

- Treating pain is essential
- When to treat infections
- [Skin and mouth care](#)
- [When eating and drinking becomes difficult](#)
- Could it be delirium?
- [Frequently asked questions about medications](#)

### Admission to Service Transitional Points

The palliative approach to symptom control is to maximise quality of life and comfort. It acknowledges that the condition is not curable, but good treatment is needed to support the person with the condition. Symptoms are dynamic, therefore regular review is essential.

Symptom management principles include:

- evaluation:
  - using assessment and scoring tools
  - exploring the characteristics of the symptoms including intensity, location, quality and frequency
- communication:
  - explain to all involved
  - explore the impact and preferences
- individualised treatment plan
- monitoring of progress and review.

### Pain

Pain is not part of the normal ageing process, and not everyone who is dying experiences pain. However, the inability to verbally communicate pain does not mean that the person is not experiencing pain. Pain in older people is often under-reported, under-recognised and under-treated, and people with dementia are prescribed and administered less pain relief than other older people. We need to address this.

Difficulties for good pain management for older people with dementia include:

- problems in recognising pain
- the belief that if people don't report pain or complain about it that they either have no pain or have a high pain threshold
- the use of agency staff who don't know the person well, or at all
- the older person:
  - losing the verbal skills to describe pain
  - losing the sense of understanding of their body
  - no longer being able to describe the type of pain e.g. 'toothache'
- untreated pain may be misdiagnosed as challenging behaviour and treated with sedation rather than analgesia.

Strategies for staff in assessing, reporting and managing pain include:

- every day and at every visit, observe and assess the person – using your knowledge and understanding of the person, watch for the non verbal signs and expressions of pain (refer to the [Abbey Pain Scale](#) and the [Symptom checklist: End of life care](#))
- inform the nurse / GP when concerns or changes are noticed
- don't focus on the dementia at the risk of overlooking other conditions and symptoms
- have a good knowledge of the existence of pain and the types of pain experienced by older people
- be familiar with good assessment tools
- be aware of the potential problems of PRN (to be taken as required). When the person with dementia has lost the ability to recognise, describe and report their pain, PRN, as a front line approach in pain management, can be a set-up for failure as the person will not be able to ask for pain relief when they need it
- be familiar with non-pharmacological pain interventions.

### Practice Tip

Regular four hourly treatment of pain can reduce what appears to be challenging behaviour

## Types of pain

Types of pain can be classified as:

- acute:
  - of rapid onset and short duration sudden and severe
  - usually responds quickly to treatment
  - is a warning signal
- chronic:
  - of long duration
  - ongoing and persistent
  - requiring continuous treatment
  - does not warn that something is wrong, but reminds us that something is wrong
- incident pain:
  - experienced during a specific activity, especially movement
  - can be expected
- breakthrough:
  - pain that occurs between regular pain relief

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 175)

*The consequences of pain that is inadequately treated, is the affect on the psychosocial and physical status of the person, including function, mood and quality of life.* (Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 176)



## Assessment of Pain

An accurate diagnosis of pain is very difficult when the person cannot tell you when, where, why or how much they are hurting. A change in the person's behaviour, which may indicate pain, is often noticed by family and friends. The intimate knowledge of the person with dementia, that families can provide, is valuable in assisting service providers in the difficult task of distinguishing between physical pain and other causes for distress.

*Some of the main observable indicators of pain are:*

- *facial expression e.g. grimacing*
- *body language e.g. restlessness, agitation, guarding a part of the body, rocking, muscle tenseness*
- *change in vital signs such as increase in pulse rate, breathing rate, blood pressure and sweating*
- *repetitive noises or inconsolable moaning.*

(Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7, 2006, p 9)

### Practice Tip

Any change in the person's usual behaviour may indicate pain and should be investigated. Don't rely on the person telling you and don't rely on the carer or family telling you about the pain as maybe "Mum has always complained of being in pain"

*The Abbey Pain Scale* is an instrument for measurement of pain in people with dementia who cannot verbalise and is one of the most commonly recognised and used tools. A copy of the [Abbey Pain Scale](#) and [Use of the Abbey Pain Scale](#) is in the Appendix and can be photocopied for use by coordinators, care workers and nurses.

## Health Deterioration End of Life

### Non-drug Treatments for Pain

There are a number of measures that can be safely used to provide comfort from pain that do not require the taking of medication. Always check with the RN or coordinator before using these.

### Changing Position

As the person's condition deteriorates they may become too weak to turn themselves over, or they may sleep very soundly in the one position for long periods of time. Gently changing a person's position and giving their aching muscles a gentle rub may be all they need to alleviate their discomfort.

### *Massage*

While not all have had training in massage, gently rubbing a person's limbs and back with a lotion can give a lot of comfort. Sometimes the benefit is that it detracts from the initial source of pain. At other times the benefit may simply be touch and kindness. If you have time, and the person thinks massage might help it may be just as effective as offering analgesia. Be mindful of sensitive areas e.g. arthritic joints, and do not massage broken or reddened skin.

### *Heat Packs*

Heat packs not only alleviate pain at the site they also provide comfort and warmth. Ensure the pack is covered and not too hot. You must adhere to the organisation's policy on the use of heat packs.

### *Relaxation*

Pain can be alleviated without the use of medication, by assisting people to relax through the use of music, a hot towel sponge or listening and talking. Touch is relaxing and is an essential requirement of human existence. Giving someone a back rub, foot or hand massage provides much comfort.

### *Meaningful Engagement*

An opportunity to do something, to accomplish a task or to look at photos, flowers or favourite things, pat a pet, smell familiar odours, and taste favourite foods may provide much needed relief from a focus on discomfort and confusion.

(Montessori-Based Activities for People with Dementia, Vol 1)

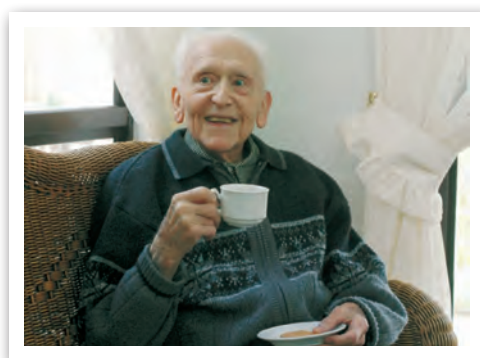
### *Splinting*

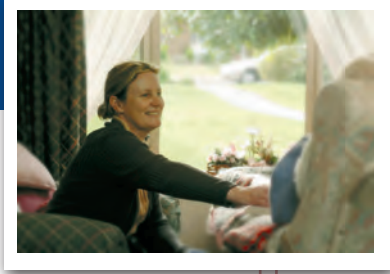
In the case of pain in areas that can be immobilised, e.g. limbs, splinting can be an effective way of preventing pain.

### *Information*

When a person does not understand what is happening, or why they are experiencing pain, their anxiety and concern can increase their pain. Ensure that those you are caring for understand what is happening to them and if you are unable to tell them find someone who can.

The key to appropriate and effective management of pain is in knowing about and understanding the pain. Care workers play a key role by accurate monitoring and reporting. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 48 to 50)





## *Infections*

As the dementia progresses and mobility declines, the person may stay in a bed or chair for most of the day. Being less mobile they may become more at risk of infections, particularly of the urinary tract (bladder and kidneys) and lungs (pneumonia / bronchitis). A person in the final stages of dementia may have a number of these infections during the last year or so of life. Antibiotics can be given for these infections and an improvement in well being may be achieved.

At the end of life, decisions need to be made about the balance between the difficulty in administering medications, the difficulty for the person in the taking of medications and the likely benefit of these medications. (Dementia information for carers, families and friends of people with severe and end stage dementia, p 21).

## *Skin*

As a person moves closer to the end of life, the lack of nutrition and hydration and increasing immobility places the skin at risk of breaking down and decubitus ulcers (bed sores) forming. Skin marking is a sign of this as the skin and tissue becomes very red when a person has been in the one position for a period of time. As people get near to death the skin marks more quickly. Regular changes in position may prevent this, but there are times when a person experiences pain, becomes restless or resists changes in position and at these times other measures may need to be put in place so that the person doesn't have to be disturbed too much. The use of aids to assist might also prevent skin breakdown. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 60)

## *Mouth care*

Good mouth care assists people to feel more comfortable and is essential when people have a terminal illness and are dying. Eating and drinking lubricates the mouth by producing saliva which assists to keep the mouth clean and moist. When a person is nearing death, they begin to lose interest in food and have difficulty maintaining enough fluid intake to keep their mouths moist.

### **Practice Tip**

A dry mouth is common and a source of great discomfort. A sip of water or crushed ice can be soothing. When a person begins to have difficulty drinking from a glass or cup, it can be easier and safer for them to suck on a moistened mouth swab. Keeping lips moist with lip balm can add to their comfort

*The following questions may help care workers in observing the person for mouth pain and discomfort, which needs to be reported to the coordinator or nurse:*

- *is the tongue a nice pink colour?*
- *is the tongue moist?*
- *can you see plaque (white spots) on the tongue or the walls of the mouth?*
- *are there any signs of lesions or ulcers?*
- *does the person have their own teeth?*
- *if they have dentures do they fit properly?*
- *has the person told you that their mouth is sore?*
- *is the person reluctant to eat and chew?* (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 56)

### ***Diet, appetite and hydration***

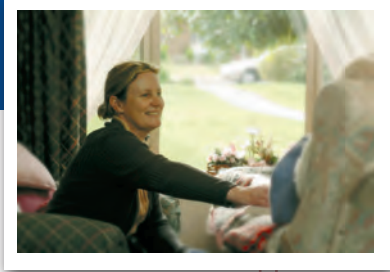
Eating and drinking can be a pleasure throughout life, but people with dementia may lose the initiative to seek food and drink. The person may also experience difficulties with swallowing in the final stages. They may seem to be choking when they eat, or cough a lot after eating, and if this happens they need to be assessed by a Speech Pathologist. They may have a condition known as dysphagia. This is when food and fluids go down the wrong passage and may enter the lungs and cause aspiration pneumonia. A person with swallowing difficulties may need to have their food mashed or pureed, and all fluids thickened.

#### **Practice Tip**

The following are some prompts that may encourage appetite:

- offer very small serves of food five or six times a day
- present the food so that it looks appetising and is clearly recognised
- offer moist food or food of soft consistency
- make nutritious drinks as people sometimes prefer a milkshake or egg flip
- ensure that the person can reach the fluids and that it is in a container they can drink from
- eating with others can encourage and stimulate the person to want to participate in eating. Create an atmosphere of it feeling 'like it's a treat'

Sometimes certain foods or drinks are given to assist with certain conditions, for e.g. prune juice may be prescribed to assist with constipation. Remember that the person with dementia may not remember to drink this, and it will need to be given to them and they will need to be encouraged to drink it.



While it is useful to have strategies to encourage appetite, the reality is that people who are dying simply may not want to eat. In the terminal phase their body will not be able to use food to create energy or get well again. When they are not using up energy they often just don't want to eat. We need to respect this and attempt to help the family to come to terms with this as some families feel strongly about encouraging the person to eat. A conversation with the Speech Pathologist may help families to better understand this situation.

*Whether or not dehydration needs to be treated should be carefully considered. The nurse / GP should make this decision after consideration of the person's overall condition and discussion with the family. If a person still has weeks or months to live, clearly increasing their fluid intake is desirable. However if the person is dying the value of fluids needs to be questioned.* (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 55)

### **Behavioural symptoms**

People living with dementia may experience some of the following:

- delusions or ideas which are not based on reality but which are thought to be true by the person with dementia
- hallucinations – seeing, hearing, feeling, tasting or smelling something that doesn't really exist
- being agitated or anxious and distressed, and seeking reassurance from other people
- wandering aimlessly or pacing up and down
- being intrusive, going into places where they are not invited
- being sexually disinhibited, having inappropriate sexual behaviour
- appearing to be depressed, apathetic and withdrawn, such as having no energy, emotions or interest in what is happening around them
- being aggressive or violent
- not allowing others to look after them.

Behaviours are a form of communication for the person with dementia, and need to be monitored and responded to so that the person is comfortable. Those who know the person with dementia best, such as family, friends and health providers who visit regularly are in the best position to be able to work out the cause of the behaviour, as they know what the person was like before the behaviour started.

Confusion is the term often used to describe one or more of these behaviours. In addition to the dementia, other causes of confusion in the terminally ill include pain, constipation, a urinary tract infection, or general failing of the body's systems. Confusion is also a symptom of delirium and needs to be assessed and treated appropriately. Clear and accurate reporting of the confusion will give the nurse / GP good information which will help with treating the condition.

(Dementia information for carers, families and friends of people with severe and end stage dementia, p 17)

Near the end of life confusion can be difficult to treat. At this time it is important to deal sensitively and thoughtfully with both the person and their family and friends. If the person becomes unsafe because of their confusion report this immediately to someone who can assist. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 64)

### Practice Tip

Information on delirium can be found in the brochure *Delirium* included in the Planning for Palliative Dementia Care Resource Kit, or in the *Clinical Practice Guidelines for the Management of Delirium in Older People*.

### Principles of Care

- spend time explaining what is happening, in simple sentences. Even if the person can't understand your words your calm tone will be reassuring
- tell the person what day it is and what the time is – perhaps have a clock and calendar in the room
- do not argue - it is better to acknowledge that the person may be frightened by the delusions and hallucinations
- ask them to show you what is happening as there may be a cause for their hallucination which can be resolved
- avoid confrontation, either distract their attention or suggest an alternative activity. Distractions which may help include music, exercise, activities, conversations with friends and looking at old photos
- avoid changing the person's environment, keep it consistent
- make sure the person is comfortable
- increase lighting in the home and use night lights
- try to maintain consistent caregivers and a consistent routine
- do not take accusations personally and be aware that the person is not able to control this behaviour
- always check for physical causes of symptoms which can be treated to reduce pain, distress or confusion.

(Dementia Information Resource Kit, Sheet 5.9)





## Weakness and Fatigue

Weakness and fatigue is frequently experienced by those who are dying. It can come and go, with some days being better than others.

*While food and fluids continue to be offered and encouragement to participate in living occurs, on the days when a person feels tired and lethargic offer the opportunity to rest. Encourage activity and involvement on the days they are feeling a little stronger. While the person is the most affected by the weakness, often the most concerned are the family, who desire their relative to participate in normal activity. Sometimes families think that the weakness is because the person is not eating well. However, even if people eat they can experience weakness and fatigue. Older people and the families need reassurance that this is not uncommon and they need to allow the person to rest on the days they feel fatigued and do things on the days they feel more active. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 59)*

## Medication

Medications may be needed to treat and/or prevent symptoms associated with problems such as pain, nausea and vomiting, depression, shortness of breath, or for the treatment of co-morbidities.

Medications make a significant contribution to the prevention and treatment of symptoms, but they also have the potential to cause harm. The physical comfort of people who are near the end of life requires thorough assessment to ensure the choosing of suitable medicines, careful prescribing, excellent nursing care and ensuring that medicines are used safely and effectively.

*The core principle behind good pharmacological intervention is to use analgesics regularly, not just as required. The lowest dose possible that provides pain-free comfort should be prescribed and administered. (Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7, p 10)*

The classes of medication most commonly used in palliative care are:

- analgesics (to treat pain). Analgesics come in various forms – tablets, syrups, suppositories, injections or skin patches. Strong analgesics (opiates or narcotics) can have side effects such as constipation, nausea and vomiting, hallucinations, delirium and agitation, which can be distressing for the person and their family. At the same time, they may be the best drugs to provide pain relief and comfort
- antiemetics (to treat and also to prevent nausea and vomiting)
- laxatives (to prevent and treat constipation)
- adjuvant analgesics (medications that work with analgesics to improve pain control)
- corticosteroids (that may reduce a range of symptoms related to inflammation)
- antidepressants (to treat depression, or sometimes pain) and other neuroleptic medications (to treat depression, anxiety, or delirium) and sedatives. (Care Search Palliative Care Knowledge Network, Palliative Medications)

In a palliative approach to treatment, giving medications should be as simple and non-traumatic as possible. To continue medications for a person who can no longer swallow, a common alternative route of administration is subcutaneous (given under the skin), which is generally the least invasive and the most reliable route. Some medications are only available by oral route, so at the time when a person can no longer take oral preparations, some other medication may need to be substituted.

### *Frequently asked questions*

*Will I become addicted to morphine?*

No. When morphine, or opioid medications are used to treat pain in the setting of advanced illness, addiction does not occur. Addiction only occurs when morphine or other opioid drugs are abused and used when there is no pain present.

*How can I reduce the number of medications my relative has to have?*

The number of medications that older people with dementia are asked to take can, in itself, become a burden. It is important to occasionally review the overall goals of care and ask if each medication is helping to achieve these goals. For example, in providing a palliative approach to treatment, medications would be given that contribute to comfort for the person, and consideration would be given to stopping medications that are not helping this.

The question should be asked 'Are all the medications helping to achieve comfort?' If the answer is 'No', then some medications may be able to be stopped. Consult with the GP or a Specialist Palliative Care Team to review medications.

*Affordability is a concern – how can I reduce the cost of medicines?*

Many medications are subsidised by the Commonwealth Government under the Pharmaceutical Benefits Scheme (PBS). This scheme helps keep the cost of medications down. When people require larger than usual doses or medicines that are not subsidised, expenses for medicines can increase.

Speak to your doctor about which medicines are required and if any can be stopped. Your doctor may also be able to prescribe larger quantities on one prescription to further reduce expenses. Your pharmacist may also be able to suggest ways to save money on medicines.

For further reading refer to the [Reference List](#) at the end of this document.





## Future planning and support for the family

In this section:

- Raising sensitive issues
- [The 5 Advance Directives you need to know about](#)
- [How can you support people with dementia and their families?](#)

### Admission to Service

The focus of future planning in this resource is for staff. Information for older people with dementia and families is provided in the *Planning Ahead – an information guide for people with dementia and their families* booklet. (2009)

#### Practice Tip

The *Planning Ahead – an information guide for people with dementia and their families* booklet is to be provided to the older person and their family at the time of assessment, as a resource of information and contact details to help them as they plan for the future, to review what they have already done and what they could still do

### Strategies for Coordinators

*The Coordinator's role is one of anticipating what issues may arise, planning what needs to be done, and reviewing the impact of the journey on the person, family and the care team, including care workers. It's about balancing the needs of the person with dementia and the needs of the family and knowing when to advocate and when to stand back until invited in. This time of life, when a person is actively living and trying to make sense of their life, is precious. There is no need to fear this time as long as people work through the issues as they arise, and are open to finding ways that support the person to live well and as they wish.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 24)

A diagnosis of dementia can create fear and uncertainty about the future for the person with dementia as well as their family. As difficult as it is to raise sensitive issues about the future management of finances, care and medical treatment, it is important to have conversations about future planning early on while the person still has the capacity to express their wishes.

A person with early dementia may still be legally capable of making financial, personal and lifestyle decisions and expressing and recording their wishes. As dementia progresses the person's ability to do this decreases. For this reason it is best to organise for Advance Directives to be completed as soon as possible after the diagnosis. The person needs to be able to understand both the nature and intention of the documents and the consequences of their decisions. If the person's decision making capacity is in question, it can be formally assessed by a GP or specialist.

These conversations about future wishes can include:

- where they want to live and with whom
- food and clothing preferences
- recreational activities and holidays
- who they would like to have contact with
- choice of doctor and dentist
- beliefs about quality of life
- spiritual or religious preferences
- end of life care and treatment

Professional service providers, including coordinators, don't always feel comfortable asking people to think about making decisions as to how they would like things to be organised at the end of life.

The fundamental principle in future planning is about respecting people's choices. To help set this in place and encourage a right relationship between program staff and older people and families, it is not for staff to do the planning for them or with them, but to ensure that they have the information and that they get help and assistance from the right sources to do their planning.

#### **Practice Tip**

Coordinators are encouraged to read the *Planning Ahead – an information guide for people with dementia and their families*. It will answer your questions and give you confidence when talking with people with dementia and their families

### **Advance Directives**

Advance Directives are legal documents which record people's future plans and wishes should they be unable to make their own decisions in the future. They allow people to:

- state their wishes about a variety of lifestyle, medical, financial and legal matters, and/or
- appoint people they trust to make decisions on their behalf.

There are 5 legally recognised Advance Directives in South Australia:

- Financial decisions – Enduring Power of Attorney\* and a Will\*
- Lifestyle and Medical decisions – Enduring Power of Guardianship\*
- Medical decisions only – Medical Power of Attorney and Anticipatory Direction (previously known as a Living Will)

Some of these cover the same areas of decision-making responsibilities – they do not all need to be completed. People are advised to seek advice from a solicitor about which would best suit their needs.

#### **Practice Tip**

The Advance Directives marked with a \* cover all needed areas and are recommended for all adults



Advance Directives are made with the knowledge that individual circumstances will change through the course of the illness and, in the case of medical decisions there may be advances in medical treatment options. For these reasons it is advisable to review Advance Directives regularly.

Talking with the person with dementia and their family about these matters is an ongoing process about their goals, values, preferences, life style, health care needs and treatment options – a relationship in which people are given permission to think about these things and then talk about them when ready.

Sometimes people can't see beyond the actual task. It may be helpful to describe this process as similar to having a will. At death, where there is no will in place, the government is bound to identify who has control of the deceased person's financial affairs. Similarly, the Guardianship Board may be asked to appoint someone to manage the decisions of a person who has lost capacity and has not expressed their wishes or given anyone authority to make decisions on their behalf. Where there is family conflict about the management of a person's affairs, the Guardianship Board can also be called on to review the situation and appoint a guardian. The guardian may be a family member or someone unknown to the person.

### Practice Tip

A question to ask at this time:

*'How can we fulfil your wishes if we don't know what they are?'*

Encourage the person to write down their wishes

*For people with dementia, discussions about future care and treatment early in the context of the disease and approached with extreme sensitivity, have the potential to empower the older person.* (Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 168)

There are different types of planning to be done. The person's GP may talk with them about making Advance Directives about medical care and treatment. In this resource, our focus and interest is on the person's wellbeing. Advance Directives allow the person to state their wishes as to how they want to live their life including the end of their life. These wishes may be recorded in an Enduring Power of Guardianship which is for nominating a person who can state these wishes when the person no longer has the capacity to do so.

Timing is important; when and how to raise these issues. There may be disagreement or conflict between what the person and/or their family consider to be good care and in the best interests of the person. This is an appropriate time for coordinators to discuss future planning with families.

### Practice Tip

Keep in mind at all times that your role is not to do the planning for the person but to assist them to get it done

Ensure that you and your staff have a good understanding of advance care planning so that you feel confident when talking with people about these issues

## **Strategies for Care Workers**

Care workers often develop deep relationships with the person with dementia and the family. They have the key role of providing hands-on care, ensuring a palliative approach to care and also providing palliative care as directed by the GP or nurse.

Care workers see the person with dementia often enough to notice changes in their condition.

Any change in functional ability, especially if the person seems to be physically deteriorating, needs to be reported to the coordinator. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 26)

### **Practice Tip**

If the person with dementia or their family talks about future needs with the care worker, the care worker can arrange for them to talk with the coordinator. The care worker should encourage the person and their family to complete Advance Directives or write down their wishes



## ADVANCE DIRECTIVES for South Australia – A SUMMARY

### Financial decisions

#### Enduring Power of Attorney

- allows you to appoint one or more people to make decisions about financial, property and related legal matters only
- you can give those you appoint the power to act alone or together in making decisions
- is effective from the time you choose and remains effective when you are no longer able to make decisions for yourself
- needs to be lodged with the Land Titles Office if there is to be sale of property

#### Will

- gives specific instructions about how you would like your assets to be distributed after you die
- you can also record any special funeral arrangements you may want
- must be followed by the person you appoint to be executor

### Lifestyle and Medical decisions

#### Enduring Power of Guardianship

- allows you to appoint one or more people to make decisions about lifestyle and medical treatments only
- you can give those you appoint the power to act alone or together in making decisions
- you can express personal preferences, such as where you would wish to live, services you will have, your medical treatment and care
- is effective from the time you are no longer able to make decisions for yourself

### Medical decisions only

#### Medical Power of Attorney

- allows you to appoint one or more people (medical agents) to make decisions about your possible future medical treatment and care
- your medical agent cannot be a health professional responsible for your care

#### Anticipatory Direction

- allows you to legally record the kind of medical care and treatment you want or do not want towards the end of your life
- does not involve the appointment of another person to make decisions but provides direction for those responsible for providing your health and medical care. (e.g. GP, Enduring Guardian, Medical Agent)
- can be registered with the Australian Medic Alert Foundation and copies given to family members and your GP
- cannot be used as a means of requesting someone to actively or deliberately end your life.

## Transitional Points

### Health Deterioration

### End of Life

### *Supporting families*

A palliative approach to care involves supporting both the person and their family.

*Without family or a carer, many people with a life limiting illness would not be able to continue living at home for as long as they do. Anyone central to the support network of the person is regarded as 'family', regardless of whether or not they are related; it is the bond of affection that is important. Therefore the family carer may be either a friend or a family member.*  
Department of Health and Ageing 2006

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 87)

The person with dementia and their family have both separate and common needs, and both of these needs need to be considered.

*It has been found that up to three quarters of primary carers for terminally ill patients have chronic health problems themselves.* (A Guide to Palliative Care Service Development, 2005, p 27)

#### **Ways of supporting the person's family include:**

- providing information about relevant services and entitlements. Helping families to provide effective care is one way to assist them to find meaning in their caring experience
- encouraging the family to look after their own health by emphasising the benefits of this for both them and their family member
- assessment and monitoring of the carers' needs. Support mechanisms need to be responsive and flexible because needs change over time
- sensitive exploration of the person's wishes and those of the family to determine the goals of care
- assisting the family with problem solving approaches e.g. how to manage behaviours. Including a range of other supports is likely to help more than offering just one option
- providing practical support and information in ways that are easily accessible as busy families have limitations because of their caring commitments
- providing information about various symptoms and their management
- consideration of cultural preferences



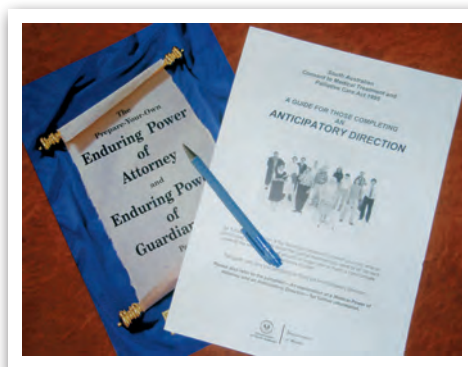
- providing access to appropriate and flexible respite arrangements, such as respite being available quickly in the case of an emergency such as carer illness. Respite needs to be available at frequent intervals as the benefits are likely to be short lived
- considering end of life care needs in advance allows the family to access supports quickly when they require them
- supporting the family as death approaches by helping them understand what to expect and assisting them to use strategies to cope. This may help them with the post-bereavement experience as well as the experience at the time of death.

(Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting, 2008, p 149)

### Practice Tip

When caring for someone dying at home, the family's greatest concern is that they are providing the right care and that they will know what to do in the event of an emergency. They need to know what they can expect as death approaches, how to access appropriate services and how to cope with the practical and emotional demands of care. Above all, they need speedy professional support and backup when requested

For further reading refer to the [Reference List](#) at the end of this document.









## Team work

In this section:

- You can't do it alone
- Communication with the person with dementia
- The impact of different values and beliefs
- Taking care of yourself
- The ethical approach to interventions

### Admission to Service Transitional Points

Supporting people with dementia and their families, is important, emotional and demanding work. It is essential to the person and their family that the team that is supporting them works together to share and work through problems.

The role of the primary care provider is key in promoting good lives and good endings for people with dementia. The primary care provider in this resource is the aged care provider, but may also include GPs, nurses, allied health staff and staff of a residential aged care facility.

*Primary care providers will need to have established and supportive relationships with specialist palliative care services to ensure continuing development of their skills and to ensure quality of care so that the client, carer and family needs can be met' (A Guide to Palliative Care Service Development, 2005, p 29)*

All people diagnosed with dementia require access to a primary care provider who has knowledge and skills in the care of people with a life limiting illness.

Specialist palliative care services may be required to assist the person with dementia at times when they experience problems of increased complexity which is beyond the capabilities of the primary care provider or service. For most people this is likely to be episodic (a number of episodes or occasions rather than ongoing), and provided in partnership with their primary care provider. (A Guide to Palliative Care Service Development, 2005, p16)

### Supporting Staff

For the primary care provider team this work can be challenging and demanding, but also rewarding.

#### Practice Tip

The members of the team need to support each other, share information and skills and be clear about relationships and roles

## Care Workers

The care worker role is not to know everything or be a counsellor but to support the person and their family. Caring for someone when they are dying brings people closer together and it is a privilege to be invited in to share this experience. When a person has end stage dementia things happen physically and psychologically. Some of the changes may be quite subtle and need only to be observed and recorded on the progress notes. Other changes might be sudden, worrying or even alarming and require reporting more immediately to the coordinator or nurse.

### **A person in the advanced stage of dementia may:**

- experience the loss of ability to understand or use speech
- be incontinent of both urine and faeces
- be unable to recognise everyday objects
- have no recognition of family and friends
- be restless and agitated
- be aggressive
- suffer delirium
- experience swallowing difficulties
- be disturbed at night
- suffer from immobility or becoming bedridden
- have uncontrolled movements
- require assistance with eating, washing, bathing or dressing.

(Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the community, p 38)

### **Other factors that can impact on the person's condition and behaviour:**

- effects of medication or reactions from combinations of drugs
- impaired vision and hearing
- acute illnesses such as urinary tract infection, pneumonia, gastrointestinal infection, fever or delirium
- chronic illnesses or co-morbidities such as angina, heart problems, diabetes or pain associated with arthritis, ulcers or headaches
- dehydration – many people with dementia do not get enough fluid because they no longer recognise the sensation of thirst or they may forget to drink. Symptoms of dehydration may include confusion, dizziness, skin that appears dry, flushing and fever and rapid pulse
- constipation can be very uncomfortable and can lead to painful bowel problems and an increased level of confusion
- fatigue – disrupted sleep patterns can cause angry or agitated behaviour
- physical discomfort – hunger, hot, cold, needing to go to the toilet

(Dementia Information Resource Kit, Sheet 5.2)

Identifying symptoms and changes is not easy, but can be learned through education and experience. Care workers should always contact the coordinator or RN when there are changes or when they are not sure what to do.

### **Practice Tip**

Care workers, as a member of the team, have a responsibility to monitor changes and report to other members of the team any concerns they might have about the person



## Communication

Listening is the cornerstone of effective communication.

Communication is made up of three parts:

- 55% is body language – facial expression, posture and gestures
- 38% is the tone and pitch of the voice
- 7% is the words used

*Sometimes what people are saying is not what is heard. This is because their actions, the way they are standing, or the expression on their face, is not sending the same message as their words. Body posture, dress, movements, expressions and mannerisms tell much about people. "Actions speak louder than words". (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 83)*

The people we work with, including the older person and their family, are observing non-verbal communication, and interpreting body language, whether consciously or unconsciously, while listening to what is being said. Entering a room or a conversation feeling angry, resentful or fearful, will be reflected in one's body language and facial expression and may be interpreted by the other person.

### Practice Tip

Good communication relies on body language giving the same message as the words that are spoken

## Communicating with the person with dementia

People with dementia retain their feelings and emotions even though they may not understand what is being said, so it is important to always maintain their dignity and self esteem.

### Ways of talking

- introduce yourself and your role
- remain calm and talk in a gentle, matter of fact way
- keep sentences short and simple, focusing on one idea at a time
- always allow plenty of time for what you have said to be understood
- use names whenever you can, such as "your daughter Mary"
- hand gestures and facial expressions, pointing, touching or holding their hand are all ways of holding their attention and making yourself understood
- a warm smile and shared laughter can often communicate more than words.

### The right environment

- avoid competing noises such as TV or radio
- stay in the person's line of vision while talking with them
- regular routines help minimise confusion and assist communication
- it is less confusing for the person if everyone uses the same approach.

### **What Not to do**

- don't argue – it will only make the situation worse
- don't order the person around
- don't tell them what they can't do – state what they can do
- don't be condescending – a condescending tone of voice can be picked up, even if the words are not understood
- don't ask a lot of direct questions that rely on a good memory
- don't talk about people in front of them as if they are not there.

(Dementia Information Resource Kit, Sheet 2.1)

### **Communication in Teams**

Direct communication is either talking to a person face to face or on the telephone. At times members of the care team need to communicate directly about the person. Every member of the team needs to know who they are responsible to and who they should report to. It is important to have clear guidelines about who to communicate directly with and when. The right language and terminology need to be used to ensure that accurate information is passed on.

While communication directly with other team members may be essential in some circumstances, there are times when adequate communication can be made indirectly via communication books, progress notes and care plans.

#### **Practice Tip**

Teams are only effective if communication between the team members is effective

Regardless of the number of people involved in the care team, good, clear and accurate communication is necessary to keep the team functioning well

### **Values and Beliefs**

Values and beliefs are important to everyone as we all have differences in attitudes to death, ways of showing love, respect and spiritual needs, how we communicate with others and deal with conflict. When caring for older people with dementia and their families, it is important to do so without placing your own values on to others.

Also, respect people for who they are and avoid making judgements. This can be quite difficult especially when people come from different social and cultural backgrounds.

With different values and beliefs it is easy to make judgements about other people's behaviour. These judgements, although not stated, can be seen as easily by others through body language and facial expression, as they can through words.

#### **Practice Tip**

It is essential when dealing with the public in a professional capacity not to allow personal judgements to interfere with communications and relationships with people. Coordinators, nurses and care workers meet people from all walks of life and have a responsibility to them to accept them as they are



## **Honesty and Respect**

In communicating with others there is an expectation of honesty. This can be difficult especially if hard questions are asked, such as “Am I going to die?” Giving a dishonest response betrays the person’s trust and destroys any opportunity for an honest and respectful professional relationship. If asked a question you cannot answer, it is best to say so and find someone who can answer the question for the person. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 85)

## **Health Deterioration End of Life**

### **Dealing with Negative Emotions**

*Individual beliefs and attitudes mean that different people respond to situations in different ways. Empathy relates to an ability to convey to a person that you understand how they are feeling. To listen empathetically is to attempt to acknowledge the feelings of others. Sometimes when people are crying, or angry or talking about things that make them feel emotional, the easiest and simplest way to help them is to simply acknowledge their feelings e.g. if some one is crying and saying “I don’t want to leave my family”. Being silent and letting them continue is a good strategy but if you feel a need to say something, you can simply say – “You are feeling sad”. This is a way of reflecting what they are saying.* (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 59)

## **Self Care**

Caring for those who are very frail, ill, or dying and their families, while very rewarding, can also be quite emotionally draining. Each day care staff may be faced with others’ sadness, anger and anxiety. On top of other people’s emotions each staff person has their own emotions. Depending on the situation, staff might feel helpless, sad, or anxious and unsure. These emotions, if not dealt with adequately, may build up to the point where people feel stressed. While it is not always easy to avoid feeling these kind of emotions, it is important for care staff to learn to take care of themselves and manage well those things that cause stress.

### **Some ways to take care of yourself include:**

- having supportive and enriching relationships
- having personal interests, hobbies
- good nutrition
- regular exercise
- massage, meditation
- work that is energising
- having meaning and connection – a spiritual life
- allowing yourself to grieve your losses
- having a philosophy of practice – how you approach your work, your attitude, do you enjoy going to work, or
- occasionally treating yourself - this may be as simple as picking a flower for yourself on the way home.



### Practice Tip

Having strategies in place, including finding a balance between time spent at work and activities out of work, and having opportunities for support and de-briefing, is central for health and well-being

### Ethical Dilemmas

Throughout the time of supporting a person with dementia, and particularly as they near the end of their life, staff might be confronted with ethical dilemmas. These can include being asked to give the person food and liquids either naturally or artificially, using physical or chemical restraint, or intravenous antibiotics.

*Ethical conduct is about doing what's right for the person. For people who are dying, ethical care requires that it does no harm and that the overall benefit outweighs any potential harm that may be caused by an intervention. The dilemma of whether to use invasive interventions or not on a person who has lost mental capacity and has an extremely poor prognosis raises the question of the intervention being in accord with their wishes, expressed or understood by the family.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

### Hydration and Nutrition

Loss of appetite and difficulties with swallowing (dysphagia) are a normal part of the disease process and key indicators that the person is near the end of their life. Advanced disease causes the body to shut down reducing the individual's interest in food and possibly fluids, resulting in malnutrition and dehydration. In many cases, families are faced with making difficult decisions on whether or not to initiate artificial hydration and nutrition. (AHN). (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

Sometimes medications, dental problems, oral thrush, constipation, mouth ulcers, infections and a dislike for certain food can trigger a refusal to eat. It is important to consider if the refusal to eat is part of the overall decline or if an infection is causing more confusion for the person. Either way, offer small amounts of the person's favourite foods without force. (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

*Families and carers find issues about nutrition complex. Some of the most perplexing issues arising in end of life care are starvation and dehydration or feeling that the person with dementia may be hungry or thirsty, and the distinction between 'killing' and 'allowing to die'.* (Palliative Care and Dementia, Alzheimer's Australia Discussion paper 7, p 11)

*Literature suggests that the benefits of terminal dehydration far outweigh the burdens of AHN where decreased urine output and reduced chest secretions cause less distress to the person with advanced dementia.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)





### Practice Tip

For additional information on Hydration and Nutrition refer to the [Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7](#), 2006, pages 10 to 13

### Restraint

*Restraining someone against their will can only be ethical when the intervention, like hip surgery after a fracture, outweighs the potential harm. Restraining someone as a way of controlling their behaviour is rarely appropriate.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

### Practice Tip

For additional information on Restraint refer to the [Decision Making Tool: Responding to issues of restraint in Aged Care](#), Australian Government, Department of Health and Ageing, 2004

### Intravenous Antibiotic Therapy

*This intervention depends on the condition of the person and how close to death they are. Use of antibiotics for any infection is appropriate as long as the overall benefit outweighs the potential harm. If fever is the most distressing symptom, alternative interventions may be more appropriate.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

If the family chooses intravenous antibiotic therapy this will normally require the person to be admitted to hospital. For a person with advanced dementia this will not be a familiar environment and may cause more stress. This decision requires a balance between the benefits and additional overall harm to the person.

### In General

*It is recognised that in most circumstances where there is doubt about the value of potentially life-sustaining measures like assisted ventilation, intravenous antibiotic therapy and artificial hydration and nutrition, it is more difficult to cease than to not start them.* (Better Practice Framework – Palliative Care for People with Dementia, 2006, p 21)

For further reading refer to the [Reference List](#) at the end of this document.





## Supportive relationships

### Admission to Service

In this section:

- When should specialist services be involved?
- What can specialist services offer?
- [How best to work together with specialist services](#)

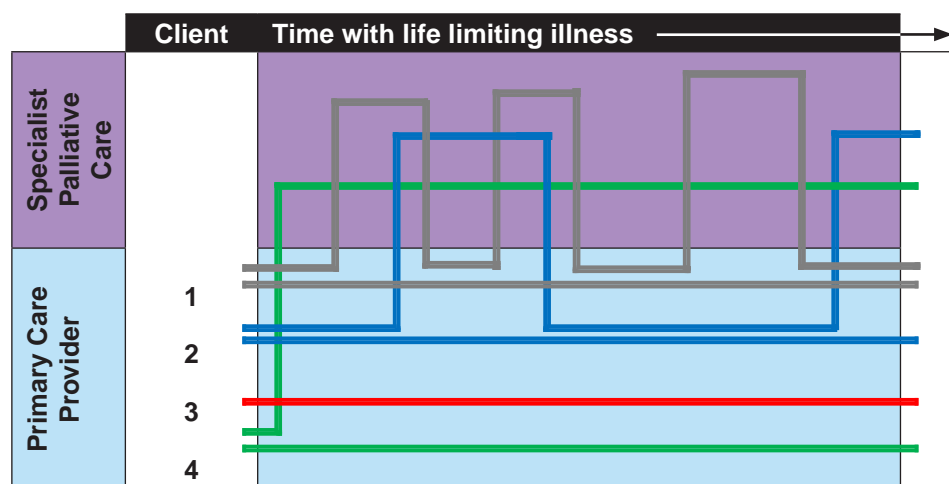
Evidence based best practice identifies that the aged care provider is the primary care provider. This means that as long as the person wishes to remain at home, the aged care provider is the primary care provider. The aim is to support the older person to remain at home for as long as is possible with the full range of services available.

*All people diagnosed with a dementia need access to a primary care provider who has knowledge and skills in the care of people with a life limiting illness. These skills, attributes and knowledge applied within the context of a primary care relationship are referred to as a palliative approach.* (A Guide to Palliative Care Service Development, 2005, p16)

However the primary care provider does not need to work alone, but may work together with specialist palliative care services (SPCS).

*Dedicated specialist palliative care services meet the needs of people with complex or resource intensive needs that are beyond the expertise or exceed the capacity of primary care providers. Specialist palliative care is generally provided through either individual client based consultation or co-case-management with primary care providers.* (A Guide to Palliative Care Service Development 2005 p.32)

*Specialist palliative care services may be required to assist the person with a life limiting illness when they experience problems of increased complexity which is beyond the capabilities of the primary care provider. For most people this is likely to be episodic, and provided in partnership with their primary care team. A person may expect to access specialist services on a number of occasions while receiving ongoing care from their primary care provider. This is described in the diagram on the next page.*



(A Guide to Palliative Care Service Development 2005 p16)

This chart shows that the primary care provider remains involved with the person throughout the journey with dementia.

## Transitional Points Health Deterioration End of Life

### **Specialist palliative care is provided in two main ways**

*Firstly, specialist services can provide consultation based advice and support to primary care providers. In this situation specialist providers undertake a direct assessment of the person and establish a plan of care with the person, family and primary care provider. The primary care provider, using criteria established by the specialist service, then undertakes the ongoing care and reassessment of the client.*

*Secondly, and much less commonly, specialist services may be involved for a longer period of ongoing care. In general all care provided by a specialist palliative care service will be provided in partnership with a primary care provider. (A Guide to Palliative Care Service Development, 2005, p 33)*

#### **Practice Tip**

Coordinators and nurses need to have knowledge of the specialist palliative care services in their area, and the services they provide. It is recommended that coordinators and nurses make themselves and their service known to the specialist palliative care service providers, and over time develop a working relationship with them

For each person, depending on their individual circumstances, the providers will need to establish how they will partner together and how much support is required for the primary care provider

The role of the aged care provider may cease if it is decided that the person needs to move into a residential aged care facility or a hospice. However, if the person remains at home until death, the aged care provider continues as the primary care provider right up to post death, where the focus is to support the family and the care team members.



## Specialist Palliative Care Services in Adelaide and surrounds

Central Adelaide Palliative Service:

[Mary Potter Hospice](#)

Ph: 8239 9144

Royal Adelaide Hospital

Ph: 8222 2021

[Lyell McEwin Palliative Care Service](#)

Ph: 8182 9833

Modbury Palliative Care Service

Ph: 8161 2351

Southern Adelaide Palliative Services

Ph: 8275 1732

Western Adelaide Palliative Care

Ph: 8222 6825

Gawler and Districts Palliative Care Service

Ph: 8522 3890

[Adelaide Hills Palliative Care Service](#)

[Mt Barker](#)

Ph: 8393 1888

[Murray Mallee Palliative Care Service](#)

[Murray Bridge](#)

Ph: 8535 6800

## Resources

**MAPCARE (the Metropolitan Acute Palliative Care Resource for South Australia)**

[www.mapcare.org.au](http://www.mapcare.org.au)

MAPCARE is a resource which has been developed specifically for health care professionals in Adelaide, and is targeted at acute care services. Information includes assessing and managing symptoms, communication in challenging situations, specialist services, bereavement support and self management strategies for health professionals.

**The Directory of Specialist Palliative Care Services** in your local area

[www.caresearch.com.au](http://www.caresearch.com.au)

Click on *Finding Services*

Click on *Palliative Care Services*

Click on *National Palliative Care Service Directory*:

- indicate the type of service you require
- indicate your postcode
- click on Search

[The Rural Palliative Care Project 2008 - 2010](#)

For further reading refer to the [Reference List](#) at the end of this document.





## Grief support

In this section:

- What is ambiguous loss?
- Symptoms of grief
- What you can do to help

### Admission to Service Transitional Points Health Deterioration

Loss and grief are issues that affect everyone in everyday life. We tend to think of loss and grief as being confined to the death of someone close to us, but life is a process of losses and adjustments. We can experience losses in many ways, such as the loss of a partner through separation and divorce, being made redundant, or a child leaving home. These situations are common losses and people experience grief in relation to these losses, as well as those related to facing end of life. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 97)

For the person with dementia and their family, grieving begins at the time of diagnosis, and they experience progressive losses over an extended period as death approaches. Good bereavement support should start at the time of diagnosis. Loss and grief issues for them include:

- an ongoing series of losses, including health, mobility, physical and mental ability, employment, finances, relationships, roles, meaning and purpose
- anticipatory grief
- ambiguous loss, “Goodbye without leaving” – where a person is physically here, but their mind or memory is gone. There may be personality changes
- difficulty for the person with dementia to express their grief as they face ongoing losses and impending death.

Grief may be expressed in a variety of ways:

**Physical signs** - in recent grief a person may be shaking, have a dry mouth, experience palpitations, feel clammy, cry profusely or not cry at all. If the grief is not so recent a person may experience problems sleeping, lose or gain weight, look unkempt or unwell.

**How a person is feeling** - for instance sad, angry, guilty, anxious or relieved.

**How a person is thinking** - they may become confused doing everyday chores such as paying bills. They may think that they have seen the deceased in the shopping mall or in the street. They may think they were responsible in some way for the person dying or experiencing discomfort.



***The way a person behaves*** – they may become very busy or withdrawn from people. They may become involved in risk-taking behaviour like driving a car fast or becoming promiscuous. Sometimes the grieving person uses substances such as alcohol or drugs to try to numb the pain. The behavioural changes observed may be very different after the loss compared to behaviour before the loss.

Social behaviour may change. A woman who has lost her husband may feel that she no longer fits into the company that her and her husband kept prior to his death and so isolates herself. Friends and acquaintances may not be sure what to say and so avoid her, adding to her isolation.

***The person's spiritual and belief system may be challenged*** – A grieving person may examine their belief system and find it lacking and look for a reason that fits this traumatic event that has happened to them. People may lose or find a faith, or find that their faith supports them. Others who have no religious leanings look for other ways to explain such an event. (Provide Palliative Care for People with Life-Limiting Illness in the Home Care Setting, p 100 and 101)

#### **Practice Tip**

Creating a caring and friendly atmosphere for those grieving is often most welcome

Validating the person's circumstances often helps the family to put their experience into perspective

People respond to their grief in different ways until they can adjust to living without the physical presence of that person

For those who are finding it difficult to adjust to loss, a referral to counselling and support may be valuable:

- [The Loss and Grief Centre](#) – 08 8305 9670
- The National Dementia Helpline – Freecall 1800 100 500\*
- The National Carer Counselling Program – Freecall: 1800 242 636\*
- The Palliative Care Information and Support Line – Freecall: 1800 772 222\*

\* Calls from mobile phones are charged at applicable rates

## **End of Life**

### **Funerals**

Attending the person's funeral can be helpful for staff as a way of saying goodbye and reflecting on your work. For families, the presence of the primary care provider may be an important support at a sad time. Discuss this with the team to decide what is appropriate.

For further reading refer to the [Reference List](#) at the end of this document.

# Glossary of Terms

**Advance care planning** – the process of planning for future medical care, financial and lifestyle needs in advance of when it is needed, including end-of-life care.

**Anticipatory Direction** – one of the advance directives covered under South Australian legislation which allows a competent individual to record his or her wishes for end-of-life care if he or she is unable to communicate those wishes.

**Advance directive** – a legally binding document that records a person's wishes or directions in advance of an event when he or she may become unable to make decisions or communicate those decisions. There are 5 types of advance directives available in South Australia: Enduring Power of Attorney (finances), Will (finances), Enduring Power of Guardianship (lifestyle and medical), Medical Power of Attorney (medical), Anticipatory Direction (medical).

**Artificial nutrition and hydration (ANH)** – the administration of food and fluids via a feeding tube when food and drink can no longer be taken naturally by mouth.

**Aspiration pneumonia** – inflammation of the lungs caused by inhalation of fluid, food or other foreign matter.

**Capacity (competence)** – the ability to understand the context of an issue and make a decision knowing the consequence/s of that decision. Capacity is a legal concept and assumed until proven otherwise.

**Co-morbidity** – The presence of one or more disorders (or diseases) in addition to a primary disease or disorder.

**Dehydration** – excessive loss of water from the body.

**Delirium** – an acute state of confusion of the mind that is life-threatening and potentially reversible, and may involve high fever, intoxication, shock or other causes.

**Dementia** – decline in memory and at least one other cognitive function (e.g. language, space, problem solving) sufficient to affect daily life in an alert person.

**Dysphagia** – difficulty in swallowing caused by obstruction or spasm of the oesophagus.

**End-of-life care** – when death can be expected within a period of hours, days or weeks. Determining when this phase begins can be difficult. Some authors refer to this as 'terminal care' and others refer to end of life care over a much longer time period.

**Enduring Power of Attorney** – an advance directive that allows a competent adult to nominate a proxy decision-maker (i.e. an attorney) to make decisions about finance, legal and business issues on their behalf, from the time they choose and enduring after mental capacity is lost.

**Enduring Power of Guardianship** – an advance directive that allows a competent adult to nominate a proxy decision-maker (i.e. a guardian) to make decisions about lifestyle and medical issues on their behalf, and this power endures after mental capacity is lost.

**Formal arrangements** – legal documentation of proxy decision-makers with respect to finances, lifestyle and medical issues.

**Guardian** – a person who is legally responsible for a vulnerable person, someone who guards, watches over, or protects another person.

**Guardianship Board** – a court-like tribunal that has the power to make important decisions affecting the lives and property of people over whom it has jurisdiction. Before the Board can consider any issue, somebody must complete an application form to request the Board's involvement. At the hearing, people provide information about what they know and what they think should be done. Usually the Board will make its decision at the end of a hearing. Orders made by the Guardianship Board are legally enforceable.

**Hallucinations** – sensory experiences that cannot be verified by anyone other than the person experiencing them. Such experiences may include any of the senses, but the most common are visual and auditory hallucinations – the person sees or hears something that is not there.

**Informal arrangements** – advance care planning that is not formalised into legal documents like advance directives.

**Intravenous infusion** (IV fluids) – the administration of liquid substances (medication or fluids) directly into a vein – also referred to as a drip.

**Palliative approach to care** – an approach to care that links palliative care to the management of a life-threatening condition with little or no prospect of cure.

**Nurses** – in this resource guide the term nurses includes Registered Nurses (RNs) and Enrolled Nurses (ENs) working in the community in specialist roles, as well as those working in residential aged care facilities.

**Palliative care** – total active care of a person with a life-threatening condition where the disease is no longer responsive to curative treatment. It is an approach that improves the quality of life of an individual and their family facing life-threatening illness, addressing the physical, social and spiritual needs, from diagnosis to the final stage. It is not limited to end of life care but includes it.

**Person-centred care** – care that is primarily focused on the person's individual needs.

**Personhood** – acknowledging that some abilities and capabilities of the person with dementia remain.

**Prognosis** – the probable outcome of a disease.

**PSAI – Planning Services Around the Individual** – a systematic approach for staff in planning service delivery with people. It is about working in partnership with people and focuses on supporting them to retain their roles and continue to be a contributing member of society.

**Quality of Life** – broadly defined as the quality of an individual's life as determined by a holistic self-determined evaluation of what's important to the individual. Quality of life is influenced by many factors including financial status, housing, employment, spirituality, social support network and health.

**Relationship-centred care** – focus of care is broader than person-centred care and concerned with the relationships between the person with dementia, their family carer/s and health and social professionals.

**Specialist palliative care service** – a service provided by specially trained multidisciplinary clinicians and volunteers in palliative care. Three types of specialist palliative care services are: in-patient service, community based service and consultancy.

**Subcutaneous** – given under the skin

**Will** – a legal document expressing the desires of the author with regard to the distribution of property after the author's death.



# Reference List

**A Guide to Palliative Care Service Development**, Palliative Care Australia, 2005  
[www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf](http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf)

**A palliative care approach**, Susan Ashcroft-Simpson, Admiral Nursing, 2007

**Advance Directives Help Sheets**, Office of the Public Advocate  
[www.opa.sa.gov.au](http://www.opa.sa.gov.au)

**Ambiguous Loss**, Pauline Boss, Harvard University Press, 1999

**Better Practice Framework – Palliative Care for People with Dementia**, ACH Group, 2006

**Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community**, Queensland University of Technology, 2008

**Clinical Practice Guidelines for the Management of Delirium in Older People**, Australian Department of Health and Ageing, October, 2006

**Delivering PSAI (Planning Services Around Individuals) People in Partnerships**, ACH Group, 2007

**Dementia – Changes in the ability to live independently**, University of Western Sydney, 2006  
[www.uws.edu.au/research/nforce/projects/2006](http://www.uws.edu.au/research/nforce/projects/2006) - click on *Poster*

**Dementia information for carers, families and friends of people with severe and end stage dementia**, University of Western Sydney, 2<sup>nd</sup> Edition, 2007  
[www.uws.edu.au/research/nforce/projects/2006](http://www.uws.edu.au/research/nforce/projects/2006) - click on *Family Information Booklet*

**Dementia Information Resource Kit**, Alzheimer's Australia, 2006

**Decision Making Tool: Responding to issues of restraint in Aged Care**

, Australian Government of Department of Health and Ageing, 2004

**Directory of Specialist Palliative Care Services in the local area**

[www.caresearch.com.au](http://www.caresearch.com.au)

**Draft Guidelines for a Palliative Approach for Aged Care in a Community Setting,**  
Department of Health and Ageing, 2006

**Evidence-based Best Practice in Community Care** Interim Report, Australian Institute  
for Primary Care, 2008

**Gold Standards Framework,** England: National Health Service, 2005

<http://www.goldstandardsframework.nhs.uk/>

**Living Well at the End of Life** Adapting Health Care to Serious Chronic Illness in Old  
Age, Joanne Lynn, David M Adamson, 2003.

Available from [www.medicaring.org/whitepaper/](http://www.medicaring.org/whitepaper/)

**Montessori-Based Activities for Person with Dementia Volume 1,** Cameron J Camp  
Editor, 1999

**Multicultural Palliative Care Guidelines,** Palliative Care Australia, 1999

**Palliative Care and Dementia, Alzheimer's Australia Discussion Paper 7,** Alzheimer's  
Australia, 2006

**Palliative Dementia Care and Advance Care Planning – A Literature Review,** ACH  
Group, 2008

**Planning Ahead – an information guide for people with dementia and their families,**  
ACH Group, 2008

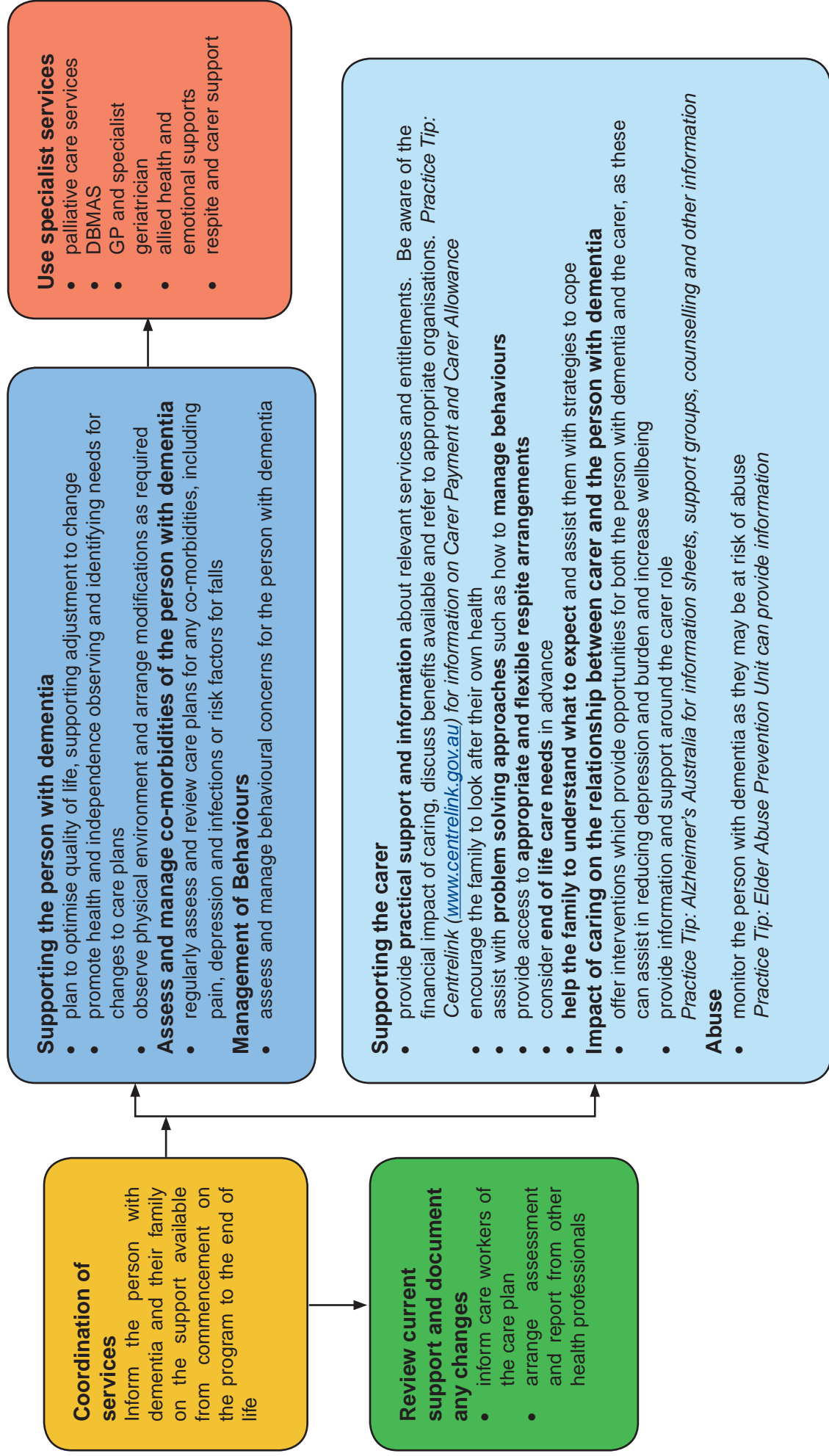
**Provide Palliative Care for People with Life-Limiting Illness in the Home Care  
Setting,** Department of Health and Ageing, RDNS and partners

# Appendices

1. Coordinators and Nurses Care Pathway for Supporting a Person with Dementia
2. Care Workers Care Pathway for Supporting a Person with Dementia
3. Coordinators and Nurses Care Pathway for Supporting a Person with Advanced Dementia
4. Care Workers Care Pathway for Supporting a Person with Advanced Dementia
5. End of Life Care Pathway for a Person with Dementia who is Actively Dying
6. Abbey Pain Scale
7. Use of the Abbey Pain Scale
8. Australia - Modified Karnofsky Performance Scale
9. SNAP Phases of Palliation
10. Gold Standards of Palliative Care
11. Dementia – Changes in the ability to live independently
12. Advance Directives, South Australia – a Summary

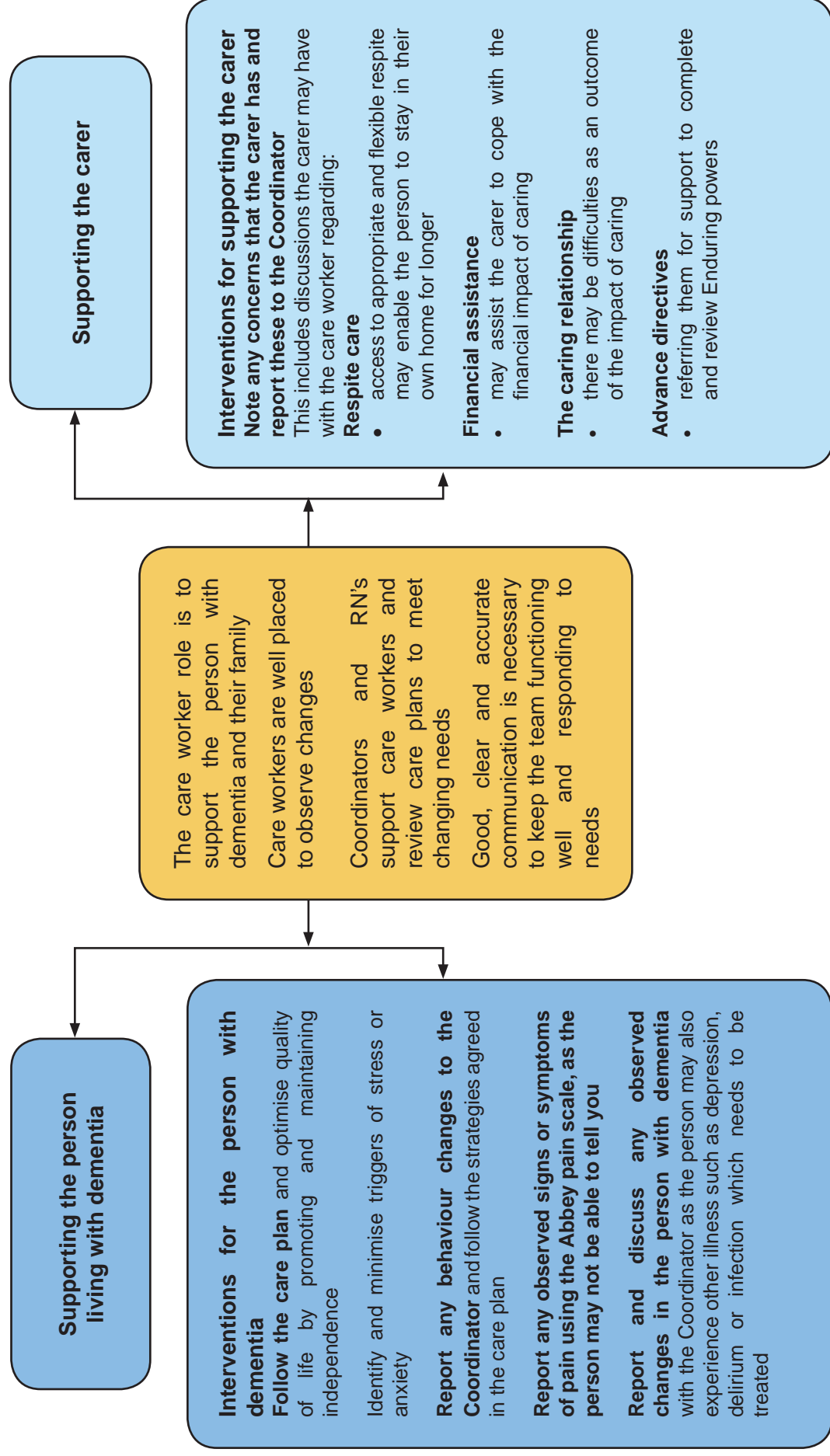


## Appendix 1 - Coordinators and Nurses Care Pathway for Supporting a Person with Dementia



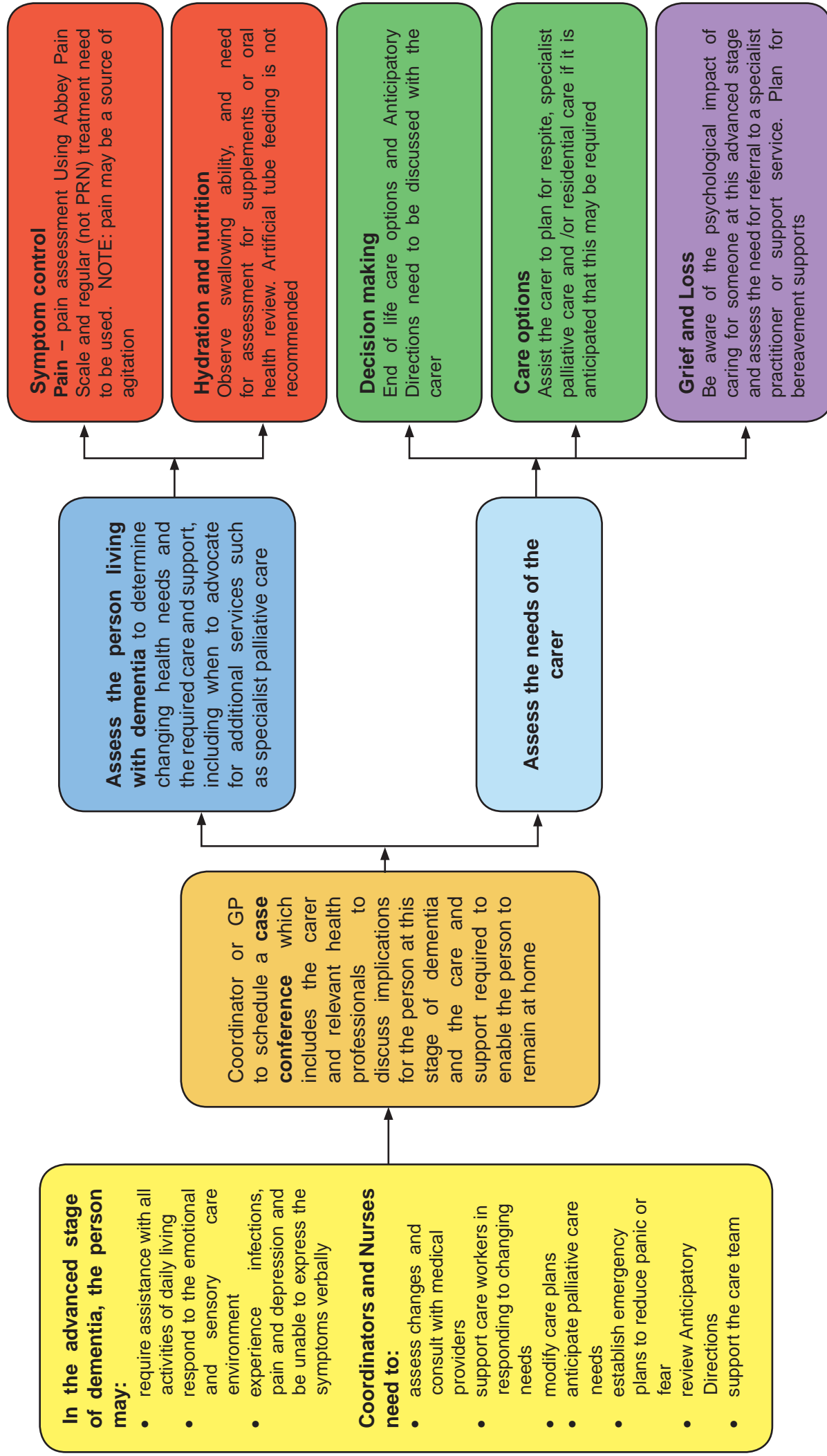
Pathway continues – Coordinators and Nurses Care Pathway for Supporting Person with Advanced Dementia

## Appendix 2 - Care Workers Care Pathway for Supporting a Person with Dementia



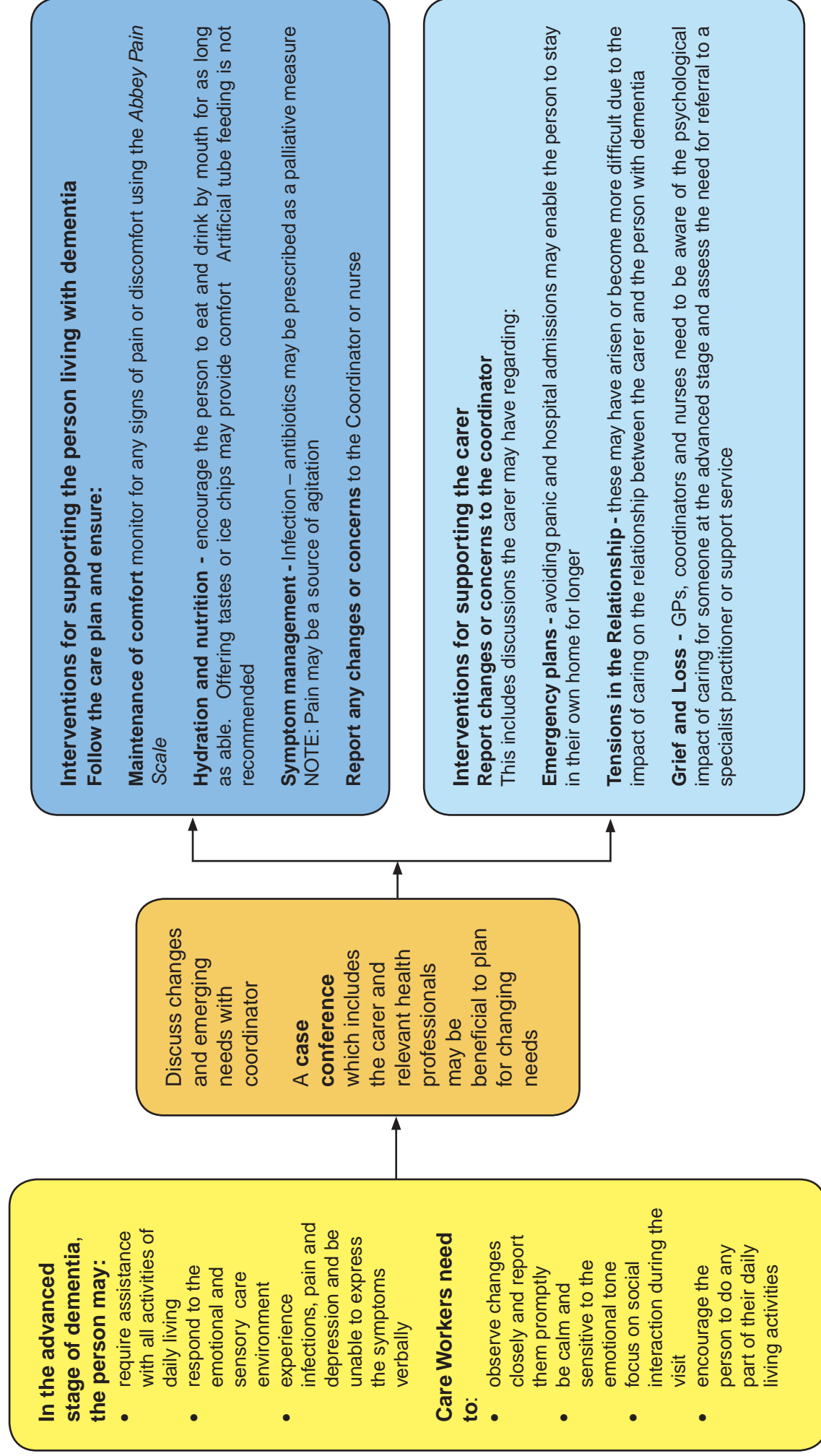
Pathway continues – Care Workers Care Pathway for Supporting Person with Advanced Dementia

## Appendix 3 - Coordinators and Nurses Care Pathway for Supporting a Person with Advanced Dementia



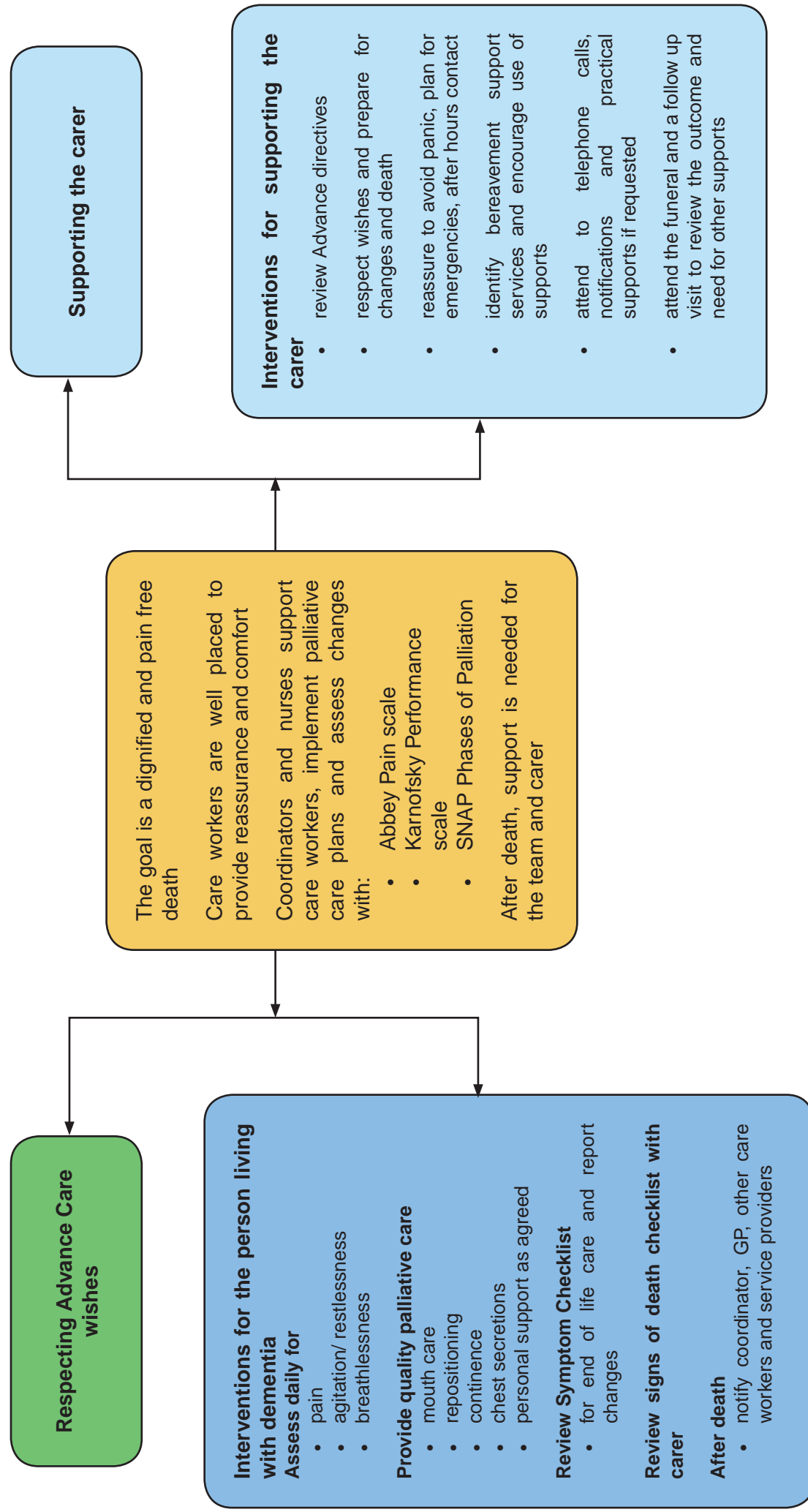
Pathway continues – End of Life Care Pathway for a Person with Dementia who is Actively Dying

## Appendix 4 - Care Workers Care Pathway for Supporting a Person with Advanced Dementia



Pathway continues – End of Life Care Pathway for a Person with Dementia who is Actively Dying

## Appendix 5 - End of Life Care Pathway for a Person with Dementia who is Actively Dying



## Appendix 6 – Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the client, score questions 1 to 6.

Name of client: .....

Name and designation of person completing the scale: .....

Date of assessment: ..... Time: .....

### Q1. Vocalisation

**e.g. whimpering, groaning, crying**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q1** ☐

### Q2. Facial Expression

**e.g. looking tense, frowning, grimacing, looking frightened**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q2** ☐

### Q3. Change in body language

**e.g. fidgeting, rocking, guarding part of body, withdrawn**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q3** ☐

### Q4. Behavioural Change

**e.g. increased confusion, refusing to eat, alteration in usual patterns**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q4** ☐

### Q5. Physiological Change

**e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q5** ☐

### Q6. Physical Changes

**e.g. skin tears, pressure areas, arthritis, contractures, previous injuries**

Absent 0      Mild 1      Moderate 2      Severe 3

**Q6** ☐

Add scores for 1 – 6 and record here —————→

**Total Pain Score** ☐

Now tick the box that matches the Total Pain Score

————→	0 – 2 No Pain	3 – 7 Mild	8 – 13 Moderate	14 + Severe
-------	------------------	---------------	--------------------	----------------

Finally, tick the box which matches the type of pain

————→	Chronic	Acute	Acute on Chronic
-------	---------	-------	------------------

Jennifer Abbey, Neil Piller, Anita De Bellis, Adrian Esterman, Deborah Parker, Lynne Giles, Belinda Lowcay (2004).  
The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. International Journal of Palliative Nursing, Vol 10, No 1, pp 6-13

## Appendix 7 - Use of the Abbey Pain Scale

The pain scale is best used as part of an overall management plan.

### Objective

The pain scale is an instrument designed to assist in the assessment of pain in people who are unable to clearly articulate their needs.

### Ongoing assessment

The scale does not differentiate between distress and pain, therefore measuring the effectiveness of pain relieving interventions is essential.

Recent work by the Australian Pain Society <sup>1,2</sup> recommends that the Abbey Pain Scale be used as a movement based assessment.

The staff recording the scale should, therefore, observe and record on the scale while the person is being moved e.g. during pressure area care, while showering etc.

Record results in the person's notes. Include the time of completion of the scale, the score, staff member's signature and action taken in response to the results of the assessment.

A second evaluation should be conducted one hour after the intervention taken in response to the first assessment, to determine the effectiveness of any pain relieving intervention.

If, at this assessment, the score on the pain scale is the same, or worse, undertake a comprehensive assessment of all facets of the person's care, monitor closely over a 24 hour period, including any further interventions undertaken, and if there is no improvement, notify the medical practitioner.

1. Australian Pain Society (2005). Residential Aged Care Pain Management Guidelines, August. Available from <http://www.apsoc.org.au>
2. Gibson S, Scherer G and Goucke R (2004). Final Report. Australian Pain Society and the Australian Pain Relief Association Main Management Guidelines for Residential Care: Stage 1, Preliminary field-testing and preparation for implementation, November.



## Appendix 8 - Australia-modified Karnofsky Performance Scale

The Karnofsky Performance Scale (KPS) is considered the Gold Standard scale in palliative care (Gold Standards Framework 2005) and the Australia-modified KPS has been found to be the most accurate tool for assessing functional status for community based palliative care clients (Abernathy *et al*, 2005). People scoring 40 and below have a poor prognosis.

<b>100</b>	Normal; no complaints; no evidence of disease
<b>90</b>	Able to carry on normal activity; minor sign of symptoms
<b>80</b>	Normal activity with effort; some signs or symptoms of disease
<b>70</b>	Cares for self; unable to carry on normal activity or to do active work
<b>60</b>	Requires occasional assistance but is able to care for most needs
<b>50</b>	Requires considerable assistance and frequent medical care
<b>40</b>	In bed more than 50% of the time
<b>30</b>	Almost completely bedfast
<b>20</b>	Totally bedfast and requiring extensive nursing care by professional and/or family
<b>10</b>	Comatose or can barely be aroused
<b>0</b>	Death

When a person's KPS score drops to 30 or below, it may be appropriate to refer to a palliative care service if the needs are complex or pain and other distressing symptoms are not being controlled (Abernathy *et al*, 2005).

## Appendix 9 – SNAP Phases of Palliation

(Subacute and Non-Acute Patient classification system)

<b>Stable</b>	Symptoms are adequately controlled by established management.
<b>Unstable</b>	The person experiences the development of a new problem or a rapid increase in the severity of existing problems.
<b>Deteriorating</b>	The person experiences a gradual worsening of existing symptoms or the development of new but expected problems.
<b>Terminal</b>	Death is likely in a matter of days.
<b>Bereaved</b>	Death has occurred and the carers are grieving.

(Lee LA, Eagar KM, Smith MC. Subacute and non-acute casemix in Australia. MJA 1998:169)

## Appendix 10 – Gold Standards for Palliative Care

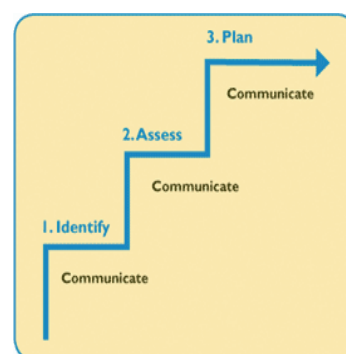
The United Kingdom Department of Health developed an end of life care initiative for adults nearing the end of life to have access to specialist palliative care to enable them to live and die in the place of their choice (DH 2006). From that initiative came the *Gold Standards Framework (GSF)*, a practice based system to improve the organisation and quality of care for people with advanced disease.

The *Gold Standards Framework* was developed after wide consultation and much debate over what was the best standard of care for people nearing the end of their life. They are the ideal, something to aspire to, somewhere to aim for best care possible, and summarised as **1,3,5,7 GSF**.

**1 Aim** – one chance to aim for the best for all – one ‘Gold Standard’ to aspire to for all people nearing the end of their life, whatever the diagnosis, stage or setting.

**3 Processes** – all involve improved communication

1. identify people’s needs of palliative/supportive care towards the end of life
2. assess their needs, symptoms, preferences and any issues important to them
3. plan care around people’s needs and preferences and enable these to be fulfilled, in particular allow people to die where they choose



**5 Goals** – are to improve high quality care for people in the final months of life

1. people’s symptoms are as controlled as possible
2. place of care – people are enabled to live well and die well in their preferred place of choice
3. security and support – better advance care planning, information, less fear, fewer crises / admissions to hospital
4. carers are supported, informed, enabled and empowered
5. staff confidence, communication and co-working improved

**7 Key Tasks** – the 7 C’s

- C1 – Communication
- C2 – Coordination
- C3 – Control of Symptoms
- C4 – Continuity of care, including out of hours
- C5 – Continued learning
- C6 – Carer support
- C7 – Care in the dying phase

(Gold Standards Framework.nhs.uk [homepage on the Internet]. England: National Health Service; 2005 [cited 2006 Jul 5]. Available from <http://www.goldstandardsframework.nhs.uk/>)



# DEMENTIA - Changes in the ability to live independently

As dementia progresses, changes to the brain occur that affect the way an individual thinks, acts and moves around.

30

## Pre- Diagnosis

### The first signs of dementia start.

- Names of new people may be forgotten.
- Items of value might be misplaced or lost.
- The affected person might start to become anxious in unfamiliar locations.
- The affected person will probably deny that anything is wrong if questioned.
- Other people may not notice anything is wrong yet.

25

## Mild Dementia

MMSE 21-26

### Memory problems become noticeable.

- Current events are forgotten.
- Complex tasks like doing the shopping become too difficult.
- Complicated interests and hobbies are abandoned.
- The affected person needs prompting to have a shower, groom hair.
- The affected person begins to withdraw from challenging situations.
- The affected person denies there is a problem.
- Behavioural Problems commence in this period.
- The affected person's mood appears flat.

20

## Moderate Dementia

MMSE 10-20

### Confused for most of the time. Can no longer survive without assistance.

- Unable to remember important things like the home telephone number, or the names of the grandchildren.
- Will not be able to say what the day/date/time/place is.
- Sleep disturbances.
- Early in this stage will be able to go to the toilet alone, but later on will need full assistance.
- May become agitated, isolated, sad, anxious.
- May begin to have delusions (mistaken beliefs) and think people are stealing from them, or that people are impostors.
- May become delirious with an infection.

15

## Severe Dementia

MMSE less than 10

### Sketchy memory of past life, but is largely unaware of recent events and experiences.

- Usually remembers own name but sometimes forgets husband/wife/partner's name.
- Unable to solve any problems.
- Will need help to go to the toilet at first, but will eventually forget how to use a toilet and become incontinent
- Will need full assistance to bathe, dress and groom self. May become afraid of having a bath.
- Will start to have trouble walking and becomes at high risk of having a fall.
- May start to have trouble eating and sometimes swallowing. If this happens will need to have their diet modified so that swallowing is easier.
- Delusions may continue.
- Hallucinations (seeing and hearing things that aren't really there) may be a problem.
- May be anxious, aggressive, agitated, depressed.
- May pace up and down constantly, go into other people's rooms, cry out or scream.
- Disturbed sleep may continue.

10

## End Stage Dementia

MMSE = 0

### The dementia has severely affected the brain so that the individual cannot do any of the things he/she used to do.

- Unable to talk anymore, may scream out at times.
- Only recognises spouse or regular caregivers sometimes.
- Incontinent of urine and faeces.
- Needs full assistance to eat and drink.
- Unable to walk, stays in a chair or bed all the time. At risk of pressure ulcers.
- May hit or bite when care needs to be done (resistive to care).
- Will have problems swallowing, the diet will need to be changed to purees and thickened fluids.
- May develop increasing numbers of infections, such as in the lungs (pneumonia) and urinary tract (kidneys and bladder).
- Will become increasingly frail.
- May lose weight despite receiving enough food and fluids.

5

## References

Trajectory adapted from Feldman H. & Grundman M. Symptomatic treatments for Alzheimer's disease. In Gauthier S. (Ed) 1999 Clinical Diagnosis and Management of Alzheimer's Disease 2nd Edn. London: Martin Dunitz and Vollicer L, Hurley A. 1998. Hospice Care for Patients with Advanced Progressive Dementia New York: Springer Publishing Company.

University of Western Sydney

BLUE MOUNTAINS  
SCHOOL OF DISTANCE EDUCATION

SYDNEY WEST  
ALIA HEALTH SERVICE | NSW HEALTH

## Where to get further information and support:

Alzheimer's Helpline  
1800 100 500 or  
[www.alzheimers.org.au](http://www.alzheimers.org.au)  
Dementia Advisory Services  
Your General Practitioner

## KEY

Behavioural problems may commence in this period and continue in various forms as the dementia progresses. Placement in a residential care facility is often required from this time due to difficulty in managing behaviours like wandering. A palliative approach to care, that improves comfort and function and maintains quality of life is commenced.

The dying process and eventually death can occur at any time from the moderate stage of dementia onwards. It is very unpredictable, and depends on what other diseases a person has.

The Mini-Mental Score (MMSE) is a test used to determine the dementia diagnosis and changes to memory that are occurring.

## Appendix 12 – Advance Directives, South Australia - A Summary

ADVANCE DIRECTIVES, South Australia – A SUMMARY	
<b>Financial decisions</b>	
<p><b>Enduring Power of Attorney</b></p> <ul style="list-style-type: none"> <li>allows you to appoint one or more people to make decisions about financial, property and related legal matters only</li> <li>you can give those you appoint the power to act alone or together in making decisions</li> <li>is effective from the time you choose and remains effective when you are no longer able to make decisions for yourself</li> <li>needs to be lodged with the Land Titles Office if there is to be sale of property</li> </ul> <p><b>Will</b></p> <ul style="list-style-type: none"> <li>gives specific instructions about how you would like your assets to be distributed after you die</li> <li>you can also record any special funeral arrangements you may want</li> <li>must be followed by the person you appoint to be executor</li> </ul>	
<b>Lifestyle and Medical decisions</b>	
<p><b>Enduring Power of Guardianship</b></p> <ul style="list-style-type: none"> <li>allows you to appoint one or more people to make decisions about lifestyle and medical treatments only</li> <li>you can give those you appoint the power to act alone or together in making decisions</li> <li>you can express personal preferences, such as where you would wish to live, services you will have, your medical treatment and care</li> <li>is effective from the time you are no longer able to make decisions for yourself</li> </ul>	
<b>Medical decisions only</b>	
<p><b>Medical Power of Attorney</b></p> <ul style="list-style-type: none"> <li>allows you to appoint one or more people (medical agents) to make decisions about your possible future medical treatment and care</li> <li>your medical agent cannot be a health professional responsible for your care</li> </ul> <p><b>Anticipatory Direction</b></p> <ul style="list-style-type: none"> <li>allows you to legally record the kind of medical care and treatment you want or do not want towards the end of your life</li> <li>does not involve the appointment of another person to make decisions but provides direction for those responsible for providing your health and medical care. (e.g. GP, Enduring Guardian, Medical Agent)</li> <li>can be registered with the Australian Medic Alert Foundation and copies given to family members and your GP</li> <li>cannot be used as a means of requesting someone to actively or deliberately end your life.</li> </ul>	



# Resource List

**Aged Care Information Line** – provides information about Australian Government funded residential aged care, and support and programs for older people in the community.

Phone: 1800 500 853

[www.health.gov.au](http://www.health.gov.au)

**Alzheimer's Australia** – is the national peak body for people living with dementia, their families and carers and provides leadership in policy and services. The website has many worthwhile resources and can be accessed through

[www.alzheimers.org.au](http://www.alzheimers.org.au)

**CareSearch** – an electronic resource for palliative care – contains sections: What is palliative care, Finding services, Clinical practice, For patients and families, professional groups and education. Available from <http://www.caresearch.com.au/home/Default.aspx>

**Dementia Behaviour Management Advisory Service** – telephone based assistance for health professionals and carers. Phone: 1300 366 448

**GPs caring for carers of people with dementia** (pamphlet) is available from

<http://www.racgp.org.au/dementiacarer>

**MAPCARE** – the Metropolitan Acute Palliative Care Resource for South Australia - a resource which has been developed specifically for health care professionals in Adelaide, to point people in the right direction

[www.mapcare.org.au](http://www.mapcare.org.au)

**National Dementia Helpline** – a confidential and sensitive professional counselling service and individual support. Phone: 1800 100 500.

An Interpreter service is available on 131 450

**Office of the Public Advocate (OPA)** - was established under the Guardianship and Administration Act 1993 to promote and protect the rights and interests of people with reduced mental capacity and, where appropriate, their carers. The OPA also has responsibilities under the Mental Health Act 1993. Information on advance directives can be found at [www.opa.sa.gov.au/cgi-bin/wf.pl](http://www.opa.sa.gov.au/cgi-bin/wf.pl)

**Palliative Care Australia** – is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all

[www.pallcare.org.au](http://www.pallcare.org.au)

**Palliative Care Council of South Australia** is the peak body that raises public awareness and advocates for the community and industry to the government. A list of metropolitan and country SA Palliative Care services can be found on the website at 'Location of Services'.

[www.pallcare.asn.au](http://www.pallcare.asn.au)

