Considerations for a palliative and end-of-life model of care for Southern NSW

December 2017

COORDINARE

phn SOUTH EASTERN NSW

An Australian Government Initiative

The South Eastern NSW Primary Health Network (COORDINARE) seeks to increase the efficiency and effectiveness of medical services for patients across the Illawarra Shoalhaven and Southern NSW region, particularly those at risk of poor health outcomes.

COORDINARE works directly with General Practitioners (GPs), primary and secondary health care providers and hospitals to improve and better coordinate care for patients across the network. COORDINARE is committed to finding innovative ways of building a coordinated and sustainable health system, with better consumer experiences, improved health outcomes and reduced costs.

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Direct quotations have been amended for clarity and readability. Case studies presented in the guide have been fictionalised and names have been changed to protect anonymity.

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Contents

1. Introduction

This document is a reference for health services and health professionals providing or coordinating care of patients with a life-limiting or terminal illness in Southern NSW. Included are considerations for a proposed whole-of-health sector model for best practice and collaborative palliative and end-of-life care in our region.

The document was developed in recognition of the growing demand on palliative care services within the region, and the critical role that General Practitioners (GPs) can play in supporting palliative and end-of-life care.

Where is Southern NSW?

The Southern NSW region extends upwards from the south coast of NSW and the Southern Tablelands, across the Great Dividing Range and the Snowy Mountains and surrounds much of the Australian Capital Territory. It spans seven Local Government Areas over an area of over 44,500 square kilometres and includes the towns of Bega, Moruya, Batemans Bay, Cooma, Queanbeyan, Goulburn and Yass.

The purpose of this document is to:

- Describe the current service delivery profile of palliative and end-of-life care in Southern NSW, including strengths and opportunities for improvements
- Present a proposed palliative and end-life model of care that:
    - supports more consistent involvement of GPs
    - strengthens the coordination and management of care between providers, and
    - improves outcomes for patients with palliative needs and their families and carers, including by providing greater support for dying at place of preference.

The document also identifies opportunities to strengthen our health system and support local tailoring and implementation of the proposed model. This is important if we want to drive improvements in palliative care for our communities.

This model of care has been developed to support the care of adults living with a life-limiting or terminal illness. While many of the principles of care are similar for children and young people with a life-limiting illness, such as holistic, person-centred and tailored care, children and young people often have specific needs and may require specialised paediatric services.

For more information on paediatric palliative care, visit the NSW Paediatric Palliative Care Programme website.

Who this document is for

The proposed model has been developed primarily to support GPs and other primary care providers working in community and/or residential aged care facility (RACF) settings in Southern NSW.

The proposed model is also relevant, however, for all those involved in the delivery of palliative and end-of-life care, including specialist palliative care nursing teams, RACF staff, health professionals working in acute healthcare settings, volunteers, as well as patients and their families and carers.

We hope that defining and documenting a proposed model of care for Southern NSW can contribute to a shared understanding among stakeholders of palliative and end-of-life care delivery in our region.

How the proposed model can be used

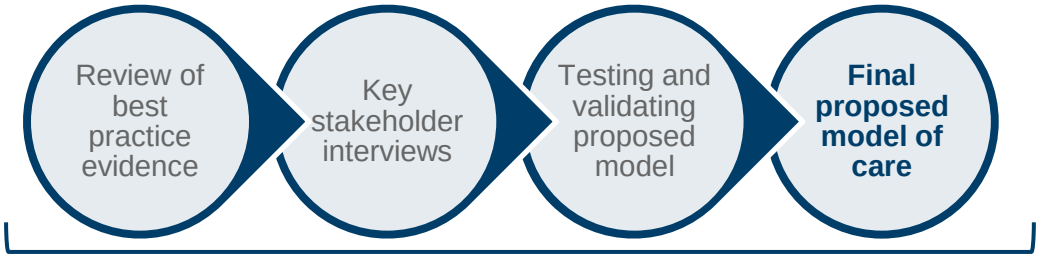
The proposed model of care provides clarity on the way palliative and end-of-life care is delivered in Southern NSW. The proposed model:

- Presents **guiding principles** for the delivery of person-centered palliative and end-of-life care
- Clarifies **roles and responsibilities** of key care providers
- Outlines **appropriate care and services** across levels of palliative and end-of-life care
- Defines care arrangements for varying complexity of patient needs based on a **stepped care approach**.

The proposed model also defines opportunities for coordination and communication between care providers and presents key system changes required to support successful implementation of the model. While the proposed model is intended to inform clinical practice, it does not provide specific clinical guidance or protocols for patient care. Additional available tools and resources are outlined in Appendix I.

How the proposed model was developed

This document has drawn on existing models of care from Australia and internationally[1,2,3,4,5] and has been developed to align with key policy and health system changes in NSW and Australia. The proposed model of care has been refined for the local context in Southern NSW through consultation interviews, input from a local Expert Advisory Group, and testing and validation with stakeholders from across the region. See Appendix II for further information.



COORDINARE would like to acknowledge the valuable contributions of the Expert Advisory Group, Southern NSW Local Health District (SNSWLHD) specialist palliative care nursing teams, as well as the GPs, specialists, and other care providers and consumers who shared their insights and helped shape this proposed model.

2. Palliative care in Southern NSW

Defining palliative and end-of-life care

> *'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering.'*[6]

There is variation in the way language and terminology regarding palliative and end-of-life care is used and understood, both among healthcare professionals and in the general community. For the purpose of this document, we have adopted the following definitions:

- **Palliative care**: holistic care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness[7]. It neither hastens nor postpones death, but affirms life and approaches dying as a normal process[8].
- **End of life**: the period of time when a person is living with an advanced, progressive, life-limiting illness[9]. Because estimating when someone will die is difficult, it is more useful to identify those for whom increasing disability and illness will lead to their death sometime in the next year.
- **End-of-life care:** care provided to people approaching the end of life by all health professionals, including those working in health and aged care systems.

Palliative and end-of-life care includes:

- Early identification and assessment of need, plus advance care planning
- Relief from pain and other problems, including physical, psychosocial and spiritual
- Enhancement of quality of life, including support to help people live as actively as possible
- Resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues.

People with a life-limiting or terminal illness are likely to have a wide variety of needs (physical, psychological, social, cultural and/or spiritual) as well as individual and dynamic care journeys. Palliative and end-of-life care should be personalised and responsive, based on an individual's unique needs.

Case study: Responding effectively to changes in patient need

Jane is a 51-year-old school teacher who has a longstanding relationship with a GP at a local practice in Queanbeyan. Several years ago, Jane presented to her GP acutely unwell with a bowel obstruction. She was transported by ambulance to the Emergency Department where she was later diagnosed with metastatic colorectal cancer.

Jane is married with two young children and her husband supports her throughout her diagnosis. She has early conversations with her GP about advance care planning, her treatment options, and available support services. Jane's GP notices that Jane is highly distressed about her illness and what would happen to her family when she was gone. Her GP provides advice and support to Jane and refers her to a local psychologist. In discussion with her family, oncologist and GP, Jane chooses to undergo chemotherapy and palliative surgery to extend and maximise her quality of life. She continues to see her GP for routine medical care.

During one of her frequent hospital admissions, Jane is referred by the oncology team to the specialist palliative care nursing team. Following an initial palliative care assessment, her GP has a phone conversation with the palliative care nurse, where they both agree on their respective roles. Jane's palliative care is generally non-complex and her palliative care needs are primarily managed by her GP, including pain management. The specialist palliative care nurses and the GP work together to coordinate Jane's care. When Jane becomes too unwell to attend her GP practice, the GP undertakes regular home visits over several weeks. Not long after, Jane passes away peacefully at home with her family.

Palliative and end-of-life care: Perceptions vs. reality	
Perception	**Reality**
Palliative care is only for people who are at their end of life.	Palliative care may be suitable for any person with a life-limiting or terminal illness. A person may receive palliative care for many years before they reach the end of their life.
Palliative and end-of-life care is just for managing physical pain.	Palliative and end-of-life care is holistic and person-centred, addressing physical, psychosocial, cultural and spiritual needs.
Palliative and end-of-life care is best when provided by specialist palliative care services.	The active engagement of GPs and other primary care providers in delivering palliative and end-of-life care can support positive patient outcomes. This is acknowledged in NSW, national and international strategy documents and the published literature.
GPs in Southern NSW don't have access to specialist medical support.	GPs across Southern NSW have 24-hour access to specialist telephone-based support, plus tools and clinical guidance to support care (see Appendix I).

Why a sustainable model is needed

Australia's population is ageing. In NSW, the number of people aged over 65 years is projected to increase by 65% between 2002 and 2021.[10] The Southern NSW region has a higher proportion of people aged 65 years and older (19.1%) than the NSW average (15.5%). Eurobodalla (28.4%) has the highest proportion of people aged over 65 years in our region.[11]

Palliative and end-of-life care in Southern NSW (as in Australia generally) is provided to patients with a range of diseases and chronic illnesses, but the predominant conditions include cancer, cardiac disease such as congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), kidney failure and Alzheimer's disease.

Southern NSW burden of diseases associated with palliative and end-of-life care needs

Disease/condition	Incidence and prevalence in Southern NSW
Cancer	There were an estimated 6,084 new cases of cancer diagnosed in Southern NSW for all cancers (combined) between 2008 and 2012, or 487.4 cases per 100,000 persons. Urogenital, lymphatopoetic, skin, breast and bowel were the most common cancer types diagnosed in the period.[12]
Heart failure	Overall circulatory system disorders* are estimated to have a prevalence of 17.8 per 100 population in Southern NSW. This is higher than the Australian national estimate of 17.3 per 100.[13]
COPD	COPD is estimated to have an overall morbidity rate of 2.7 per 100 population in Southern NSW. This is higher than the Australian national estimate of 2.4 per 100.[14]
Alzheimer's disease	Over 2,400 people are estimated to have dementia in Southern NSW with sub-areas of the region projected to have between 93% to 238% growth in cases by the year 2050.[15]

* Figures specifically on heart failure not available

Demand for palliative care services is growing in Southern NSW, as in Australia more generally.

The burden of disease associated with ageing is leading to higher demand for palliative care services. For example, of all patients seen by SNSWLHD palliative care services, approximately 40% are aged over 75 years[16]. Referrals are expected to grow out of proportion with population and demographic changes, mainly due to the increased incidence of cancer and dementia.

As our population continues to age, there will not be enough specialist palliative care services to meet demand and therefore it is important that primary care plays an increasingly key role in addressing this increasing demand for palliative care.[17] More consistent involvement of primary care in palliative and end-of-life care also has significant benefits to patients and the community, including increased support for, and likelihood that, people will die out of hospital[18] (the preference of most patients). **Most GPs (76%) also acknowledge that palliative care is an important part of their role[19],** despite significant barriers. We know that the most sustainable approach to supporting people to die at home involves primary care and a well-resourced specialist palliative care service working effectively together to deliver care.

An Australian Productivity Commission review of palliative care[20] found that:

- Approximately 50-90% of the 160,000 people who die each year in Australia would benefit from high-quality end-of-life care
- More than 80,000 people die in hospitals each year and about 60,000 die in residential aged care — two of the least preferred places to die
- About 70% of Australians would prefer to die at home but few are able to do so

Palliative care is delivered in a challenging social and health service context. Many people would rather die at home, which adds complexity to the delivery of care near the end of life. In general, health services are oriented towards curative treatment, with less emphasis on maximising quality of life for people for whom death is inevitable[21].

The delivery of palliative and end-of-life care for our region needs to account for these complexities in order to deliver best practice approaches, tailored for local patient needs.

Who provides palliative and end-of-life care in our region?

Palliative and end-of-life care in Southern NSW is delivered across almost all health settings, from general practice, residential aged care facilities, community settings, and regional hospitals.

Specialist palliative care nursing teams provide assessment, care and consultative support for people living in the community. They work in coordination with GPs, residential aged care staff and other providers, and are accessible via community health intake services in five regional centres: Goulburn, Queanbeyan, Moruya, Cooma and Bega Valley. Palliative care specialist nurses also support inpatient palliative care in some regional hospitals.

'I feel supported by the palliative care team. They're experts – we collaborate, they advise on medication dosing, the care pathway, timeframes. They're really good; I trust them.'
- GP, Goulburn area

A range of **specialist medical advice, consultation and/or other support models** are in place across the region:

- In **Eurobodalla**, telephone support and monthly outreach is provided by Calvary Hospital (Kogarah)
- In **Cooma,** a GP specialising in palliative care is available part-time for consultations
- For **Goulburn**, a medical outreach and telephone support service is planned with Western Sydney Local Health District (WSLHD)
- In **Queanbeyan**, a medical telehealth support service is planned, also with WSLHD
- **ACT-based inpatient, outpatient and hospice services** are available to some NSW residents
- **ACT-based specialists can provide 24/7 medical advice and support** to GPs and other clinicians providing palliative and end-of-life care in Southern NSW.

What is most important is that all health professionals providing care for patients with palliative care needs, irrespective of setting, work effectively together to deliver coordinated care of consistently high quality. Developing trust and effective working relationships between care providers is essential.

A summary of the role of key care providers is provided below. Care is provided in collaboration with a range of partners, including community pharmacies and home care package providers.

Summary of roles in palliative and end-of-life care delivery for Southern NSW[22]

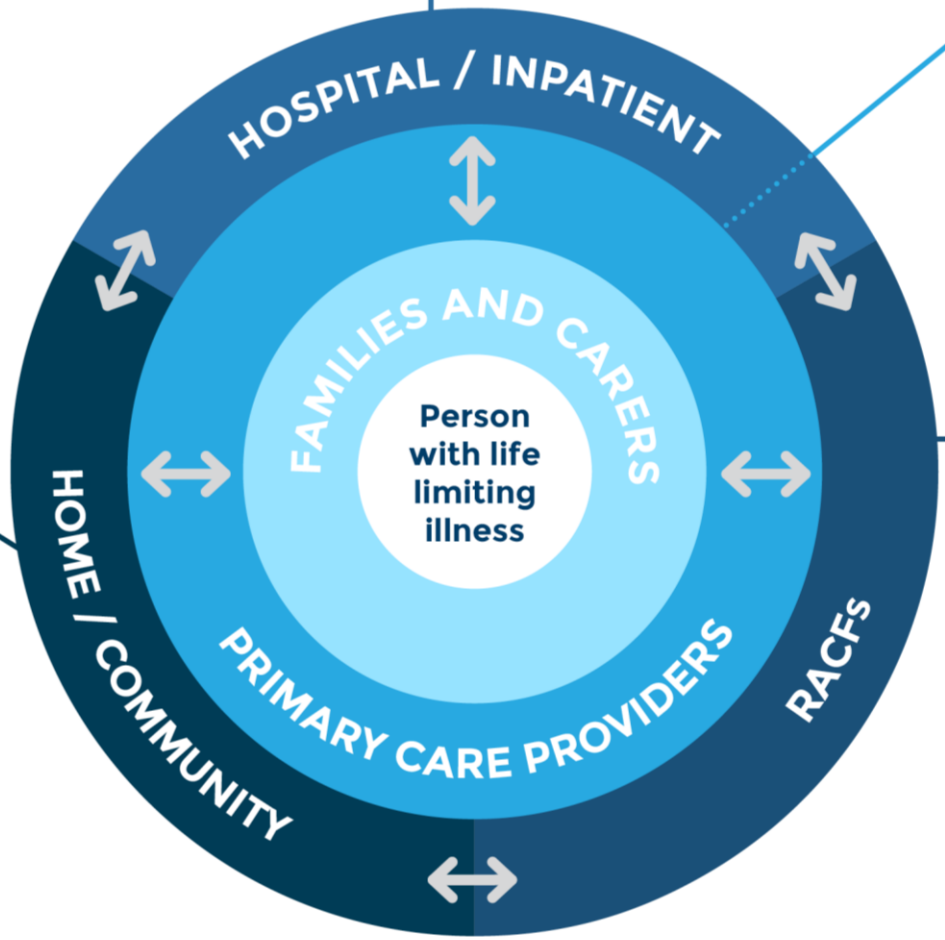
Patients	Actively participate in their care and ongoing decision-making.
Families and carers	Are supported throughout the care process including bereavement support and are included in care planning and ongoing decision-making.
General practitioners	Provide the first line of care to people approaching and reaching end of life. Work to coordinate care with other providers, including the specialist palliative care nursing team and on-call medical specialists.
General practice nurses	Also known as practice nurses, provide a range of patient care, coordination and education activities in conjunction with GPs.
RACF staff	Provide care for aged care residents in conjunction with general practitioners, nurse practitioners and/or local palliative care service.
Nurse practitioners	Nurse practitioners (including palliative care, aged care and chronic disease nurse practitioners) may support palliative and end-of-life care, for example in assessment, prescribing, and ongoing management in coordination with GP/other care providers, particularly when patient is no longer able to visit GP.
Palliative care services, including specialist team	Specialist nursing teams provide care for patients with complex or unstable symptoms or meet other high-level needs associated with end-of-life care. They may provide episodic or ongoing partnerships with primary care providers in caring for a patient. Also provide consultative arrangements, inpatient care and on-call advice. Telephone-based specialist medical advice (as well as medical outreach in some locations) is available in Southern NSW. ACT- and Sydney-based inpatient and outpatient services are also available.
Community nurses	Community nurses work alongside the specialist palliative care nursing teams. Care roles are determined based on patient need, and care is escalated to specialist nurses when required. Depending on requirements, joint visits with specialist and community nurses may be undertaken.
NSW Ambulance	Can provide palliative care to patients in their residence if a NSW Ambulance Authorised Adult Palliative Care Plan is in place.
Non-palliative care specialists/services	End-of-life care by specialists whose substantive work is not in palliative care. For example, oncology teams and staff in inpatient settings.

The role of volunteers in supporting care

A range of volunteer organisations and networks operate in various areas of Southern NSW to support patients with palliative care needs, as well as their families and carers. These organisations, which are made up of local community volunteers, provide a range of practical, social and emotional support services for a holistic and person centred approach to palliative and end-of-life care. A list of organisations can be accessed on HealthPathways.

The diagram overleaf provides an overview of palliative and end-of-life care providers in Southern NSW.

Palliative and end-of-life care provision in Southern NSW



These arrows represent key transition points for patient care and interactions between care providers, including for assessment and referral, inter-professional care planning, transfer of care and ongoing care management. Strengthening these interactions is critical to support coordination, continuity and communication of patient care.

- Inpatient beds within SNSWLHD
- Inpatient and hospice care outside of SNSWLHD (ACT, Sydney-based services)
- Volunteer support

- GPs
- Practice nurses
- Services for Aboriginal people, including Aboriginal Medical Services

- SNSWLHD specialist nursing
- team, including afterhours support where available^
- Access to 24/7 phone-based specialist support*
- NSW Ambulance service
- NGO providers
- Allied health providers
- Home care package providers
- Counselling, bereavement and funeral services
- Volunteer support

- Residential aged care providers
- SNSWLHD specialist nursing support
- Access to 24/7 phone-based specialist support*
- NSW Ambulance service
- Counselling, bereavement and funeral services
- Volunteer support

^ After hours care currently available for Goulburn and surrounding areas, and in Cooma on an as-needed basis.
* Providers of phone-based specialist support vary across the region. See *'Who provides palliative and end-of-life care in our region?'*.

Insights from our region

We consulted with a range of GPs, palliative care specialist nurses, aged care providers, other health professionals and Aboriginal consumers from across Southern NSW to better understand the current state of palliative and end-of-life care in the region.

Our strengths and current challenges

High quality palliative and end-of-life care relies on the skills, dedication and commitment of all those involved in supporting people with a life-limiting or terminal illness. Our region faces particular resourcing and structural constraints in supporting people's desire to stay at home as they reach the end of life. Strengths and challenges are presented in the table below.

Strengths	Challenges
A significant number of **highly capable GPs** who are actively engaged in supporting high quality palliative and end-of-life care	**Variation in care delivery**, often dependent on levels of engagement of a patient's GP (including some GPs who are unwilling/unable to undertake home visits)
High quality **specialist palliative care nursing teams**, nurse practitioners, on-call specialist medical advice, and (where available) afterhours nursing support	**Resourcing and service gaps**, including workforce capacity limitations, lack of available afterhours nursing support and hospice-type care in many parts of the region, limited access to counselling and bereavement support, and minimal use of case conferencing to support coordination
Some available resources to support home-based care, including homecare funding packages and equipment hire	**Inconsistent uptake of advance care directives** and NSW Ambulance palliative care plans
A **strong sense of community** in local areas which supports personalised and tailored care	The **significant burden on family members** (including time, emotional and financial) supporting their loved one's care at home; difficulty **attracting GPs and other clinicians to positions in rural areas**; and barriers to access medical care in rural areas
A **collaborative and agile approach** to developing services which meet the needs of patients while addressing geographic, cross-border, and workforce complexities	**Structural barriers** to information sharing and coordination across providers and time required to build sustainable care models and relationships across providers

Key needs and options identified by palliative and end-of-life care providers

Identified need	Options to address need
Stronger communication and coordination across care providers	• Regular multidisciplinary team (MDT) meetings • Case conferencing or shared consultations • Use of technology platforms/systems
Access to timely specialist support/advice	• Specialist nursing service • Specialist medical advice (e.g. phone) and/or outreach (select areas)
Increase understanding of palliative approach and capabilities among care providers, including GPs	• Specialist nursing/medical advice • Formal education and training • Knowledge sharing through 'community of practice' (see Section 4) • HealthPathways and other learning platforms/resources (Appendix II)
Reduce burden of palliative care management on individual GPs	• Practice models which share care among GPs within a practice • Registry of GPs with palliative care interest (see Section 4) • More formalised communication and coordination between providers

What is important to patients, their families and carers

Previous consultation and published literature tell us what matters most to people with a life-limiting or terminal illness, as well as to their families and carers. This includes the need for care to:

- **Promote early discussions with patients and family** around palliative and end-of-life care options, ideally with GP involvement[23]
- **Respect and respond to preferences around place of death**, with a key need to ensure services can support home-based care, including through active GP involvement in care, good communication with a specialist palliative care nursing team and adequate after-hours support[24]
- **Be person and family centred**, including through actively involving patient/family in care planning and decision-making[25], and by ensuring dignity in acute care settings[26]
- **Assist family and carers to be involved in care**, particularly to support care coordination, provide psychosocial support, and receive timely support, information and advice[27]
- **Recognise and respond to people's changing needs over time**[28]
- **Support family and carers' needs following bereavement**[29]

Providing culturally safe care for Aboriginal and Torres Strait Islander people

Best practice palliative and end-of-life care involves the tailoring of care to the needs of individuals, including consideration of any culturally-specific needs, such as those of Aboriginal and Torres Strait Islander people. These may include[30]:

- The concept of 'health' for Aboriginal and Torres Strait Islander people is **not only the physical wellbeing of an individual, but the social, emotional and cultural wellbeing of the whole community** and includes the cyclical concept of life-death-life
- The **place of dying and death** is culturally and spiritually significant for many Aboriginal and Torres Strait Islander people. The need to 'return to country' is very important for many Aboriginal and Torres Strait Islander people at the end of their lives
- The differences among Aboriginal and Torres Strait Islander cultures means **models of care need to be flexible** to address the specific needs of different cultural groups
- Models of palliative and end-of-life care should integrate **traditions, values and cultural practice** relating to palliation and end-of-life transitions
- There is a **significant role for Aboriginal Health Workers** in the delivery of quality palliative and end-of-life care
- It is important that non-Indigenous health professionals develop **culturally safe practices** through education or training and appropriate engagement with local Indigenous communities.

Information on services available for Aboriginal and Torres Strait Islander patients can be found on HealthPathways.

'When you're talking to family about illness, prognosis and so on – it's all about sensitivity and respect … our elders need to be guided through and given lots of support and love.'
- Aboriginal-identifying health worker

Case study: Culturally safe care in an inpatient setting

Janine is an Aboriginal elder whose brother Jack was living with end-stage kidney disease. When Jack entered the palliative phase, he chose to stay at home for as long as possible. Janine and other members of the family played a big role in caring for him at home. Jack also received care in his home from a health worker from the local Aboriginal Medical Service (AMS) and the palliative care nursing team. Gaining the trust of the family and working together to deliver care was important.

Once Jack's palliative needs increased, he was admitted as an inpatient to the local hospital, with Janine and her other family providing support on rotation. The hospital's Aboriginal Health Worker met with Jack and his family members to ensure they were comfortable and understood the palliative care Jack was receiving. Jack's bed was in a private room, and the hospital provided extended family members, some of which have travelled from interstate, food and drink and a place to rest, and allowed Janine to stay overnight with Jack so that he was not alone. The Aboriginal Health Worker also linked the family with available support services in the local community, and childcare arrangements were offered for the children present.

Jack passed away in the local hospital with his extended family present. After he passed away, Janine and her family were given sufficient time to undertake their cultural rituals and to say goodbye to Jack. The Aboriginal Health Worker also linked family members with bereavement and other support services.

3. A proposed model of care for Southern NSW

Palliative and end-of-life care is delivered in Southern NSW through the dedicated work of GPs, specialist palliative care nursing teams, RACF staff and other care providers throughout the region.

This proposed model of care aims to build on the strengths of care delivery in the region through outlining best practice care and services as a patient undergoes their palliative and end-of-life care. It provides key principles, clarity on the way palliative and end-of-life care is delivered in Southern NSW, and defines care arrangements for three levels of patient complexity at different stages of care. While the proposed model is intended to inform clinical practice, it does not provide specific clinical guidance or protocols for patient care. See Appendix I for additional available tools and resources.

Principles of person-centred palliative care

The below principles help to guide the delivery of high quality palliative and end-of-life care in Southern NSW:

Principle	What this means for providers of palliative and end-of-life care
Person and family centred care	Care is delivered in partnership with patients, their families and carers and is responsive to their needs (physical, psychological, cultural, social and spiritual), preferences and values
Individual needs based care	Early and holistic assessment of individuals' palliative and end-of-life care needs are made using standardised assessment tools
Care as close to home as possible	People approaching the end of their life should be able to access care as close to their home as possible
Accessible	People approaching the end of their life have access to local primary care and to specialist support based on need
Equitable	Palliative and end-of life care is available regardless of age, diagnosis, geography or culture
Integrated	All care providers work together to enable seamless palliative and end-of-life care at the right time and right place
Safe and effective	Care avoids preventable harm, is evidence-based, and occurs with involvement of patients and their families and carers

Adapted from the NSW Agency for Clinical Innovation's Framework for the Statewide Model for Palliative and End of Life Care Service Provision[31].

Stepped care

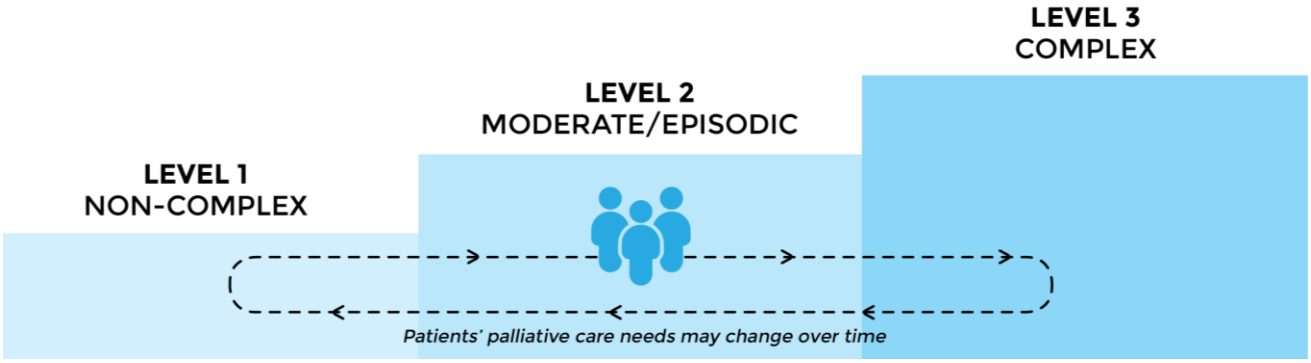
The proposed model for palliative and end-of-life care in Southern NSW is based on a **stepped care approach**. This approach involves **a hierarchy of care and services, from the least to the most intensive, matched to the needs of the individual**. While there are three levels within the defined stepped care model, these levels do not operate in silos or as one directional steps, but rather offer a spectrum of services and interventions. It is possible that a patient's needs may increase and/or decrease over time, and thus patients can move along levels of care (in both directions) during their palliative and end-of-life journey.

A shared and multidisciplinary approach

The proposed model also supports a **shared approach to care**. This involves the joint participation of primary care providers and specialist care teams in the planned delivery of care, informed by information exchange over and above routine referral notices. A shared and collaborative approach to care can provide patients with the benefits of specialist intervention combined with continuity of care and management from primary care GPs and nurses who maintain responsibility for the patients' healthcare in conjunction with the specialist palliative care nursing team as required.

A key component of this model is **multidisciplinary care**. Multidisciplinary care occurs when professionals from a range of disciplines with different but complementary skills, knowledge and experience work together to deliver comprehensive healthcare aimed at providing the best possible outcome for the physical and psychosocial needs of a patient and their carers. Members and composition of the multidisciplinary team may change as the needs of the patient changes over time.

Overview of stepped palliative and end-of-life care and provider roles



Overview of patient need[1]	Patients with non-complex needs • Largest patient cohort • May include non-malignant diagnosis • Most palliative needs met by primary care provider	Generally non- complex needs with intermittent/episodic needs of higher complexity • Sporadic exacerbation of pain and other symptoms • Coping compromised	Unstable patients or ongoing, complex needs • Highly complex physical, psychological and/or social needs which do not respond to simple care protocols • Requires highly individualised care plan Includes most patients at or near end of life.
Key care providers	GP +/- advice from specialist palliative care nursing team and/or palliative care medical specialists[2] +/- RACF staff (if applicable) +/- support from GP practice nurse +/- other medical specialists (e.g. oncologist, geriatrician)[3]	As per Level 1, +/-: • Specialist palliative care nursing team (episodic involvement), including afterhours service where available[4] • Nurse practitioner[5] • NSW Ambulance[6] • Inpatient care team (local hospital/Multi-Purpose Service)	As per Level 2, +/-: • Specialist palliative care nursing team (regular/active involvement) • Specialist medical consultation[z] • Sydney/ACT specialist palliative care inpatient admission
Overview of care arrangements	GP is the primary coordinator of care, responsible for early conversations with the patient (including advance care directive, active treatment options and role of palliative care), assessment, early referral to palliative care as appropriate, involvement/support of family/carers, and care coordination and management, including script writing and patient visits. On-call specialist palliative care medical support/advice available.	GP is the primary coordinator of care, responsible for pre-emptive script writing and coordinating care with other key providers. Episodic care from specialist palliative care nursing team and/or nurse practitioner[5] may occur. Agreement on delineation of roles required after referral to specialist nursing team. Equipment Hire program (Mobility Matters) available through LHD palliative care services.	Formalised/documented care arrangement shared between GP, specialist palliative care nursing team, nurse practitioner (as available), specialist palliative care medical provider/s (as available) and other care providers may be required. Coordinator of care to be determined in initial case conference/MDT meeting. May include ongoing case conferencing.
Key services available	• On-call specialist palliative care advice[7] • NSW Palliative Care After Hours Helpline • Care in the home packages[8] • DecisionAssist telephone advice • Volunteer networks (relieving carer stress)	As per Level 1, plus: • Specialist palliative care nursing team – home/residence visits (as required) • NSW Ambulance home/ residence visits (as required) • In-patient admission (local hospital/Multi-Purpose Service)	As per Level 2, plus: • Tele/video conferencing with specialist nursing team/other specialist providers • Sydney/ACT specialist palliative care inpatient/hospice admission
Important protocols and tools	• NSW Health Advance Care Directive • NSW Ambulance Authorised Palliative Care Plan (Paediatric, Adult) • HealthPathways • Therapeutic Guidelines: Palliative Care (Version 4, 2016) • Specialist palliative care nursing service referral form (for Levels 2 and 3) • Decision Assist (palliative care and advance care planning education and advice for aged care staff)		

[1] While clinical symptoms are a key determinant of an increase in care requirements, other factors may inform the decision to initiate higher levels of care and/or referral to the palliative care service, including family/carers' capability and/or willingness to play an active role in care or an identified need to access support services such as the equipment hire program
[2] Type and provider of specialist palliative care medical advice varies across region
[3] Non-palliative care medical specialists are also responsible for early conversations with patients about treatment options and early referral to palliative care
[4] Currently available for Goulburn and surrounding areas, and in Cooma on an as-needs basis
[5] Nurse Practitioners may support palliative and end-of-life care in some areas, for example in prescribing medications when a patient is unable to visit GP
[6] NSW Ambulance paramedics are able to provide in-residence palliative care under a NSW Ambulance Authorised Adult Palliative Care Plan
[7] Includes advice from the specialist palliative care nursing team, plus medical advice from various sources
[8] Includes My Aged Care packages and the NSW-wide Palliative Care Home Support Program administered by HammondCare

An expanded role for general practice nurses in palliative care

A general practice nurse is an enrolled nurse or registered nurse who works within a general practice clinic. There are over 12,000 nurses working within general practice in Australia[32] with around 65% of general practices employing at least one nurse[33]. The Practice Nurse Incentive Program (PNIP) provides incentive payments to practices to support an enhanced role for nurses working in general practice.

General practice nurses are likely to play an increasingly important role in delivering and supporting continuous care to patients as part of future primary care reforms in Australia (see Section 5). There are opportunities for this involvement to include expanded support for palliative and end-of-life care, such as:

- Undertaking outreach and patient needs assessments
- Brokering referrals to community services
- Planning and coordinating patient care and follow up as per care plans
- Patient education, support and advocacy
- Managing referral processes and procedures with other services, for example in arranging case conferences and coordinating information sharing between the GP, RACF staff, LHD services and the patient.

What local system changes will support implementation of the model?

A range of local system changes will support implementation of the model of care across Southern NSW, including to:

- Develop and implement a comprehensive stakeholder engagement strategy to support further engagement in model development, formalisation and rollout
- Update existing resources such as HealthPathways to align with proposed model and profile available palliative and end-of-life care services
- Explore and expand use of communication and information sharing platforms/ approaches (e.g. case conferencing, secure messaging and patient held records) to support coordination between care providers
- Support ongoing education of GPs to strengthen understanding of palliative approach and delivery of care
- Establish a regional ‘community of practice’ for GPs and other care providers with an interest in palliative and end-of-life care
- Explore options for sharing knowledge among service planners and managers within and outside of Southern NSW
- Explore feasibility of establishing a register of GPs with interest in receiving palliative care referrals and ability to undertake home visits
- Support increased uptake of advance care directives and NSW Ambulance Authorised Adult Palliative Care Plans (see case study overleaf)
- Advocate for expanded resourcing and improved delivery of palliative and end-of-life care in Southern NSW

Specific considerations for implementing these system changes are described in Section 4.

Case study: the role of advance care planning in high quality care

Bill, an 85-year-old man has advanced dementia and is cared for by his wife Robyn in their Port Kembla home. They have had a strong relationship with their family GP for over 10 years. Since Bill was diagnosed with dementia eight years ago, they have also developed a strong relationship with their geriatrician and the local hospital.

Robyn has been looking after Bill at home with the help of community services delivered through a non-government organisation (NGO). Over the years, both their GP and the geriatrician have communicated with Robyn about the terminal nature of dementia.

Robyn, Bill's GP and the geriatrician have together discussed an advance care plan for Bill that revolves around a palliative approach. This advance care plan documents what treatments and ongoing care was acceptable to Bill. Consistent with this plan, when Bill stops walking and Robyn can no longer look after him, he enters a residential aged care facility. The GP and geriatrician continue to visit and the aged care facility is aware of the advance care plan. He may modify his original ACP at any time as his circumstances change.

When Bill develops aspiration pneumonia, he already has a plan in place for palliation and he has prompt management of pain and other symptoms without having to leave his nursing home or having any unnecessary investigations or interventions. He passes away peacefully in the aged care facility.

Overview of GP and specialist nursing team roles

The table below details roles for two key groups of care providers, GPs and the specialist palliative care nursing teams. Care will often be provided in collaboration with a wider range of care partners, including nurse practitioners, NSW Ambulance, allied health, ambulatory care services, general practice nurses, home care package providers, RACF staff and community pharmacies. Undertakers and funeral homes also play an important role after a patient passes away. GPs regularly work to coordinate care across providers involved in the full spectrum of palliative and end-of-life care.

Stage of care	Care provider	Usual activities		
		Level 1: Non complex	**Level 2: Moderate/ episodic**	**Level 3: Complex**
Assessment	**General practitioner**	Assess patient's palliative care needs, using validated tools where available, including: • Pain and other symptoms • Palliative care emergencies • Psychological, social, cultural and spiritual needs Initiate conversation around death and dying with patients, families and carers Consult with specialist nursing team if needed Early referral to specialist team may be appropriate[9]	*As per Level 1, plus:* • Refer patient to specialist nursing team as determined by patient need	*As per Level 2*
	Specialist nursing team	Provide advice and support to GPs/other care providers if required, including sharing of information and educational resources	*As per Level 1, plus:* • Conduct timely assessment upon patient's referral to service	*As per Level 2*
Care planning	**General practitioner**	• Complete Advance care directive (ACD) with patient, their family and carers • Develop care plan with patient, their family and carers, and other care	*As per Level 1, plus:* • Directly after referral to specialist nursing team, consult with specialist nursing team (e.g. through case conference or	*As per Level 1, plus:* • Agree and formalise/document a care arrangement shared between GP and

[9] Early referral or introduction to the specialist palliative care team may be beneficial to help ensure a patient can smoothly and efficiently transition to higher levels of care when required.

Stage of care	Care provider	Usual activities		
		Level 1: Non complex	**Level 2: Moderate/ episodic**	**Level 3: Complex**
		providers if relevant, including NSW Ambulance Authorised Palliative Care Plan (Paediatric, Adult)	phone call) to agree recommendations for care arrangements to meet patient needs	specialist nursing team, defining clear role of each care provider (if required)
	Specialist nursing team	Provide advice and support to GPs/other care providers if required, including sharing of information and educational resources	*As per Level 1, plus:* • Timely consultation (e.g. through case conference or phone call) with the primary care provider to agree on recommendations for care arrangements to meet patient needs	*As per Level 1, plus:* • Agree and formalise/document a care arrangement shared between GP and specialist nursing team, defining clear role of each care provider (if required)
Care management	**General practitioner**	• Assess/reassess patients palliative care needs • Provide patient with information, education and support • Undertake home/RACF visits and after hours support as required • Manage patients symptoms and pain (including prescribing medications) • Support patient care coordination/ navigation • Support family/carer(s) with information, guidance and access to relevant services • Address patient supportive care needs (including bereavement) directly or through referral	*As per Level 1, plus:* • Support patient access to specialist care and other palliative care resources as required • Consult with specialist nursing team/seek specialist medical advice if care deviates from standard care protocols • As appropriate, coordinate care with nurse practitioner(s) • Review the care plan with patient, carer and family and specialist nursing team as required • Provide referral to available services as required	*As per Level 1, plus:* • Consult with the specialist nursing team and provide care to the patient, carer and family as agreed • Review the care plan with patient, carer and family and specialist nursing team as required
	Specialist nursing team	Provide advice and support to GPs/other care providers if required, including sharing of information and educational resources	*As per Level 1, plus:* • Provide assessment and treatment recommendations (may be episodic/time limited) based on patient needs • Provide episodic advice regarding assessment, care planning and/or management to the primary care provider, as requested by the GP • Input into care plan with patient, carer, family and GP as required • Provide bereavement support	*As per Level 1, plus:* • Provide care to the patient, carer and family as agreed, including as inpatient if required • Support 24/7 care to patient and provide advice to carer and primary care provider • Review the care plan with patient, carer, family and GP as required • Provide bereavement support (written and/or face-to-face as requested by GP or bereaved carer)
Communication and information sharing	**General practitioner**	• Liaise with the patient, their family and carers • Two-way communication with other care providers (e.g. medical advice,	*As per Level 1, plus:* • Regular two-way communication with specialist medical officers, specialist nursing team, nurse practitioner(s)and/or	*As per Level 2*

Stage of care	Care provider	Usual activities		
		Level 1: Non complex	**Level 2: Moderate/ episodic**	**Level 3: Complex**
		allied health, counselling services etc.)	other care providers for advice as required	
	Specialist nursing team	• Suggest opportunities for training and professional development for GPs (e.g. PEPA placements, training updates, education modules)	*As per Level 1, plus:* • Regular two-way communication with GP, nurse practitioner(s) and/or other care providers as required	*As per Level 2*

4. Putting a formalised model into practice across Southern NSW

A range of local system changes will support implementation of the model of care across Southern NSW. The table below provides possible activities to support these system changes, acknowledging that an implementation plan may need to be developed to guide activities undertaken by stakeholders across the region.

Proposed initiatives	Purpose	Possible activities	Possible stakeholders
Develop and implement a comprehensive stakeholder engagement strategy to support further engagement in model development, formalisation and rollout	• Builds awareness, understanding and buy-in from service providers, consumers and carers	• Develop stakeholder engagement strategy and communication plan, outlining purpose, audience(s), key messages and approach • Implement stakeholder engagement strategy with partners	• COORDINARE • Southern NSW Local Health District (SNSWLHD) • Other(s) as identified
Update existing resources such as HealthPathways to align with proposed model and profile available palliative and end-of-life care services	• Resources (including HealthPathways) are aligned with proposed model and provide care providers with information on available services to support care	• Integrate key components of agreed model into existing resources, including HealthPathways • Create directory of available service(s), including specialist medical advice	• COORDINARE/ other HealthPathways stakeholders

Explore and expand use of communication and information sharing platforms/ approaches (e.g. case conferencing, secure messaging and patient held records) to support coordination between care providers	• Strengthens ongoing and timely communication and care coordination between GPs and specialist nursing team, including increased use of case conferences/MDTs and phone conversations
	• Supports formalised shared approach to care, including case conferencing/MDTs
		• Explore most appropriate platforms/approaches to support strengthened communication and coordination, e.g.:
		  ○ Telehealth/case conferencing
		  ○ Patient held records
		  ○ Argus secure messaging
		  ○ Encrypted email
		  ○ Palliative care plan templates to support sharing of care between GP, specialist team and other providers (Level 3)
		  ○ Phone directory of GP practice managers or other mechanism to facilitate efficient specialist communication with GP
		• Established protocols, implement, promote, and monitor and evaluate use of identified platform/approach
			• COORDINARE
			• SNSWLHD

Proposed initiatives	Purpose	Possible activities	Possible stakeholders
Support ongoing education of GPs to strengthen understanding of palliative approach and delivery of care	• Supports more consistent understanding of the palliative approach and greater confidence in delivering palliative care among GPs	• Build awareness of available educational services[10], resources and initiatives[11] • Facilitate on-the-job educational opportunities such as 'education' MDTs • Establish regular forum for GPs and other palliative care providers to share information and insights • Work with partners to expand training of medical students/junior doctors on the palliative approach	• COORDINARE • SNSWLHD • GPs
Establish a regional 'community of practice' for GPs and other care providers with an interest in palliative and end-of-life care	• Supports mentoring, skills and knowledge sharing, and collaboration • Facilitates periodic educational sessions and link with specialist palliative care teams • Empowers engaged GPs to act as champions for palliative care among colleagues	• Explore and define purpose, scope and design of community of practice • Identify GPs, RACFs, SNSWLHD staff, Aboriginal Health Workers and other care providers interested in forming a community of practice • Provide ongoing support for community of practice	• COORDINARE • Interested GPs and other service providers
Explore options for sharing knowledge among service planners and managers within and outside of Southern NSW	• Sharing strengths, enablers, approaches and opportunities to support high quality palliative and end-of-life care among service planners/managers in comparable settings	• Explore options to share knowledge, for instance through existing knowledge sharing platforms or through establishing regional knowledge sharing network	• COORDINARE • SNSWLHD • Other(s) as identified
Explore feasibility of establishing a register of GPs with interest in receiving palliative care referrals and able to undertake home visits	• Supports GPs with willingness and capability to provide care to more patients within area • Provides support and mentorship to GPs who are less confident/willing to deliver palliative care	• Explore feasibility of establishing register, particularly by identifying GPs/practices with an interest in participating, as well as feasible locations • If feasible, support maintenance of register and promote among GPs	• COORDINARE • GPs

[10] This includes the Program of Experience in the Palliative Approach (PEPA) and COORDINARE-sponsored clinical education sessions
[11] See tool and resource list, Appendix II.

Proposed initiatives	Purpose	Possible activities	Possible stakeholders
Support increased uptake of advance care directives and NSW Ambulance Authorised Adult Palliative Care Plans	• Ensures patient wishes on treatment at end of life are documented • Supports paramedics to provide palliative care in the home, potentially avoiding unnecessary hospitalisation	• Agree on standardised advance care directive tool for Southern NSW across different care settings, considering possible compatibility with GP software • Actively promote use of standardised advance care directives and NSW Ambulance Authorised Adult Palliative Care Plans to GPs, RACFs, Aboriginal Health Workers and other key service providers • Engage NSW Ambulance to encourage development of digitised Authorised Adult Palliative Care Plans to reduce administrative burden • Work with RACFs to embed advance care directives in resident admission process	• COORDINARE • SNSWLHD • GPs • RACFs
Advocate for expanded resourcing and improved delivery of palliative and end-of-life care in Southern NSW	• Influences decision-makers to support different care and funding models and support expanded access to palliative and end-of-life care	• Advocate to NSW Health for appointment of specialist palliative care medical position (or locum arrangement) for SNSWLHD • Advocate for expanded access to PEACH and other home care packages, including to address access barriers for people under 65 years old • Consider a strategic approach to influencing palliative care funding models (including Medicare items and PBS subsidy for all palliative care-related medications) that support greater involvement of GPs, including to undertake home/residence visits • Develop proposal for a hospice-type service model within the region • Advocate for resourcing to address key constraints in specialist palliative care nursing service, including for more consistent availability of afterhours nursing support	• COORDINARE • SNSWLHD • Other partner(s) as identified

Considerations for GP remuneration

GPs can face a range challenges to remuneration for clinical practice that supports palliative and end-of-life care. A number of Medicare Benefits Schedule (MBS) items for patients with chronic or terminal conditions may support GP remuneration[34], including:

- Supporting development of a **GP Management Plan (GPMP) (item 721)**
- Supporting preparation of **Team Care Arrangements (TCAs) (item 723)**
- Quarterly (or earlier if required) **review of GPMP or TCAs (item 732)**
- Contribution to a **Multidisciplinary Care Plan** being prepared by another Health or Care Provider **(Item 729)** and for a RACF resident **(Item 731)**

A number of **home or RACF visit** items (including **after-hours** items) are also regularly used to support palliative and end-of-life care (see MBS online).

Monitoring or support services provided by a GP practice nurse or Aboriginal health practitioner may be claimed under Medicare Item 10997 under certain conditions.

Case conferencing

A range of **case conferencing items** allow for support or participation in a meeting or discussion to ensure a patient's multidisciplinary care needs are met[35]. The case conference:

- Must include a GP and at least two other health or community care providers, with each team member providing a different kind of care or service to the patient
- Can include the patient's informal or family carer (however carers do not count towards the minimum of three service providers)
- Does not require participation of the patient.

A patient would generally not usually require more than five case conferences in any 12 month period. Items include:

- **735:** Organise/coordinate a case conference (15 to <20 minutes)
- **739:** Organise/coordinate a case conference (20 to <40 minutes)
- **743:** Organise and coordinate a case conference (40+ minutes)
- **747:** Participate in a case conference (15 to 20 minutes)
- **750:** Participate in a case conference (20 to 40 minutes)
- **758**: Participate in a case conference (40+ minutes)

For further information on MBS items, see:

- GPMP and TCAs
- Case conferencing
- MBS online

Emerging service models such as Health Care Homes and other medical home models provide different remuneration structures that could support GP involvement in palliative and end-of-life care. These are discussed in Section 5.

5. Shaping our future together

Palliative and end-of-life care in Southern NSW will always rely on the commitment, skill and passion of the people working in our local system. Improved care will rely on strengthening and building on existing relationships and coordination across all points of care – from general practice and other primary care through to community, hospital and residential aged care settings.

We know that there is the goodwill, interest and dedication to build a sustainable model of care for Southern NSW to deliver improved outcomes for our patients, their families and carers. A sustainable model will need to be responsive to local needs and developments, integrated in systems, strategies, processes and practice, and ultimately owned by those providing and receiving care.

Current and future reforms

There are a number of current reforms that are likely to impact the delivery of palliative and end-of-life care in Southern NSW into the future, including a number described below.

Reform	Relevance to Southern NSW
Health Care Homes (HCHs) and medical home models	The Australian Government HCHs is in 200 general practices and Aboriginal Community Controlled Health Services around Australia. In this model, primary care will assume a greater role for care coordination, including the development of a comprehensive shared care plan and identifying the best local providers to meet the whole of person needs of patients with chronic or complex conditions.
Hospital in the Home (HITH) programs	Increasingly LHDs in NSW are implementing HITH programs to deliver certain types of multidisciplinary acute care to suitable patients at their home or clinic setting as an alternative to inpatient care. HITH programs are likely to be utilised for an increasing number of conditions given potential benefits for patient care and relieving burden on inpatient facilities.
My Aged Care reforms	Commonwealth funded aged care services are undergoing significant reforms based on a consumer-directed care model. Changes to home support and home care packages are primarily designed to support people to stay at home and as part of their communities; increase choice and flexibility and improve sustainability and affordability into the future. Alignment with these changes is critical given the interrelationship between aged care and palliative and end-of-life care.
National Disability Insurance Scheme (NDIS) roll-out	The roll-out of the NDIS, which includes individual packages of support to people with disability, has significant implications for care delivery in the disability sector. As there is some crossover between disability support and palliative and end-of-life care, ensuring services respond to these changes is important.
My Health Record	The Australian Government is continuing the national roll out of the My Health Record and general practice accounts for the vast majority of health care provider registrations. The government has also announced plans to introduce an opt-out model. Given the lack of a centralised patient record is a key barrier to care coordination between GPs and other care providers, developments in this area are likely to have significant impacts. Concurrently, the principles and strategic priorities of the National Digital Health Strategy (2017) should be considered in the introduction of new digital solutions to improve communication and information sharing between care providers.

NSW Heath funding for specialist palliative care medical positions, including locum positions specifically to support GPs, may also have implications for the delivery of care in Southern NSW. This model of care will need to be responsive to future policy and funding environments. Opportunities for periodic review of the model and the ability to adapt if required will also support sustainability.

Monitoring our progress

This model of care is strengths-based, building on the high quality care that is delivered every day throughout Southern NSW. It is also about continuous improvement. To guide implementation of the model, indicators should be developed and regularly measured to track progress in key areas, including numbers of people who are able to die at home. Other indicators such as palliative care hospitalisations and uptake of aged care directives could also be explored. Partnership with Palliative Care Outcomes Collaboration (PCOC) could support data development and promote greater primary practice usage of tools that monitor the quality and effectiveness of treatment.

A regular review and update cycle will also ensure the model continues to be relevant in the context of funding, policy and service changes within our region.

If you would like to know more about this model of care, please contact:

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Appendices

I. Tools and resources

A wealth of resources is available to support palliative and end-of-life care and learning and education. Key resources are presented below. A directory of palliative/end-of-life care services can be accessed through HealthPathways.

Summary	Resource	Author	Description	URL
Guidelines, handbooks and tools				
Comprehensive clinical guidance and information	**HealthPathways – ACT and Southern NSW**	Capital Health Network, COORDINARE, ACT Health, SNSWLHD	Comprehensive guidance and information on palliative care. Includes key resources, referral information, and care plan forms	https://actsnsw.healthpathways.org.au/
Therapeutic guidelines	**Therapeutic Guidelines: Palliative Care (Version 4, 2016)**	Therapeutic Guidelines Limited	Evidence-based guidelines for palliative care symptom management and related clinical issues in Australia	https://tgldcdp.tg.org.au/guideLine?guidelinePage=Palliative%20Care&frompage=books
Clinical guidance	**palliAGEDgp (smartphone app)**	CareSearch/ Flinders University	Smartphone-based app for information to support palliative care for GPs	https://www.palliaged.com.au/tabid/4351/Default.aspx
Clinical guidance, RACF	**RACGP Medical care of older persons in residential aged care facilities: Palliative and end of life care (Silver Book) (4th ed., 2006)**	RACGP	Clinical guideline for GPs delivering quality health care in residential aged care facilities	http://www.racgp.org.au/your-practice/guidelines/silverbook/general-approach-to-medical-care-of-residents/palliative-and-end-of-life-care/
End-of-life resources	**Last days of life toolkit**	NSW Clinical Excellence Commission	Tools and resources to support high quality palliative and end-of-life care	http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/last-days-of-life
Tool – NSW advance care directive	**NSW Health Advance Care Directive**	NSW Health	NSW Health's Advance Care Directive form, with information and guidance	http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf
Tool – NSW Ambulance	**NSW Ambulance Authorised Adult Palliative Care Plan**	NSW Ambulance	Supports paramedic decision making in meeting the needs and wishes of patients with palliative needs	https://www.slhd.nsw.gov.au/btf/pdfs/Amb/Adult_Palliative_Care_Plan.pdf

Tool – prognosis support	**SPICT™ (Supportive and Palliative Care Indicators Tool)**	University of Edinburgh (Scotland)	Assists healthcare professionals identify people at risk of deteriorating	http://www.spict.org.uk/the-spict/
Tool – early conversations	**Your Conversation Starter Kit**	Institute for Healthcare Improvement and The Conversation Project	Supports conversations about wishes for palliative and end-of-life care	https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf
Tool – early conversations	**ACPTalk**	Cabrini Health	Supporting advance care planning with people from different religious and cultural backgrounds	http://www.acptalk.com.au/
	Learning and education			
Online training	**COORDINARE learning: Palliative care**	COORDINARE	Online learning module covering early identification, advice and referrals, advance care planning and medication use	https://cometlms.medcast.com.au/course/view.php?id=137 (login available from COORDINARE)
Online resources	**palliAGED**	CareSearch/Flinders University	Repository of evidence-based information and resources on palliative care in the aged care setting	https://www.palliaged.com.au/
Online resources	**CareSearch**	CareSearch/Flinders University	Repository of evidence-based information and resources on palliative care, including a GP Hub	http://www.caresearch.com.au
Online resources	**The Palliative Care Bridge**	HammondCare et al	Educational videos from experts and specialists in palliative care and related fields	http://www.palliativecarebridge.com.au
Funding for workplace training	**Program of Experience in the Palliative Approach (PEPA)**	Commonwealth Department of Health	Funded palliative care workplace training opportunities (via clinical placements), workshops and support networks for GPs, nurses, allied health professionals, and others	http://pepaeducation.com/

II. Acknowledgments

We would like to acknowledge the valuable contributions of the Expert Advisory Group, the SNSWLHD specialist palliative care services, as well as the GPs, specialists, other care providers and consumers who generously provided their expertise and insights to inform this model.

Expert Advisory Group

Name	Position
Angela Nye	Katungul Aboriginal Medical Service
Cherie Puckett	Nurse Manager, Leadership and Development, SNSWLHD
Cheryl Johnson	Manager, Palliative Care Home Support Program, Hammond Care
Dr Jan Maree Davis	Area Director South East Sydney LHD, Southern Sydney Sector Palliative Care Service
Dr Marjorie Cross	General Practitioner, Bungendore Medical Practice Bungendore
Dr Michael Chapman	Geriatrician and Palliative Specialist, Calvary Hospital Canberra; Chair, ACT Palliative Care Network
Dr Suzanne Rainsford	General practitioner, Cooma; Palliative Care Specialist Cooma (and Calvary HealthCare Clare Holland House, Canberra)
Faye Salter	Eurobodalla Volunteer Palliative Support Group
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Rob Sutherland	Associate Director, ZEST Health Strategies
Hayden Jose	Consultant, ZEST Health Strategies
Angela Nye	Katungul Aboriginal Medical Service

Formative stakeholder interviews

Role/description	LGA/location of stakeholder	Number
Aboriginal elder	Yass	1
Aboriginal-identifying health worker	Bega Valley	2
	Yass	1
	Region-wide	1
Aged care facility representative	Eurobodalla	1
Clinician, aged care (LHD)	Eurobodalla	1
Clinician, palliative care service	Goulburn	1
General Practitioner	Bega Valley	3
	Cooma-Monaro	2
	Goulburn	2
	Queanbeyan	2
	Yass	1
Aged care representative	Region-wide	1
Palliative care specialist	ACT	2
	Total	**20**

III. Key definitions and glossary of terms

End of life	The period of time when a person is living with an advanced, progressive, life-limiting illness. Because estimating when someone will die is difficult, it is more useful to identify those for whom increasing disability and illness will lead to their death sometime in the next year.
End-of-life care	Care provided to people approaching the end of life by all health professionals, including those working in health and aged care systems.
Multidisciplinary care	Multidisciplinary care occurs when professionals from a range of disciplines with different but complementary skills, knowledge and experience work together to deliver comprehensive healthcare aimed at providing the best possible outcome for the physical and psychosocial needs of a patient and their carers. Members and composition of the multidisciplinary team may change as the needs of the patient changes over time.
Palliative care	Holistic care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. It neither hastens nor postpones death, but affirms life and approaches dying as a normal process.
Stepped care	A staged approach involving a hierarchy of care and services, from the least to the most intensive, matched to the needs of the individual. While there are multiple levels within a stepped care approach, they do not operate in silos or as one directional steps, but rather offer a spectrum of services and interventions. A continuum of palliative care providers within a stepped care approach can make the best use of available workforce and resources within the local region and ensure these are aligned with individual and population needs[36].
Shared approach to care	The joint participation of primary care providers and specialist care providers in the planned delivery of care, informed by information exchange over and above routine referral notices. A shared approach to care can provide patients with the benefits of specialist intervention combined with continuity of care and management from primary care doctors and nurses who maintain responsibility for the patients' healthcare in conjunction with specialist palliative care as required[37].

IV. References

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