Appendix 1: Resources for implementing palliative care projects for underserviced 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 [37] 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.
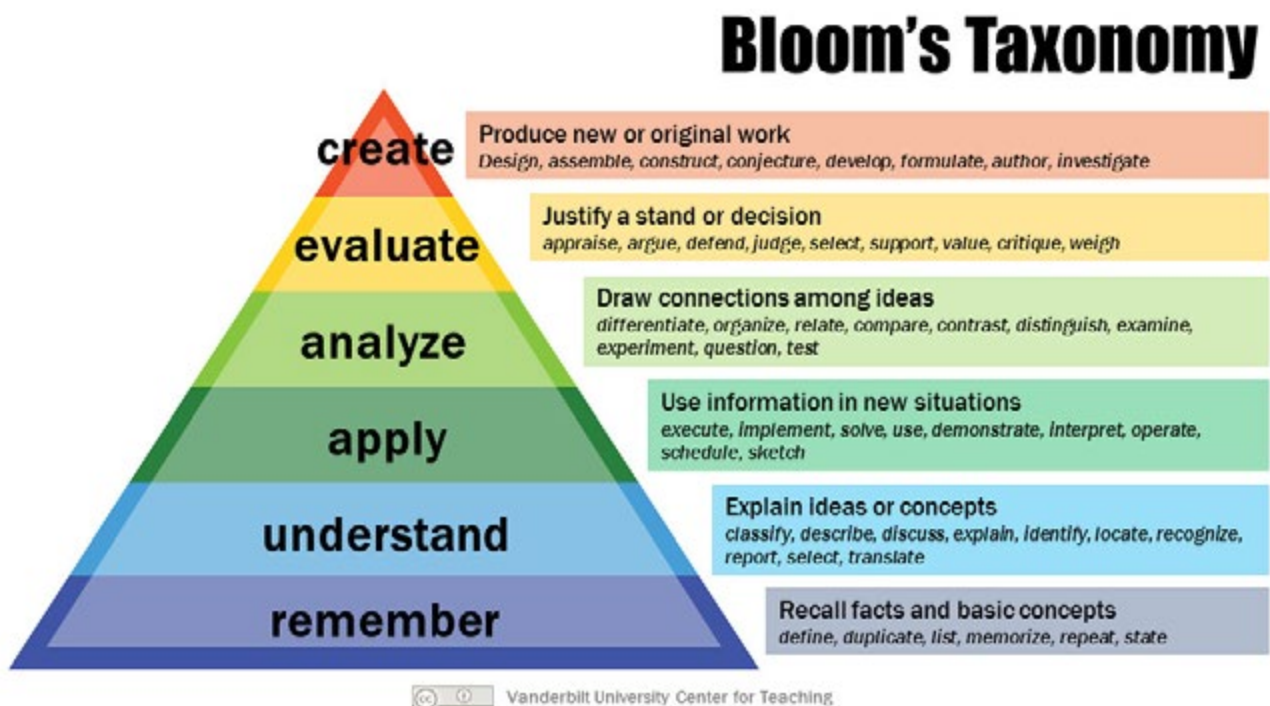
Figure 1: Bloom's Taxonomy

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
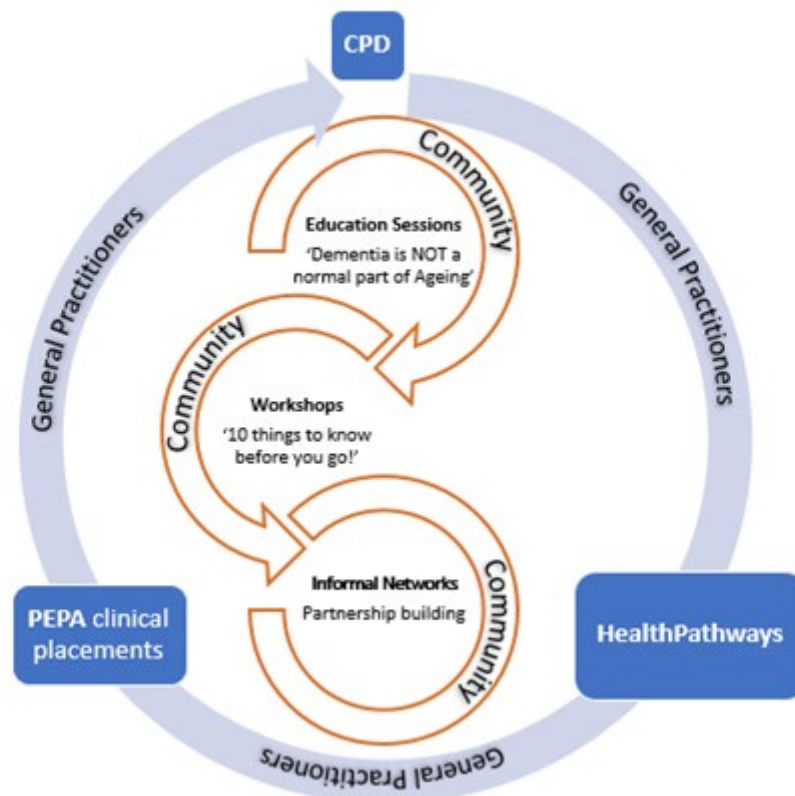
Community Activities

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 t 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 [38].

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 [39] 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)
1. Person centred care	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
2. Care based upon need	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
3. Integrated care	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
4. Family and carer needs	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
5. Evidence based care	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
6. Equity of access		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
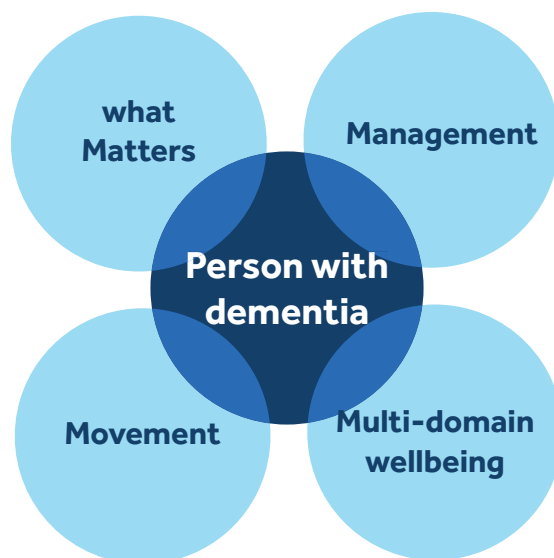
Four domains of palliative care

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
• Disease management • Symptom management • Function • Nutrition • Hydration • Wounds management • Habits e.g alcohol, gambling, smoking	• Impact of disease • Emotions • Fears • Control/ independence • Dignity • Depression • Anxiety • Coping • Conflict • Pre-existing mental illness	• Carer/s • Withdrawal • Connections • Support networks • Family • Finances • Legal	• Peace of mind • Values, beliefs, • Meaning • Religion • Pastoral support • Customs, rites, rituals

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.