

## Appendix 2: Resources to assist clinicians

These resources have been developed to assist clinicians to ensure that people with dementia receive equitable, quality care. The complex nature of the health of many people with dementia calls for care by a multidisciplinary team of health professionals working collaboratively with the person with dementia and their carer/family to provide healthcare that meets the person's goals and wishes.

Ultimately dementia is a life-limiting condition, and it is paramount that palliative care is available from diagnosis throughout the expected disease trajectory. These resources are provided to assist:

- timely diagnosis of Dementia

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- recognition that Dementia is a life limiting disease

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- early introduction to a palliative approach to care

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- management of care based on the person's current stage

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- ongoing timely assessment and identification of needs in each of the palliative care domains

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- referral to appropriate services to fulfil needs where needed

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- effective transfers between care settings when necessary

The working group adapted the 4Ms Framework <sup>39</sup> to develop the resources as described in ["2. Developing resources for clinicians: the 4Ms framework" on page 40](#)

### The roles of a multidisciplinary palliative care team in SWS.

People with dementia in the South Western Sydney region covered by SWSPHN and SWSLHD may have palliative care needs consistent with any of the three tiers of palliative care available and their need may vary over time. Considering that access to services is variable and dependent on clinical assessment/need, a range of clinicians and services may contribute to the provision of palliative care to people with dementia in SWS as part of a multidisciplinary team. When a range of clinicians and services are providing elements of care or when transitions are required between settings of care, having clarity of roles and responsibilities improves understanding by each clinician/service provider, communication about care and continuity of palliative care <sup>42 43 44</sup>.

#### GP's role

The Royal College of General Practitioners (RACGP) state that GPs play a fundamental role in a palliative approach to caring for a person with dementia through a) supporting their wellbeing and quality of remaining life while respecting their values, goals and treatment choices, and b) a proactive systematic approach to anticipating and planning clinical care needs and preferences from diagnosis through clinical and functional decline towards end of life and the transition of goals of care from treating illness to providing comfort and managing death. The [RACGP aged care clinical guide \(Silver Book\)](#) can assist GPs in this role that is playing an increasing part of general practice as the population ages.

[Part A:](#) Common clinical conditions in aged care chapters include but are not limited to Dementia, Palliative and end-of-life care, Medication Management and Deprescribing and practice points for each chapter.

[Part B: General approaches to aged care](#) includes relevant chapters on a palliative care approach, advance care planning, anticipatory care, families and carers and chapters that aid cultural appropriateness

- Perform [75+ years health check assessments](#)
- Ensure early assessment of Dementia
- Discuss the illness trajectory to help the person with dementia and their carer/family understand and cope with their situation

- Initiate advance care planning conversations ([Advance Care Directive](#))
- Ensure that ACP, ACD are uploaded to My Health Record
- Manage symptoms to minimise impact of Dementia on activities of daily living
- Assessment and identification of palliative care needs
- Manage acute deterioration in the community.
- Monitor conditions that can cause Delirium
- Coordinate the provision of a multidisciplinary approach to chronic and complex care needs
- Lead case conferences
- Review medicines and treatments and consider de-prescribing unnecessary medication when appropriate
- Arrangements for death at home if desired
- Refer patients to local specialist care services when appropriate
- Refer patients to [SWSLHD Palliative Care](#) only for:
  - Pain management
  - Symptom management
  - Psychological and social support
  - Counselling for patients and families on request
  - Bereavement support
- Ensure that medical records, medication charts and prescriptions are legible (45)

### **General Practice Nurse's role:<sup>45</sup>**

- Support GPs during [75+ years health check assessments](#)
- Ensure early assessment of dementia
- Facilitate effective communication between patient, family, and GPs around dementia as an end-of-life condition and planning for a good death ([Advance Care Directive](#))
- Support, facilitate, perform and/or lead Advance Care Planning discussions with patients and family
- Support or directly refer patients to [SWSLHD Palliative Care](#) when appropriate

### **Specialist physician's role. (e.g. Geriatrician private or public and Community Outreach Geriatricians, Oncologist)**

- Discuss the illness trajectory to help the person with dementia and their carer/family understand and cope with their situation
- Initiate advance care planning conversations if not already completed
- Ensure that ACP, ACD are uploaded to My Health Record
- Manage complex comorbidities
- Assesses, supports, and coordinates palliative care to people in both the community (home) and residential aged care facility in accordance with individual ACP/ACD
- Manage acute deterioration in the community or residential aged care
- Participate in case conferences
- Review medicines and treatments and consider de-prescribing unnecessary medication when appropriate
- Refers a person to hospital if specialist in-patient care is needed
- Refer patients to [SWSLHD Palliative Care](#) if necessary for:
  - Complex pain management
  - Complex symptom management
  - Psychological and social support
  - Counselling for patients and families on request
  - Bereavement support

### **Residential Aged Care registered nurse's role**

- Initiate advance care planning conversations if not already completed
- Ensure that clinical care is provided in accordance with a resident's ACP/ACD
- Ensure clinical deterioration assessment and management is part of daily practice including appropriate response procedures during acute and subacute conditions
- Facilitate effective communication with GPs and other visiting health professionals to ensure their residents receive quality health care
- Implement and ensure use of an appropriate clinical handover tool when contacting GP

(e.g., ISBAR) or Ambulance including ACP/ACD wishes

- Ensure GPs are contacted appropriately, and in a timely manner regarding important or serious matters relating to a resident's health and wellbeing during working hours and afterhours in accordance to previously established agreements
- Implement response process and procedures during afterhours emergencies in accordance with the resident's ACP/ACD to avoid hospitalisation

### **Specialist palliative care physician's role**

Provides direct management and support for complex- persistent, unstable needs (refractory pain and other symptoms, complex social or psychological distress)

- Works in partnership with primary care clinicians and other specialists through home visits, phone consultation, and out-patient review
- Communicates and shares decision making with primary care providers
- Provides consultative services to residential aged care facilities
- Advocates for addresses advance care planning where appropriate- including nominated or identified substitute decision makers, treatment/care goals, preferred place of care, cultural considerations.
- Aids managing acute deterioration in the community
- Collaboration and facilitating access to specialist support- outpatient clinic, hospital, palliative care units in persons with dementia requiring in-patient care
- Ensuring optimal end-of-life care working together with primary clinicians and care providers in care planning and provision, anticipatory prescribing, reviewing unnecessary medicines and treatment, verification of death and medical cause of death certification
- Help identify families or carers that potentially will have complex bereavement and grief and facilitate referrals for help and support

### **Specialist palliative care nurse's role**

- Has an expanded scope of practice with specialised knowledge and experience in palliative care
- Assesses, supports, and coordinates palliative care to people in both the community (home) and residential aged care facility in accordance with individual ACP/ACD or advocating for these to be considered
- Delivers care independently or in conjunction with other services within the healthcare system or in collaboration with non-government organisations
- Provides equipment and coordinates the provision of other community-based support and provides a liaison role with hospital services
- Provides education and mentoring for clinicians providing generalist palliative care
- In community preparing for end of life at home and verification of death procedures & bereavement support/information
- Provides information & support to carers to support them in their caring role

### **Nurse practitioners' role**

- Same as the SPC nurse including:
- Coordinates care in some residential aged care and in many SPC settings
- Assesses people with complex needs
- Prescribes a range of predetermined medicines within their specialty area
- Orders blood tests and other tests
- Refers people to other services including specialists such as renal etc.
- Provides information, support & services for carers
- Works from ACP/ACD or advocates for these to be addressed where appropriate
- In community preparing for end of life at home and verification of death procedures & bereavement support/information

## Generalist community nurse's role

- Provides home nursing care and support for people and families
- Assists and supports families in accessing information, equipment, and additional community services, and provides a liaison role between hospital and community to facilitate ease of transfer and delivery of care in the community
- Identifies if ACP/ACD is available and where appropriate promotes consideration of these through discussion with the person's GP
- Delivers palliative care in the home with SPC nurses and liaison with GP, including preparing for end of life at home and verification of death procedures & bereavement support/information
- Coordinates care and liaises with members of the wider palliative care team as necessary

## Specialist palliative care pharmacist's role

- Responsible for the medicine needs of the person receiving palliative care within the specialist unit or dedicated beds within the hospital
- Reviews a person's medicines on admission and at discharge, making recommendations as appropriate
- Provides advice on appropriate drug doses, alternative routes of administration of medicines when people are unable to tolerate oral medicines
- Monitors for and provides advice on the management of adverse effects
- Assists in deprescribing of medicines
- Counsel people and caregivers regarding medication-related issues whilst an inpatient and on discharge
- Provides pharmaceutical advice for people receiving palliative care with complex medicine regimens (particularly useful in care settings and locations where generalist clinicians provide most palliative care services) Note: Palliative care hospital pharmacists have undergone specialist training and have an extended scope of practice
- Liaises with pharmacists in other practice settings to organise ongoing supply of a

person's medicines and provide them with appropriate transfer of information related to the person's medicines regimen

- Assists in accessing medicine that is not readily available in the community, such as non-PBS and Special Access Scheme (SAS) medicines

## Pharmacist's role (e.g. community)

- Assists in the delivery of community-based palliative care, particularly medication management and deprescribing
- Supports people receiving palliative care at home along with their caregivers
- Provides MedsCheck services to review current medicines and develop a medication plan considering the person's palliative care journey and goals of care
- Reduces the risk of medication misadventure
- Provides Home Medicines Reviews to rationalise medicines, and provide support and education for both the person and caregiver
- Ensures the pharmacy is prepared to supply injectable medicines that may be required during the terminal phase
- Provide advice/education regarding medication disposal (particularly S4 and S8) post death

## Aboriginal and/or Torres Strait Islander health worker's role

- Assists healthcare providers to develop respectful relationships with Aboriginal and Torres Strait Islander people and their families
- Identifies key family members, spokesperson, and decision makers, and guides culturally appropriate communication regarding palliative care, death and dying
- Provides appropriate support. Healthcare providers need to be mindful that Aboriginal health workers are usually part of the person's cultural community, and the person may be a member of their close or extended family. Appropriate support may need to be provided to the workers themselves
- Promote culturally appropriate ACP & information
- Provide support to Carer/Family/Community in Sorry Business including Return to Country and Funeral organising

### **Bereavement counsellor's role**

- Provides support to the person's caregivers and those close to the person prior to and after death
- Provides one-on-one, group and support session counselling
- Refers people to specialist practitioners in cases of complicated grief

### **Counsellor and psychologist's role**

- Provides specialist psychological interventions to people with complex needs and pre-existing mental health
- Supports the person and their caregivers and people close to the person to address complex life issues
- Provides therapeutic psychological intervention and manages mental health diagnoses
- Provides support for healthcare providers working in palliative care

### **Dietitian's role**

- Assists optimal nutritional intake and develops a nutritional plan that focuses on the person's needs and wishes
- Considers current disease context, treatment plans and overall quality of life to set realistic nutritional goals

### **Music, art and complementary therapist's role**

- Provides holistic palliative care
- Improves quality of life through a variety of diversional, music and complementary therapies

### **Paramedic's role**

- Assist in the management, transfer and care of people receiving palliative care at home, particularly for those in the final days of their life
- Transfer and support of the person and caregiver throughout their journey from the hospital to place of care and vice versa
- Manage symptoms to support home care in line with the wishes of the person and caregivers
- They may also have a role in the after-death care. The person may die expectedly at home

or in a RACF. This role may include verifying expected deaths in areas where a GP, SPC service or community nursing service is unavailable

### **Extended care paramedic's role**

- Ambulance support for people receiving palliative care according to the Ambulance protocols and an ACD
- Paramedics who have completed additional training in palliative care amongst training
- Work collaboratively with palliative care providers to manage and treat people in their usual residence. Particularly those who wish to be cared for and die at home or in their residential aged care facility (RACF)

### **Pastoral care worker and chaplain's role**

- Assists people in identifying existential distress
- Addresses concerns associated with dying such as a search for meaning, inner conflict and unresolved personal issues
- Provides pastoral and spiritual care for all people and their families and friends, irrespective of what religion or world view held
- Provides support for healthcare providers working in palliative care

**Note: A chaplain is usually formally qualified, whilst a pastoral care worker will have worked in another healthcare field such as nursing, teaching or social work, before retraining in pastoral care**

### **Physiotherapist and occupational therapist's role**

- Assists people to maintain and improve function
- Supports patients to achieve greater quality of life and fulfil their goals of care
- Provides equipment and home modification
- Provides education and support regarding fatigue, breathlessness, and anxiety management, breathing techniques and exercise

### **Social worker's role**

- Assists access to social care and financial support
- Provides counselling and support for the person and their caregivers
- Organises and facilitates 'family meetings' to discuss the person's wishes
- Assists in navigating advance care planning documents, including power of attorney, enduring guardian, wills, and funeral planning
- Provides pre-bereavement and grief support and counselling for bereaved relatives

### **Diversional Therapist's and Recreational Therapist's role**

- University qualified therapists
- Prescribes and adapts individual and group leisure and recreational activities to promote the psychological, spiritual, social, emotional and physical wellbeing of individuals
- Provides leisure education and leisure counselling
- Undertakes leisure assessments
- Provides health promotional activities
- Provides lifestyle management

### **Leisure & Lifestyle staff, Wellness Officer, Health and Well-being staff, Activities Officer, Diversional Therapy Assistant roles**

- Diploma or Certificate level training
- Implements individual and group leisure and recreational activities

### **Speech pathologist's role**

- Identifies priorities and preferences in maintaining communication and managing swallowing difficulties
- Develops strategies that minimise the impact of symptoms on comfort and quality of life

### **Volunteer's role**

- Provides a support service for the person and their caregivers including spending time with the person at home, in hospital or the hospice environment
- Builds supportive relationships with people and their caregivers
- Provides activities such as having a cup of tea or reading a book with the person, taking the person to appointments, assisting with shopping
- Some SPC services provide specific training and accreditation e.g., writing a person's biography or making a memory box



## Dementia: the 4Ms framework

### What matters in dementia

#### Timely Diagnosis

A person with early dementia may:

- Appear more apathetic and to have less 'sparkle'
- Lose interest in hobbies and activities
- Be unwilling to try new things
- Show reduced capacity to adapt to change
- Show poor judgement and make poor decisions
- Be slower to grasp complex ideas and take longer with routine jobs
- Blame others for "stealing" lost items
- Become more self-centred and less concerned with others and their feelings
- Become more forgetful of details of recent events
- Be more likely to repeat themselves or lose the thread of their conversation
- Be more irritable or upset if they fail at something
- Have challenges handling money (46)

Timely and accurate diagnosis of dementia enables appropriate care and facilitates future planning especially Advance Care Planning. Timely discussions on prognosis of dementia is also essential to allow patients and family to prepare emotionally and logistically for the end-of-life <sup>47</sup>.

Although dementia can be difficult to diagnose it is important to know what normal cognitive decline with age is and what it is not. Cognitive assessment should be carried out:

- When a memory issue is reported by a patient, their family or carer. It should not be dismissed as a normal part of ageing without discussion. [Distinguishing points between normal memory loss and dementia.](#)
- Routinely as an element of an annual 75+ Health Assessment (MBS Item 701) or Aboriginal Health Assessment (MBS Item 715) for Aboriginal and Torres Strait Islander people, aged over 55 years

Assessment for cognitive decline - Refer to the [Cognitive Impairment and Dementia HealthPathway](#)

Key messages and practice points on communicating a dementia diagnosis can be found in The Cognitive Decline Partnership's [People with Dementia: a care guide for general practice](#) <sup>48</sup>

#### Advance Care Planning (ACP)

From the 4Ms framework we see that for all older people, what matters is that care is aligned to their own goals, values and care preferences, including, but not limited to, end-of-life care, and across settings of care. This is achieved through discussion, planning of care and anticipatory planning in the form of an Advance Care Directive or Plan.

The focus here is on how advance care planning differs when a person has dementia based upon the work of the Cognitive Decline Partnership (47).

- To provide better outcomes for individuals with dementia, ACP should cover an extended period of time and include a wider range of issues
- It is important to ensure that individuals receive a timely diagnosis of dementia and information about the potential prognosis
- ACP should be done as soon as possible after diagnosis of dementia, if not done previously
- Effective ACP for individuals with dementia requires conversations that focus on understanding a person's values and beliefs as values don't change with time or dementia
- The person with dementia should be involved in discussions and decision-making as much as possible
- The appointment of one or more substitute decision-makers is critical

## When to commence ACP:

If not done previously, Advance Care Planning should commence early in the course of the disease while the person can be actively involved in expressing preferences and setting care goals, **ideally, within a few months of a dementia diagnosis.**

The progressive decline of cognitive function in dementia means that leaving ACP to closer to the end of life may result in the person's values and wishes not being known or respected and family or carers being placed in the distressing position of having to make very difficult decisions. By starting early, clearer and better decision-making that reflects the person's wishes can be implemented throughout the dementia illness. This is especially so approaching end-of-life thus the end of life journey can be improved for the person with dementia, their family or carer and their health professionals.

The advance care plan of a person with dementia is likely to be needed over a longer time; therefore, it is strongly recommended that it should be **reviewed regularly.**

[Factsheet on Advance Care Planning for the person with dementia](#)

## Who should be involved in ACP conversations when a person has dementia?

**The person with dementia** should be involved in conversations and decision-making as much as possible. Capacity to participate in future planning conversations and decision-making should be presumed unless it is clearly absent. It is also important to recognise that capacity is decision specific and that people with dementia may be capable of making certain decisions but not others.

Information on Capacity can be found in:

- The [Capacity Toolkit](#) published by the NSW Attorney General's Department <sup>49</sup>
- [Decision-making capacity and dementia: a guide for healthcare professionals in NSW](#) <sup>50</sup>

The legal appointment of one or more Substitute Decision Makers (SDM) is crucial and the SDM/s should be present during advance care planning discussions. Gaining an understanding of the values and beliefs of the person with dementia will

increase their ability to make decisions based upon the values and beliefs of the person with dementia and not their own.

[Factsheet on appointing Substitute Decision Makers for people with dementia](#)

[Factsheet for the Substitute Decision Maker](#)

See Queensland University of Technology's website for further information and training modules on [End of Life Law for Clinicians](#).

## What should be included in an ACP/ACD for a person with dementia?

The progressive loss of cognitive function means that substitute decision makers may be called on to make decisions that cover a wider range of issues than health care at the end of life such as lifestyle and financial arrangements. Key issues for consideration and discussion in addition to health and end of life care include but are not limited to:

- Future living arrangements,
- Continuation of community and religious involvement
- Care of pets – where there is no help available from family, friends or neighbours the [RSPCA – Community Aged Care Program](#) may be able to assist.
- When it's no longer safe to drive
- Visitors and contact (especially with those where there may be conflict)
- Preferences for personal care

For further information on Advance Care Planning for people with Dementia see [Advance Care Planning Australia](#).

**Advice on advance care planning is available through Advance Care Planning Australia advisory service on 1300 208 582, 9am - 5pm (AEST) Monday to Friday.**

The NSW Ministry of Health document [Making an Advance Care Directive](#) provides comprehensive information for community members and a well laid out form that ensures that the resulting ACD covers everything needed to be valid



### Where should the completed plan be kept?

Advance Care Directives can be uploaded to My Health Record. This will ensure it is available to both Primary Care, hospital and residential aged care clinicians.

[My Health Record factsheet for aged care](#)

[My Health Record factsheet for general practice](#)

[My Health Record ACP Factsheet for individuals](#)

Paper copies of the Advance Care Directive and the form nominating a substitute decision-maker can be given to:

- family
- the substitute decision-maker/s
- your hospital, treating specialists and local doctor
- anyone else felt appropriate
- it is also a good idea to have a copy in a readily accessible place at home in case of emergencies.

### How to tips:

Communication style – some changes may assist the person with dementia to feel respected and a part of the discussion.<sup>51</sup>

- Direct speech to the person not their carer, family member or friend. Don't prejudge my level of understanding;
- Keep questions simple and provide information in smaller chunks avoiding jargon;
- Make eye contact and speak clearly, use short sentences, with one idea at a time;
- Be patient and understanding, sometimes it takes longer for a person with dementia to process information and find the right answer. Don't rush them, allow them time to speak;
- Ensure there is less noise and fewer distractions, such as bright lights, to help the person to focus.

Patients and families frequently require multiple visits and time to understand, process and then decide on what their future wishes will be. Clinicians should be prepared for multiple conversations/visits to allow the individual and family to have the medical situation explained, their wishes and values to be elicited, substitute decision-makers nominated, decisions made about what future treatments to have/not have, and finally to document a formal Advance Care Directive.

Open discussion of the disease, the prognosis and **disease trajectory** around the time of diagnosis can increase appreciation and engagement with advance care planning conversations by the person with dementia, their carer and family. This knowledge of how dementia may progress can also have significant impact on the choices that people make in an advance care directive. (47)

Conversations that focus on **understanding the values and beliefs** of a person with dementia are more effective than a focus on end of life only and may assist clinicians feel easier about initiating the conversation<sup>47</sup>. Values and beliefs remain consistent over a person's life and it has been demonstrated that people with mild to moderate dementia are more likely to engage and participate meaningfully in a conversation with family and carers when it is based upon values.

[SWSLHD Statement of Values and Wishes](#) can be used to document the values and beliefs of a person with dementia.

[GP guide - MBS items for advance care planning](#)

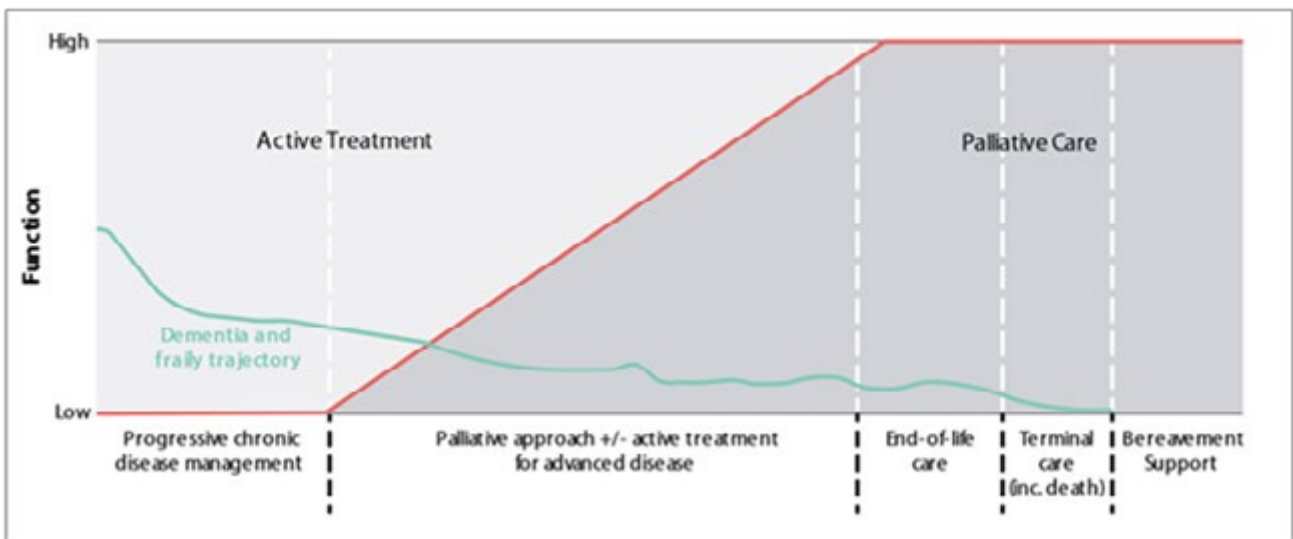
## Management: a palliative approach in dementia

### Early introduction of palliative care

A palliative approach to care that regularly identifies, assesses and assists with the person's needs should be introduced from soon after the time of diagnosis and maintained over the course of their illness is recommended (52). Early introduction of palliative care can reduce provision of clinically non-beneficial treatments, prolong life in some, while significantly reducing hospital presentations and costs <sup>53</sup>.

In dementia, a **person's initial palliative care needs may not be physical**. From the time of diagnosis difficulties may be experienced, to various degrees, within the psychological, social, and spiritual domains such as social withdrawal, anxiety and fear of dementia itself, fear of loss of independence, and fear of becoming a burden. As palliative care goals are centred around quality of life remaining, palliative care can be delivered at the same time as active treatment as illustrated in figure 1 that shows the dwindling decline of a person with dementia and the relative balance between active and palliative treatment.

**Figure 1: Simultaneous palliative and active care across the typical illness trajectory of dementia adapted from the RACGP Aged Care Clinical Guide (Silver Book) <sup>52</sup>**



### Early Dementia Stage

#### Recommendation

In early dementia provide palliative care and disease management concurrently. Introduce interventions to optimise comfort and function e.g. medications to slow progression if appropriate. Regular review and assessment of needs to identify palliative needs, anticipate and manage symptoms, exacerbations and acute events <sup>52</sup>.

A person with dementia may experience deterioration and require end of life care or terminal care. Recognition of deterioration at regular assessment points is vital to ensure the person with dementia receives **an appropriate level of palliative care to meet their needs**. Refer to the assessment of deterioration segment for details.

## Moderate Stage

### Recommendation

As dementia progresses to the **moderate stage** as described by Dementia Australia, a person may experience increased challenges and disability such as:

- Being more forgetful of recent events
- Memory for the distant past generally seems better, but some details may be forgotten or confused
- Being confused regarding time and place
- Becoming lost if away from familiar surroundings
- Forgetting names of family or friends, or confusing one family member with another
- Forgetting saucepans and kettles on the stove or leaving gas unlit
- Wandering around streets, perhaps at night, sometimes becoming lost
- Behaving in a disinhibited way, for example going outdoors in nightwear
- Experiencing auditory and/or visual hallucinations
- Becoming very repetitive
- Being forgetful of hygiene or eating and drinking
- Becoming angry, upset or distressed through frustration
- Significant global deterioration in all aspects of functionality
- Reduced mobility and falls

During the moderate stage of dementia, the balance of care continues to shift from active disease management towards palliative care as function continues its inevitable decline as shown in the figure above.

### Re-evaluate targets for active management

of chronic conditions against recent tests and guidelines in discussion with the person with dementia and their carer. Reduce dose or deprescribe medications where appropriate. Regular review and assessment of needs to identify palliative needs, anticipate and manage symptoms, exacerbations and acute events.

### Assess other supports required.

## Advanced Stage

### Recommendation

Progression into **Advanced Dementia**, the last 6-12 months of life (End-of-life) and the Terminal Phase (last days of life) causes the person to need total care and they may have:

- Significant global deterioration in all aspects of functionality
- Increasing sarcopenia and frailty
- Be unable to remember occurrences for even a few minutes, for instance forgetting that they have just had a meal
- Lose their ability to understand or use speech
- Be incontinent
- Show no recognition of friends and family
- Need help with eating, washing, bathing, toileting and dressing
- Fail to recognise everyday objects
- Be disturbed at night
- Be restless, perhaps looking for a long-dead relative
- Be aggressive, especially when feeling threatened or closed in
- Have difficulty walking and increased falls, perhaps eventually becoming confined to a wheelchair
- Have uncontrolled movements
- Have permanent immobility <sup>46</sup>

## End of Life

### Recommendation

**End-of-life** is defined as the last 6 – 12 months of life and will occur in the advanced phase of dementia if it not previously, especially when the person with dementia has had co-morbid chronic disease/s. As the disease progresses discussions about non-beneficial interventions or treatments, and place of death need to take place if not already completed. When assessing patient benefit from treatment, consider the following questions:

- How useful is the treatment for my patient?
- What choice would best promote the comfort of my patient?
- Does each individual drug or therapy contribute to this patient's comfort? If not, can it and should it be ceased?

During this phase palliative care increases to become 100% of the care provided to the person with dementia as indicated in the graph above. Discussions around goals of care shift towards providing comfort and preparation for the terminal phase.

Assess for common symptoms in end-stage dementia patients, including Pain. Consider using the [Abbey Pain Scale](#) if the patient is

- Unable to verbalise
- Constipation, Delirium, Nausea, Agitation

Review level of functioning and advise that the patient is in the end-of-life phase of the disease to both the person with dementia and carers. There are a number of tools for guiding conversations with patients about a life-limiting illness such as

- CEC: [PREPARED model](#)
- [SPIKES-A six-step protocol for delivering bad news](#)
- End of life essentials: [NURSE mnemonic](#)

If the person is still living at home, determine through discussion with the person, their carer, substitute decision maker and family if a [transfer to RACF care](#) is appropriate.

Review and update patients advance care directive liaising with any appointed enduring

guardian/s regarding ongoing care decisions. If there is no enduring guardian or guardian appointed to make medical decisions, a "person responsible" should be identified to seek consent for treatment from, using the hierarchy below. Once identified, liaise with them regarding ongoing care decisions.

A 'person responsible' can be (in this order):

- the spouse of the person, if the relationship is ongoing and the spouse is not under guardianship
- a person who has the unpaid care of the person
- a close friend or relative of the person. <sup>49</sup>

Assess and manage any palliative symptoms, including any emergencies. Provide details of palliative care support services. If unsure, The Advance Project Referral Triage tool may aid decision making about the need for specialist palliative care assistance. Specialist palliative care services can provide:

- Help with assessment and treatment of complex problems.
- Advice on challenging issues such as ethical dilemmas of nutrition and hydration, management of depression and other symptoms, spiritual issues, and concerns held by the patient, relatives, and staff toward the end of life.
- Advice on need for transfer to specialist palliative care for supplementary care.

If assistive technologies are required, refer for palliative care equipment loans and purchase

Reassess the patient if:

- There has been a significant functional or medical decline
- There is a sudden acute event

## Terminal Stage

### Recommendation

Patients at the terminal stage of dementia can be effectively managed by the primary care team. Advise that the patient is now in the terminal phase of the disease to both the patient and carers.

Assess and manage problematic symptoms in palliative care patients:

- [Bowel Obstructions](#)
- [Breathlessness](#)
- [Delirium](#)
- [Nausea and/or Vomiting](#)
- [Pain](#)
- [Respiratory Secretions \(Death Rattle\)](#)
- [Restlessness and/or Agitation](#)
- [Terminal Crises](#)

Consent for and prescribe crisis medications where appropriate; morphine/ hydromorphone, midazolam, glycopyrrolate and haloperidol.

These medications are commonly prescribed, as they are readily available for use and not dependent on a medical review, ensuring that they can be administered when most needed.

Prescribe personal comfort measures. Personal Comfort measures within palliative care concentrates on providing physical comfort in an active way where all involved in decision making are flexible, sensitive and realistic of the needs of the dying patient.

Practice/Registered Nurse support and guidance is highly recommended in this stage. The following areas are all likely to need careful thought and attention:

- Positioning to promote comfort
- Mouth care
- Difficulty in breathing
- Skin care
- Bowel and bladder management
- Mobilisation
- Personal support
- Timeliness when needing support
- Loneliness
- Smells and tastes (eating and drinking)
- Alcohol

If unsure of management, seek [palliative care advice](#).

If clinical improvement occurs, reassess patient regularly.

# Recognition of deterioration

## Assess for signs of clinical deterioration

- Presenting to hospital more than once in a three-month period
- Declining function
- Increasing fatigue
- Declining or fluctuating oral intake
- Declining or fluctuating conscious state
- Increase in agitation or confusion
- Irreversible weight loss
- Carer fatigue
- Family distress and feedback
- Mental health decline
- Recurrent aspiration and infections
- Recurrent more frequent infections and hospitalisations
- Determine if deterioration is due to dementia, treatment side-effects and/or concurrent illness
- Be aware to identify a patient who may have a potential reversible [delirium](#) causing deterioration
- For patients with co-morbid illnesses - optimise treatment of these e.g. exacerbation CCF/COPD, AKI, progression of cancer (although not always possible)

If there is evidence of clinical deterioration, assess whether the deterioration indicates the patient has reached end-stage dementia:

Consider using one of the following screening tools:

- Use of the surprise question: "Would I be surprised if this patient were to die in the next 6–12 months?"
- [SPICT Tool](#)
- [Gold Standards Framework Proactive Identification Guidance](#)

## Assessment for indicators of active dying

If three or more of the symptoms below are present, it is likely the patient is in the terminal phase (last days of life).

- Deteriorating irreversibly on a rapid day to day basis
- Lapsing into semi-consciousness or unconsciousness
- Increasing loss of ability to swallow
- Refusing or unable to take food, fluids or oral medicines
- Occurrence of an acute event, requiring revision of treatment goals
- Profound weakness
- Changes in breathing patterns
- Skin changes such as mottling and cyanosis

If no indicators of active dying, assess for common symptoms in end-stage dementia patients, including:

- Pain. Consider using the [Abbey Pain Scale](#) if the patient is unable to verbalise
- Constipation
- Delirium
- Nausea
- Agitation



## Multi-domain wellness in dementia

### Psychological:

In early dementia, discuss the disease trajectory with the person with dementia and their carer/ family with consent to assist them to understand and cope with their situation<sup>52 43</sup>. The person with dementia may experience feelings of grief and loss or depression following diagnosis. Be alert to symptoms, screen and refer to a psychologist if required.

Carers - monitor carers for symptoms of burn out and depression and refer to a psychologist if required. The [NAT-CC](#) tool allows assessment of needs of carers of people with non-cancer illnesses

If Responsive Behaviours (formerly Behavioural and Psychological Symptoms of Dementia) appear manage these using non-pharmaceutical methods. The HealthPathways program provides guidance to monitor and manage [behavioural and psychological symptoms of dementia](#) (BPSD).

Discuss considerations about the person with dementia's living environment if confusion and

agitation present. Alzheimer's Western Australia's website [Dementia: Enabling Environments](#) offers interactive advice on a room-by-room basis to assist carers and families to achieve a home that creates a balance between over-stimulation and boredom for the person with dementia.

[Dementia Australia](#) provides fact sheets on preparing the home, either online or by phoning their helpline on 1800 100 500.

For assistance with changed behaviours refer to support services such as [Dementia Support Australia](#) online or by phone on 1800 699 799. The SWSLHD Older Peoples Mental Health (OPMH) service can assist with severe behavioural problems associated with dementia once the person has been seen by Dementia Support Australia. OPMH teams also provide information and support to carers and family members and work closely with an older person's local doctor or residential aged care facility in providing care. Anyone can refer to the service by making a free phone call to the Mental Health Line 1800 011 511.

### Spiritual:

For the person with dementia, diagnosis may lead to questioning of their life's achievements and meaning and the future they face. Some will benefit from pastoral care at this stage.

Introduce conversations around beliefs and values and planning for future care through Advance Care Planning is a way of exploring these issues. Encourage maintenance of cultural and spiritual practices.

If wanted, help to arrange spiritual or religious support and enable those people the person with dementia wanted with them, carer/s, spouse, family friends.

### Social:

For the person with dementia - social prescribing and linking to supports may be needed to maintain social contact.

Carers may need assistance to maintain social connectedness and learn strategies for coping and fostering resilience to cope with their situation.

Encourage carers and family to be building an informal support network (e.g. engaging neighbours who may assist with practical help). Empower carers to build their knowledge/network. Dementia Australia can provide information and support to carers and families of people with dementia.

As the person with dementia approaches the end-of-life support carer/s and family. Communicate the person's prognosis and respect the person with dementia and their family's wishes, review the values of the patient, and any advance care plan or advance care directive. Ensure that care is patient centred, and carers and family are welcomed as partners in care of the person with dementia including the needs of the carer/s and family.

After death consider referral for family/carers for bereavement counselling.

## Movement in dementia

As populations have achieved longer lives, chronic and life-limiting illnesses such as dementia have become more prevalent,<sup>54</sup>. In order to cover such needs healthcare is becoming increasingly complex, specialised and technical requiring patients to move between many different facilities, practitioners and services imposing risks to continuity of care<sup>55 56</sup>. Times of transition/movement between these parts of the health system have been identified as times of increased risk<sup>56 57</sup>.

Particular care is needed when people with dementia are transferred between health care settings as even in the early stage of dementia the symptoms of the disease start to impact on the person's ability to manage fragmented health service delivery. Minimise transfers and provide palliative care in the person with dementia's place of residence e.g., their family home or RACF rather than transfer to hospital. Community nurses and the PEACH program provide assistance to deliver palliative care in the family home see the requests section of the [End-stage Dementia HealthPathway](#).

The use of quality communication, documentation, information sharing and collaboration between providers promotes seamless, rather than fragmented, health service delivery for people with dementia and their carers/families<sup>58 59</sup>. A focus on clinical handover when referring to specialists and allied health for management of co-morbid chronic diseases can greatly assist their patients.

## Clinical handover

Clinical handover in the context of a patient with dementia is the transfer of clinical information, responsibility and accountability between settings. Handover needs to occur where this transfer impacts on patient safety and preferably before every new professional encounter e.g.

- ➔ GP referring a patient to a specialist (geriatrician, neurologist, cardiologist, etc) allied health professional (dietitian, physiotherapy, etc), community and/or social services, mental health services, hospital (emergency department, outpatient clinics)
- ➔ Aged Care Facility referring to a GP, medical specialist, ambulance service, hospital etc

Differently from a hospital setting, face to face handover in primary health care is rarely possible as many referrals are made for services outside the practice. Referral letters sent out with patients, faxed, mailed or emailed are the preferred modality of handover in General Practices. However, problems with the quality, template and content of referral letters are of common occurrence. How information is communicated in the referral letter can pose either barriers or enablers to the effective transfer of care impacting upon a poor or good quality patient and family experience. Use of templated letters followed by telephone calls are highly valued among clinicians as an effective means of information sharing between healthcare services (60).

## Referral Letter Template

A Referral Letter template has been developed to ensure effective communication. The ISBAR format was suggested by our advisory group and endorsed in the literature<sup>61</sup> as an ideal template for clinical handover to ensure transfer of sufficient, consistent and accurate information.

<b>ISBAR Referral Letter</b>					
Date:			Time:		
<b>Identification</b>					
<b>Referred Provider/Service details</b>					
Name					
Address/ Contact Details (phone, email)					
<b>Referring Provider/Service details</b>					
Name					
Address/ Contact Details (phone, email)					
<b>Patient details</b>					
Name			DOB (Age)		
<b>ADVANCE CARE DIRECTIVE: HELD <input type="checkbox"/> NOT HELD <input type="checkbox"/> NOT YET DISCUSSED <input type="checkbox"/></b>					
<b>ADVANCE CARE PLAN: HELD <input type="checkbox"/> NOT HELD <input type="checkbox"/> NOT YET DISCUSSED <input type="checkbox"/></b>					
NFR:					
<b>DETAILED GP REQUEST</b>					
<b>Situation:</b> reason for referral e.g. changes in cognitive state, request of further specialist assessment, etc					
<b>Background:</b> relevant patient's clinical and personal history supporting the referral – including past pathology tests, imaging, allergies and medication in use					
<b>Assessment:</b> current and relevant physical and clinical information for this referral					
<b>Latest Observations</b>					
Date/Time	BP	HR	SpO2	Temp	RR
<b>Request:</b> clearly state what services or assessments you are requesting of the referred service/provider					
<b>Referring provider</b>					
Name/AHPRA reg no.			Signature		