

Live Well, Die Well

Supporting carers and families in a palliative approach
to caring for people living with dementia

Coordinators' Handbook



Resthaven
Incorporated

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Live Well, Die Well

Supporting carers and families in a palliative approach to caring for people living with dementia

About this handbook

Working alongside staff, past and current carers and the people living with dementia, Resthaven's Dementia Palliative Care Project Team identified areas of importance to be included in this handbook. It focuses on the experience of the person living with dementia, acknowledging that their personhood continues until death.

The handbook is aimed at assisting Coordinators to gain an understanding of how to work in partnership with the person and their families. It acknowledges that 95% of what are termed, 'behaviours of concern', are a form of communication caused by an unmet emotional need or pain. It details end of life care, emphasising the need to work in collaborative teams, taking into account the needs of the family and the needs of people with dementia at the end of their lives.

This project has also developed a two day Dementia Palliative Care Training course with six modules:

1. A Palliative approach to care
2. Holistic care of the person living with dementia and their family
3. Symptom management
4. Self care and support for a person living with dementia and their families and colleagues
5. Social, spiritual, cultural care
6. End of life care for people with dementia

The training focuses on maintaining quality of life throughout the person's life living with dementia and relieving any emotional, physical, psychological, spiritual, social and cultural suffering of the person and their family. The training was adapted from the Community Services Training Packages (CHC02) developed by Palliative Care Australia. We condensed this and added a focus on dementia care.

The project also developed a series of Fact Sheets for carers of people living with dementia. The topics were chosen through consultation with current and past carers. These are available in English, Polish, Serbian and traditional Chinese from www.resthaven.asn.au. The English version has been printed in a booklet titled, 'Live Well, Die Well: Information for carers and families of people with end stage dementia'.

These resources were developed by the Dementia Palliative Care Project Team:

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We recommend that this tool is used alongside the Better Practice Project, Coordinators' Handbook, *Imagining a better life for older people*, Joyleen Thomas, Better Practice Project, Aged & Community Services SA & NT, 246 Glen Osmond Road, Fullarton SA 5063, Ph: 08 8338 7111.

How to use this guide

This guide provides strategic pathways to improve support for carers and people living with dementia. This guide operates alongside the existing policies and processes for community services within your organisation, it does not replace them.

There are sixteen chapters to this manual, covering the key elements of a palliative approach to dementia care. Within each section there are strategies to help you think about identifying and achieving the goals. At the end of each of these there is a reference to the Palliative Care Standards.

Chapter 17 provides useful links and contacts, and Chapter 18 lists the references cited in the Handbook.

Contents

About this handbook	3
How to use this guide	3
Aims of the handbook	5
Palliative Care	5
Stages of Dementia	6
Factors that promote a 'good home death'	8
Palliative Care Standards	8
Person Centred Care	9
1. Getting to know the person	10
2. Identifying, anticipating and addressing the client's needs	13
3. Social, spiritual and cultural support	17
4. Advance planning	23
5. Working with the client's supportive network	25
6. Collaborative team work	30
7. Convening case conferences	33
8. Identifying transition phases	34
9. End of life care: comfort care	35
10. Pain management	40
11. Nutrition and hydration management	42
12. Impending death	44
13. After death	46
14. Grief, loss and bereavement	48
15. Supporting staff and volunteers	50
16. Documentation	51
17. Useful links and contacts	52
18. References	54
Appendix A: 'What we would like you to know about us'	56

Aims of the handbook

The aim of this handbook is to enhance the quality of life for people with dementia and their carers, through their lives living with dementia, to the end of life stage using a Palliative Care Approach.

The ultimate goal of palliative care is to relieve any emotional, physical, psychological, spiritual, cultural and social suffering promoting quality of life until death.

Palliative care

The World Health Organisation's definition of palliative care is, *'An approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.'*

A palliative approach is adopted or should be adopted when there is no longer any hope of cure for the life-limiting illness.

A palliative approach is not confined to the end stages of an illness. It provides a focus on active comfort care and a positive approach to reducing an individual's symptoms and distress throughout their illness. The family are included in all aspects of care planning.

A palliative approach does not mean the withdrawal of treatment – it is a change of intent in the treatment to the promotion of comfort and alleviation of pain and suffering rather than achieving a cure.

It is not about euthanasia or using extraordinary means to prolong life.

A palliative approach may mean that a person still receives treatment for the disease in order to maintain comfort.

A palliative approach to care is about living and having a good life until a good death.

Three forms of Palliative Care

1. A palliative approach to care

The underlying philosophy of a palliative approach is a positive and open attitude towards death and dying. The promotion of a more open approach to discussions of death and dying between the clients where possible, their family and carer and the aged care team facilitates identification of their wishes regarding end of life care.

2. Specialist palliative service provision augments the palliative approach by adding the specific input of a specialised palliative care team to:

- Assess and treat complex symptoms.
- Provide information and advice on complex issues (such as ethical questions, family issues, psychological distress) to the primary care team.

The aim of this provision is to supplement the care provided by the primary care team such as an aged care organisation. They can be called in at any time during the pathway of the illness when there is a complex need, such as pain that cannot be resolved, or for a sensitive discussion with family on whether or not to insert a feeding tube.

3. End of life care is a form of palliative care appropriate for a client in the final weeks or days of life. Care decisions may need to be reviewed frequently and care goals are sharply focused on the client's physical, emotional and spiritual comfort as well as the needs of the family.

Family

Family is defined as 'those who are closest to the client in knowledge, care and affection. The family may include the biological family, family of acquisition (related by marriage/contract), and the family of choice and friends (including pets)'. Based on this definition, family could include carers, friends, neighbours or other people. The term 'supportive network' has been used in this publication to describe family and friends.

Life-limiting Illness

Life-limiting illness is an illness that can potentially cause death. Dementia is a terminal illness that will cause death. However many people with dementia will die from other causes such as pneumonia.



Stages of Dementia

Dementia is often described in stages as the disease progresses and it groups behaviours and medical issues that tend to occur together. However it must be remembered that not all people living with dementia will necessarily experience all of these issues, nor in the order described below in the table. There is no distinct beginning or end to each of the stages.

This list is a guide of what MAY happen. Every person is different and they may or may not experience the signs and symptoms.

Many people with dementia are able to maintain their lifestyle within the community with support of families, carers, friends and health and community care services. The following table, from the *South Australian Dementia Action Plan 2009-2012*, describes the impact of dementia on the person.

Time Frame for Dementia

There are no definitive time frames as dementia affects each person differently.

As a guide, a person with Alzheimer's disease can live from two to 20 years, with about eight years being the average. Advanced stage dementia is when the person's neurological deterioration is severe, and they will more than likely need assistance with all their activities of daily living. Although it is hard to put a time frame on how long people stay in this stage, it can typically last from one to two years, differing for each individual.

Stages of Dementia

	Early onset	Mild	Moderate	Advanced
Memory	Slight forgetfulness that happens regularly, such as getting lost on a familiar route.	Noticeable short term memory loss that affects everyday life, such as false memories, forgetting the layout of home.	Substantial memory loss when only old information can be recalled and new information is rapidly lost.	Severe memory loss when only parts of old memories remain.
Orientation: time, place and persons	Generally clear, correct and aware. Reduced attention span, repetitive talk, anxiety or suspicion about partner's behaviour.	Confusion about dates and times; sometimes mistaking places and becoming lost; difficulty in recognising familiar people.	Substantial difficulty in recognising time, places and people, difficulty finding right words, mood swings, wandering.	May recognise people but not recall why; may no longer recognise close family; may no longer talk; may lose mobility. May be up all night, and not know the difference between night and day.
Judgement and problem solving	Slightly less capacity to problem solve.	Difficulty problem solving, such as handling money, driving a motor vehicle.	Increased difficulty problem solving; occasional sexual disinhibition; may become upset when faced with change.	Unable to make judgements or problem solve; severe depression often accompanied by agitation or psychosis.
Community participation	Slight communication difficulties that affect participation in social activities.	Difficulty finding words or following conversation; needs support in social activities.	Lack of interest or willingness to attend social activities, difficulty communicating more apparent, requires constant supervision.	Very limited ability to engage and interact with others socially, even with supports. Speech may be severely affected. May be anxious, agitated or sometimes violent.
Home and personal interests	Slight change in the ability to do home based activities, hobbies and intellectual interests.	Difficulty functioning at home, undertaking or completing tasks.	Only effective in simple tasks, lacks interest in usual home-based activities and interests, often suffering from depression.	Unable to find their way around the house.
Personal care	Manages own self-care.	May need prompting.	Requires assistance.	Full assistance needed.

Factors that promote a 'good home death'

The following factors promote a good death at home:

- Person centred care
- Holistic care
- Desire of the client and their carer for a home death
- More than one informal carer
- Skilled accessible medical support, optimally, providing home visits
- Effective pain and symptom management
- Effective coordinated team of palliative care services, providing home visits
- Demonstrating mutual trust and respect
- Sharing mutual goals
- Sharing knowledge
- Respecting each team member and care provider's philosophies and policy
- Coordinated communication that is effective and objective
- Respectful, open and honest relationships between care providers and the client and their supportive network
- Client, carer and supportive network cared for as a unit
- Clients, carers and supportive networks' confidence in the team supporting them
- Bereavement care
- Financial resources.

Palliative Care Standards

Palliative Care Australia's Standards for Providing Quality Palliative Care for all Australians are as follows (adapted):

1. Care decision-making and care planning are each based on respect for the unique individual, their caregiver/s and family. The client, their caregiver/s and family's needs and wishes are acknowledged and guide decision-making and care planning.
2. The holistic needs of the client, their caregiver/s and family are acknowledged in the assessment and care planning processes and strategies are developed to address those needs, in line with their wishes.
3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the client, their caregiver/s and family.
4. Care is coordinated to minimise the burden on client, their caregiver/s and family.
5. The primary caregiver/s is provided with information, support and guidance about their role according to their care needs and wishes.
6. The unique needs of dying clients are considered, their comfort maximised and their dignity preserved.
7. The service has an appropriate philosophy, values, culture, structure and environment for the provision of competent and compassionate palliative care.
8. Formal mechanisms are in place to ensure that the client, their caregiver/s and family have access to bereavement care, information and support services.
9. Community capacity to respond to the needs of people who have a life-limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.
10. Access to palliative care is available for all people based on clinical needs and is independent of diagnosis, age, cultural background or geography.
11. The service is committed to quality improvement and research in clinical and management practices.

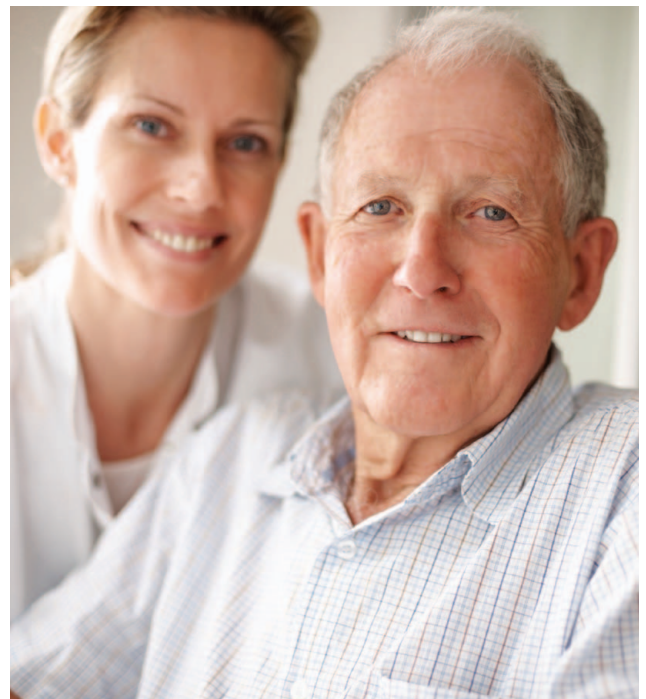
Person Centred Care

The term 'Person Centred Care' originated from Professor Tom Kitwood who witnessed distressing treatment of people with dementia living in Residential Aged Care Facilities in the mid 1990s.

Amongst the many things he witnessed was four people with dementia in a four bed ward, sitting on commodes with no curtains for privacy, being fed their breakfasts while the staff chatted amongst themselves. He thought there must be a better way!

All the elements of person centred care as described by Dawn Brooker (2007) below, need to be present to be delivering true person centred care.

1. Valuing people with dementia and their enablers, promoting their citizenship.
2. Treating all people living with dementia as individuals, appreciating that they have a unique history that will affect the way they respond to dementia.
3. Looking at the world from the perspective of the person living with dementia, stepping into their reality and walking with them.
4. Recognising that all human life is grounded in relationships and people living with dementia need an enriched life full of opportunities to connect with other people.



1 Getting to know the person

A person living with dementia does not cease to be the person they once were. The dementia may make it more difficult for them to be the way they used to be with others or more difficult to do things that they once found easy.

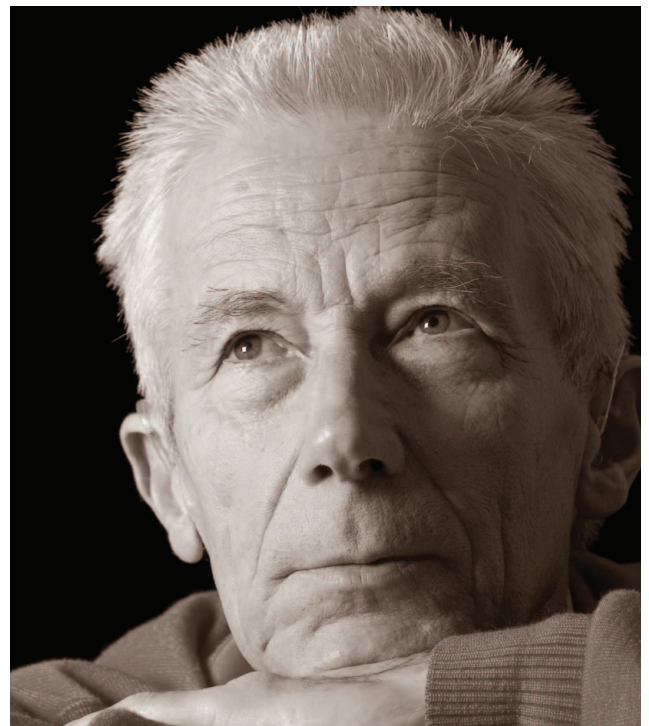
At the core of their being, however, the person still remains. The key challenge for those helping the person with dementia is to find ways of connecting with that person.

People with dementia gradually lose their ability to communicate verbally and find it more and more difficult to express themselves clearly and to understand what others are saying. We need to develop our skills, imagination and intuition to connect with what they are trying to tell us. To do this, we need to know ourselves and be aware of how we communicate with our bodies and tone or pitch of our voices. When communicating with the person with dementia, we need to listen with all our senses. There is always a reason for their communication and it is up to us to understand what they are telling us. The person's experience of living with dementia is dependent on how we respond to them.

It is difficult for human services to address a person's needs without understanding and knowing the person and what is important to them as best as you can. We need to be aware of their strengths and abilities as well as their vulnerabilities to provide individualised care. As a starting point, it is imperative to get as much information as possible from the people closest to them, finding out who the person is and what is important to them.

In western culture, cognition and memory are upheld as the indicators of personhood, which can lead to deeply embedded assumptions that people with advanced dementia have lost their personhood. This assumption can lead to the implication that people with dementia do not experience humiliation, thus negatively influencing the care provided to them; 'they are treated as objects rather than as persons worthy of dignity and respect' (Kitwood, T.). Dementia happens at the stage in life when people's personalities are well formed.

People with dementia should be valued and respected and their right to dignity and quality of life supported.



Identify the primary caregiver

It is important to identify the primary caregiver (carer) for the person with dementia. In some cultures, this person may not be the one who makes decisions about the care for the client, for example it might be the eldest son. Some cultural customs may dictate that the son(s) manage the financial tasks and the daughter(s) manage the nurturing and caring tasks.

Recognise that each person is unique

To enable us to walk alongside the person living with dementia, we must step into their world and understand what is important to them.

Identifying, acknowledging and appreciating the qualities and strengths of the person with dementia shows who the person is and counters the focus on dementia.

Get a picture of their individual story using the 'What we would like you to know about us' document (see Appendix A).

Develop the Care Plan to incorporate all the information you collect and reflect their preferred form of address, such as Doctor, Captain, Sir, Lady and/or Mr/Mrs.

Discuss with the client and their carer, their cultural customs and how these needs can be assisted.

Using the 'What we would like you to know about us' document (refer to Appendix A)

Explain the purpose of this document to the carer and ask them to complete this. Offer to assist if needed. Ideally, staff should be familiar with the content of this document prior to visiting the person with dementia, so that they can use the information to maximise their opportunity to connect with them.

The aim is to understand who the person is, what they like or dislike, what is important to them, what they value, what interests them, their hobbies, where they grew up, what they did for employment, what life experiences they have had (both positive and negative) what were/are their dreams and goals, what they have achieved, what lights up their eyes and what gets them out of bed in the morning.

Caring for a person with dementia through the end of their life stage is an emotional time for the carer, supportive network and staff. Demonstrating that you care about the person with dementia in a professional manner and showing genuine interest and respect and physical tenderness and courtesy towards the person preserves their dignity. Showing an understanding of the humanity of the person is of great comfort to the caregivers to know that you value the person they love.

Identify what works and what doesn't for the person with dementia

Gain as much information as possible from their carer about how the person with dementia likes their care delivered and incorporate this in the Care Plan.

Identify their unique routines and incorporate in the Care Plan. Avoiding stress and confusion can enhance the client's ability to cope and be as independent as possible. Maintaining regular routines help to maximise this opportunity for the people with dementia. It will also help to minimise behaviours of concerns. A person living with dementia said, 'The feeling of some things remaining the same is a heavenly thought.'

It is important to know any triggers that may take the person with dementia back to an unpleasant experience in their life that could create fear and consequently agitation or aggression. For example, a person who was sexually abused as a child may become resistant if you attempt to wash them in bed.

Instruct staff and invite the carer to document any verbal or non verbal responses they observe from the person with dementia when engaging with them, eg. any stimuli, temperature levels, music, conversational topics.

Do not rush them.

1 Getting to know the person

Delirium

If a person with dementia suddenly becomes agitated for the first time, the first thing to look for is a medical or physical problem. This may be delirium, which describes the sudden onset of an episode of agitation due to a medical condition or from medication.

The most common causes of delirium are:

- Bladder infections;
- Bad colds;
- Bronchitis or pneumonia;
- Dehydration or poor nutrition;
- Falls or new strokes;
- Flare-ups of chronic diseases eg diabetes; heart, liver or kidney disease;
- Bad reaction to medications;
- Physical problems eg pain, discomfort, worry;
- Lack of sleep.

Delirium can be treated; the cause must be explored.

Preferred place of death

Explore, and, if able, identify where the client wants to die and where the carer wants the client to die. This needs to be reviewed from time to time, with no pressure being placed on the carer.

A way to begin this conversation with the carer is to ask, 'Would you be surprised if the person died within the next twelve months?' If they would not, then it may be time to begin the discussion.

Involve the client in their end of life planning as much as possible. People with advanced dementia may still be involved in the end of life planning if they can still speak a few words. Meaningful information can be gained, although it might take some time and require a range of ways of eliciting.

Questions to prompt an answer could be, 'Have you thought about the end of your life? When the time comes that you are nearing the end of your life, have you thought about how you would like it to end?' (Godwin, B, et al)

Encourage discussion with examples and or others preferences, such as where would they prefer to die and who should be present.

When asking the person with dementia such questions, a familiar surrounding will avoid added stressors. Remove distractions such as the television or radio being on. Be a key worker in their lives, someone who knows them well. Ensure the person with dementia is comfortable with you. Include their carer, who knows and understands them, their needs and desires.

Establish the carer's preference. If the person with dementia is unable to express their wishes, ask their carer, 'Did the person ever talk about what they would like to happen at the end of his/her life?' (Godwin, B, et al)

Document this in the client information sheet.

With the client and their carer, regularly review what is important to them when considering end of life issues, as wishes may change and this **MUST** be documented in detail so that needs can be accurately met.

Although there may have been a steadfast commitment to the client remaining at home no matter what the challenges, unpredictable factors may alter that view. There is no judgement in this, and hospitalisation may be necessary to relieve the client's physical distress, or their carer's distress. The carer may become overwhelmingly fearful, and not have the night time support required.

These matters erode the sustainability of families when caring for their loved ones. In reality, although counsel and planning has striven to avoid such difficulties, family dynamics may create a situation where the client is transported to a hospital for uncontrolled pain and management review. The carer who has minimal support or who has family overseeing and supporting from interstate or from afar, may need to reassess their care options.

2 Identifying, anticipating and addressing the client's needs

Families can feel the challenges of providing ongoing care, and may need practical assistance. Various individual responsibilities can add up to a significant strain on family resources, and signs of caregiver fatigue can be missed or underestimated by health care providers. Families with elderly caregivers are especially at risk. (Kristjanson, et al)

According to South Australia's Dementia Action Plan 2009-12:

- Service responses will recognise peoples' individual journeys.
- People with dementia, their carers and families are central to making choices about care.
- All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.



Identifying needs

The assessment and care planning process will specifically assess and document the needs and wishes of the client, carer and supportive network. This can be achieved by:

- Gathering all information from other assessments to avoid duplication.
- Listening to and observing the client to understand their needs, strengths, knowledge and expectations and ensuring the assessment documentation reflects these.
- Identifying and utilising the strengths of the carer and supportive network in the management and delivery of the client's care.
- Identifying and addressing the client's, carer's and supportive network's psychological, emotional, cultural and spiritual needs, belief systems and values regarding death and dying, and incorporating these into the Care Plan.
- Involving the client in the planning and decision making wherever possible.
- Identifying and documenting all the other service providers involved in the client's care and the care they provide.
- Collecting information from all other relevant and permissible resources. For example, there may be a divided family dynamics present which may require negotiation and coordination amongst members that enables for alienated members to participate.
- Clarifying the client's health status, and special needs, for example the need for cultural advisers and interpreters as required.
- Providing sufficient time for the client, carer and supportive networks to express their needs and perspectives.
- Verbally or visually outline the needs expressed, to assist with the organisation of their thoughts and ideas.
- Instigating a medication review in the end of life stages. Often, medications can be ceased.

2 Identifying, anticipating and addressing the client's needs

Referrals may need to be submitted to other supportive services such as a Palliative Care Registered Nurse, Occupational Therapist, Physiotherapist or Massage Therapists as required.

This process of assessment is about knowing the person well and understanding that all individuals are valuable and unique. Service providers need to ensure individual attention and personal control.

Providing relevant information

To provide all the relevant information to people to enable them to make informed choices, we need to:

- Identify all relevant external services.
- Provide the carer and supportive networks with information about relevant organisations and government services that may be beneficial.
- Make referrals to appropriate specialist services (such as counselling) with the permission of the carer's and/or supportive networks.

Specialist Palliative Care services can be consulted at any time. If the General Practitioner (GP) is reluctant to make the referral, the Coordinator can, and the team will then engage with the GP. It may be useful to inform the team about the client's situation, should there be a need to involve them later in the client's care.

Anticipating future needs

A key role that the Coordinator or Registered Nurse can play is to anticipate future needs based on your knowledge of the disease pathway and issues that may arise. You can do this by:

- Meeting with the GP to discuss the potential and actual needs associated with any underlying co-morbidities, such as cancer, chronic or acute depression.
- Discuss the anticipated and actual needs with the carer and supportive networks and develop strategies and plans toward desired outcomes.

You may need to prompt the GP or Medical Palliative Specialist to review longstanding medications.

Emotional and spiritual pain requires professional expertise.

Pain is an individual experience, unique and valid. Pain is not always constant. It can vary over the day and with different activities. It may also vary depending on emotional state and family life.



Adapting to changing needs

Ongoing assessment is required to ensure changing needs are identified and incorporated into the Care Plan. (See also Transition Phases)

This can be achieved by:

- Regularly reviewing the appropriateness of where care is provided.
- Documenting the anticipated areas of concern, and provide plans where applicable, to address them promptly, if and when they occur.
- Ensuring that ongoing assessments specifically assess the responses to care and stimuli and are then updated and incorporated into the Care Plan.

In the anticipated last days of a person's life, consider if it is necessary to get them out of bed, if this is likely to cause pain.

There are other options to keep people comfortable and maintain dignity. For example, rather than using a lifter to use the commode, they may use a bed pan, incontinence pads, a catheter or urodome. A one way valve can be used so that the bag can be kept in the bed, rather than on view, hanging from the bed. Rather than a shower, would a bed bath using dermolux be more comfortable?

Remember, pain relief may be necessary prior to any personal care.

Transition to hospital

If the client is hospitalised, the Coordinator must stay in touch with the hospital staff to ensure a smooth transition and provide any support or care required.

This may involve:

- Informing all service providers that the person has entered hospital and cancel planned visits.
- Identifying and documenting the name and contact number of the most appropriate hospital staff to discuss the person's care, such as the Social Worker, Registered Nurse or Clinical Nurse, Medical Officer, or Specialist.
- Communicating with the hospital verbally and in writing about your role and what care you coordinate for the client at home. Request that this is placed in the Patient Progress Notes or file, or write this in yourself.
- Providing copies of any Advance Directives, and encouraging the carer to take this document when the client is admitted.
- Identifying if the client requires their supportive network and/ or familiar staff to visit on a scheduled basis to advocate for their safety and rights, such as whether requests for treatment or no treatment are upheld.
- Ensuring each person scheduled to visit is aware of the client's wishes and confident to uphold these.
- Training and mentoring for staff, carers and supportive networks may be necessary. If this is the case, have an experienced person mentor them for their first visit.
- Enlist the Registered Nurse within your organisation as an advocate on behalf of the client and carer to assist with the negotiations with hospital staff to return home if this is the client's enduring wish.
- Hold a case conference with the hospital team as soon as possible to establish the goals to get the client home.
- Assess if there are any other community services that may be of assistance in sustaining the client's and carer's wish to be at home.

The client may be eligible for more support through the SA Palliative Care Packages Program, phone 1300 110 600 or fax 8342 8632.

2 Identifying, anticipating and addressing the client's needs

Support the client's carer and supportive network

- Discuss respite options with their carer and supportive network and the client where appropriate.
- For possible future or emergency use, register the carer with the local respite organisation. Ask the respite organisation to consider brokering the service using staff who are familiar to the client and their care, to provide continuity. (See the list of useful contacts at end of handbook for respite providers).
- Offer respite as an option and strategy for sustainability, throughout the care program.
- Identify members of the client's informal network who may be able and willing to provide respite.

Consider the need for rest and privacy

When scheduling care, consider the client and their support network's need for privacy.

- Identify and provide opportunities where the carer and support network have some private time with the client and ensuring these are stated in the Care Plan.
- Counsel staff in the recognition and maintenance of professional boundaries, when working with clients and families.
- Discuss with the Coordinator should you be invited to participate in family gatherings and celebrations.

3 Social, spiritual and cultural support

Social needs

Social needs can be described as the needs that arise from our basic characteristic as social beings. What happens in everyday life can affect our sense of self.

This is because identity is created and continued in social relationships. Even seemingly unimportant day-to-day contacts have important effects on a person's sense of who they are.

You can help to support activities in a person's daily life that are built around past and present interests. Understanding past roles can also help to explain and deal with unmet needs.

These unmet needs and losses the person has experienced can often lead to behaviours being considered 'challenging', but may be the only way a person can communicate these feelings of loss.

"We are generally defined by our roles, such as wife, father, aged care worker, plumber and so on. For people with dementia, they may be unable to enact these major life roles, thus giving the sense that these roles have disappeared. But their past social roles are deeply tied in with their ongoing sense of self and their past social roles have great importance."

"Many people see dementia as gradual erosion of identity until there is no person left. Evidence questions this. While many personal and social competencies reduce in a person with dementia, the person's self carries on. People with dementia may have reduced ability for spoken language, but they use unique styles of communication to show us their selves." (Dementia-friendly Environments)

In Daniel George's paper, 'Overcoming the social death of dementia through language', he wrote:

"The language we use to describe dementia shapes our perceptions of brain ageing and even contributes to what has been called the 'social death' of those most severely affected.

Another dominant language pattern involves the notion that dementia creates a complete and total 'loss of self' as it lays waste to one's brain, resulting in a 'living death' or a 'death that leaves the body behind' and creating 'non-persons' or 'shells' of individuals afflicted by the disease. Language that guides us in consciously or unconsciously removing people from human networks quite literally engenders 'social death'.

Our societal perspective of dementia may be less distressing if we see it as a change in self, not unlike the many changes a person undergoes in other life stages, rather than the 'loss of self'. This does not discount that the symptoms of dementia affect one's identity in ways that can be troubling and tragic."

'Identity is never completely lost until death.' (George, D)



3 Social, spiritual and cultural support

Valued roles

Develop, maintain and protect the valued social roles of people with dementia.

This can be achieved by:

- Identifying the valued roles held by the person with dementia and developing strategies to enhance, protect and maintain these.
- Including their social activities in their Care Plans.
- Ensuring that services do not create barriers to their friends' and family's involvement in their care. For example, do not schedule a visit for the home support worker during planned time to be spent with family and or friends.
- Being flexible, so visits do not stop them from attending social functions.
- Providing support and or training to enable family and friends to be part of their lives.
- Understanding their interests and hobbies and exploring possibilities for them to connect to typical venues in the community.
- Providing support to attend social functions and being a facilitator to make them the centre of attention rather than you.
- Being aware of the potential to cause more losses. By knowing a person's capabilities, you can avoid doing something they could manage themselves, even if guidance is required. This may be something as simple as handing them a soaped face washer in the shower so they can wash their private areas.
- Knowing their capabilities so you do not cause more harm by setting them up to fail in a situation.

Purposeful activities

Identify and promote appropriate activities that give the person a sense of purpose and wellbeing.

“Good dementia care is about creating opportunities for people to respond appropriately and utilise their abilities. One key factor for some people with dementia is that they may have reduced capacity to initiate activity or interaction with people. This may be due to a number of factors, but it results in the high risk of withdrawal and isolation leading to further loss of capacity. This in turn, results in increased care needs and costs for intervention. Activities should be related to interests that were important to the person before the onset of dementia or perceived by them as important now. The value of everyday activities (such as eating and bathing) and culturally significant activities in providing opportunities for promoting self-esteem, dignity and feelings of self worth should not be underestimated.” (Alzheimer's Australia)

Many challenging behaviours exhibited by people with dementia can be caused by boredom, a sense of being useless or losing control over their lives. Having something meaningful to do can counteract this. It can give a purpose, a sense of contributing, and build their self esteem.

- Identify what skills the person with dementia has left and use them.
- Ensure any activities you introduce will be fail safe. They must also be sufficiently complex for the person with dementia not to feel it is a token gesture.

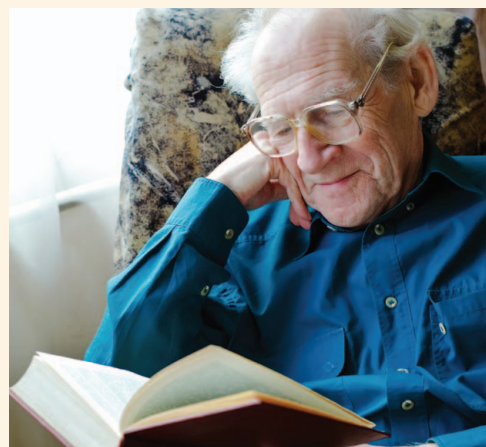
‘Colourful memories’

Elsie and Allen have been married for over 60 years. They have had a wonderful life together and still do. Allen has advanced dementia. Elsie describes him as a placid, gentle soul. The area Elsie finds the hardest to cope with is his restlessness. He wanders around the house and she feels she needs to watch him to help keep him safe. He has done things like try to open a can with a very sharp knife. Elsie has tried to anticipate the dangers and remove them, but still feels she can't rest when he is 'on the move'.

Allen has many interesting tales of his life shared with Elsie. He can join in the conversation with great enjoyment from time to time, as Elsie repeats his favourite stories. One of Allen's greatest past times was shooting. He was quite an accomplished shooter, going out with his faithful dog, which would retrieve all the ducks. Allen had also been a keen reader and still had the skill of turning the pages of books, but can't read or engage with the words.

Putting his skills together and the interest he shows in his life stories, a book was developed. This consisted of fifteen of his favourite stories. Each story was told in a colourful painting in naïve style, with a few large words on the corresponding page to explain what was happening. One of these included a painting of the church where Elsie and Allen were married, with the couple in the foreground.

Elsie reports that Allen will sit for extended periods with obvious enjoyment turning the pages - sometimes chuckling to himself and obviously connecting with the pictures. The whole family have enjoyed sitting with him reminiscing the stories. He has been able to instigate meaningful conversations, thus maintaining skills and connectedness to his family and his life.



3 Social, spiritual and cultural support

Spiritual needs

Palliative Care Australia describes spirituality as:

‘That which lies at the core of each person’s being, an essential dimension which brings meaning to life, constituted, not only by religious practices, but understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in the relationship with other people.’

Spirituality is one of the things you can still access when your cognitive power is gone.

With Alzheimer’s, the rational mind is gone, but the intuitive mind is still active.

If caregivers bring their rational mind to the task, they will judge the person with dementia as useless. People with dementia can be our teachers. They teach us that everything has its own meaning and yet is a mystery.

A daughter played some music of the medieval mystic, Hildegard. She felt it resonated with the Latin Mass era, which had meaning for her mother, who had dementia. In her last hours of life, she could see her mother connecting to the music. She described this connection for her mother as connecting to the:

‘deep wellsprings of life – to dimensions of sacred that go far deeper than language and doctrine.’

(Lefevere, P)



People with dementia know if you are being honest, so you must always work with integrity, and really listen to what they are saying. You can understand the meaning of their conversation from their tone of voice and body language and then respond authentically with the feeling they have portrayed. This will give them the sense that they have connected with you and give a great sense of well being, belonging and security. You need to be with them in their reality.

Aboriginal language does not have a word for dementia. When someone has confusion and memory loss they call it, ‘Wandering in the dreamtime’.

(Fisher, D)

Cultural needs

Australia has permanent residents from at least 200 countries and one in four Australians was born overseas. (2001 Census)

Multicultural Aged Care describes 'culture' as the way of life and a worldview of a particular group of people. It is a pattern for living that prescribes the values and behaviours of groups of people in a particular society.

Values are social principles, goals or standards accepted by persons of that culture. What is proper and improper, what is normal and abnormal behaviour is determined by one's culture.

Our likes, affinities, dislikes and aversions to certain people, objects or situations are usually influenced by our cultural roots and our specific personal experiences.

Cultural awareness is about exploring cultural and linguistic diversity and involves:

- Developing understanding about our own cultural self and cultural compass.
- Building knowledge and understanding about cultural content and contexts.
- Recognising, respecting, responding to and reflecting the cultural and linguistic diversity in our community, workplace...
- Working, living, communicating effectively in intercultural settings.

'The core essence of cultural safety is that the health professional understands their own cultural identity, and is aware of the impact their culture can have on another.' (Fenwick)

Cultural Intelligence (CQ)

We develop and demonstrate cultural intelligence in living and working in a culturally diverse society, community, work environment, by:

- Acquiring cultural experiences, knowledge and understandings.
- Applying cultural content factors to knowledge, skills and competencies.
- Adjusting behaviours: being mindful of cultural content and checking assumptions.
- Anticipating knowledge, skills and competencies to be effective in intercultural settings.

Principles of Cultural Intelligence (CQ) include:

- Accepting our cultural values and perceptions are culturally determined and not the norm.
- Respecting that other cultures are valid for their members.
- Developing knowledge, understandings, skills and competencies in determining which characteristics are the critical ones for that culture.
- Watching, not changing, our cultural response, may be practical at times.

'When working with a client and family from a culturally and linguistically diverse background, explore these areas:

- Attitudes to death, dying, care, disability.
- Cultural needs may become stronger when people know they are dying.
- Not all people from the same country or community share the same cultural needs.
- Knowing someone's cultural background does not mean you know their social, cultural or spiritual needs.
- Make sure your expectations of families or communities are not based on cultural stereotypes.' (Palliative Care Australia)

3 Social, spiritual and cultural support

‘The Boys’

Phyllis was in the last stages of her life. Her health was deteriorating rapidly and was in hospital. However, until now, she had managed to live at home by herself with the support of her children, mostly her daughter, Grace. Phyllis also has four sons, who would visit to help with tasks such as mowing the lawn. Phyllis grew up as the older sister of five brothers, so she has been surrounded by men all her life.

Phyllis and Grace treasure their relationship. They have shared a special closeness, one that Phyllis has never felt with her sons or brothers. When the conversation veers to ‘the boys’, Phyllis will always say with sadness, ‘they just don’t think’, and shows concern that Grace does it all without much help from her brothers. Phyllis can stay in this moment repeating, ‘they just don’t think’, for some time. Grace will always try to sooth and humour her mother when she becomes despondent about ‘the boys’.

Phyllis’ Coordinator has been involved in these conversations and has counselled Grace in the past, as it upsets Grace to see her mother become distressed. In conversation, the Coordinator and Grace discuss why this may affect her mother so deeply. Phyllis’ mother had died young and, as the eldest and being a female, she was expected to assume her mother’s role. She did this with little or no thanks or recognition from her father. The Coordinator shared that she believed Phyllis was at a very vulnerable time in her life and it could help to put her at ease to resolve this issue with her boys. In the past, when the boys have visited her, they have tended to talk about her to each other and not involved Phyllis. As Grace would say, ‘It’s not that they don’t care, they just don’t know how to show it.’

Now Phyllis needs the men in her life to reach out to her and reassure her that she is loved and appreciated.

The Coordinator encouraged Grace to talk with her brothers about this. Phyllis’ sons made time to visit and sit and talk, tell her how much they loved her, and refrained from talking over her when others were present.

Grace reports that her mother’s mood lightened with each reassurance her sons offered. The brothers were encouraged to not waste time, as Phyllis was experiencing more prolonged episodes of confusion and her health continued to deteriorate. Grace stated that, ‘they did not get it’, initially, but are gaining understanding as time closes in on Phyllis.

4 Advance planning

The principle of respecting people's right to be informed and to make decisions about their care is embedded in the principle of autonomy. Knowing and respecting the older person's wishes and about how they would want to be treated is not always simple, particularly when they are very frail. It is even more difficult when the person has dementia or is unresponsive.

Assisting the person's carer and their supportive network to be prepared for what is going to happen can avoid many surprises. These surprises are what often lead to the client being admitted to acute care in their last few days of life. If the carer and supportive network understand what to expect in the last few days of life, they are more likely to be able to cope.

Public consultations held by the National Health and Hospitals Reform Commission identified people's fears and concerns, 'that when the time comes, the system will fail them and their family: resulting in unnecessary burdensome treatment that doesn't respect their wishes and does not include family when requested.'



Advance Directives

When you first meet the client and their carer, establish whether or not the client has any Advance Directives. If so, these need to be followed. Ensure there are copies available to accompany the client should they need hospitalisation.

If the client does not have any documented Advance Directives and would be deemed mentally incompetent, their carer can complete a Statement of Choices in consultation with their GP to avoid any unnecessary burdensome treatment (visit www.respectingpatientchoices.org.au for information about Advance Care Planning and forms).

Strategies to help people prepare for future events include:

- The Registered Nurse or Coordinator to discuss the signs and symptoms of approaching death with the carer and supportive network.
- Provide the 'Live Well, Die Well: Information for Carers of People with Dementia' booklet for the carer and supportive network.
- If you do not have access to a Registered Nurse, the Specialist Palliative Care Team can be contacted. (See Useful Contacts section at the end of this Handbook.)
- Discuss the process to obtain a death certificate with the carer and supportive network. Sensitivity and encouragement is required to assist them to express their requests, fears, feelings and client wishes, to enable the process of bereavement.

Relevant cultural or religious end of life rituals

Confirm with the carer what the client's wishes would be in relation to specific cultural or religious customs for end of life rituals. Document these and note contact details for the relevant people who will be involved.

4 Advance planning

Plan in place for certification of death

If the client's support network plan for them to die at home, the following steps are required:

- Discuss the arrangements with the client's General Practitioner (GP) to complete and obtain a Death Certificate.
- Discuss what will happen if the client dies after hours. Is the carer comfortable to wait until the morning to call the GP? If not, who will be available to complete the Death Certificate?
- The GP must have visited or seen the client a minimum of three months prior to death. Otherwise, an ambulance and the police will need to be called.
- Establish and document if the carer and supportive network wish that certification wait until the agreed time, such as the morning after a night death.

NOTE: These steps are for an expected planned death at home. Should there be an unexpected death, the ambulance and police will need to be called.

Informing relevant authorities

- Discuss with the GP and Palliative Care team, identify any authorities required to be informed and document their contact details.
- In consultation with the carer, decide who is going to notify and inform all relevant authorities and family, friends and associates of the client's death.

Funeral Arrangements

To avoid pressure at a stressful time for the carer and supportive network, have a discussion about the funeral prior to the client's death. Some people may feel uncomfortable to do this.

Considerations:

- Document the funeral director contact details.
- Inform the funeral director of the impending death.
- Document the process for contacting the funeral director if the client dies in the 'after hours' period of the 24 hour day, and the carer and supportive network wish the body to be transported to the funeral director's premises immediately.
- Most will collect the body 24 hours a day, but there must be a GP or RN signed death certificate before they can collect the body.
- Some families choose to keep the body in the home for a day or so. Ask the funeral director to give them some information about how to keep the body, such as turning off the heating.

5 Working with the client's supportive network

'A caregiver can be a family member or a friend who is available to care for the dying person. The care may also be provided by a group of people.' (Macmillan, K)

Carers and families are to be valued and supported. Their efforts need to be recognised and encouraged. The carer has an emotional involvement in their practical role as a carer. Most have not planned to become a carer, rather finding themselves in that position. Whilst it can be a challenge, many express a sense of privilege that goes with this major responsibility.

Other significant caregivers need to be considered. These are people who are significantly involved in the care of the client and the carer but do not necessarily live with them, such as an adult child, sibling or friend.

It takes time to get to know a person and for them to feel comfortable to open up their life story. You need to be observant of their body language and their environment. A client's home is often the reflection of their identity. It is how people express themselves and shows what is important to them and will provide many cues for conversation.

Palliative care is based upon the precepts that care of the seriously ill and dying person involves care of the whole person and their families and loved ones – the physical, emotional, social and spiritual dimensions of all. (Puchalski, C, et al)

Caring is not only about shouldering day-to-day responsibilities. It is also an opportunity to return kindness and warmth to parents, relatives, or friends in their time of need, and an invitation to slow down and become more introspective in one's own life and a time for forgiveness. (Cheek, J, et al)

Families are comprised of individuals who may or may not be related through blood or legal ties. Families of people receiving palliative care are profoundly affected by the challenges of the illness. (Kristjanson, C, et al)

Communities play an important role in the quality of life of people with dementia, their carers and supportive networks.

Identify and acknowledge key support networks

It is important to identify and acknowledge on an ongoing basis all those involved in caring for the person with dementia. Some ways to do this are:

- Identifying and documenting who the carer is and their contact details.
- Providing a copy of the, 'What we would like you to know about us', document and asking them to complete if this has not already occurred (see Appendix A).
- Identifying and documenting other significant caregivers who need or desire to be involved in developing the Care Plan, reviews and decision making.
- Remember that carers may not necessarily be the key decision maker in some families or in particular cultures.
- When supporting a person through the end stages of life, you are working with the whole unit, or family.

Palliative Care Australia defines 'family' as, 'Those who are closest to the client in knowledge, care and affection. The family may include the biological family, family of acquisition (related by marriage/contract), and the family of choice and friends (including pets)'. Based on this definition, family could include carers, friends, neighbours or other people.

5 Working with the client's supportive network

Value the individuality of those in the client's supportive network

It is important to recognise the unique role of the carer and significant others in the client's network, taking into account cultural and personal meanings disclosed over the period of time. This can be achieved by:

- Exploring over time the understandings of the situation by the client's supportive network.
- Understanding the supportive network's preferences regarding disclosure, information giving and decision making. This is especially important given we are working with people with dementia and may not be certain how much the client knows, understands or comprehends about the situation.
- Promoting a relationship with the supportive network by providing time to listen and develop trust.
- Documenting what you understand about the client's supportive network.

Personal meaning is gained through life experience and is unique to each individual and not necessarily replicated.



Helping support networks to support carers

The Coordinator can work with support networks that may be able to provide respite and supportive care for carers at the end of life stages. Some considerations include:

- Considering the whole unit from the relationship circle (identified in the, 'What we would like you to know about us', document – see Appendix A).
- Consulting with the supportive networks to identify those who are willing and able to be involved and those who may need some encouragement, support and or training to be involved in the care.
- Offering to make contact or assisting the carer to make contact with the supportive network. This could be done by helping them to write a letter explaining their need for support from their network, or sending them a copy of, 'With a little help... How families and friends can support a Carer'. (Resthaven Inc)
- Inviting them all to a morning tea to discuss the care needs of the person and support needs of the carer.
- Requesting the group members nominate a roster of what, how and when they could assist. Examples may be to bring a meal in once a week, or do the shopping or even stay with the person for a couple of hours or overnight.
- Documenting the group's plans, roster or schedules, names and contact numbers.
- Preparing and encouraging family members and friends for roles associated with supporting the client.

'The best person to look after someone who's dying is someone who loves them.' (Pilotlight)

Providing information and support to carers

The needs of the carer and supportive networks for information, emotional support, education and respite are to be assessed and included in the Care Plan with ongoing assessment.

Some considerations:

- Discuss and identify what the carer and supportive networks need to enable them to sustain their caring role.
- Identify the strengths that the carer and supportive networks bring to the situation and incorporate them into the Care Plan. For example, they may prefer to perform the personal hygiene for the person with dementia.
- Assist them to assess their ability and confidence.
- Discuss the need for respite for the carer. This may be addressed by developing a schedule of visits from family and friends.
- Identify and recheck the understanding of the supportive network of care choices, options of support, and comfort care measures.
- Identify and document their expectations of what will happen and what they can expect from the service.
- Identify any sleeping, eating and or social difficulties (withdrawal), substance abuse issues and offer the appropriate support, such as linking to a counselling services or a review by their General Practitioner.
- Routinely provide verbal and written information about emotional and spiritual support focused on loss and grief for the carer and supportive network. This should occur from the beginning of diagnosis of a life-limiting illness and continue after the death of the client.
- Provide them with the, 'Live Well, Die Well: Information for Carers of People with Dementia' booklet.
- Encourage the carer and supportive networks to practice self care activities to minimise stress and promote wellbeing and safety.
- Assess the carer's and family's ability to cope with grief during the client's illness and offer support and counselling referrals based on need.

- Case Conferencing and or counselling may be required to assist carers and supportive networks to form a consensus, when there are varied preferences. The specialist palliative care services can be involved to assist with these situations.
- The carer or other members of the supportive network may want to be included in the care regime of the person with dementia. This needs to be established, encouraged and supported. When assisting carers to sustain the care that has been planned, there may be signs of fatigue. It may be appropriate for the Coordinator to suggest respite.

Facilitating family meetings

The Centre for Palliative Care Education and Research suggests that family meetings can be helpful in sharing information and decision-making. Some considerations in facilitating family meetings include:

- Obtaining a completed consent form from the client, carer and/or supportive network to share the information.
- Identifying and documenting how much information the client, carer and/or supportive network want shared with the rest of the family and friends.
- Facilitating regular family and friends 'gatherings' with the carer and supportive network to discuss what is happening.
- Exploring with the family the need and or option of having a priest or spiritual advocate present at meetings or at any other time throughout the client's care. Document these plans and or requests.
- Preparing and planning for the family meeting.
- Being aware of family dynamics and developing strategies to address these in a dignified respectful manner.
- Identifying who will be invited in consultation with the carer.
- Establishing ground rules, such as turning phones to low noise volume. You may wish to seek agreement that it is important to hear from everyone, but that one person should speak at a time, so that everyone understands completely the expressed concerns, issues and ideas of all present.

5 Working with the client's supportive network

- Inviting participants to introduce themselves if the need arises, and thank them for their assistance.
- Determining the understanding and purpose of meeting for the client and their supportive network and other participants.
- Prioritising concerns, issues and ideas and confirm in an 'Action Plan' which ones may be addressed at this meeting or future meetings. This may include referral to another multidisciplinary resource that may be helpful in the Care Plan.
- Providing information as requested, and specific to the client's and supportive network's needs, such as brochures, books and Enduring Power of Attorney, forms. Documents for Advance Care Planning can be obtained from www.respectingpatientchoices.org.au.
- Clarifying and or exploring with the family, when the client is unable or imminently dying, 'What do you believe your loved one would choose if they could speak for themselves'?
- Re-clarifying throughout the meeting, 'Is this how we understand the consensus to be concerning this issue?'
- Offering short breaks, if time allows, enabling participants to consider information, and or refocus.
- Concluding and summarising areas of consensus, unresolved areas of concern, matters that have resolved without specific action taken, ongoing plan, celebrate each one's achievements, contributions and insight. Thank all for their participation.
- Document the meeting (see record of meeting, right) and send a copy to all participants for future reference promptly post meeting.
- Keep a copy in the client home and office file.
- Make a courtesy follow up call with the carer to check if their needs were met and if they are reassured or need further encouragement.

This is an ongoing strategy that enables effective communication between the client, where possible, carer and supportive networks and Multidisciplinary Team members. If a new or additional member(s) are required to enter the client's care team, then this forum enables acceptance and lessens or prevents any disruption to care.

Record of family meeting

- Name of those present.
- The time and date of the meeting.
- Priority issues identified.
- The agreed 'Action Plan'.
- Time frame for resolution.
- Resolved issues.
- Positive outcomes.
- Referrals to other multidisciplinary team member(s).

Negotiation and mediation

There may be a need for negotiation and mediation should the client, carer, and supportive network have conflicting ideas about where, what and how care should be provided.

This can be approached by:

- Identifying and documenting areas of concern that may create conflict within the care group. Negotiate a consensus where possible, to ensure the client's and carer's Care Plan is not disrupted.
- Inviting the people involved to meet and mediate a discussion around their differences, concerns, requests, and/or fears.
- Identifying their concerns and commencing an 'Action Plan' to acknowledge and begin a process for resolution.
- Maintaining client centred and carer centred focus with all problem solving discussions, to ensure client's and carer's wishes are respected.

'Complex family situations may need advice and support from a social worker within the Palliative care team.' (Roe, P)

Susan and Peter

Susan has been caring for her husband Peter for ten years. Peter was diagnosed with dementia at 55. Susan expresses her desire to care for Peter in their home for as long as possible.

Susan became aware that she needed to accept more support, including help with Peter's personal care. It was a huge step for Susan to allow others to attend to his intimate needs. Susan experienced a period of uncertainty and stress that surrounded the transition of accepting more help and having little control of when, how, and who would provide that help.

Over time, Susan has explored the respite options for Peter, expressing grave concerns about inappropriate settings for people with younger age onset dementia. Susan had had to accept respite for Peter in a Residential Aged Care Facility, which caused him great distress and anxiety. When he returned home, his dependency on Susan had grown enormously. It took Susan some months to regain some of the lost ground from this experience. Susan was aware that she needed some extended respite to replenish herself, but was very reluctant to pursue due to this experience.

Susan was concerned that Peter was bored and was unsure of what and how she could engage him in activities at home to keep him engaged with life.

Peter's dementia has now progressed toward poorer coordination and mobility. Susan expressed that, 'everyone else gets trained to perform good manual handling practices, but me'.

To address Susan's fears and issues, the Coordinator worked with her to identify options.

Personal Care: the numbers of different staff are kept to a minimum. Susan trained them in how to perform the care.

Respite: an alternative was found in a Respite Cottage with a homelike atmosphere, where the maximum of people staying would be four. Peter could attend for short periods during the day to become accustomed to the environment and the staff. Susan had a planned break and each morning and evening the staff would text her to let her know that Peter was doing well. Susan's concerns now are that Peter's needs are increasing and they will eventually become too high for the Respite Cottage environment.

Activities: It was arranged for a Montessori trainer to spend some time with Peter at home to identify possible activities for him to engage with at home. It was found that he was attracted to the bocce balls and when shown how, he could mimic others and play a good game.

This happened just prior to Christmas and his family, including young grandchildren came to stay over the festive season. This year on Christmas Day, Peter was confused about what was going on. His family realised that last Christmas was in fact their last with Peter being connected to Christmas. This weighed heavily on them. However, Peter was able to connect with his grandchildren in a manner he hadn't been able to for some time; he played bocce with them. They would run up to him, take his hand and lead him over to the park where they played with laughter all round.

Training for Susan: It was arranged for a physiotherapist who specialised in aged care to visit and spend some time with Peter and Susan observing the assistance Peter required. The physiotherapist visited a few times and worked with them both to design and train Susan in safe manual handling techniques to assist Peter.

6 Collaborative team work

Being a carer can be physically and emotionally stressful. It does not need to be done alone. A team approach with the carer as the key member is often the best way to provide care in the home. The physical, emotional, psychological and spiritual needs of the person can be met in the best way.

Palliative care begins before the traditionally understood dying phase of care, and has become a multidisciplinary practice involving interactions with other relevant parts of the healthcare system. (Brant, J)

In some instances, the system of specialist referral disconnects the General Practitioner (GP) from their patient.

'GPs require a meaningful role, good communication and clear role delineation to be comfortable working with palliative care teams'.

'Nurses can give the GP and other team members a "real time" assessment of the patient and family, and can also give advice on possible therapeutic interventions or the need for inpatient admission.' (Hudson, P)

'Much of the personal stress in the palliative care field comes from issues related to the personal circumstances of the care worker, including their work environment, team conflicts, issues of power and control, role conflict, and role strain, with much less of the stress being due to dealing with dying patients and their families'. (Vachon, M)

Kendrick identifies that, 'the lack of shared and common language used by health professionals to describe the needs and service provisions of people approaching the end of life creates unnecessary confusion in planning palliative and end of life services.'

'What clinicians think that their patients want and what the patients and their families actually want is often very different.' (Fallowfield, L)

Identify the lead person

It is helpful to identify who will be the lead person and to communicate this to all service providers.

To develop collaborative teams it can be helpful to:

- Establish formal networks and partnerships between your services and the other providers, including the specialist services.
- Establish who will be the lead person, who will coordinate all services and disseminate all communications and facilitate case conferences. This may be a member of the Palliative Care team, the GP or the Community Coordinator or RN.
- Identify with the carer who they would prefer to relate to. It is likely to be whoever has had the most involvement with the client and their carer and knows the situation intimately.

For a client of an aged care organisation, it will most likely be the Community Coordinator or Registered Nurse who will take on the lead role.

Multidisciplinary Teams

Identify each team member of the Multidisciplinary Team and document their role and skills, such as clinical, emotional, religious or spiritual. It can be helpful to:

- Identify all the service providers involved in the client's care.
- Document the service providers involved, the contact person's details and their roles.
- Provide a copy of this for all involved.
- Monitor and assess for duplication of services.
- Identify the possible team members and organisations needed to be involved as the situation progresses.
- Coordinate contact with all multidisciplinary team members.
- Facilitate the communication between providers to provide a smooth and timely delivery of all services.
- Share the expertise and learn from any specialised provider involved in the client's care.

The role of the specialist palliative care team is to provide a consultative service and support the care team already providing the care. It is not their role to take over the case management when a Community Coordinator is involved.

Palliative care services usually respond quickly (within 24 hours) to requests for assistance when the situation is flagged as 'urgent'. Information required includes the client's name, GP, diagnosis (even though the client's need is more significant than diagnosis), consent and if the situation is 'urgent', 'not urgent' or 'when convenient'. A member of the palliative care team will usually phone the person who made the referral to assess the situation and determine the level of need.

Often all that is needed is advice on choice of medication to manage a distressing symptom and/or appropriate dose, particularly for the GP. (Roe, P)

Establishing rapport with the General Practitioner

The following steps may help to establish rapport with the client's General Practitioner (GP):

- The Coordinator or Registered Nurse should make a time to visit the GP.
- Prepare and explain to the GP's receptionist the purpose of your visit and that the cost will be covered by the program.
- Include, where appropriate, the carer and/or a member of the client's supportive network in this discussion.
- Provide and refer to precise verbal and written information of the service's involvement, for the GP.
- Express the desire to work with them to ensure a 'good death at home' for the client and their carer and supportive network.
- Establish and document the best means of communication between the GP and Coordinator/RN and ensure you follow this.
- Confirm and document the GP's availability for home visits and support through the 'end of life' phase.
- Explain your role to facilitate the case conferences and establish how the GP's services can be re-funded through the Enhanced Primary Care initiative through Medicare (see Useful Links and Contacts at end of booklet).
- Explain the role of the Specialist Palliative Care Team (if involved), of which the GP would be a necessary and valued member.
- Ensure the GP is aware of any Advance Directives or Plans that have been established.
- Establish how, when and why medication reviews will take place.

6 Collaborative team work

'GPs are very busy people and will digest the essence of a situation quickly, as long as everyone speaks the same language. The language of palliative care often includes functional status (Karnofsky Performance Scale www.hospicepatients.org/karnofsky.html) phase of palliative care, ratings on pain scales, Advance Directives and specific symptoms. Key words like "deteriorating", pain, "refusing food", and "fever" are clinically significant for a person with end-stage dementia. It's vital to have a concise and accurate description of the need for the GP to respond appropriately to your 60-second phone conversation.' (Roe, P)

Identify anticipated problems for the client's situation

You can identify anticipated problems by:

- Discussing with the GP any anticipated co-morbidities that may or may not exist and would require nursing considerations, and any potential implications.
- Confirming 'treatment/care standard orders' that can be implemented in Care Plans that would address the client's co-morbidities, such as chronic airways disease, anaemia, diabetes.

Formal networks established to provide respite and supportive care for caregivers

- Identify and establish contact and develop team relationships with respite providers in the region.
- Where appropriate and with permission, register the carer with the Commonwealth Respite and Carelink Centre, in case they need emergency respite (see Useful Contacts at the end of this Handbook).
- Identify appropriate supportive services, such as a pastoral carer, Alzheimer's Association and Carers Association (see Useful contacts at the end of this Handbook).
- Offer and request permission for other support services to be notified and informed of the family's need and potential access.

Negotiate after hours support

Talk with other providers, including medical services about the availability of after hours support.

Develop an After Hours Support Information Form and clearly document who is available and for what. Keep the After Hours Support Information Form in the front of the client's home file.

Extended Care Paramedics (ECP)

This service is operated through the SA Ambulance Services. The ECP are highly skilled clinicians who work collaboratively with other health care professionals to manage and treat people in their usual residence. They operate in metropolitan Adelaide and fringe areas and can provide telephone advice to local professional teams in rural areas. They are an alternative to hospital admission and can provide assistance with wound care, including suturing and skin tears, pain management, gastroenteritis, catheter/urinary tract infection/urinary retention, replacement of urinary catheters, supra pubic with acute problems (not routine replacements), rehydration, cellulitis, chest infections, PEG (tube feeding) replacements (acute, not routine), confusion/dizziness/lethargy, confirmed migraine, epistaxis.

Clients can be flagged with the ECP team by phoning 1300 13 62 72 or they can be contacted at all times by dialling 000.

7 Convening case conferences

Case conferences give the opportunity to define clear, long term and short term goals to inform service providers, carers and supportive networks about the processes which will provide comfort, the actions to be taken if emergencies arise, and the purpose, type and limitations of any ongoing treatment.

'The focus of a case conference should be:

- How useful is the treatment for the person with dementia?
- What choice would best promote the comfort of the person with dementia?
- Is the benefit of the intervention greater than the burden of the intervention for the person receiving treatment?' (Abbey, J)

'Inclusion of a palliative approach should not be delayed until the end stages of an illness. Incorporating a palliative care approach in the early stages may, alleviate physical and psychological distress at that time.'

(Kristjanson, L, et al)



Establish goals for the client's care

To establish the goals for client care, take the following steps with the Multidisciplinary Care Team:

- The Coordinator discusses the purpose of a 'Case Conference' with the client's carer and supportive network.
- The Coordinator contacts the GP to discuss the need for a Case Conference. The GP is encouraged to be present, but if this is not possible, they may prefer to be included via a phone conference.
- The Coordinator organises those who need to be present at the case conference, such as the social worker, speech pathologist, and palliative care team.
- The Coordinator forwards an agenda and outline of the meeting to all attendees.
- Provide the opportunity for team members to notify the Coordinator of any issues they would like addressed at the meeting, whether they can attend or not.
- Invite the carer and supportive networks to attend and provide a supportive environment to encourage them to discuss any issues that they have.
- Inform the Home Support Worker/s of the case conference, and give them the opportunity to provide the Coordinator with any issues they wish to have discussed. The Home Support Worker/s may be included in case conference if necessary.
- Comprehensively document the case conference meeting.

Document the issues that arise using an 'Action Plan', and determine the action required to resolve the issue. Key members responsible are to be identified as being instrumental in the resolution process. Time priorities can then be established. This will enable greater reassurance for the client and carer that a systematic and thorough approach is being applied to provide better outcomes.

Record and update the 'Action Plan' and forward any other relevant information to all Multidisciplinary Team members, the client and their carer within a few days after the meeting.

8 Identifying transition phases

‘The client is more vulnerable during transition points in their life, or periods of destabilisation resulting in a change in the level of care and/or support required.’ (Cheek, J, et al)

An alternative place of care is often sought when the carer or supportive network loses confidence and/or energy.

The following has been taken from the work done by the Centre for Health Service Development, University of Wollongong on the Karnofsky Rating Scale.

Ongoing assessment identifies transition phase

Regular and ongoing assessment is needed in order to identify the transition into the terminal phase.

Unless a systematic approach is adopted to identify that a person is entering the terminal phase, reversible conditions may be overlooked.

Considerations in this process include:

- Symptoms of the end of life must be assessed and documented with appropriate frequency, and treatment based on the wishes of the client, carer and family or supportive network.
- Recognising when the death of a client with dementia is imminent may be difficult to determine when other medical conditions exist.
- Families can be guided and cautioned that the dying process may be longer than expected, or that death may occur suddenly.

Stable phase

The stable phase refers to all clients who are not classified as unstable, deteriorating, or terminal. Considerations include:

- Ensuring the client's symptoms are adequately controlled by established management.
- Planning further interventions to maintain symptom control and quality of life.
- The situation of the carer and supportive network is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.

Unstable phase

- The client experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which requires an urgent change in management or emergency treatment.
- The carer and supportive network experience a sudden change in their situation requiring urgent intervention by members of the multi-disciplinary team.

Deteriorating phase

- The client experiences a gradual worsening of existing symptoms or the development of new but expected problems. These require the application of specific plans of care and regular review but not urgent or require emergency treatment.
- The carer and/or supportive network experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the person. This requires a planned support program and counselling as necessary.

9 End of life care: comfort care

The process of dying is a powerful process of living. Coordinators are often given the privilege of sharing this process with individuals living their final days. The caring role in such circumstances is one of true caring.

The main focus of providing care is to preserve the rights and provide for the needs of the client, their carer and supportive network. It is essential that the client's Advance Directives are followed at this time.

To establish a meaningful and effective relationship with clients, their carers and supportive networks, Coordinators must recognise and support the cultural beliefs and rituals associated with death and grieving. Sensitivity and understanding are fundamental for the development of successful relationships when dealing with issues of death and bereavement.

Each person will experience their own unique journey as they near the end of their life. Carers and their supportive networks are also to be treated with respect and supported to help them through what can be a very challenging time.

Generally, the Registered Nurse is responsible to assess and regularly review the individual's needs and develop a Palliative Care Plan to include the areas of comfort care. They will refer to the GP or specialist palliative care team as required. (See your organisation's Clinical Care manual).

When is the end of life?

Dementia, in all its forms, shortens life. It is an incurable and progressive disease. Identifying the end of life can be very difficult.

The end of life Care Plan may be influenced by any formal legal documents such as an Advance Directive.

The symptoms that are experienced at the end of life are similar in many terminal illnesses and should be taken into consideration when the Care Plan is being developed.

Support the client, carer and supportive network, as well as provide support to one another.

Aspects of an end of life Care Plan may appear to represent the withdrawal of care, challenging the notion of caring for another.

This is where open communication and support within the team is essential to work through any issues that may arise in the planning of end of life care.

- A plan should be developed for what will happen when the client dies, such as what happens when death occurs after hours. Depending on what the carer wants, the body can stay in the home until the next day.
- Family should have as much time as they wish with the deceased.

9 End of life care: comfort care

Personal hygiene

'The dying person frequently finds comfort in the provision of basic hygiene, but the activity of showering, or even a full bed sponge, is often found to be exhausting.' (Paris, M, et al)

Prior to the client's death, Coordinators need to ensure that care workers are aware of what is needed culturally, for example, are you allowed to touch the body?

Actions to be considered in attending to personal hygiene include:

- Reassessing the situation regularly and ceasing showering when it no longer is of comfort or a pleasure for the client.
- Completing a Palliative Care Plan and review regularly.
- Ensuring all staff are aware of any changes and are skilled in bed baths.
- Bed sponging may be very comforting.

Mouth care

Oral care must be individualised and includes the care of natural teeth, dentures, the tongue and the mouth cavity.

The care goal is that the mouth and lips are clean and moist.

Cleaning a person's mouth is not difficult. By helping the person have a clean mouth, you will increase comfort, preserve oral mucosal integrity and possibly improve appetite. (Macmillian, K)

- Assess and regularly review the condition of the client's mouth and develop an oral Care Plan.
- Include in the Palliative Care Plan.
- Attend to regular oral hygiene, including rinsing with water.
- Ensure staff are trained in oral care.

Favourite beverages can be used on mouth swabs to keep the mouth moist. Fluids such as pineapple juice help clean a dirty mouth. Do not use when mouth ulcers are present.

Palliative Care Australia suggests that rinsing with water, a soft toothbrush and toothpaste and regular soaking of dentures in a weak non-toxic solution is most effective.

A range of simple measures instigated early can reduce the need for dental and other interventions.

Tips in oral care:

- ½ teaspoon sodium bicarbonate dissolved in ½ teaspoon water can help clean a dirty mouth.
- Ice chips, especially those made from frozen fruit juice, can help a dry mouth.
- Thrush is a common end of life oral infection, and should be treated with an antifungal agent.
- Dissolvable aspirin can be used as a mouth wash for painful mouths.
- At the end of life, mouth ulcers can be painful, but treatable. Amosan mouth wash is very useful in the treatment of ulcers.

Eye care

Dying people are seldom able to maintain their eye hygiene.

The care goal is that eyes are clean and moist.

- Removal of exudate may be required several times per day, using lukewarm water and cotton swabs.
- Carers and people who are part of the supportive networks should be given the opportunity to help with this task.
- Artificial tears may be used if the client is experiencing discomfort.
- For people with glaucoma, management should continue to prevent distress from pain.

Difficulty in breathing (dyspnoea)

‘Severe shortness of breath can be frightening for both the person experiencing it and anyone watching. If you know what to expect, it may be less daunting.’ (Macmillan, K)

The care goal is that the client has no episodes of respiratory distress or excessive respiratory secretions.

Palliative Care Australia suggests breathlessness directly affects all aspects of a client's activities of daily living, limits mobility and can be due to increased anxiety: dyspnoea can leave clients feeling fearful and socially isolated.

Dyspnoea can be frightening for the family.

- Assess, document and report respiratory symptoms regularly.
- Gain the client's history re pre-existing illnesses.
- Repositioning can be effective in managing secretions.
- Having a cooling fan on their face may help.
- Suctioning is not usually required.
- Report if the client's breathing is becoming noisy.
- Treat the cause. For example, check if it is an infection and whether antibiotics will relieve the symptoms, or, if it is anxiety, provide comfort and stay with the person.
- When an episode occurs, administer the medication/ intervention and determine the effectiveness, document and report.

The evidence suggests that 70% of people receiving a palliative approach experience dyspnoea in the last six weeks of life.

Skin integrity

The skin is the largest organ of the body. For the client and the palliative carer, the challenge and reward is maintaining skin integrity that in turn promotes dignity and comfort. The goals set to achieve this require a realistic consensus of strategy, by all of the care team.

The major skin problems associated with people who are bed bound and dying, include oedema of the limbs, wounds, and pressure areas and skin and surrounding tissue breakdown.

The care goal is to keep the skin clean and moist.

Recommendations from Palliative Care Australia and the National Palliative Care Program:

- Assess the individual skin care required and document in Palliative Care Plan.
- Avoid products that dry or harm the skin.
- The need for pressure area care should be balanced against the need for comfort.
- Wounds should be managed in the least invasive way (no time to heal).
- If the client is incontinent ensure skin protection products are used.
- An air mattress may be necessary to avoid too much repositioning for the client.
- Sheepskins can reduce pressure ulcers.
- High specification foam mattresses can reduce the incidence of pressure ulcers.

Treatment of skin integrity should be realistic and agreed by all concerned.

9 End of life care: comfort care

Positioning

Frequency of repositioning should be reviewed regularly. Comfort should take priority over pressure relieving interventions that cause distress.

The care goal is that a comfortable position is maintained.

- Use the individual's preferred position as often as reasonable.
- Use analgesia in advance of repositioning where indicated.
- Distress resulting from repositioning may be pain related, anxiety related, or a combination.
- If there is pain, then it is best managed as incident pain. This means the administration of prescribed PRN (to be given as necessary as per GP orders) analgesia at a suitable time before repositioning.

Bowel management

Palliative Care Australia identifies that bowel care is a key component to the palliative approach. Bowel symptoms can impact on wellbeing and the quality of end of life experience for the client.

The care goal is that the individual is not agitated or distressed by constipation or diarrhoea.

- Aperients should be started as soon as the client has commenced an opioid.
- Daily assessment of bowel function needs to be part of the Palliative Care Plan.
- History of bowel habits needs to be ascertained.

Symptoms of constipation may include nausea and vomiting, straining, infrequent bowel movements, incomplete emptying, frequent small diarrhoea, rectal pain or discomfort, stomach pain/distension and hard stools.

Interventions need to be prompt so as to not compound constipation and lead to impaction of faeces.

Comfort and privacy are important considerations for the client's dignity, as is proper management of faecal incontinence.

Urinary management

The care goal is that the individual will be dry and comfortable.

- Urinary aids such as pads are used if the person is incontinent.
- Urinary output is reduced during the last days of life.
- Urinary retention should be excluded if the individual becomes restless. If retention is assessed, catheterisation may be necessary to relieve the symptoms. However, indwelling catheters are usually avoided.
- Generally, urine output reduces dramatically at the end of life, due to reduced fluid intake and reduced renal function.

Nausea and vomiting

The care goal is to reduce nausea and vomiting.

- Clinical history needs to be ascertained, such as whether the client has had a long history of nausea and vomiting, or has it just started? When does it occur?
- Clearly document when it occurs, the colour, smell and amount.
- Areas to investigate include what the client eats, when and how, or whether there are strong odours in the house.
- Management may include avoiding strong cooking odours or perfumes, offering small meals, camouflaging wound odours, and avoiding lying the client flat for half an hour before and after meals.
- Medication may be required.
- Alternative therapies may include music.

Holistic support

'It soon became clear that death was as individual as the life that preceded it and that the whole experience of that life was reflected in a patient's dying. This led to the concept of 'total pain', which was presented as a complex of physical, emotional, social, and spiritual elements. The whole experience for a patient includes anxiety, depression and fear and concern for the family who will become bereaved; and often a need to find some meaning in the situation, some deeper reality in which to trust.' (Saunders)

Holistic support means taking into account emotional, psychological, spiritual, cultural and social support needs.

We have the responsibility to alleviate pain and discomfort by being vigilant with assessment and prompt accurate action can enhance a good outcome for the family.

Assist at this important time with provision of fluids, cups of tea, or answering phone calls for the family, who need to remain undisturbed.

Maintain the temperature of the room at a pleasant level. Adequate ventilation of the room may need to be adjusted if there are many people surrounding the client.

Lighting often requires adjustment. Subdued lighting is often preferred, but it is not a rule. Night lights or sunshine may be the choice.

Some cultures and beliefs may surround the concept that the spirit needs to escape or travel from the room during this phase and finally with death. Therefore, the ability to open windows and doors may need attention.

Sometimes, those who are dying may require 'permission' to pass away.

Aromatherapy oils can often provide comfort and manage odours. Take caution with strong oils, they cause irritation and create a lasting association memory for those who remain.

The number of visitors can be monitored in accordance with the family's wishes, and is a very personal choice.

Length of time and discussion around the bed or chair can be encouraged to be harmonious and not fraught with discord between family members. Exhaustion for the closest carer can vary. They may have had sufficient opportunity and time to say good bye, and so promote opportunities for others to visit, if they have not already done so, to say their farewells.



10 Pain management

‘Pain is a physical symptom with spiritual, psychological, cultural and social dimensions.’ (Palliative Care Australia)

Pain in people with dementia is often not recognised or treated. The part of the brain that receives messages of pain is not affected in Alzheimer’s Disease. Therefore, we must assume that all people with dementia experience pain. However, they may not be able to interpret or report it.

Due to co-morbidities in people with dementia, illness has the potential to cause high levels of symptom distress.

The palliative approach involves noting the full range of symptoms that clients may encounter. There should not be complacency about the inevitability of pain. Active efforts to manage pain should be encouraged in every situation.

Given the few numbers of palliative care patients a general practitioner may see per year, their knowledge of pain management may be limited. They rely on Palliative Care Specialists to provide effective pain prevention and treatment. (Chye, R)

There are two broad spectrums of pain management; pharmacological and non-pharmacological.



Identifying pain in people with dementia

To ensure symptoms of pain are detected:

- Observe the client closely.
- Be aware of the personal signs of showing pain. This may be gained from their carer or gathered over time whilst getting to know the client. These may include changes in behaviour, moaning, facial expressions, aggression, increased body movements, guarding of an area.
- Document the client’s personal signs of pain in their Palliative Care Plan.
- Ensure staff are aware of their responsibility to document and report any signs of pain.
- Follow any pain management regimes, even if the client does not appear to be in pain. Document an ongoing and systematic approach to recording, assessing and managing pain.
- Explore pain management options that can be utilised safely and easily for the client in the home.
- Discuss with the carer and client if possible, and/or Multidisciplinary Team, the provision of pain management out of hours. For example, provision for overnight, weekends and holiday periods. Explore health funds policy with end of life provisions.
- Provide the carer with a controlled medication chart for recording prescribed medication, time given, and signature of administration. Explain how to use it.
- Provide 24 hour phone assistance for the carer if pain management issues arise, eg the Extended Care Paramedics (see next page), negotiate with their GP or the locum.

‘Relaxation, distraction, music therapy, and hypnosis should be considered for incorporation in the plan of care...they are complementary to pharmacological and procedural treatments.’ (Brant, J)

- Register the client with the South Australian Ambulance Service (SAAS) Extended Care Paramedics (ECP), if the RN or Coordinator anticipates that after hours pain issues may arise. SAAS EPC service is available to administer drugs to control breakthrough pain in extreme situations. There is no charge to those who have SAAS cover, a DVA Gold Card and some private health funds may cover this (see Useful Contacts section at the end of this handbook).
- Monitor and counsel the concerns and unknowns that lead to fear for the carer and supportive network when managing morphine and or other medications.
- Be clear that palliative care neither hastens (euthanasia) nor slows the dying process.
- Develop a 'Family and Friends Support Roster' that can be updated and maintained by a key care worker. This promotes security for all involved in knowing that the awkward and difficult times of the 24 hour period are covered, such as over-night and weekends.
- Ensure all are willing and able to administer pain relief.
- Provide training for carers and supportive networks and have written instruction available for pain relief (check your organisation's policies on this prior to implementation).
- Non-pharmacological pain management includes position change, hot and cold packs, diversion, music, massage – touch, passive exercises and companionship.

Through thorough assessment of the client's medical history, documented observations, exploration of the carer's knowledge of the client and their behavioural response to pain, one can determine location, intensity, type, when pain starts and stops, what makes it better or worse, and whether the medication or alternative therapy relieves the pain.

A better pain management regime can be developed if it commences early, rather than waiting until the pain gets worse.

Pain can be influenced by anxiety, depression, social situation, spiritual questions, fatigue and insomnia.

'When used appropriately, morphine and other opioids are not dangerous and patients don't die even from high dosages.' (Chye, R)

Debunking the myths about Morphine

MYTH: 'Using morphine means the client is going to die'

Some people with chronic pain can be on opioids for years.

MYTH: 'The client will become addicted'

Physical dependence and tolerance may occur but addiction or psychological dependence is rare and almost never occurs in a person without a history of drug use prior to their illness.

Other myths described by Palliative Care Australia:

MYTH: 'It will eventually become ineffective'

As long as morphine is the correct medication for the pain you are able to titrate [increase] up until the client is pain free. There is no ceiling to the analgesic effects... As the dose is raised, analgesic effects increase.

MYTH: 'Opioids hasten death and should not be used with older persons'

Older people are more sensitive to the effects of opioids, so the dose does need to be calculated carefully – 'start low, go slow' – but death will not be hastened. In fact, relieving pain can prolong life.

MYTH: 'Morphine causes respiratory depression'

When the dose of morphine is started low, and titrated slowly, respiratory depression is very rare. If it does occur it usually is in opioid-naïve individuals (those who have never had it before).

11 Nutrition and hydration management

‘Nutritional care is given to alleviate symptoms and not to seek a prolongation of life... decisions in relation to the nutritional needs of a person with a terminal illness should be taken within a holistic framework and should, therefore, encompass a range of views from the Multidisciplinary Team of health professionals, as well as the terminally ill person, his or her family and significant others.’ (O’Connor, M)

Difficulty in eating and drinking is especially prominent in end stages of dementia. This can be very distressing for the family and professionals caring for the person. Typically, professionals have relied on feeding tubes that go directly into the stomach (Percutaneous Endoscopic Gastrostomy [PEG]) to provide nutrition. However, feeding tubes are not useful in preventing malnutrition, nor healing pressure sores, nor do they prevent aspirational pneumonia. They do not provide comfort, nor do they improve functional status or extend life. Forgoing tube feeding has been associated with neglect and abandonment, so it is a very sensitive area and needs to be dealt with sensitively at the end of life stages.

The Specialist Palliative Care Team can be called in to have this discussion with the family to give the relevant information to assist their decision making regarding having a tube inserted or not.

Palliative Care Australia suggests that eating and drinking may be no longer relevant for a client who is at end of life, due to decreased metabolic rate.

It is best for people with dementia to be lovingly assisted to eat by another person for as long as possible.



A reduced desire to eat and difficulties with eating and swallowing are a normal part of the disease process and are often key indicators that the person is moving towards the end of their life.

The effects of dehydration in the terminally ill are that pulmonary secretions decrease and there is less coughing. Shortness of breath, congestion, nausea, vomiting and abdominal pain is reduced and there is less urinary output, resulting in fewer linen changes and less disturbance to the client. This may lead to electrolyte imbalance and cause muscle spasms and an altered level of consciousness.

Some considerations regarding nutrition and hydration:

- Careful attention to nutritional intake is both a clinical and a quality of life issue.
- Explore wishes with the client, if possible, and family and document.
- Identify causes for inability to maintain hydration.
- Assess and identify reversible client health issues, such as medication side effects and/or reactions, bowel dysfunction, constipation, impaction, diarrhoea, dental problems, oral health, ulcers, oral thrush, infections or even unfamiliar or disliked foods.
- Monitor weight loss and/or oedema and the impact it has on the client's wellbeing. Consider issues such as dentures no longer fitting.
- Consult with specialists, such as a speech pathologist, dietician or dentist.

(Abbey, J)

Identify who should decide when tube feeding can be discontinued and document.

‘In all cultures and throughout history, offering food has been a sign of caring and hospitality. Our mothers made sure we were all well fed. Most people enjoy eating with family and friends, especially on special occasions. In most religions, food is part of sacred rituals. It is no wonder, then, when someone we love is unable to eat and drink naturally, that we feel compelled to ‘feed’ them in some way. It seems to be basic caring.’

(Lynn, J, et al)

If the desire for food has waned, it may be just as pleasing for the client to experience ‘tastes’ of their favourite or craved foods, in the form of ice blocks or food or fluid soaked swabs.

Presentation may be all that is needed to maintain food pleasure for a client who is dying. Very small, delicate portions of foods may be more palatable and give a sense of communion with family and friends.

12 Impending death

Death is the expected outcome in the late stages of dementia. A good death requires that the values of the individual be integrated into the process of dying.

'How people die remains in the memories of those who live on.'

(Saunders, C)

Signs and symptoms of impending death

The inability to recognise and appropriately treat those who are dying is a barrier to achieving quality care. (Puchalski, C, et al)

The following group of symptoms and signs may occur in the last days of life. (Paris, M, et al)

Agitation, anxiety, restlessness – 'terminal restlessness'

The possible causes of terminal restlessness are many, and the exact cause will be evident in about 50% of cases. This can be due to unresolved issues. If possible, help the client work through these.

Noisy, moist breathing – 'death rattles'

As the client progresses through the dying process, the ability to cough and clear secretions is impaired. Concurrently, there may be an infective process occurring in the lungs, or fluid accumulating due to deteriorating cardiac function.

Secretions may cause noisy respirations, which may be distressing for family and staff. The noise that can be heard is the breath passing through trapped secretions. The best treatment is explanation. Most people can cope with symptoms if they understand what is occurring and are reassured that the client is not suffering. Attempts to suction out the secretions will be uncomfortable for the client and unsuccessful if the secretions are accumulating lower in the lungs.

The decision to use oropharyngeal suction is an important decision for the carer and all the others involved to ascertain if this action is appropriate. The discomfort of suctioning has to be weighed up with the benefits to the client. This breathing phase can be alleviated with prescribed small doses of morphine to settle the sound and decrease breathing discomfort or effort.

Peripheral shutdown

As the client's breathing patterns change and the lungs work less efficiently, oxygen fails to pass through the blood and clients are observed to have peripheral shutdown, cyanosis (bluish tinge) and cooling of extremities. Peripheral shutdown may be an indicator of impending death, particularly if the cyanosis is increasing, moving from toes to feet, fingers to hands. It is part of the natural process and is observed to varying degrees in many people who are dying.

Blood will pool under the skin where they are lying. For example, if the client is lying on their back, the blood will pool there, as the heart is unable to pump it around the body. The skin will become mottled.

Cardiac response

The pulse will be weak and thready and the client will be hypotensive (low blood pressure) due to heart pump failure and low blood volume within the vessels. There may be periods of tachycardia, rapid heartbeat felt at the pulse point of the wrist.

Inability to swallow

As the client's condition deteriorates, the ability to swallow alters. Swallowing ability needs to be assessed carefully each time a drink is offered and if the client coughs, or fails to swallow, fluids should not be encouraged. Providing moisture to the mucosa of the mouth by moist swab will maintain comfort.

Alteration in consciousness

It is not possible to predict the nature of the client's death. Some people remain conscious until almost the moment of death. Others may move in and out of consciousness for a period of time. Many will lapse into an unconscious state and not regain consciousness prior to death. While the client appears comfortable, there is no need to intervene in this process. However, should a client awaken and become confused or distressed, attempts should be made to identify the cause and options for comfort considered and implemented.

Changes to respiratory patterns

Cheyne-Stokes breathing can be identified by deep and shallow, rhythmic, breaths, followed by a long pause that can appear as though the client has died. This may occur over a short or long period of time and cause concern and apprehension for those caring for and close to the client.

Identifying the terminal phase

In the terminal phase, death is likely in a matter of days and no acute intervention is planned or required. Considerations include:

- Systematic monitoring and documentation can help to identify this stage.
- Accurate communication about the day to day client status may be difficult to interpret amongst families and cultures when emotions are high and stressed. Often there are questions asked, such as, 'When is the right time to alert distant family?' It is difficult to know exactly when the end will come, but recognising the transition phases gives a guide.
- Sometimes the dying person may 'rally' or come to a greater awareness, even responding verbally in a meaningful way, then decline to unconsciousness as if they have given their last contribution to their family and life.

Keep everyone informed

Some considerations in ensuring that all providers of care are informed of the imminent death phase or actual death include:

- Being aware of language and some word usage, when discussing death, it may have taboo connotations in some cultures (Taylor, A, et al).
- Identifying all the service providers from the information sheet and inform them all as soon as possible by phone.
- Writing to all the service providers to thank them for their collaboration and sharing of knowledge and expertise in contributing to a 'good death at home', for the client, following the funeral.

'The intensive care unit (or busy acute medical care ward) frequently becomes the hospital's palliative care unit. This is not only expensive for our society, but can be a cruel way to spend one's last few days.'

(Hillman, K)



13 After death

‘When death has occurred, a peaceful and calm approach is required by the Coordinator and care team to facilitate each individual’s closure... relatives, staff, carers and volunteers may require an opportunity to debrief and express their emotions, especially if the death was particularly difficult or protracted.’ (Paris, M, et al)

What to do after the person has died

- Immediately following the death of the client, and during the early bereavement phase, carers and supportive networks are given time and continuing care to provide comfort and to assist with the adjustment to the death of the client.
- Ideally, all arrangements regarding the death certificate and funeral have already been completed, so this can be a peaceful time with no added pressure on the carer and supportive network.
- Check the advance Care Plans. Does the carer want the body to stay in the house for a while or to be removed as soon as possible? Check that whatever is written is still their wish.
- Advise whoever is required to be informed according to the plans. Check with the carer whether they wish to do this themselves or want you to do it.
- Provided the death was expected and the GP has seen the person within the last three months, there is no need to call an ambulance or police.
- Plan and include the carer if they wish to prepare the client’s body for collection by the funeral directors. This may include brushing hair, washing their face, dressing them in ‘special clothes’, replacement of dentures, supporting the jaw with a rolled up towel or similar, to keep the mouth closed. Close the eyes. Open the windows and doors in the room to release the spirit, if this is important to their culture.
- There may be equipment attached to the body which can be discreetly removed by the RN or delegated care worker, to lessen the distress of the carer and supportive network.
- The carer and supportive network may be reassured and comforted by ‘preparing the body’ as a final act of love, or forgiveness.
- Families may have cultural and religious rituals that need to be performed and this would be planned for in previous assessments and meetings.



- Give the carer and supportive network time to say their farewells.
- Some may be fearful of being alone with the body, while others may need this time to be alone with them.
- Encourage the carer and supportive network to share their memories, stories, joys, frustrations, anger, and appreciation, whatever their experience is, as this may be therapeutic immediately post death and over time.
- Carers and supportive networks may require reassurance that it is acceptable to kiss, lay with, or hug the body, or to cry, or sit in silence.
- Provide an atmosphere that is unhurried and private that facilitates carers and supportive networks to spend as much time with the body as they wish.
- Guide staff with appropriate 'boundaries' for when to remain in the room to support the carer and supportive network once the client has died.
- A Certificate of Death must be completed by the GP. This can wait until morning if the person has died over night. Check the arrangements made with the GP re this.
- Registered Nurses can complete death certificates. This will depend on your organisation's policies.
- Determine if the Coroner needs to be involved. (Since 1 July 2005, the Coroner's Act (SA) 2003 no longer requires deaths caused by dementia to be reported to the Coroner's Office).
- Contact the funeral director and inform them of when the carer would like to have the body removed.
- Carers and supportive networks may need comfort and an opportunity to reflect upon the client's life.

Ongoing support for the carer and family

Provision of ongoing support should be based on the identified need of the carer and supportive network of the client. Some considerations include:

- The carer's and supportive network's ability to cope with grief should be assessed throughout the process. If necessary, referrals to counselling services should be offered.
- Ensure referrals to specialist counselling services have been suggested and encouraged. Follow up if necessary.
- The Registered Nurse, Coordinator or Home Support Workers (with permission from the Coordinator) who worked closely with the family, may have a follow up visit to the carer after the death to see how they are getting on.
- Allow staff to attend the funeral.
- Give the carer a courtesy call four months after the death.
- Send a card on the first year anniversary of the death of the client, saying you are thinking of them.

14 Grief, loss and bereavement

‘When someone very close has a life limiting illness, the adjustment can be extremely difficult. It usually takes a long time and a lot of effort to come to terms with what is happening. For all involved there is a sense of approaching change and loss. This is termed as anticipatory grief.’ (MacMillan, K)

Grief is a normal part of life and we all grieve differently.

Anticipatory grief can make it more difficult for the carer to care for the person with dementia. It can lead to feelings of guilt, wishing it was all over, and potential disharmony in families.

‘Loss is the severing or breaking of our attachment to someone or something that results in a changed relationship.

Grief is the normal response to loss. It includes a range of responses: physical, mental and emotional. These are usually associated with unhappiness, anger, guilt, pain and longing for the loss, person or thing.

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

Emotional and spiritual support

Emotional and spiritual support focussed on loss and grief includes the carer and supportive network. It begins when a life limiting illness is diagnosed.

Factors to be considered:

- Multidisciplinary Team and care workers are to be aware of anticipatory grief and how it may present in carers, supportive networks and clients.
- Home Support Workers are to report to the Registered Nurse or Coordinator if they believe that either the carer(s) or client is demonstrating complicated emotional and behavioural responses with their impending loss.
- The Registered Nurse or Coordinator is to assess, monitor and document the carer’s and supportive network’s anticipatory grief, taking into account any history of managing previous grief and loss. Your organisation may have a risk assessment form.
- Provide time to listen to the carer, show empathy and acceptance, beyond your own values and attachments.
- Reassure the carer and supportive network that their feelings are normal.
- Refer to other resources such as the Multidisciplinary Team, for counsel and guidance as required (this may involve the GP, Palliative Care Counsellors or Social Worker).
- From the beginning of the diagnosis of a life-limiting illness, the Registered Nurse or Coordinator is to routinely provide verbal and written information about emotional and spiritual support, focused on loss and grief, for the carer and supportive network.
- Ongoing support based on self-determined need is to be offered to the carer and supportive network.

According to Palliative Care Australia, grief is not an illness, but some people can develop complicated grief, which can become an illness.

Common grief reactions include:

- **Mental:** disbelief, pre occupation, sense of the dead person's presence, hallucinations.
- **Emotional:** anxiety, fear, sadness, anger, guilt, inadequacy, hurt, relief, loneliness.
- **Physical:** hollowness in the stomach, tightness in the chest and throat, digestive and related problems, over-sensitivity, a sense of depersonalisation, breathlessness, muscle weakness, lack of energy, dry mouth, insomnia, loss of appetite.
- **Behavioural:** crying, sleep disturbances, sighing, restlessness and over activity, appetite disturbances, absent mindedness, social withdrawal, dreams of the deceased, avoiding reminders of deceased, searching and calling out for the deceased, visiting places and carrying reminders of the deceased.
- **Spiritual:** feeling of anger, feeling of alienation from God, hope appears lost, feeling that life has lost its meaning.



15 Supporting staff and volunteers

‘It is vital that staff caring for the dying person receive care themselves.’

(Paris, M, et al)

‘Becoming emotionally close to patients is inevitable for many of us working within the so-called caring professions and has a cost...’ (Fallowfield, L)

‘...stress is the disparity between the adverse circumstances of our life and our ability to cope with them.’ (Mears)

Staff and volunteer education

Quality care is delivered when the workforce is well trained and supported. Coordinators, staff and volunteers need to have access to education about the principles, objectives and practices of palliative care, as they relate to the standards, to enable them to provide palliative care. This can be achieved through:

- Providing or accessing support and training for Coordinators, Registered Nurses, staff, volunteers to maintain sustainable practice and services, throughout the palliative and end of life care of the client.
- Providing opportunities and processes to enable staff and volunteers to reflect upon their feelings, responses, and closure.
- Providing emotional and practical support toward staff and volunteers to promote their insight and communication skills when interacting with clients, carers and supportive networks.
- Finding opportunities to support the staff and volunteers further if the need is identified.
- Considering roster rotation to assist staff if the end of life period has been prolonged.

Support mechanisms

Mechanisms for supporting staff and volunteers are identified and utilised as required through:

- Training staff and volunteers in self care.
- Providing opportunities for staff and volunteers to debrief with their Coordinator and have access to Chaplaincy or employee assistance services if required.

As part of this project, a series of six training modules was developed. It focuses on maintaining quality of life throughout the person’s life living with dementia and relieving any emotional, physical, psychological, spiritual, social and cultural suffering of the person and their family. The training was adapted from the Community Services Training Packages (CHC02) developed by Palliative Care Australia, condensed and with an added focus on dementia care.

‘The image that corresponds best to this work is that of standing too close to a fire. The challenge is to stand near enough to feel the warmth and yet to maintain a suitable distance that will prevent one from getting burnt.’ (Lattani)

16 Documentation

‘A concise and accurate description of the client’s presentation is important to help the Registered Nurse and General Practitioner manage pain and other symptoms such as terminal restlessness.’

(Paris, M, et al)

It is important to document the client’s responses to all care and interventions:

- Did it work?
- Did it cause pain?
- Did it cause pleasure?
- Did it calm the client?
- Did it irritate the client?
- Did it relieve the pain?
- Did it cause a response you could not read?

Gather and record information throughout the process.

This includes:

- Document the client’s exceptional responses. This helps to assess when and what might cause pain and or discomfort and alternatively what the client may find comforting and soothing.
- Use a pain assessment tool to assist in identifying and managing pain.
- Demonstrate and explaining its use to the carer and supportive network.
- Document pain assessment and responses by all members of the care team, who observe and witness these responses.
- Encourage the carer and supportive network to document what they observe, reinforcing their importance in the team.

- Use ‘Exceptional Documentation’ in progress notes at the end of life stage, to assist with thorough and comprehensive communication and care outcomes.
- Review the progress notes daily. Add the client’s and carer’s verbal feedback. This will ensure that the client and carer are being heard and maintain their general wellbeing. This will facilitate the ongoing ‘Action Plan’ in the resolution of issues that may arise.

Documentation is only useful when ‘exceptions’ and ‘action’ taken are stated, in all instances. The client’s progress notes will be read by all members of the care team. Therefore, written notes are to be objective, state observation, action taken and outcome.

Actions may be acknowledged as initial, intermediate or resolved as required.

Copies of all Advance Directives

Copies of all Advance Directives are to be filed in the client’s file at the office and in the client’s home folder.

- Request the carer keeps the originals separate from the client’s home file.
- When and if the client presents at Accident and Emergency or is admitted to hospital, provide hospital staff with a copy from the client’s home file. If they are not returned home with the client, replace it with another copy from the client’s office file.
- Place a Gold Advance Directive Rose sticker (or whatever your organisation uses to provide an alert to the fact that an Advance Directive exists) on the front cover of all home and office files, indicating the presence of the Advance Directives.

The Coordinator or Registered Nurse is to determine if the General Practitioner is aware of the Advance Directives.

Communicate with the GP by letter and phone the client’s palliative approach to care at home, and provide a copy of the Advance Directives and Care Plans as required. Recommend in the letter that the Coordinator and/or Registered Nurse, would value an appointment to discuss how they can work with the GP to assist the family.

17 Useful links and contacts

Useful contacts for information, counselling, respite and support groups:

Organisation and Address	Region	Phone
Resthaven Incorporated PO Box 327, Unley SA 5061 www.resthaven.asn.au	Metropolitan Adelaide, Adelaide Hills, Murraylands, Riverland & Limestone Coast	1300 13 66 33

Carer Support Services

Carers South Australia: Carers Advisory and Counselling Service	State Wide	1800 242 636
Carer Support 290 Glen Osmond Rd, Fullarton	South and East Metropolitan	8379 5777
Northern Carers Network Shop 15/130 Peachey Rd, Davoren Park	North Metropolitan	8284 0388
Carers SA Western Carers 66 Tapleys Hill Rd, Royal Park	West Metropolitan	8240 2900
Carers Link Carer Wellness Centre 39 Main St, Woodside	Adelaide Hills	8391 4476
Carers Link 26 Second St, Nuriootpa	Barossa and Districts	8562 4000
Carers Link 37 Old North Rd, Clare	Lower North	8842 1118 or 1800 246 300
Carers Link 9 Taylor Street, Kadina	Yorke Peninsula	8821 2444
South Coast Carer Support 63 Victoria St, Victor Harbor	Fleurieu Peninsula	8552 7419 or 0422 004 903
Kangaroo Island Carer Support Centre 20 Dauncey St, Kingscote	Kangaroo Island	8553 2262
Carers SA: Northern Country Carers 11 Loudon St, Pt Augusta West	Northern Country	8641 1844
Carers SA: River Murray and Mallee Carers Shop 4, Edwards St, Loxton	Riverland and Mallee	1800 806 580 or 8584 6855
Carers SA: South East Carers 61a Commercial St East, Mt Gambier	Limestone Coast	1800 654 429 or 8724 7188
Carers SA: Eyre Carers Shop 6, 2-4 King St, Port Lincoln	Eyre Peninsula, West Coast and Far North West	1800 350 004

Organisation and Address	Region	Phone
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Commonwealth Respite and Carelink Centres

33 Mackay St, Port Augusta	North and West Country	1800 052 222
77 Gibson St, Bowden	North and West Metropolitan	1800 052 222
290 Glen Osmond Rd, Fullarton	South and East Metropolitan	1800 052 222
95 Swanport Rd, Murray Bridge	South and East Country	1800 052 222

Palliative Care Specialist Teams

Southern	Mon-Fri, 9am to 5pm	8275 1732
Western	Mon-Fri, 9am to 5pm	8222 6825
Central	Mon-Fri, 9am to 5pm	8222 2021
Northern – Lyell McEwin Hospital	Mon-Fri, 9am to 5pm	8182 9208
Northern – Modbury Hospital	Mon-Fri, 9am to 5pm	8161 2351

Other Support Services

Agedcare Alternatives

An information service that will assist you to navigate, decipher information and identify options to meet your aged care needs.
www.agedcarealternatives.net.au

Statewide
 Mon-Fri, 9am to 5pm 8271 3888

Lifeline Statewide 13 11 14

Alzheimer's Australia SA
www.alzheimers.org.au Statewide 8372 2100

National Dementia Helpline Statewide Mon-Fri, 9am to 5pm 1800 100 500

Dementia Behavioural Management Advisory Service Statewide
 24 hours, 7 days a week 1800 699 799

Palliative Care South Australia Mon-Fri, 9am to 5pm 8291 4137

SA Palliative Care Packages: support for end of life care Statewide
 8am to 8pm, 7 days per week 1300 110 600

Metropolitan Referral Unit
 For referrals for hospital avoidance support and the SA Palliative Care Packages. Statewide
 8am to 8pm, 7 days per week 1300 110 600

Useful websites:

Respecting Patient Choices website:

www.respectingpatientchoices.org.au to obtain all documentation and information about advance care planning.

Extended Care Paramedics website:

www.emergencymedicalparamedic.com/extended-care-paramedic/ to access call '000' and ask for this service or, to flag a client with them, call 1300 13 62 72.

Enhanced Primary Care initiatives enable GPs to be paid through Medicare for various items such as Multidisciplinary Case Conferences
www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-caseconf-factsheet.htm

www.hospicepatients.org/karnofsky.html to download the **Karnofsky scale** used in end of life stages.

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Appendix A:

‘What we would like you to know about us’

An example of how the information gained by using this booklet can be used by carers of people living with dementia.

It is difficult for service providers to address a person's needs without understanding and knowing the person and what is important to them. Service providers need to be aware of the client's strengths and abilities as well as their vulnerabilities to enable them to provide individualised care.

People with dementia gradually lose their ability to communicate verbally and find it more and more difficult to express themselves clearly and to understand what others are saying. Therefore it is imperative to obtain as much information as possible from the people closest to them, finding out who the person is and what is important to them. It is also important for service providers to understand what is important for the carer.

This information helps service providers to see the person with dementia as a whole person and it takes the focus away from the dementia.

Please complete as much of this information as you are comfortable. Your Community Coordinator can help you if you wish.

References:

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An example that people living with dementia and their carers can complete:

Personal information about the client:

Details of my birth: place, time, year, what was happening in the world etc

My name is Peter and I have Dementia. My wife Susan and I would like to share with you 'what we would like you to know about me'. It is important for you to be aware of 'what makes me' as I am unable to communicate the moments that I feel an emotion, the task I would like to do, and the important message that I must convey. The following may help you to connect with me and me to connect with you!

I was born on Anzac day 1947, in Henley Private Hospital. I was the first born and named after my proud father. I am an elder brother to three other siblings. The Queen and Prince Phillip announced their engagement and married in the November the year I was born. The Transistor Radio and Britain's first Nuclear Reactor, were also a first in my year of birth.

My history, and cultural background: (eg where did I grow up, go to school, work etc)

As a young man I grew up by the beach surfed and attended the local public schools. My parents had the vegetable garden for the chooks, or the chooks had the vegetable garden for my parents! I loved all sports and played most of them. The pool table at home was my favourite pastime. My working life began as a teller in a Bank, then pursued finance for a car repossession company, then the latter 22 years of my career, I progressed through credit manager to store manager for a large retail store.

Important people in my life:

The most important people in my life are my wife Susan and my three children. I have special friends, special care workers, two special grandchildren, and special parents in law.

Things I like to talk about or things you can talk to me about:

I will enjoy you talking to me about travel anywhere, photography, and sport. The Crows football club have my vote.

Things you shouldn't mention:

I have an estranged son who lives interstate and I have feelings of anger and frustration when I hear his name.

What do people like about me:

I love to laugh and this usually means I am happy, but if you get me to laugh then you have made me happy. I am a gentle, unassuming bloke, determined in nature.

Appendix A: 'What we would like you to know about us'

How my spiritual needs are met:

I have Christian beliefs and went to Sunday school as a lad. I find spirituality in nature, being a friend and sunsets. I like to sit and contemplate with nature.

I am the happiest when:

I am the happiest when Susan and my family are with me, as long as they move about quietly. I enjoy listening to music at night with Susan as it helps us to relax and sleep better.

Things that make me feel safe and comfortable:

The things that will help me feel comfortable and safer are if, when you are assisting me, that you slow down the pace. I will get there eventually... then I don't have to deal with you losing patience with me. I can understand you better if you talk little and slowly...I can keep up better!

How to communicate with me:

I love people but I become anxious if there is a lot of noise happening all at the same time. I can be good company if I spend company with one person at a time, where that person listens to my attempts to converse. When I am done, and that is the best I can do, my 'good company' can reflect back what they understand I have conveyed. If it is not right, then we can start all over again.

I have noticed that most people learn to work out what I am saying, and give me the time to do it.

What is important to me:

I like to do things alone and thank you for giving me the opportunity to try. There will be things that I can not do, but I will forget what they have been, so please do not grieve for me. You are the one who will suffer the most.

Personal information about the carer:

Details of my birth: place, time, year, what was happening in the world etc

My name is Susan and I am Peter's wife of 35 years. I grew up in the foot hills, and did not know about Peter and his surfing childhood by the beach.

My history, and cultural background: (eg where did I grow up, go to school, work etc)

I also attended the local public schools and graduated to become a typist in a solicitor's office. They call typists stenographers now or legal secretaries. I worked until Peter and I married and had our children. My role was to stay at home and care for the children but only went back to work when my youngest child started school. I enjoyed my work as a receptionist for a medical radiologist firm for 15 years. I retired when I needed to care for Peter full time. I have made some special friends during that time.

Things I like to talk about or things you can talk to me about:

I love to talk about Peter our family our travels and life together. I am immensely proud of Peter's photography that adorns our home walls.

What is important to me

It is most important to me that Peter is happy and comfortable. I do not want him to feel abandoned. He is my priority. My children their children my mother and father also need me and it is most important that they are happy in life too. I value being fit relaxed and healthy and know that it is vital for me to be so to support Peter.

What do people like about me:

I believe I have an abundance of commitment, dedication, loyalty, patience and kindness as sustaining strengths for me to continue caring for Peter.

How my spiritual needs are met:

My needs are met and supported by being a Christian being able to meditate for 20 minutes a day and sharing Peter's love of nature.

I am the happiest when:

I have the most fun and experience the most happiness when Peter is happy and smiling and laughing, when I have had time to walk along the beach or park, receive a massage, listen to my relaxation tape in the evening with Peter, holidays, friends and time to shop.

Things that make me feel safe and comfortable:

The best gift that others can give me is to treat Peter with respect and dignity.

