



South Western Sydney

# Peace of Mind project report 2021

Palliative care for people with dementia

**phn**  
SOUTH WESTERN  
SYDNEY

An Australian Government Initiative

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## Introduction

This is the final report of the South Western Sydney PHN (SWSPHN) Peace of Mind Project (the Project). The Project commenced in January 2018 following the submission of a successful expression of interest (EOI) to the Commonwealth Department of Health for funding under its Greater Choices for At Home Palliative Care measure.

- SWSPHN submitted an EOI focussed on improving palliative care access in the place of choice for people with dementia. This had been elucidated through needs assessment activities and the following factors informed this strategic direction:

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- Population planning estimates predicted significant growth in the ageing population in the region to 2030 and beyond;

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- There were forecasts of major increases in the incidence and prevalence of dementia in our region (see table 2 below);

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- The joint position statement released by Palliative Care Australia and Alzheimer's Australia<sup>1</sup> (now Dementia Australia) had described the difficulties people with dementia may experience accessing "appropriate palliative care that responds to their needs and respects their wishes"; and

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- There was no data available about the number of people with dementia who had received palliative care in the region.

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This report represents a summary of the work undertaken, successes and learnings of the Project to 30 June 2021.

## Dementia

The World Health Organisation describes Dementia as "a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.

Dementia results from a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke.

Dementia is one of the major causes of disability and dependency among older people worldwide. It can be overwhelming, not only for the people who have it, but also for their carers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care. The impact of dementia on carers, family and society at large can be physical, psychological, social and economic".<sup>2</sup>

## A snapshot of dementia

The number of people with dementia in SWS is expected to increase by 84.2% from 10,513 in 2016 to 19,367 people by 2031<sup>3</sup>

Dementia is the second leading cause of death of Australians contributing to 5.8% of all deaths in males and 11.3% of all deaths in females each year<sup>4</sup>

In 2020, it is estimated almost 1.6 million people in Australia are involved in the care of someone living with dementia<sup>4</sup>

In 2020, there is an estimated 459,000 Australians living with dementia<sup>4</sup>

People with dementia account for 52% of all residents in residential aged care facilities<sup>4</sup>

Aboriginal people over 60 years of age, who live in urban areas, have very high rates of dementia (21%), which is three times higher than the non-Indigenous population<sup>3</sup>

Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the third leading cause of disability burden overall<sup>4</sup>

Currently an estimated 250 people are developing dementia each day<sup>3</sup>

In 2016, an average of 36 people died per day where dementia was the underlying cause of death<sup>3</sup>

Dementia prevalence is growing in South Western Sydney (SWS) as the region is experiencing a significant growth in the older population<sup>3</sup>. The number of people over 70 years of age is expected to increase from 84,350 people in 2016 to 161,350 older people in 2031 (91%). The growth over the following 15 years is expected to be particularly significant amongst those over 85 years of age, with an increase of 92% equating to an additional 14,660 people.

The estimate of dementia prevalence in the SWSPHN region in 2016 was 10,513 people. It is forecast that this will increase by 84.2% to 19,367 by 2031. Research commissioned by Dementia Australia<sup>5,6</sup>, predicts further growth to 2058 as shown in table two. The significant growth in dementia is likely to put pressure on health services within the region if it is not considered in planning for future services including palliative.

**Table 2: Dementia prevalence estimates to 2058 in SWS Local Government Area**

LGA	2021	2058	% Growth
Canterbury -Bankstown	6413	14315	223.22
Camden	1137	6109	537.29
Campbelltown	2360	7405	313.77
Fairfield	3673	9081	247.24
Liverpool	2901	9549	329.16
Wingecarribee	1510	2486	164.64
Wollondilly	793	2440	307.69

## Dementia and palliative care literature review

Internationally, the World Health Organisation supports the implementation of a palliative approach for people living with life limiting and life-threatening health problems. They also suggest most palliative care needs do not require specialist palliative care but can be met by generalist health care team including GP's and Registered Nurses with some basic training and understanding of palliative care. They see the implementation of palliative care into primary health care as essential to ensuring the relief of suffering for people living with serious or life-threatening conditions<sup>7</sup>.

Nationally, a palliative approach to care is the expected model of care for all people with a life limiting or terminal illness. This is evidenced through the National Palliative Care Strategy and National Palliative Care Projects<sup>8</sup>, and specific palliative care funding for national programs such as:

- [End of Life Directions for Aged Care \(ELDAC\)](#)
- [CareSearch palliative care knowledge network](#)
- [Palliative care curriculum for undergraduates \(PCC4U\)](#)
- [Program of Experience in the Palliative Approach \(PEPA\)](#)

Within NSW, the Palliative and End-of-Life Care Blueprint for Improvement<sup>9</sup> recognises and supports the palliative approach for people with life limiting illnesses and more recently the End of Life and Palliative Care Framework 2019 – 2024<sup>10</sup>.

At a local level, the South Western Sydney Local Health District developed an advance care planning, end of life and Palliative Care strategic plan for 2015-2021 as the guiding document for service delivery and planning cross the health district<sup>11</sup>.

An outstanding theme of the dementia and palliative care literature is the realisation dementia is not seen as a terminal illness either by the community as a whole or by health professionals<sup>12</sup>. There is therefore a failure to link dementia care with palliative care<sup>13</sup> and this further extends to a lack of recognition that dementia is a life limiting or terminal illness. McInerney et al<sup>13</sup> found in an online course on dementia that there was little direct link or understanding of the relationship between dementia and palliative care. This showed a limitation in the health literacy, information and education being offered regarding dementia and its essential connection to palliative care. Conversely, palliative care has been very closely related in the general thinking with dying and not traditionally seen as a three-phase process. The study also showed 'there was a greater focus on the event of death rather than the process of dying which is very problematic as the dementia trajectory may take weeks or months with associated symptom burden being undermanaged'.

A direct consequence of this is people living with dementia, and suffering from the symptoms associated with end stage dementia, are not receiving palliative care support, either through referral and specialist review or as part of an

overall health approach<sup>14 15 16</sup>. There is a lack of implementation of a palliative approach for the people with dementia and they are underrepresented in palliative care<sup>17</sup>, yet their symptoms can be significant and challenging and further complicated by the often multiple co morbidities of people with this condition and the frailty of advanced age<sup>16</sup>; this disconnect leads to people with dementia experiencing poorer symptom and pain control<sup>18</sup>.

People with advanced dementia would benefit from referral to palliative care, or an approach guided by a palliative philosophy<sup>16 18</sup>, yet the literature shows the focus is on specialist palliative support and often that referral is not made and with that there is 'lack of awareness of the palliative approach in end stage dementia'<sup>13</sup>. There is an understanding, or misunderstanding that palliative care is purely about the terminal phase of illness, and 'a significant danger in Australia of palliative care being care provided at the terminal phase'<sup>16</sup> and therefore early and timely referral for palliative review regarding symptom management is often not considered. Further complicating this is a difficulty in identifying the final stages for non-cancer illness, including dementia which also impacts on the

poor referral rate and therefore outcomes<sup>17</sup>.

The often-slow progression and unpredictable nature of decline with dementia also impacted on health practitioner's ability and confidence in identifying the end stage and planning accordingly. In addition, the frailty of advanced dementia with age and the complexity of co morbidities also impacts on this unpredictability of decline and death<sup>19</sup>. The policy statement from Palliative Care Australia and Dementia Australia<sup>1</sup> reinforces the issues of lack of recognition of dementia as a life limiting illness and appropriate access to palliative care at end of life.

Advance Care Planning (ACP) has a pivotal role in improving quality of life and death for people with dementia. Low levels of completion of ACP across community settings and confusion around which form to complete contributes to low levels of ACPs in place for people with dementia. Skills in having difficult conversations to complete ACPs are not widely available across the aged care workforce. The national ACP prevalence study<sup>20</sup> showed low levels of completion of ACP across the low number of organisations that contributed to the study.

## EOI

From the literature it had been learned that dementia is a life-limiting condition for which a palliative approach to care and support is recommended from early in the course of the disease. Unlike other life-limiting illnesses, the dementia trajectory may be long with gradual dwindling in the capacity to communicate and make decisions without assistance. In addition, the age of the cohort, and the prevalence of co-morbid chronic diseases which themselves may require palliative care in the final stages can lead to associated symptoms being undermanaged, yet many people with dementia struggle to access palliative care<sup>1</sup>. It was apparent better preparedness for the last stages of life using advance care planning and engagement with palliative care early in the diagnostic process (within the first six months) could improve outcomes people with dementia, their carer/s and family.

Based upon this, SWSPHN submitted a successful response to the 2017 call for expressions of interest (EOI) in the new Greater Choices in At Home Palliative Care measure. The project was to be named the Peace of Mind project as that is what the PHN hoped to bring to people with dementia their carers and families through timely diagnosis, early engagement with end-of-life planning and a palliative approach to care coupled with an easier to navigate system.

**Project Aim: The aim will be to improve the end-of-life journey for consumers, carers and families through greater preparedness and knowledge through early intervention while the consumer's capacity is intact.**

## Project Objectives:

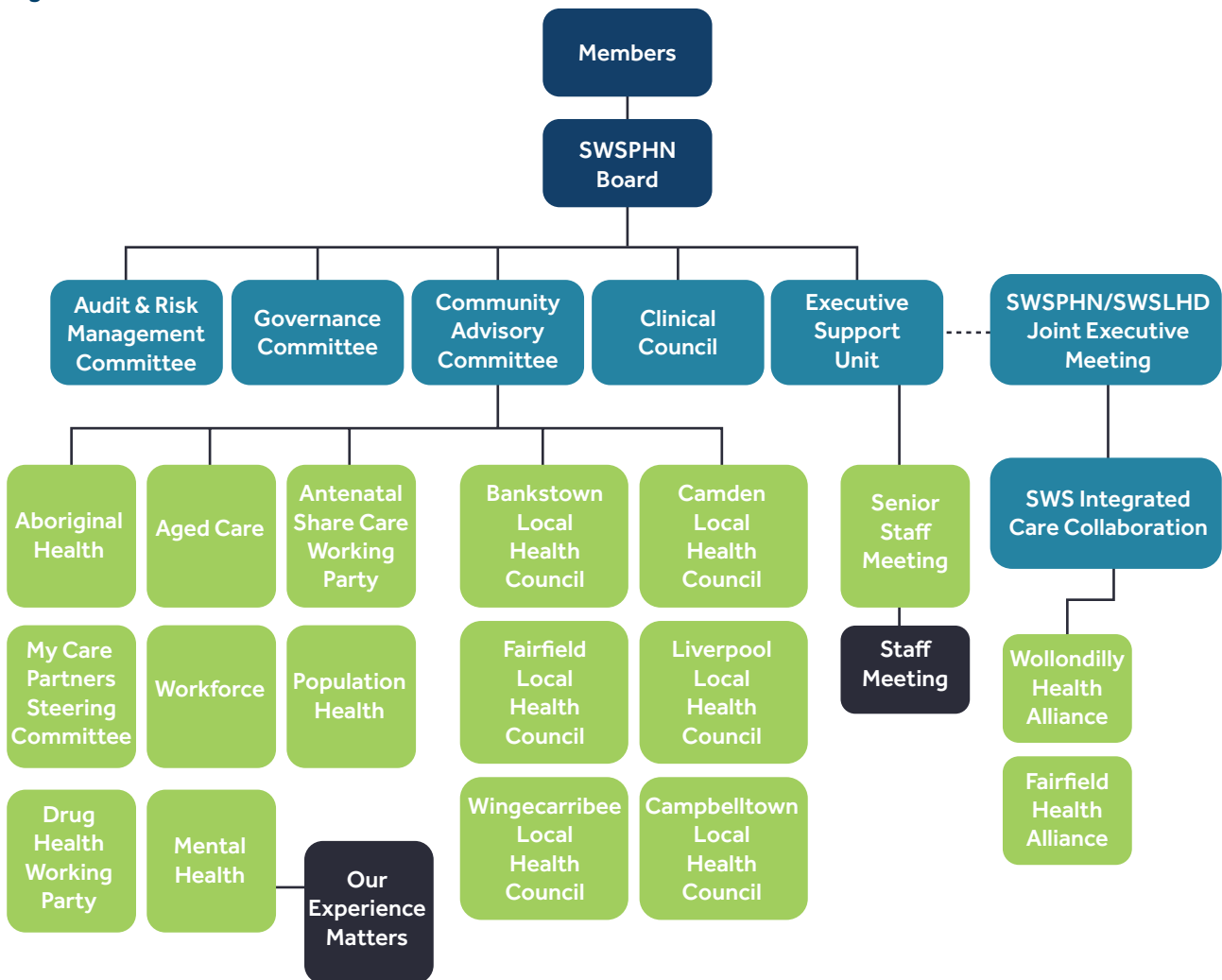
1. To undertake a rapid, but rigorous palliative care needs assessment which will build on the current PHN needs assessment, and the findings of the SWSLHD strategic plan for palliative care
2. To develop a health pathway using the HealthPathways methodology tailored to the South Western Sydney context that features diversity of cultures and geographies. The health pathway will feature clear trigger points for escalation, linkage to and support from Specialist Palliative Care Services where required and linkage to bereavement support for carers and families
3. To promote timely diagnosis especially of dementia in older people
4. To increase early initiation of discussions with the person, their Carer and family about planning for future palliative and end-of-life care
5. To provide education and orientation to palliative care for consumers, Carers and families about what to expect during the end-of-life journey
6. To develop informal support networks such as Compassionate Communities with consumers
7. To increase awareness and linkage of people with dementia to the SWSLHD PEACH program for provision of home-based palliative care packages during and after normal business hours during the last weeks of life
8. Development and maintenance of multi-sector partnerships to ensure timeliness and productivity continue throughout the project
9. The collection and appropriate sharing of salient data

# The project initiation phase

## Project governance structure

The Project has operated under the governance structure of SWSPHN as shown in Figure 1. The Project staff have sat within Aged Care reporting directly to the Integrated Health Team Manager and the Aged Care Committee. The Project staff have made annual presentations to the Clinical Council and presentations and consultations with the Community Advisory Committee. The Aged Care Committee reports to the Clinical Council quarterly by way of meeting minutes.

Figure 1: SWSPHN Governance Structure





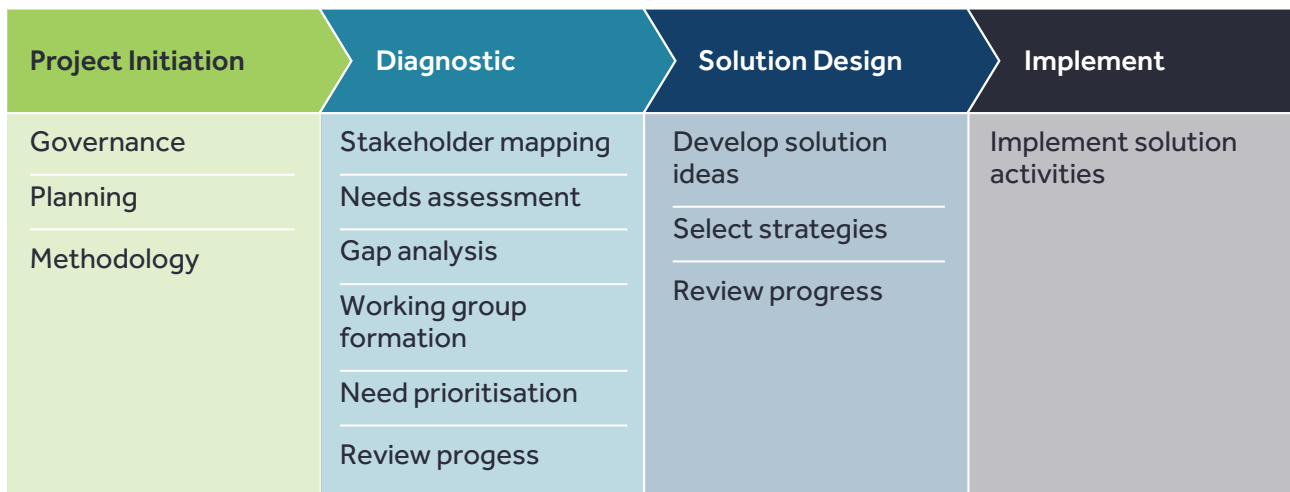
## Methodology

This section of our report contains a summary of the way the project has been undertaken. SWSPHN has employed a range of methods over the course of the Project and the range of activities undertaken.

In the initial stages of the Project, palliative care was a field in which SWSPHN had limited previous engagement beyond findings for early iterations of the PHN Needs Assessment and collaboration with the SWSLHD Palliative Care Services in the provision of GP continuing education.

In the initiation phase, a project lead was recruited internally, and project tasks and workflow planning commenced guided by the methodology developed in the Framework for the development of a model of care by the NSW Agency for Clinical Innovation<sup>21</sup> illustrated in Figure 2 below. The framework provides a useful starting point for a project, describing actions to be taken in each phase of a project to develop a new state services based model of care. Some actions were removed after being considered not appropriate for a primary care project and others were added.

**Figure 2: ACI framework workflow**



A project officer position description was developed but the Project was approached by a local business the [Palliative Aged Care Consultancy Service \(PACCS\)](#). PACCS was established in June 2010 as a fee for service palliative care and complex pain management service providing consultancy and education in residential aged care. The service is based upon the designated linkage worker strategy identified in the work of Decision Assist and demonstrated through their linkage projects as enhancing connections between aged and palliative care services. PACCS was able to offer in-depth local system knowledge, a range of skills within the one service and a valuable network of contacts with local palliative and aged care stakeholders. With time constraints in mind, it was decided to leverage local expertise in preparation for the diagnostic phase of the project. SWSPHN contracted PACCS to undertake a rapid but robust needs assessment of the local palliative care environment for people with dementia.

# The diagnostic phase

## Service mapping - palliative care service provision in South Western Sydney

Palliative care in South Western Sydney has a three-tiered structure as described by Palliative Care Australia<sup>1</sup> and shown in Table 3. People with dementia may have needs that fit within any of these groups especially those with multiple morbidities. It can be seen from tables 3 - 5 that there is a range of services and clinicians who provide palliative care in SWS. People with dementia can be referred to any of the region’s palliative care services that provide care that meets their level of need. Details for referring to any of SWSLHD palliative care services across the region can be found in the palliative care requests section of the [Community HealthPathways website](#).

**Table 3: The tiered structure of Palliative Care in SWS based upon palliative care needs**

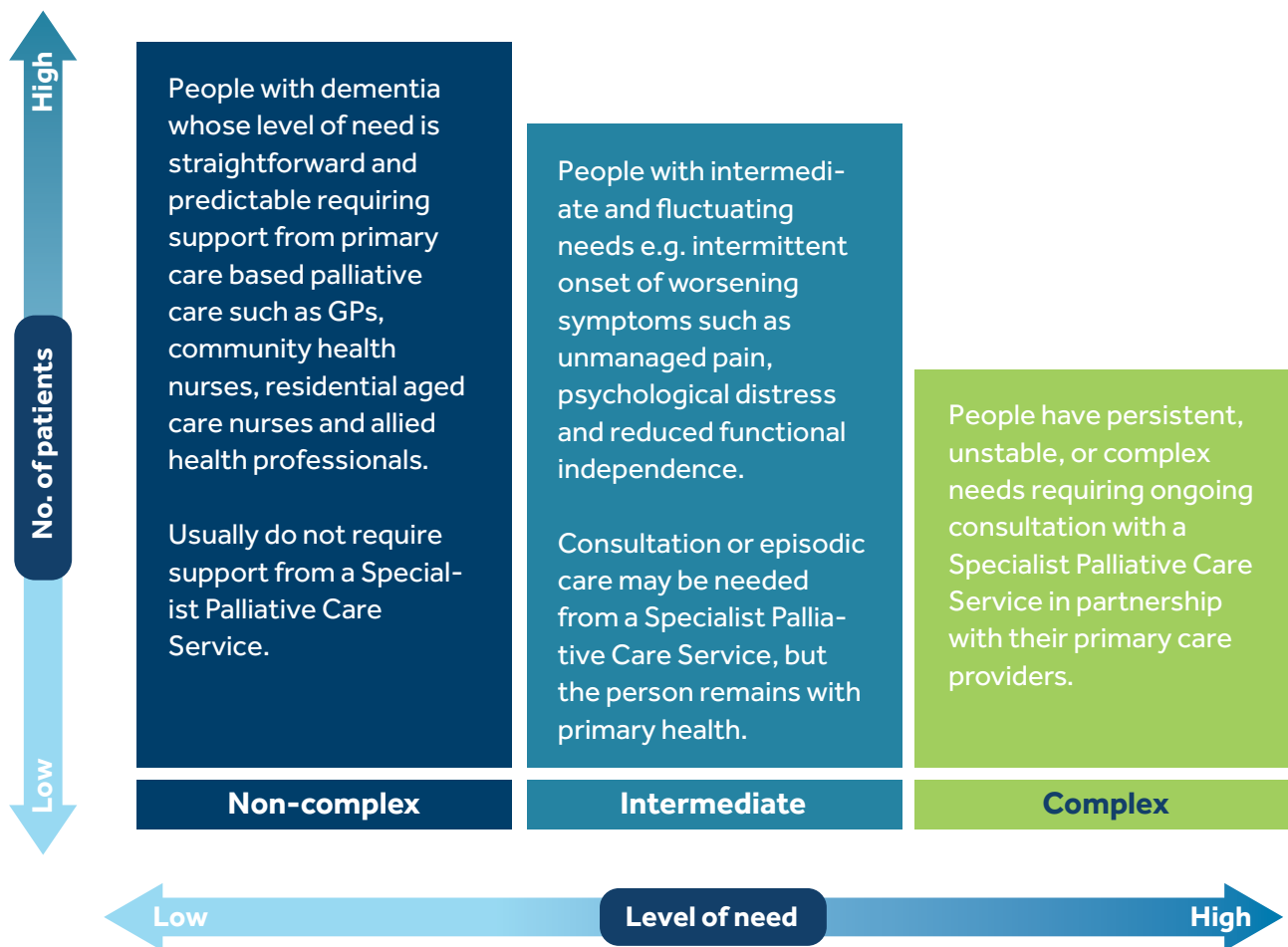


Table 4: Health system palliative care services and supports in South Western Sydney<sup>11</sup>

Primary care providers, hospital and community based	South Western Sydney Local Health District (SWSLHD) Palliative Care Specialist Services		
General practitioners, practice nurses, medical deputising service, community pharmacists, private allied health practitioners.	<b>Palliative care hospital-based services</b>		
South Western Sydney PHN	<b>Bankstown-Lidcombe Hospital</b> <ul style="list-style-type: none"> <li>• Consultative service</li> <li>• Outpatient clinics</li> </ul>	<b>Camden Hospital</b> <ul style="list-style-type: none"> <li>• Inpatient Unit</li> <li>• After-hours 1300 number</li> </ul>	<b>Palliative care community-based services</b>
Residential Aged Care Facilities including palliative care clusters - Lavender Suite, Hammond Care	<b>Bowral and District Hospital</b> <ul style="list-style-type: none"> <li>• Clinical Nurse Specialist</li> <li>• In-reach medical consultative service</li> </ul>	<b>Fairfield Hospital</b> <ul style="list-style-type: none"> <li>• In-reach medical consultative service from Braeside Hospital</li> <li>• In-reach nursing consultative service from Prairiewood CHC</li> </ul>	<b>Bankstown CHC:</b> CNC, CNSs & RNs
SWSLHD hospital specialist and community health services. E.g. emergency department, cancer, respiratory, aged care/rehabilitation, pain, allied health, community nursing service, pharmacy, pastoral care, carers service, organ and tissue donation service	<b>Braeside Hospital</b> <ul style="list-style-type: none"> <li>• Inpatient Unit</li> <li>• Day hospital</li> <li>• Outpatient clinics</li> <li>• After-hours 1300 number</li> </ul>	<b>Liverpool Hospital</b> <ul style="list-style-type: none"> <li>• Inpatient Ward (4C)</li> <li>• Consultative service</li> <li>• Outpatient clinics</li> </ul>	<b>Bowral CHC:</b> CNC
Tharawal Aboriginal Medical Services	<b>Campbelltown Hospital</b> <ul style="list-style-type: none"> <li>• Consultative service</li> <li>• Outpatient clinics</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Inpatient unit/ward:</b> comprises medical, nursing and allied health staff</li> <li>• <b>Consultative services:</b> comprises medical staff, a CNC &amp; nurses</li> </ul>	<b>Hoxton Park CHC:</b> CNC, CNSs & RNs
Gandagara Health Services	<b>Palliative care district-wide services</b>		
Southern Highlands Bereavement Service (NSW Health funded NGO)	<ul style="list-style-type: none"> <li>• After-hours 1300 number</li> <li>• Equipment loan pool</li> <li>• Volunteer program</li> <li>• End-of-life coordinators</li> </ul>	<ul style="list-style-type: none"> <li>• Bereavement counselling service (Braeside)</li> <li>• Research, including clinical trials</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative Care Home Support Packages (PEACH) program</li> </ul>
Other NSW Health entities. E.g. Local Health Districts, Networks and Ambulance Service of NSW	Triple I Hub: referral and coordination (extended work hours and weekends)		
Private hospitals			

[Triple I \(HUB\)](#) is the SWSLHD Primary & Community Health centralised Intake, Information and Intervention centre. Triple I (HUB) accepts referrals for palliative care nursing in a patient's home from GPs as well as self-referrals and those from carers and families.

**Table 5: The SWSLHD specialist palliative care staffing profile is indicative of the services available in the region's LGAs**

Community-based services					
Service	Bankstown LGA	Fairfield LGA	Liverpool LGA	Macarthur region LGAs	Wingecarribee LGA
Clinical Nurse Consultant	✓	✓	✓	✓	✓
Clinical Nurse Specialist/RNs	✓	✓	✓	✓	✗
Bereavement Counselling	✓ Braeside (district-wide from Braeside Hospital)				
Specialist Allied Health	✓ SW	✓ SW, OT and Physio	✓ SW, OT and Physio	✓ SW	
	✗ Psychology, OT and Physio	✗ Psychology	✗ Psychology	✗ Psychology, OT and Physio	✗ Psychology, SW, OT and Physio
Equipment Loan Pool			✓		
Volunteers	✓	✓	✓	✓ Camden	✓

Hospital-based services							
Service	Bankstown-Lidcombe	Braeside	Fairfield	Liverpool	Campbelltown	Camden	Bowral
End-of-life Coordinators	✓	✗	✗	✓	✓	✗	✓
Consultative Services: on-site	✓ medical, nursing	✓ medical	✗	✓ medical, nursing	✓ medical, nursing	✓ medical, nursing	✓ nursing
Consultative Services: inreach	✗	✗	✓ medical	✗	✗	✗	✓ medical
Outpatient clinics	✓	✓	✗	✓	✗	✓	✗
Day Hospital	✗	✓	✗	✗	✗	✗	✗
Palliative Care Ward	✗	✗	✗	✓ 20 beds	✗	✗	✗
Palliative Care Unit	✗	✓ 20 beds	✗	✗	✗	✓ 10 beds	✗
Specialist Allied Health	✗	✓ SW, Psychology, OT, SP, Physio, DT and Dietician	✗	✓ SW, OT, Physio, Psychology, DT and SP	✗	✓ SW and Physio Psychology, DT and SP	✗
Volunteers	✓	✓	✗	✓	✗	✓	✗

## Stakeholder mapping

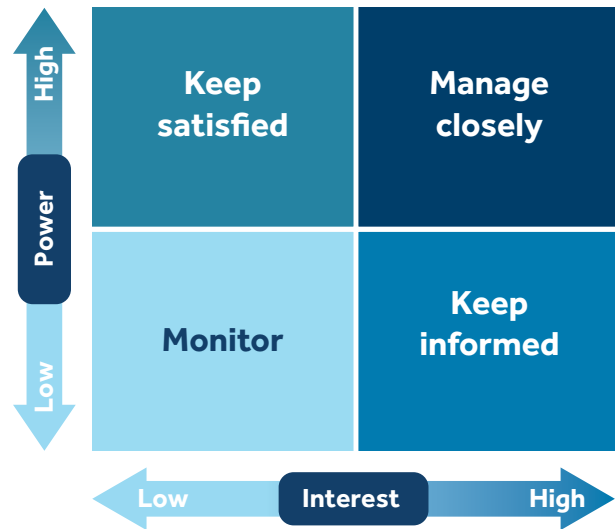
During the diagnostic phase it was vital for SWSPHN to begin engagement with the regional stakeholders in palliative care and dementia. The mapping tool<sup>22</sup> at Figure 3 was useful in identifying who the stakeholders were in order to make initial contact and measure their level of interest in the Project.

Figure 3: Stakeholder mapping



Following identification, the stakeholders were analysed using the Power/Interest Grid, one of a range of tools available for the purpose. Combining the two activities allowed the grey arrows to be replaced by lines that represent the nature and purpose of the relationship to be built with the stakeholders, ranging from networking to collaborating as described The Partnership analysis tool<sup>22</sup>.

**Figure 4: Power/Interest Grid**



## Local needs assessment

In August 2018 the Palliative Aged Care Consultancy Service (PACCS) undertook a needs assessment in the SWSPHN region and delivered a discussion paper on the current environment for palliative care and dementia in South Western Sydney<sup>23</sup>. The discussion paper identified the following challenges.

### Health Literacy

The Australian Commission on Safety and Quality in Health Care through their health literacy policy has set the requirement for the consideration of health literacy at individual and the organisational levels. The commission sets out the consequence of low health literacy especially for the elderly,

**“In older people, low individual health literacy is associated with a poorer health status and with a higher risk of premature death<sup>24</sup>.”**

Furthermore, there is a correlation between low health literacy and poor health outcomes due to people not being able to act on information given to them because they couldn't understand the information. Slow recognition of the relevance of health literacy and low levels of organisational commitment to being health literate organisations contributes to difficulties in understanding the websites, written resources, fact sheets and forms related to Dementia, Palliative Care and Advance Care Planning<sup>24</sup>.

The application of readability tools on the advance care planning literature, tools and forms reveals they are pitched above the reading level of the general Australian public. As an example, The Palliative Approach Toolkit<sup>25</sup> is an evidence-based resource for the aged care sector, but aged care providers struggle to implement the various tools and processes offered within the toolkit. Several aged care providers have reviewed the tools and adjusted the language within the toolkit to assist aged care workers to interpret and utilise the toolkit.

The Aged Care Quality Standards that guide and direct Aged Care in Australia make no reference to the term palliative care. The standards refer to end of life care only, yet palliative care is recognised as a three-phase process; a palliative approach, specialist palliative care, and terminal or end stage care. Omitting the term palliative care ignores the fundamental importance of a palliative approach to care in guiding and directing aged care into the future. It is essential that the term palliative care is part of the everyday language in the setting of standards in Aged Care to ensure there is ongoing opportunity for knowledge, skill and understanding of what palliative care is and how it relates to Aged Care. This current 'oversight' reflects a fundamental issue of health literacy around palliative care where we see yet another missed opportunity to increase the understanding of palliative care for not only those working in health and aged care, but also for the consumer and decision makers moving forward<sup>26</sup>.

## General Practitioners

Another aspect needing to be considered throughout this project is General Practitioner (GP) interest, training, educational opportunities and support regarding the speciality of palliative care. As we have become more specialised in many areas of medicine the concern may be we have dis-enabled and dis-empowered the General Practitioner from confidently taking on the role of care for those living with and dying of life limiting illness.

A national survey of 1000 GPs<sup>27</sup> found nearly two thirds of participating GPs were interested in providing palliative care, but they could be categorised into four distinct groups for confidence and preference in caring for patients needing palliative care.

- i. Palliative Care Experts (25%): are comfortable, knowledgeable, interest and engaged. They do substantially more PC than average, value a holistic approach to patient care, and find PC much more rewarding than other segments.
- ii. Palliative Care Aspirers (39%): are interested in doing more PC, but their current skill/knowledge levels and lower exposure to palliative patients hold them back.
- iii. Palliative Care Indifferent (23%): will do PC if required, but do not seek it out. They are less comfortable with, and less technically skilled in, PC.
- iv. Palliative Care Avoiders (14%): actively avoid PC, and dislike many of the tasks associated with it. They are uncomfortable with the soft skills that other GPs told us are required for best practice PC, including dealing with emotion, talking about death, and liaising with families.

The survey of 1000 GPs does not identify any specific region across Australia, and it is not possible to know where the GPs of South Western Sydney would be allocated across the four categories. However, it is clear there is no 'one size fits all' approach to engaging the different segments and their different attitudinal and behavioural patterns need to be catered for.

## Interviews with Community service providers

Within SWSPHN community settings there is no capacity for people with dementia to die at home due to lack of availability of aged care packages. Where packages are available the level of the package is too low for the level of care required to enable the person with dementia to stay at home.

Community based service providers describe a situation of very little to no community-based persons with dementia dying at home across the South Western Sydney region. Persons with advanced dementia are usually placed in aged care facilities or transferred to acute facilities and then placed following a hospitalisation. Community service providers describe how the number of funded hours for people with dementia on aged care packages are not enough to enable carers to manage a person with dementia during their cognitive and physical decline. Often the person with dementia is admitted to hospital when a family is in a caring crisis.

## Interviews with Facility based service providers

One of the RACFs visited, Summit Care, had implemented a palliative approach to care throughout their facility. An after-death audit of the recent death of a person with dementia reveals that there is a PA Link person in place within the facility; the person with dementia had an ACP in place; a case conference was undertaken for the dying person with dementia; the person with dementia was commenced on an End-of-Life pathway at an appropriate time; and the person with dementia died within the facility in accordance with their ACP. The facility has well developed connections to the community specialist palliative care team. The executive has identified a need for education and training for facility workers in the recognition of the deteriorating resident to assist with the timely commencement of a palliative approach.

Staff knowledge and confidence in assessment and communication impacts on outcome for people with dementia. Because of the unpredictable trajectory of dementia there is hesitation and delay on making referral to palliative

care (14). Health care professionals also find it difficult to recognise the final phase of life for people with dementia and therefore the focus remains of active and investigative treatment and not on end-of-life care<sup>28</sup>. Doctors worry they can't accurately spot those who are going to die or will be pushed into a prognosis<sup>29</sup>.

At the time of the Project's needs assessment, the national aged care sector was busy with the introduction of new Aged Care Standards

which commenced on 1 July 2019. The Royal Commission into Aged Care Quality and Safety commenced on 8 October 2018. All aged care providers were requested to supply to the commission specific information regarding complaints and care issues. The region's aged care providers expressed that all available resources were attending to this task and the new aged care standards.

## Project working groups – activity and findings

SWSPHN established two working groups of local stakeholders identified by the earlier stakeholder mapping process in November 2018, to progress the work of the Project: a community working group comprised of community representation and community-based health and aged care service providers; and a clinical working group comprising clinicians from general practice, privately practising geriatrics and Local Health District specialist services and residential aged care.

The PACCS discussion paper contained a set of recommendations for prioritisation, discussion and solution design by the working groups who met monthly from December 2018 to August 2019 under the facilitation of the Palliative and Aged Care Consultancy Service (PACCS).

The 13 recommendations concentrated on increasing community and professional awareness of dementia as a life limiting illness and the actions required to prepare the aged care and primary care workforce to care for people with dementia at their end-of-life. An initial activity of the working groups was prioritisation of the recommendations from the discussion paper. The two working groups were combined to hear the recommendations presented by PACCS in one meeting and provided their individual ranking from one (1) to thirteen (13) where one was the highest priority for implementation and thirteen the choice of least priority before the next combined meeting. At the next meeting, in February 2019, the pooled results as shown in Table 6 below were presented and discussed by the combined working groups.

**Table 6: Discussion paper recommendations**

Recommendation	Ranking
Develop Dementia health pathway – from diagnosis to end of life care	1
Facilitation and assistance with the implementation of the palliative approach in aged care provider settings – both community and residential aged care facilities and development of a palliative approach community of practice for aged care providers implementing the palliative approach	2
SWSPHN continue to collaborate with SWSLHD on implementation of Advance Care Planning actions and activities detailed in SWSLHD Advance Care Planning, End of Life and Palliative Care Plan 2016 - 2021.	3
Ensure that aged care workforce's issues such as low levels of health literacy, high levels of English as a second language, cultural variation in approaches to death are considered when developing the model of care/referral pathway	3



Recommendation	Ranking
Education and training on the recognition of deterioration in older persons for staff in primary care settings, residential aged care facilities and community providers.	4
SWSPHN continues with Goal 2 of the SWSPHN strategic plan in enhancing the health literacy of the community	5
Engagement of ELDAC facilitators to assist building connections between aged and palliative care providers across SWS PHN with a specific emphasis on persons with dementia.	6
Ensure that clinical aged care workforce issues such as high resident to carer ratio and a heavy reliance on non-nursing care staff are considered when developing the model of care/referral pathway	7
SWSPHN to collaborate with Groundswell to commence compassionate communities' model for SWSPHN region.	8
SWSPHN lead a Dementia Friend's initiative across the SWS PHN region in collaboration with Dementia Australia.	9
In conjunction with PEPA NSW identify past PEPA placements completed, potential current need and develop a priority list for future aged care staff PEPA placements.	10
In consultation with Palliative Care NSW review booklet Dementia and Palliative Care for currency and collaborate to update booklet for dissemination	10
In consultation with Western Sydney University, review Stages of Dementia booklet for currency and collaborate to update booklet for dissemination	11

The working groups continued to meet until August 2019 facilitated by PACCS. The clinical working group focused on clinical care needs of people with dementia to guide development of a health pathway for end-stage dementia, the highest ranked recommendation from the needs assessment discussion paper. During this time, PACCS completed additional consultations across the SWSPHN Community Advisory Group and aged care service providers within the SWSPHN region. At the conclusion of the working group meetings SWS health system issues that may create barriers to access to palliative care for people with dementia were recognised. These issues are listed in alphabetical order in Table 7 on the following page, were ready to be taken into the solution design phase of the Project.

**Table 7: Issues for the end-of-life care of people with dementia in South Western Sydney**

Ambiguity around roles of care in palliative care in SWS
Bereavement follow up
Four groupings of GPs for preferences in dealing with palliative care
Inconsistency in the initiation of Advance Care Planning
Lack of recognition of palliative care need in the deteriorating resident among aged care staff and primary care staff

Lack of recognition of palliative care needs of a resident not acutely ill but approaching end of life among aged care staff and primary care staff
Lack of referral pathway and guidance document on what to do before making a referral to SPC
Low initiation of NSW Ambulance Authorised Adult Palliative Care Plans
Low levels of adoption and use of validated resources for GPs
Low levels or partial adoption and implementation of aged care palliative care toolkits within RACFs.
Need for Referral pathway & referral criteria for each service
Recognition of cultural aspects of Aboriginal & Torres Strait Islander peoples in end-of-life care
Recognition of cultural aspects of Culturally & Linguistically diverse peoples in end-of-life care

The Community Working Group guided the development of community facing strategies to enhance health literacy around dementia, advance care planning and palliative care. This group also undertook a strengths-based approach to identify a vision for end-of-life care for people with dementia in South Western Sydney. Working group members were able to identify positive experiences of end-of-life care for people with dementia and were able to develop a vision statement, and principles of care for end-of-life care for people with dementia in South Western Sydney.

*"We want person focused, dignified care which respects choices and goals of care. The care will involve good communication and symptom control. The care will also involve working together with family, carers, GPs and other service providers in respecting those choices and goals of care in a place that is a familiar, loving and safe environment. Care is in accordance with a person's Advance Care Plan. Unnecessary and futile treatments have no place in the care of persons with dementia in South Western Sydney."*

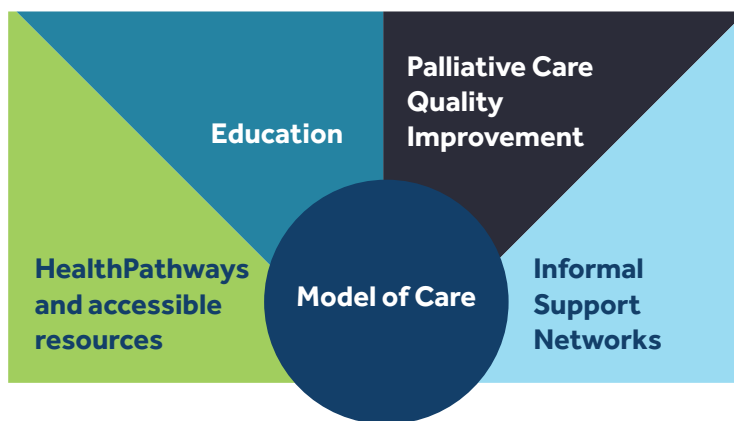
To achieve the vision, we have identified a needed focus of care within RACFs and general practice where there is:

1. Discussion on goals of care
2. Discussion on Advance Care Planning
3. A culture of care within the organisation, facility and general practice
4. An awareness of the limits of acute health care
5. A positive message of the care that is available

## The solution design phase

At the start of the solution phase of the Project, the vision of what quality palliative care for people with dementia would look like had been clearly established as were barriers obstructing the vision.

SWSPHN project staff worked with project working group and formulated a four-component capacity building model with activities that would target the barriers to people with dementia receiving quality palliative and end-of-life care and explore the implementation of compassionate communities to provide informal support to people with dementia, their carers and families.



**Figure 5: The four-component model of care to improve the end-of-life journey for people with dementia in South Western Sydney**

A project logic model was constructed which illustrates the range of activities seen to be required to make an improvement and their goals as shown in Table 8 below.

Table 8: Peace of Mind project Logic Model

Situation	Priorities SWSPHN Strategic Plan	Inputs	Outputs	Who we reach	Short Term Outcomes	Mid Term Outcomes	Long Term Outcomes
Palliative care is not always considered for people with dementia	Goal 4.1: Developing evidence-based models of care for vulnerable & hard to reach population groups relevant to identified needs	<ul style="list-style-type: none"> <li>Funding</li> <li>Staff</li> <li>Partners</li> </ul>	<b>Component 1</b> Develop and promote a health pathway linking Palliative and Dementia Care supported by appropriate resources	<ul style="list-style-type: none"> <li>People with dementia</li> <li>Carers &amp; families of people with dementia</li> <li>GPs</li> <li>Community</li> <li>Health Professionals</li> </ul>	A health pathway is available for use	General Practitioners use the health pathway to guide care of their patients with a dementia diagnosis	Through use of the health pathway, palliative care for people with dementia is business as usual
Low community health literacy on dementia, PC and ACP	Goal 2.1: Strengthening health literacy to help the community make better informed decisions	<ul style="list-style-type: none"> <li>Funding</li> <li>Staff</li> <li>Partners</li> </ul>	<b>Components 2 and 4</b> Provide events on Dementia, PC and ACP	Community members	Increased attendee knowledge and use of ACP	More people attend and growth begins in the community	Community is informed & empowered to make their end-of-life wishes known
			2. Provide '10 Things to know before you go' Workshops through the Groundswell Project		Attendees tell others		
			3. Explore concept & interest for informal support network development		Communities are energised to develop informal networks	Community members begin to plan and implement ≥informal support network	≥ one informal network provides support for people with dementia and the carers/families
Paucity of ACP and PC assessment in General Practice	Goal 2.3: Engaging GPs & PCPs to ensure fit for purpose systems that contribute to improved health outcomes	<ul style="list-style-type: none"> <li>Funding</li> <li>Staff</li> <li>Partners</li> </ul>	<b>Components 2 and 3</b> <ul style="list-style-type: none"> <li>GP Education</li> <li>General Practice QI activity</li> </ul>	GPs	Raised GP awareness of cognitive decline, dementia diagnosis and the need for early ACP and a PC to care	Increased early dementia screening, diagnosis and discussion of disease progression, prognosis and ACP by GPs. Increased PC approach to care of people with dementia	Earlier diagnosis, quality patient education on dementia, advance care planning and palliative care are everyday practice for people with dementia
Variable palliative care access and quality in RACFs	Goal 1.2: Developing innovative models that ensure quality care is delivered	<ul style="list-style-type: none"> <li>Funding</li> <li>Staff</li> <li>Partners</li> </ul>	<b>Component 3</b> Needs assessment and codesign of QI activities with aged care providers in SWS	Aged care providers People with dementia, their families and loved ones	Knowledge of providers needs and readiness for change	A QI plan and facilities engaged	Improved access and quality in PC provision in engaged RACFs with a plan for sustainability
Health system barriers in the SWS	Goal 3.2: Effectively linking primary & hospital providers for improved continuity of care	<ul style="list-style-type: none"> <li>Funding</li> <li>Staff</li> <li>Partners</li> </ul>	<b>Component 3</b> Formation of a systems improvement working group	Key stakeholders in SWS	Identified system issues are addressed	Identified system issues are addressed	Identified system issues are addressed

## Component 1: Health pathway and accessible resources

The Project staff would work with the SWS HealthPathways program to develop a pathway that linked dementia, advance care planning, palliative care and end-of-life together to complement the pathways already available for Mild Cognitive Impairment, Dementia, Advance Care Planning, and Palliative Care. The pathway would utilise the HealthPathways format of assessment, management, referrals and to ensure it would be appropriate for use during a GP consultation. Tools and resources for the GP to use with or provide to their patients would also be

linked to the pathway for easy time saving access.

Culturally appropriate information would be made available to cater to the region's rich cultural and linguistic diversity. The SWS HealthPathways sister site for community "Health Resource Directory" (HRD) has the capability to read information to members of the public with reading disabilities. Project staff would locate information sources in a range of community languages commonly spoken in the region to add to the HRD and the SWSPHN website.

## Component 2: Education

### Community Education

Community education about dementia, palliative care and future care planning was identified as a key strategy to empower communities by the needs assessment and both working groups. The Project team devised a plan to provide free community education sessions during relevant national "weeks" such as Advance Care Planning Week, Palliative Care Week, Dying to Know Day and Dementia Awareness Week. The sessions would be delivered by subject matter experts on dementia, advance care planning and palliative care with time for questions and answers and written information available for participants to take home. The sessions would be delivered in a face-to-face format in easily accessed locations comfortable for senior community members. Furthermore, the PHN would increase the availability of supplementary education resources suited to a range of literacy levels and community languages by linking them into the HealthPathways to be created and the PHN website.

### General Practice education and capacity building

Discussions within the Project's clinical working groups about how to support GPs who actively avoid palliative patients and those who need more confidence, skill and knowledge suggested the need to support GPs to be upskilled in their knowledge and confidence in providing care for palliative patients. The role of practice nurses in recognising patients at risk of dementia and palliative patients and liaising with GP and family were discussed. It was felt upskilling practice staff in dementia and palliative care and would assist GPs in their work. A strategy to link GPs and practice staff with diverse continuous professional development (CPD) opportunities was developed. These opportunities would encompass CPD meetings delivered by the PHN, linkage to opportunities available through government funded programs such as the Program of Experience in the Palliative Approach (PEPA), Dementia Training Australia, Dementia Services Australia, End of Life Directions in Aged Care (ELDAC), CareSearch and Advance Care Planning Australia. To ease access issues for general practice, the PHN would centralise tools to support diagnosis of dementia, advance care planning, palliative care needs assessment and management on the PHN website and HealthPathways. The tools would be supplemented with resources for consumers that could be used at the point of care by health providers.

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## Component 3: Palliative care quality improvement

### Residential Aged Care

To start to address the variability in quality of palliative care delivered in residential aged care (RAC) SWSPHN engaged with the Palliative Care Outcomes Collaborative (PCOC). A plan was developed to collaborate with the PCOC trial in aged care. SWSPHN would promote the trial and recruit up to three RACFs to participate in the trial. SWSPHN would be able to receive progress reports and data from PCOC to progress data collection objective of the DoH.

### General Practice

The project staff would work with GPs to codesign an approach to general practice quality improvement and improve GP engagement with palliative care and advance care planning in the region.

### The Local Health System

SWSPHN would form a working group made up of clinicians from general practice, palliative care services, private specialists, community and aged care. This working group would work address the system barriers utilising where appropriate the seven strategies initially developed by Decision Assist and now incorporated into ELDAC toolkits. It was envisaged the group would remain in place after the end of the Project as an ongoing collaborative quality improvement group.

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## Component 4: Informal support networks

Informal networks were a new area of work for SWSPHN. Following readings from the literature and discussions with groups associated with public health approaches to palliative care the decision was made to work towards the establishment of at least one Compassionate Communities network in SWS. Informed by the final report of the Compassionate Communities feasibility study<sup>30</sup> and the short term nature of the Project funding, an alternative to the community development approach was planned to assess the appetite for compassionate communities in SWS.

A community partnerships approach was planned in partnership with a partnership broker that would be comprised of:

- The delivery of a full day workshop for interested community members that would provide participants with a clear understanding of compassionate communities and partnerships, enable the participants to develop their common vision for a compassionate community in their own communities and identify practical approaches to partnering to build an action plan to move their vision forward. The full day workshop would:
  - Be presented in up to three locations dependent upon demand.
  - Be followed up with two half-day workshops in each location to follow up and implement the plans developed with the workshops.
- Beyond the workshops SWSPHN would provide support to the groups until the end of the Project when it was expected that the groups would become self-sustaining.

# The implementation phase

## Component 1: Health pathways and accessible resources

To support appropriate access to services, timeliness in care and safer transitions for patients with dementia a new pathway was designed titled [End-Stage Dementia](#) and is available for General Practitioners but may be useful for other clinicians as well. The pathway is divided into condition background, assessment, management, diagnostic procedures and referral pathways including a supplementary section of local services

and information resources for patients and relatives including translated patient information where available.

SWSPHN now has HealthPathways covering the continuum from Mild Cognitive Impairment through to End-Stage Dementia. The new end-stage pathway has been viewed 53 times since October 2020.

## Component 2: Education

### Community Education Events

Based on clinical and community working group recommendations identified in the diagnostic phase of the Project regarding embedding dementia and end of life planning discussions between community and general practitioners, SWSPHN has developed an integrated education model. The model may assist other PHNs or organisations with similar issues in their region. Full details of the model are contained in Appendix 1: Palliative Care Projects for Underserved Groups Toolkit.

Beginning in 2019, SWSPHN has delivered a series of face-to-face community education events. Initially there were three presentations covering dementia, advance care planning and palliative care. A fourth topic, organ donation, was trialled at the final event in 2019 after receiving a request to present from the SWSLHD. The addition proved popular with the audience and has been retained. The events were entitled 'Dementia is NOT a normal part of Ageing'. The two-hour events were divided into four presentations covering topics including:

- ➔ Dementia – What it is, how it can affect future decision making and prevention (40 min)
- ➔ Palliative Care – What it is? What services are available? Who should I discuss with? (20 min)
- ➔ How to plan ahead when circumstances change in life? (20 min)

➔ What I should know about organ and tissue donation decision-making (20 min)

➔ Plus a networking tea break (15 min)

The COVID-19 pandemic caused the cancellation of some planned events in both 2020 and 2021. A total of eight events were held in the Wollondilly, Campbelltown, Camden and Liverpool local government areas. Attendances increased from 2020 after the PHN collaborated with the Wollondilly, Camden and Campbelltown local councils in the delivery of the community sessions. Councils recommended holding the sessions during their "Seniors Festivals", provided venues and catering for the events and event promotion.

In total 175 people have attended the community education sessions made up of 70 people across four events in 2019, 41 at one event in 2020, and 64 across three events in 2021. All people who attended the 2021 events (64) completed a post event participant survey (see Appendix 1). Demographic data collected showed that 72% of attendees were female. The majority of people attending (85%) were aged between 40 and 70+ and 49% were retired. Responses to the survey indicated that the education events were well received by the attendees. Not all respondents answered every question.

Table 9: Key results from the 2021 post event participant survey

Question	Number of responses to question (N)	Proportion who agreed to strongly agreed (%)	Proportion who responded neutral to strongly disagreed (%)
The event has shown me where I can find more information about Dementia, Palliative Care and organ donation	59	97	3
The event has made me feel more comfortable to talk about dementia and palliative care with family and friends	59	95	5
The event has made me feel more comfortable to discuss my values and wishes about end-of-life with family and friends	60	95	5
I feel comfortable in starting conversations about my wishes at the end of life with my GP	59	92	8
I feel my GP will be open to discuss Advance Care Planning with me	62	85	15
<b>Following today's event, I will take action to plan ahead by ...</b>			
Preparing a Will	45	78	22
Appointing an Enduring Guardian with a Lawyer	46	78	22
Appointing a Power of Attorney with a Lawyer	47	72	28
Having Advance Care Planning conversations	55	93	7
Informing my family about my organ donation wishes	57	88	12

These community sessions became a positive and sustainable strategy. Over the course of the project, growth in attendance numbers and attendees from previous sessions returning and bringing colleagues, friends and family members. In this way the community transformed the events into a community hub to meet up with friends and family while receiving education about how to better support those living and experiencing dementia. In 2021 the decision was made to add another activity to the community education program. The added activity sought to cater for education session participants who, at the end of the session, felt activated to take a step further in their learning about planning for end-of-life.



## Community Workshops

SWSPHN worked with The Groundswell Project (Groudswell) a not-for-profit organisation advocating for death literacy and palliative care improvements to offer a workshop titled "10 Things to Know Before You Go". The workshop was a comprehensive four-hour event that consolidated the information presented in the Community Education sessions. Through a series of activities to engage participants, the workshop covered practicalities such as: writing a will, appointing a power of attorney, appointing an enduring guardian, and planning your funeral and burial. It also covered broader, social elements that can impact our end of life in a positive way such as strengthening social networks and communicating our wishes.

SWSPHN commissioned three workshops with the first been delivered in May 2021. The remaining workshops were cancelled due to COVID-19 restrictions. The workshop was attended by 15 community members. Nine attendees (60%) completed the post event survey that asked them to rate their before and after workshop selves in four areas. Respondents used a number between 1 and 10 where 1 was a very low rate and 10 was very high. Their responses shown in Table 10 indicated that the workshop had been positively received and effective. Groundswell reports receiving feedback that participants left feeling more empowered with knowledge about navigating different aspects of the end-of-life system and 80% of participants have reported that they took direct action in end-of-life planning as a result of the workshop.

**Table 10: Workshop survey responses showing changes from before to after the workshop across five variables.**

	Comfort discussing end of life issues:		Level of knowledge regarding end of life:		Ability to plan for end of life:		Confidence in telling someone your plan:	
	Before?	After?	Before?	After?	Before?	After?	Before?	After?
<b>P1</b>	5	<b>10</b>	1	<b>8</b>	1	<b>9</b>	1	<b>9</b>
<b>P2</b>	8	<b>8</b>	8	<b>8</b>	8	<b>8</b>	8	<b>8</b>
<b>P3</b>	4	<b>6</b>	3	<b>5</b>	2	<b>5</b>	3	<b>5</b>
<b>P4</b>	10	<b>10</b>	5	<b>9</b>	4	<b>9</b>	10	<b>10</b>
<b>P5</b>	7	<b>10</b>	7	<b>10</b>	7	<b>10</b>	5	<b>9</b>
<b>P6</b>	6	<b>6</b>	2	<b>4</b>	2	<b>6</b>	2	<b>6</b>
<b>P7</b>	7	<b>10</b>	6	<b>10</b>	6	<b>10</b>	7	<b>10</b>
<b>P8</b>	5	<b>10</b>	6	<b>6</b>	1	<b>7</b>	1	<b>9</b>
<b>P9</b>	3	<b>8</b>	2	<b>8</b>	4	<b>9</b>	7	<b>9</b>

### Participant comments regarding the workshop

- Really liked the templates provided for end-of-life planning documents...
- Very interesting, thank you to ... for putting this workshop on
- Thought it was a great day – thank you!
- There was lots to think about
- Extremely informative day

### Aboriginal Education Material

Aboriginal people refer to the period of cultural practices and protocols associated with death as Sorry Business. Sorry Business is an important time of mourning that involves responsibilities and obligations to attend funerals and participate in other cultural events, activities or ceremonies with the community. We value the importance of advance care planning yarning so in cooperation with SWS Local Health District Palliative Care Service, Gandangara Land Council and community the '[Journey Into Sorry Business](#)' resource has been developed to provide culturally appropriate, respectful, and mindful information to encourage Aboriginal people to open conversations about their rights, wishes and how to plan ahead when circumstances change through life. The development of this resource involved a series of consultation sessions with Aboriginal Elders living in SWS held at Miller's Community Centre and at Tharawal Aboriginal Medical Practice. Their recommendations have guided the content of this material. An aboriginal artwork was commissioned to provide culturally appropriate imaging and graphic design.

Journey into Sorry Business has been well received since its launch in May 2021, the SWSPHN web page where the booklet is available has been viewed 1076 times between 17 June and 27 October 2021. Some of the interest and activity around the resource includes:

- Being added to resources section of (yet to be released) updated ACI Palliative Care Blue Print
- It will be distributed with all graduates of relevant UTS Bachelor and master's degrees
- Being presented to the Nepean Blue Mountains Palliative Care Committee by their Multicultural project officer
- Promotion of the resource by ANZ Society of Palliative Care to their members
- Inclusion in the Sydney Partnership for Health Education Research and Enterprise newsletter
- Inclusion in Palliative Care Australia's Newsletter
- Request received from Murrumbidgee LHD renal service to adapt the referral section and use the resource in their region
- Inclusion in the SWSLHD bulletin on dementia during Alzheimer's Awareness Week
- Five requests for printed copies to be available for patients

### General Practice Education

SWSPHN has facilitated nine face to face or Zoom based CPD events linked to the Project for GPs. Practice nurses were also able to attend events about advance care planning. SWSPHN worked with the PEPA program to deliver three workshops and the Advance Project to deliver one workshop.

The Project's CPD plans were extensively affected by the COVID-19 pandemic while the shift to virtual events hosted on the Zoom platform were established and the shift in focus of GPs as they managed the pandemic and vaccination roll out. All events were well received by those who attended but attendance has been disappointing at some events. The move to virtual CPD events has allowed the program to deliver events to the whole of the region at one time improving attendance and providing efficiency gains for the PHN. In addition to these events the Project gave two presentations at the 2019 SWSPHN Women's Health Conference attended by 156 GPs.

Table 11: CPD Events facilitated by the Peace of Mind project 2018 – 2021

Event Name	Mode of Delivery	Number of Attendees
<b>2018</b>		
Delivery of palliative care in the home	Face to face	25
Dementia from prevention to BPSD management	Face to face	32
Palliative care in general practice x 2 with PEPA	Face to face	33 in total
The essentials of talking and planning for EOL with patients	Face to face	41
<b>2019</b>		
Management of BPSD	Face to face	15
Advance care palliating workshop	Face to face	3
<b>2020</b>		
The Advance Project ACP workshop	Zoom	43
<b>2021</b>		
Palliative Care in Dementia with PEPA	Zoom	22

## Component 3: Palliative care quality improvement

### Residential Aged Care

As planned SWSPHN promoted the PCOC trial to RACFs in late 2019 and recruited two RACFs to participate in the trial. SWSPHN liaised with PCOC and the facilities to coordinate the start-up of the trial in each location and attended the RACF staff pre-trial education sessions in February 2020. Unfortunately, with the COVID-19 pandemic hitting facilities hard from March 2020 both recruited facilities withdrew from the trial.

### General Practice

The planned co-design of General Practice quality improvement was unable to proceed due to the demands the COVID-19 pandemic placed upon GPs time and focus.

### The Local Health System

SWSPHN has formed a working group made up of clinicians from general practice, palliative care services, private specialists, community and aged care. The working group addresses SWS health system barriers that may reduce access to palliative care for people with dementia utilising where appropriate, the seven strategies initially developed by Decision Assist and now incorporated into ELDAC toolkits. While interrupted by COVID-19, especially group meetings, work has continued for the group, thus far they have:

- ➔ Helped guide the community education component of the Project,
- ➔ Developed a Roles and Responsibilities document for clinicians providing palliative care to people with dementia in SWS to address the identified issue of role ambiguity (see p15). The completed document appears in Appendices 1 and 2
- ➔ Begun initial discussions of ways to support GPs across the continuum of engagement with palliative care.
- ➔ Worked on developing resources for clinicians caring for people with dementia focused on a palliative approach and the points of difference at each stage of dementia. Appendix 1 includes a description of the framework used to develop the clinician resources. The resources are contained within Appendix 2.

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## Component 4: Informal support networks

SWSPN provided two introductory partnerships workshops to people interested in forming a compassionate community around people who are ageing and frail, have a life-limiting illness, particularly dementia, and are approaching the end of life. The original intent was to provide a series of three workshops for participants over the following months. However, only a small group of people indicated an intent to continue with the task of growing an informal support network/ compassionate community making the original plan not a viable or suitable approach.

At the end of 2019 an alternative approach was developed, SWSPHN would collaborate with the small, interested group and facilitate a community of practice approach. Communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly. This appeared a viable plan as most of the group were already a group of volunteers assisting elderly frail people. When contacting the leader of this group, resistance was encountered in the form of prevarication

when attempting to plan continuing meeting and eventual loss of contact as emails and calls went unheeded. Without the cooperation of the leader, other group members' support also faded. This was later described as "gatekeeping" behaviour often encountered when attempting to establish compassionate communities<sup>31</sup>. With, at that stage, only a few months remaining of the Project it was too late to continue with the strategy.

Our key learnings from this component of the Project are that:

- ➔ Compassionate Communities is a new concept and one that community members don't find easy to understand especially as it is linked to end of life and in our case people with dementia,
- ➔ A Compassionate Community project should not be attempted without an initial community engagement element,
- ➔ These projects take a lot of time to gain traction and develop and are therefore not readily suited to time limited multi-component projects.

## Conclusion

In summary, SWSPHN submitted a successful expression of interest to undertake a project aimed at improving the end-of-life journey for people with dementia. The submitted project was aspirational with nine objectives to meet. The project was undertaken during a time of upheaval in the health and aged care sectors that can be attributed to the Royal Commission into Aged Care Quality and Safety and its findings, and the COVID-19 pandemic. However, the project gained the sustained support and engagement from our key stakeholders; the SWSLHD Palliative Care Service, working group GPs, geriatrician, PACCS and community representative. This allowed the project to progress, achieve, and gather learnings all of which we have shared in this report of the pilot GCfAHPC.

**Table 12: Project objectives and status at conclusion of pilot.**

	Objective	Status
1.	To undertake a rapid, but rigorous palliative care needs assessment which will build on the current PHN needs assessment, and the findings of the SWSLHD strategic plan for palliative care	Complete
2.	To develop a health pathway using the HealthPathways methodology tailored to the South Western Sydney context that features diversity of cultures and geographies. The health pathway will feature clear trigger points for escalation, linkage to and support from Specialist Palliative Care Services where required and linkage to bereavement support for carers and families	Complete
3.	To promote timely diagnosis especially of dementia in older people	Complete
4.	To increase early initiation of discussions with the person, their Carer and family about planning for future palliative and end-of-life care	Activities undertaken but data not collected
5.	To provide education and orientation to palliative care for consumers, Carers and families about what to expect during the end-of-life journey	Complete
6.	To develop informal support networks such as Compassionate Communities with consumers	Activities undertaken but not successful
7.	To increase awareness and linkage of people with dementia to the SWSLHD PEACH program for provision of home-based palliative care packages during and after normal business hours during the last weeks of life	PEACH program promoted
8.	Development and maintenance of multisector partnerships to ensure timeliness and productivity continue throughout the project	Completed
9.	The collection and appropriate sharing of salient data	Project data collection complete.

SWSPHN is grateful for the funding provided the Commonwealth Department of Health that enabled this project and again for continued funding over the next four years that will allow the PHN to continue the work started during the pilot, share our success and learnings and improve the end-of-life journey for a vulnerable population, those with dementia.

# Glossary

The terms listed here are based upon those described by Palliated<sup>32</sup> unless otherwise referenced.

## Advance care directive

A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care and appoint a substitute decision-maker to make decisions about health care and personal life management. In NSW An Advance Care Directive must be followed, Health Professionals and Persons Responsible have no authority to override a valid Advance Care Directive. An Advance Care Directive is valid if:

- The person had capacity when it was made, and it was made voluntarily
- It has clear and specific details about treatments that the person would accept or refuse; and
- It applies to the situation the person is in at the time<sup>33</sup>.

While Common Law directives can be written or oral, to ensure the Advance Care Directive has the best chance of being followed in the future by a health professional, it is recommended that it be:

- In writing
- Signed and dated by the person, and
- Witnessed <sup>34</sup>

## Advance care plan

An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf and should be prepared from the person's perspective to guide decisions about care.

## Advance care planning

A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.

## Carer

A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged. An individual is not a carer merely because they are the spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care.

## Dying

The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks. This is sometimes referred to as 'actively dying'.

## End of life

The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients

who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.

## End-of-life care

Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean that they are expected to die within 12 months
- Existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

## Family

Those who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.

## Goals of care

The aims for a patient's medical treatment, as agreed between the patient, family, carers and healthcare team. Goals of care will change over time, particularly as the patient enters the terminal phase. Medical goals of care may include attempted cure of a reversible condition, a trial of treatment to

assess reversibility of a condition, treatment of deteriorating symptoms, or the primary aim of ensuring comfort for a dying patient. The patient's goals of care may also include non-medical goals - for example, returning home or reaching a particular milestone, such as participating in a family event.

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### **Life-limiting illness<sup>8</sup>**

A person with life-limiting illness may die prematurely. This term is often used for people living with a chronic condition that may seem life-threatening but can continue for many years or even decades.

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### **Non-beneficial treatment**

Interventions that will not be effective in treating a patient's medical condition or improving their quality of life. Non-beneficial treatment may include interventions such as diagnostic tests, medications, artificial hydration and nutrition, intensive care, and medical or surgical procedures. Non-beneficial treatment is sometimes referred to as futile treatment, but this is not a preferred term.

### **Palliative care or palliative approach**

An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

ACFI 12 Complex Health Care includes a complex health care procedure described as "Palliative care program involving End of Life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting".

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### **Pastoral Care<sup>35</sup>**

Pastoral care complements the care offered by other helping disciplines while paying particular attention to the spiritual. It is focussed on healing, guiding, compassionately supporting, nurturing, liberating and empowering of people. It is person centred and holistic. *(Adapted from Dr Bruce Rumbold)*

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### **Specialist palliative care**

Services provided by clinicians who have advanced training in palliative care. The role of a specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate palliative care generalist clinicians.

### **Spirituality and Ageing<sup>35</sup>**

Spirituality is an essential dimension that brings meaning to life; it is deeply associated with relationship, transcendence and hope. Increased awareness of spirituality is often seen in later life, especially through transitions, issues of health, end of life, and the need for forgiveness and reconciliation.

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### **Substitute decision-maker**

A person appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories). More than one substitute decision-maker may be appointed.

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### **Surprise question<sup>36</sup>**

The 'surprise question' is used for patients with advance disease or progressive life-limiting conditions. The clinician asks themselves 'Would you be surprised if the patient were to die in the next year?'

The answer to this question is an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, a palliative approach should be considered, and measures taken to improve the patient's quality of life now and in preparation for possible further decline.

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### **Terminal phase**

The hours, days or, occasionally, weeks when a patient's death is imminent. This is sometimes referred to as the period when a patient is actively dying.

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# Appendix 1: Resources for implementing palliative care projects for underserved groups

## 1. Education and professional development model

The SWSPHN Peace of Mind Project aimed to improve the end-of-life journey for people with dementia. The embedding of dementia and end of life planning discussions between community and general practitioners was vital to improving that journey but we discovered barriers such as low health literacy around dementia, discomfort about talking about dementia and death, lack of knowledge that dementia is a life limiting illness and the resultant disconnect in people's minds between dementia and palliative care. Education for the community and for health practitioners was needed as a key component of the project. We have developed this model that may assist other PHNs or organisations with similar issues in their region.

The model is based upon the 2001 revision of Bloom's Taxonomy<sup>37</sup> of learning (Figure 1) and proposes a progressive building block strategy for community members to have the opportunity of improving their familiarity with an initially perceived confronting topic. The model commences with the delivery of introductory knowledge on the topic as a precondition to building further understanding, skills to utilise available resources and act. Thus, community members are empowered to participate in discussions about dementia with an understanding that it is a life-limiting condition, optimise care planning, and future plan for end-of-life enabling better outcomes for their own health and impact on their loved ones.

Figure 1: Bloom's Taxonomy

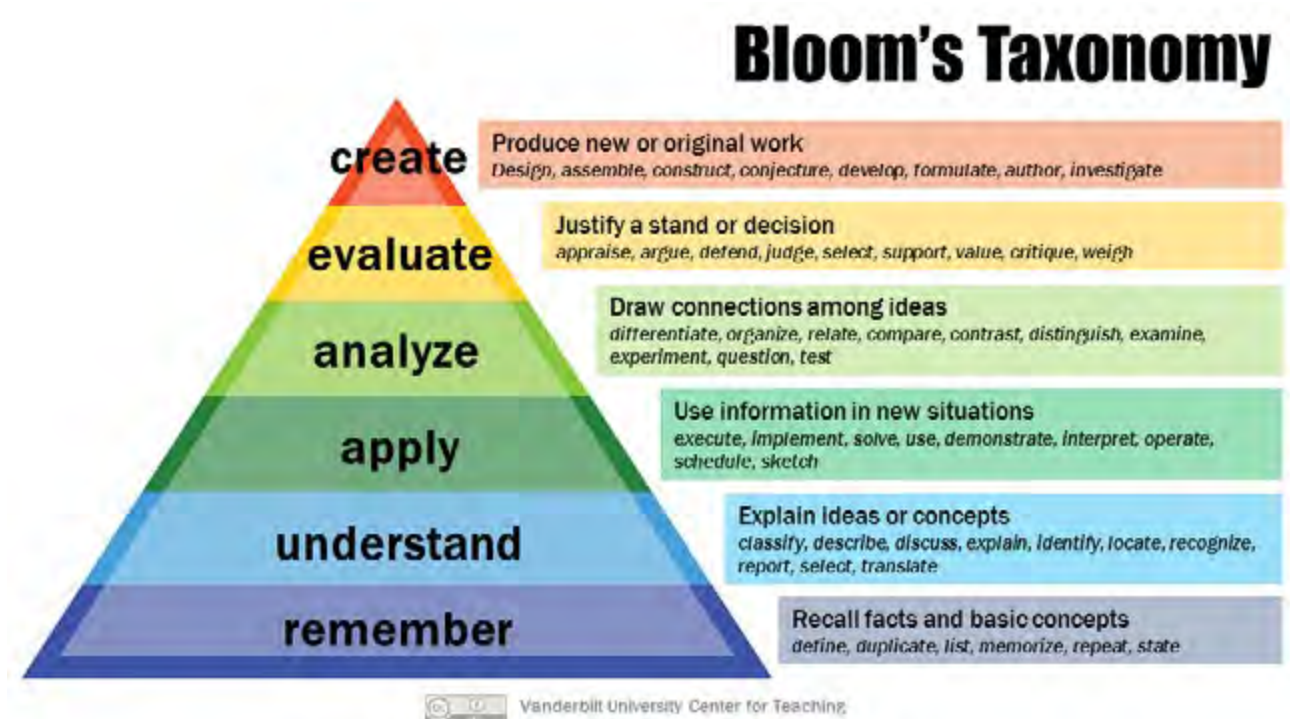


Figure 2 exemplifies this education model rationale with the respective target groups and their educational strategies. Community is located in the centre of the model with capacity building strategies introduced in a stepped approach:

- Education Sessions,
- Workshops,
- Informal Network Building.

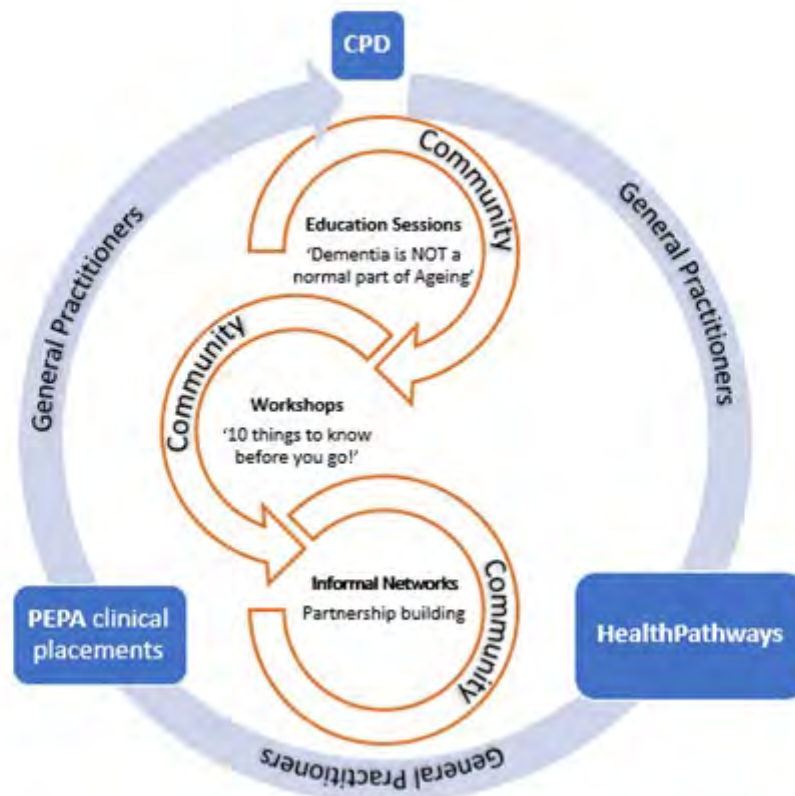
General Practitioners are located in the outer layer coupled with capacity building strategies of:

- HealthPathways and accessible resources,
- Continuing Professional Development,
- Program Experience in the Palliative Approach (PEPA) program clinical placements.

These activities aim to increase the GPs' knowledge, skills and confidence to provide sustained support to their patients as part of their daily practice.

This model supports patient centred care, in which community and patient education are at the centre and GPs and other health professionals expand on and improve patient capacity through supplementary education strategies e.g., one to one during appointments in general practices, at outpatient clinics in hospital settings and/or when visiting RACFs.

**Figure 2: Model for Education and Professional Development on dementia as a life limiting illness for community and general practitioners**



## Community Activities

### Education Sessions

Education sessions on dementia are readily available in a range of formats (online, face to face, interactive dashboards) and delivered by different organisations but rarely tailored for SWS. The 'Dementia is NOT a normal part of ageing' is a tailored two-hour education session aimed to introduce community to key definitions and concepts of dementia and palliative care while raising awareness about existing services available in the region. Covering the first 2 steps of Bloom's Taxonomy, remember and understand, the session's program introduces recallable facts and basic concepts on how to identify early signs and symptoms of dementia, how to plan ahead and how to access existing services in SWS. The event is designed in a way that community members can relate to with the information presented in accessible language using case studies, testimonials, Q&A and a networking tea break. A 15- minute networking break offers attendees the opportunity to connect with other community members experiencing or caring for someone with dementia or help themselves to written information resources to supplement their learning.

#### 'Dementia is NOT a normal part of Ageing'

A suggested program for a 2-hour event that is divided into four presentations is provided below:

- Opening and Introductions (5min)
- Dementia – What it is, how it can affect future decision making and prevention (40min)
- Networking tea break (15min)
- Palliative Care – What it is? What services are available? Who should I discuss with? (20min)
- How to plan ahead when circumstances change in life? (20min)
- What I should Know about organ and tissue donation decision-making (20min)

#### Our tips

→ **Speakers:** Importantly speakers should be either local health service providers caring for people with dementia or researchers/academics also familiar with local models of care and referral pathways.

→ **Venue:** Community centres or a local organisation known to, and used by, community

→ **Local councils are valuable resources** with close links to and knowledge of their community leaders

#### Our experience:

These community sessions became a good and sustainable strategy with steadily increasing attendance numbers over time and attendees from previous sessions returning and bringing colleagues, friends and family members. Events have also been transformed into a community hub to meet up with friends and family while receiving education about how to better support those living and experiencing dementia.

#### Workshops

Attendees of the community education sessions were offered a follow up workshop. The workshops were used as strategy to consolidate the information presented in the community education sessions and provide tools on how to act, apply and analyse concepts as stated in Bloom's Taxonomy by documenting their wishes and goals of care at the end of life.

The '10 Things to Know Before You Go!' workshop is a comprehensive four-hour event with a series of activities to engage participants to start planning for their end-of-life needs. The workshop covers

practical aspects such as: writing a will, appointing a power of attorney and an enduring guardian, planning your funeral and burial. It also covers broader, social elements that can impact our end of life in a positive way such as strengthening social networks and communicating our wishes. Participants have left feeling more empowered with knowledge about navigating different aspects of the end-of-life system, 80% of participants have reported that they took direct action in end-of-life planning as a result of the workshop.

### Our experience

The '10 Things to Know Before You Go' workshop is one of a series of education programs available from the Groundswell Project, a not-for-profit organisation advocating for death literacy and palliative care improvements. SWSPHN commissioned delivery of the workshop which delivered efficiencies for the PHN and increased sustainability beyond the Peace of Mind project as the workshops are offered on an on-going basis independently of the project. Overall community received the event positively as shown by the comments of participants on the post event survey.

### Our tip

→ **Target audience:** Events are best limited to a maximum of 20 participants and clearly promoted as a community event to facilitate networking amongst attendees. This may encourage the development of informal networks of support between attendees during tea breaks.

## Culturally Appropriate Educational Material for Aboriginal and Torres Strait Islander People

SWSPHN lies in a region of great cultural diversity. The needs of people with dementia from culturally diverse communities was a consideration for the project from commencement.

Aboriginal people in our region refer to the period of cultural practices and protocols associated with death as Sorry Business. Sorry Business is an important time of mourning that involves responsibilities and obligations to attend funerals and participate in other cultural events, activities or ceremonies with the community. We value the importance of advance care planning yarning so in cooperation with SWS Local Health District Palliative Care Service, Gandangara Land Council and community the 'Journey Into Sorry Business' resource has been developed to provide culturally appropriate, respectful, and mindful information to encourage Aboriginal people to open conversations about their rights, wishes and how to plan ahead when circumstances change through life.

The development of this resource involved a series of consultation sessions with Aboriginal Elders living in SWS held at the Miller Community Centre and at Tharawal Aboriginal Medical Practice. Their recommendations have guided the content of this material. An aboriginal artwork was commissioned to provide culturally appropriate imaging and graphic design that pertains to the South Western Sydney region and the PHN itself.

### Our tips

→ We highly recommend undertaking the process of consultation with the Aboriginal and Torres Strait Islander people in your region as best practice

→ This work is necessarily time consuming. We recommend commencing early in your project

## Informal Networks: a partnership building approach

Informal Networks play a strong role in the support and care of people through illness and end of life, their families and carers. Community members may not necessarily have the skills or knowledge to build a strong network and their effort may be enhanced by partnerships with healthcare and other relevant services that can provide linkages and assistance to support the activity of the network and even assist to identify and form further partnerships needed to support the network over time.

By establishing their own informal networks, communities are creating new and original products thus completing the learning outcomes intended in Bloom's Taxonomy and the SWSPHN education model.

## **Our experience**

SWSPN provided two introductory partnerships workshops to people interested in forming a compassionate community around people who are ageing and frail, have life-limiting illness particularly dementia and are approaching the end of life. Through these workshops a small group of people were identified who intended to continue with the task of growing an informal support network.

The original intent was to provide a series of four workshops but with only a small, interested group this is not a viable or suitable approach. SWSPHN will instead form a partnership with the group and facilitate a community of practice approach. Communities of practice are groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly.

## **Health Professionals**

### **Continuous Professional Development sessions**

Face to face and webinar CPD events are available for GPs and Nurses practicing in SWS and cover best practice and timely care management strategies for Dementia and how to consider timely palliative and advance care planning discussions.

### **HealthPathways**

HealthPathways is an online clinical and referral information portal used by clinicians at the point of care. HealthPathways provides GPs access to management and treatment options on a range of clinical presentations and information about local clinical services and their referral processes.

The site uses a scalable format allowing users to customise the level of detail displayed, providing a quick access during consultations or more detailed information to be viewed at a later time.

Links to reputable patient information (including translated patient information where available) and clinical resources are also provided in most clinical pathways.

### **The Program of Experience in the Palliative Approach (PEPA)**

The Australian Government Department of Health funds a range of national palliative care projects including PEPA. Specifically, PEPA aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

PEPA provides opportunities to develop confidence, knowledge and skills in the palliative approach to care through:

- funded clinical workforce placements or workshops
- integration of learning into your workplace
- establishing networks of support

The PEPA learning experience can help health care providers, to:

- gain a clear understanding of the principles of good palliative care
- identify the needs of your patients with life-limiting conditions
- understand the role of your discipline in managing common problems faced by palliative care patients
- recognise your own knowledge base/scope of practice in regard to optimal palliative care provision
- identify personal coping strategies for effective management of personal issues related to working in this area.

This program provides an ideal opportunity to learn from experienced specialist staff to enhance skills, knowledge and experience in the palliative approach <sup>38</sup>.



## 2. Developing resources for clinicians: the 4Ms framework

Resources were 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
- recognition that Dementia is a life limiting disease
- early introduction to a palliative approach to care
- management of care based on the person's current stage
- ongoing timely assessment and identification of needs in each of the palliative care domains
- referral to appropriate services to fulfil needs where needed
- effective transfers between care settings when necessary

To guide the development of the clinical resources the working group adopted the 4Ms Framework<sup>39</sup> developed in 2017, the John A. Hartford Foundation and the Institute for Healthcare Improvement in partnership with the American Hospital Association and the Catholic Health Association. The 4Ms Framework was a response to their recognition of the rapid growth in the number of people over 65 years of age and the increase in complexity due mainly to multimorbidity in many older people. Health systems that have evolved to manage individual diseases often don't cope well with complex multimorbidity. With a focus on four evidence-based elements applicable to all older people, the aim of the 4Ms Framework is to make health systems more age-friendly.

### The framework comprises:

- 1. What Matters** – Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care;
- 2. Medication** – if medication is necessary, use age-friendly medication that does not interfere with What Matters to the older adult, Mobility or Mentation across settings;
- 3. Mentation** – prevent, identify, treat, and manage dementia, depression, and delirium across settings of care; and
- 4. Mobility** – ensure that older adults move safely every day in order to maintain function and do What Matters.

These elements identify the core issues in the care of all older adults regardless of the type or number of diseases they may have thus making complexity more manageable and care more holistic. This approach aligns well with six principles that appear across key palliative care documents and that the project's community working group encompassed in their desired model of care as shown in Table 1 below. Table 2 maps the six palliative care principles to the four elements of the 4Ms Framework.

Table 1. Six palliative care principles

Principles	Working Group (40)	ACI Blueprint (9)	National Palliative Care Strategy (8)	PCA National Standards (41)
<b>1. Person centred care</b>	Care is in accordance with a person's Advance Care Directive/Plan, Care is provided in a familiar, loving and safe environment	Patient, carer and family centred care	Palliative care is person centred care	The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions
<b>2. Care based upon need</b>	Unnecessary and futile treatments have no place in the care of persons with dementia in SWS	Care is provided based on need	Death is recognised as a part of life	Initial and on-going assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs, The provision of care is based on the assessed needs of the person
<b>3. Integrated care</b>	Care will also involve working together with family, carers, GPs and other service providers	Care is integrated and coordinated	Everyone has a role to play in palliative care	Care is integrated across the person's experience to ensure seamless transitions within and between services
<b>4. Family and carer needs</b>	Care will involve good communication	Patients, carers and families have access to local and networked services to meet their needs	Carers are valued and receive the support and information they need	The needs and preferences of the persons family and carers are assessed, and directly inform provision of appropriate support and guidance about their roles, Families and carers have access to bereavement support services and are provided grief and loss information
<b>5. Evidence based care</b>	Care will involve good symptom control	Care is evidence based, safe and effective	Care is high-quality and evidence based	Informed by evidence, and is consistent with the values, goals and preferences of the person as documents in their care plan
<b>6. Equity of access</b>		Care is equitable	Care is accessible	

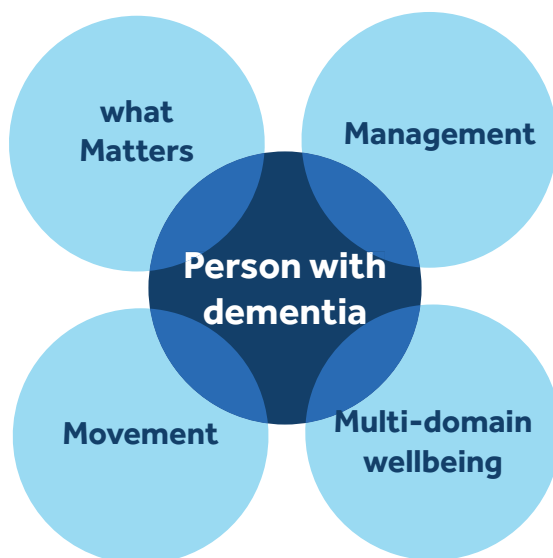
**Table 2: Mapping the six principles of palliative care to the 4Ms Framework**

What Matters	Management	Mental Wellbeing	Movement
Care is aligned to each older adult's specific health outcome goals and care preferences, including, but not limited to, end-of-life care, and across settings of care	Care is provided that is based upon need, is best practice ensures quality of life is maintained	Care is holistic, maintains dignity and quality of life and supports carers and families	Where the care environment needs to change there will be systems in place to ensure that transitions are smooth and quality handover is achieved without exception
1. Person centred care	2. Care based upon need	4. Family and Carer needs	3. Integrated Care
6. Equity of access	5. Evidence based care		

In deciding to document our clinician's resources using the 4Ms Framework we questioned if the term mentation was a good fit within the Australian vernacular and if its meaning as described in the framework was too narrow for the purpose of our project. Likewise, the term Mobility had limitations in the context of dementia and palliative care particularly as end-of-life was approached and would be better used to describe movement between services than human movement. It was decided to adapt these terms to better suit the purpose of this project. The original four elements have been altered to:

1. **What Matters** - care is aligned to each older adult's specific health outcome goals and care preferences, including, but not limited to, end-of-life care, and across settings of care
2. **Management** – palliative care (including medication) is provided that is based upon need, is best practice and ensures quality of life is maintained
3. **Multi-domain Wellbeing** - care is holistic, maintains dignity and quality of life in the four domains: physical, social, psychological, and spiritual and supports carers and families; and
4. **Movement** (between services) - where the care environment needs to change there will be systems in place to ensure that transitions are smooth and quality handover is achieved without exception.

Figure 1: Adaptation of the 4Ms Framework for an Age- Friendly Health System



### Four domains of palliative care

To further assist clinicians the working group has ensured that the resources contextualise the four domains of palliative care.

Physical	Psychological	Social	Spiritual and Cultural
<ul style="list-style-type: none"> <li>• Disease management</li> <li>• Symptom management</li> <li>• Function</li> <li>• Nutrition</li> <li>• Hydration</li> <li>• Wounds management</li> <li>• Habits e.g alcohol, gambling, smoking</li> </ul>	<ul style="list-style-type: none"> <li>• Impact of disease</li> <li>• Emotions</li> <li>• Fears</li> <li>• Control/ independence</li> <li>• Dignity</li> <li>• Depression</li> <li>• Anxiety</li> <li>• Coping</li> <li>• Conflict</li> <li>• Pre-existing mental illness</li> </ul>	<ul style="list-style-type: none"> <li>• Carer/s</li> <li>• Withdrawal</li> <li>• Connections</li> <li>• Support networks</li> <li>• Family</li> <li>• Finances</li> <li>• Legal</li> </ul>	<ul style="list-style-type: none"> <li>• Peace of mind</li> <li>• Values, beliefs,</li> <li>• Meaning</li> <li>• Religion</li> <li>• Pastoral support</li> <li>• Customs, rites, rituals</li> </ul>

#### Physical

The physical domain is concerned with disease and symptom management and personal care. Each person with dementia will have individual needs and a comprehensive assessment and individual care plan are required.

#### Psychological

This domain focusses on awareness of the possibility of psychological concerns such as anxiety, depression or previous mental health issues. The diagnosis of a life-limiting disease such as dementia is psychologically challenging. Beginning early after diagnosis, people with dementia and their carers should be assessed for any issues that are worrying them throughout the disease process. Psychological assessment informs the development of individual care plans.

## Social

This domain is based around ensuring that the person with dementia has a network of support that may include a spouse, family, friends, neighbours and services.

## Spiritual

The final domain is about assessing the spiritual needs of the person with dementia. A person's spiritual care includes faiths, cultures, beliefs, and traditions and is the right of older people to express their spirituality in a way that is meaningful for them.

Meaningful Ageing Australia developed the [National Guidelines for Spiritual Care in Aged Care](#), (831kb pdf) which gives an overview of some key spiritual needs of older people, including the five domains of spiritual care.

## 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](#)

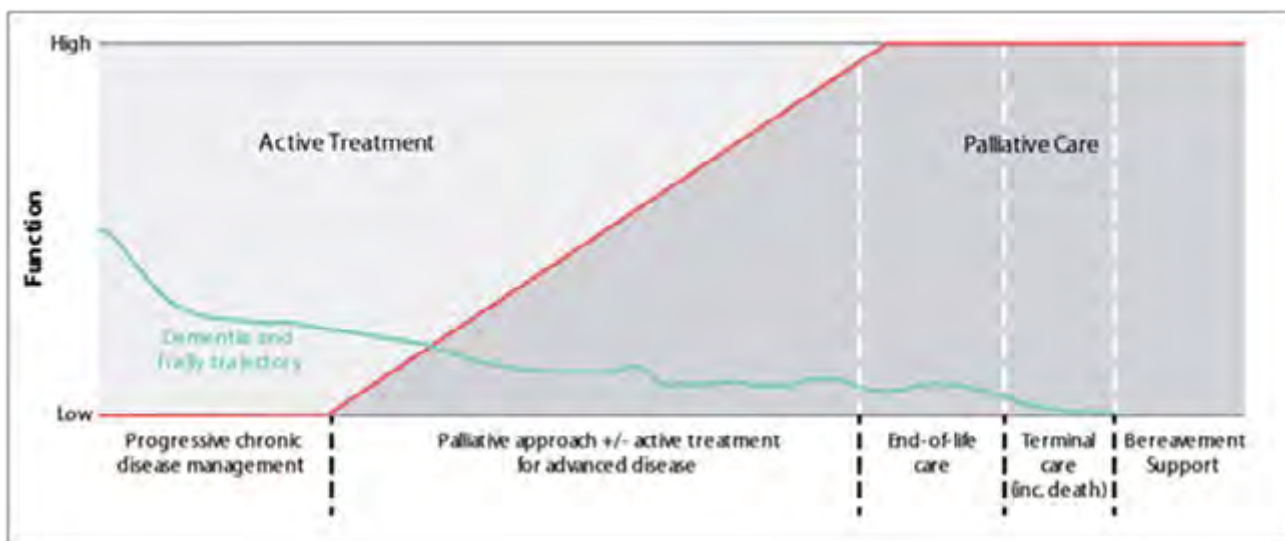
## Management: a palliative approach in dementia

### 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:</b> HELD <input type="checkbox"/> NOT HELD <input type="checkbox"/> NOT YET DISCUSSED <input type="checkbox"/>					
<b>ADVANCE CARE PLAN:</b> HELD <input type="checkbox"/> NOT HELD <input type="checkbox"/> NOT YET DISCUSSED <input type="checkbox"/>					
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		