A palliative and end-of-life model of care for Illawarra Shoalhaven

November 2017

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.

COORDINARE

Moruya office
41 Queen Street
Moruya

Nowra office
107 Scenic Drive
Nowra

Queanbeyan office
Level 1
80 Morisset Street
Queanbeyan

Wollongong office
Ground Floor
The Central
Innovation Campus
Squires Way
North Wollongong

General enquiries

PO Box 325 Fairy Meadow NSW 2519

1300 069 002
info@coordinare.org.au
www.coordinare.org.au

Produced by ZEST Health Strategies on behalf of COORDINARE.

Disclaimer: All information and content in this Material is provided in good faith by COORDINARE, and is based on sources believed to be reliable and accurate at the time of development. COORINARE and their respective officers, employees and agents, do not accept legal liability or responsibility for the Material, or any consequences arising from its use.

Content within this publication may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source.

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.

Version: 1.0

24 November 2017

Contents

1. Introduction **1**

2. Palliative care in Illawarra Shoalhaven **3**

Why a sustainable model is needed 5

What is important to patients, their families and carers 6

Who provides palliative and end-of-life care in our region? 8

3. A model of care for Illawarra Shoalhaven **10**

Overview of stepped palliative and end-of-life care and provider roles 13

Key roles of care providers 16

4. Putting the model into practice **19**

5. Shaping our future together **23**

Monitoring our progress 24

Appendices **25**

I. Tools and resources 25

II. Acknowledgments 27

III. Key definitions and glossary of terms 28

IV. References 29

1. Introduction

This guide is a reference for health services and health professionals providing or coordinating care of patients with a life-limiting or terminal illness in the Illawarra Shoalhaven region. Included is a whole-of-health sector model for best practice and collaborative palliative and end-of-life care in our region.

The guide 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.

The guide aims to:

- Support more consistent involvement of GPs in palliative and end-of-life care
- Strengthen the coordination and management of palliative and end-of-life care between GPs, the specialist palliative care service, primary health nurses and other care providers
- Improve outcomes for patients with palliative needs and their families and carers, including greater support for dying at preferred place of choice.

The guide also identifies opportunities to strengthen our health system and support local tailoring and implementation of the model of care. 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 guide is for

The 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 Illawarra Shoalhaven.

The model is relevant however for all those involved in the delivery of palliative and end-of-life care, including specialist palliative care services, 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 model of care for Illawarra Shoalhaven can contribute to a shared understanding among stakeholders of palliative and end-of-life care delivery in our region.

How this model can be used

The model of care provides clarity on the way palliative and end-of-life care is delivered in Illawarra Shoalhaven. The model:

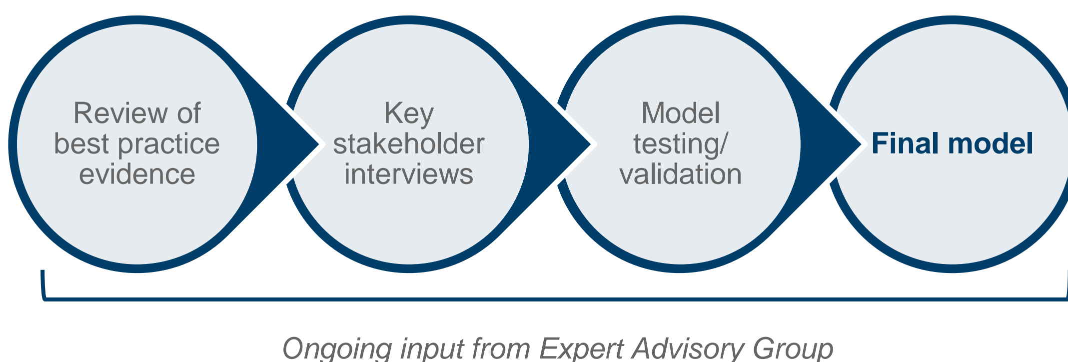
- Presents **guiding principles** for the delivery of holistic and person-centred palliative and end-of-life care
- Clarifies **roles and responsibilities** of key care providers
- Outlines **appropriate care and services** across levels of palliative and end-of-life care
- Defines care arrangements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

The 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 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 this model was developed

The model of care 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 model has been refined for the local context in Illawarra Shoalhaven 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, Illawarra Shoalhaven Local Health District (ISLHD) specialist palliative care services, as well as the GPs, specialists, and other care providers and consumers who shared their insights and helped shape this model.

2. Palliative care in Illawarra Shoalhaven

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 Smith is a 51-year-old school teacher who has a longstanding relationship with a GP at a local practice in Wollongong. 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 service. 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 primary care nurses, 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: Perception 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 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.
Palliative and end-of-life care is too complex to be managed by a GP	Palliative and end-of-life care is best when a person's GP plays an active role. GPs have 24-hour access to specialist 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 Illawarra Shoalhaven region has a higher proportion of people aged 85 years and older (16%) than the NSW average (14%). Shoalhaven (21%) and Kiama (18%) have the highest proportions of people aged over 85 years, however based on numbers, Wollongong has the largest predicted growth in this population.

Palliative and end-of-life care in Illawarra Shoalhaven (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.

Illawarra Shoalhaven: burden of conditions associated with palliative and end-of-life care needs

Condition	Incidence and prevalence in Illawarra Shoalhaven
Cancer	The estimated number of new cases of cancer diagnosed each year for all cancers (combined) was 1,208 among females and 1,454 among males. Urogenital, bowel, respiratory, breast and skin were identified as the most common cancer types diagnosed in Illawarra Shoalhaven.[11]
Heart failure	Overall circulatory system disorders* are estimated to have a prevalence of 18.5 per 100 population in Illawarra Shoalhaven. This is higher than the Australian national estimate of 17.3 per 100.[12]
COPD	COPD is estimated to have an overall morbidity rate of 2.9 per 100 population in Illawarra Shoalhaven. This was higher than the Australian national estimate of 2.4 per 100.[13]
Kidney failure	It is estimated that 19.5% of people 18 years and above in Illawarra Shoalhaven have signs of chronic kidney disease which is double the national average.[14]
Alzheimer's disease	Over 8,000 people are estimated to have dementia in Illawarra Shoalhaven with sub-areas of the region projected to have between 93% to 147% growth in cases by the year 2050.[15]

* Local estimates on heart failure currently unavailable.

Demand for palliative care services is growing in Illawarra Shoalhaven, 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 the ISLHD specialist palliative care service, 57% 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] Greater 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 challenges.

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] Illawarra Shoalhaven's demographic profile is also important to consider. For example, despite the Illawarra region having three times the population size of the Shoalhaven region, the Shoalhaven had just over half the number of deaths as Illawarra.[22]

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

What is important to patients, their families and carers

In developing this model of care, we spoke to a number of people with a life-limiting or terminal illness and their carers in Illawarra Shoalhaven to better understand what a person-centred approach means in practice. These consumers highlighted:

- The important role of their GP in their palliative care, particularly in managing their care and linking to the palliative care service when required
- The critical role of the specialist palliative care service, particularly in supporting complex pain management
- The value of clear information and communication from care providers to support navigation of different services, and to enable consumers to make the most of available services
- Information and practical guidance to help carers support their loved ones at home, for example on how to physically move their family member and encourage their family member to take medications.

'My GP plays an active role in my palliative care. He comes to see me at the nursing home, speaks to me about managing pain and writes scripts. When the pain got severe, he referred me to palliative care straight away. The care from the nurses and doctors in the palliative care service is terrific. If it wasn't for them, I wouldn't be here –- the pain that I had was so severe. They got the pain under control within a fortnight.'
- Palliative care patient, Shoalhaven area

Providing culturally safe care for Aboriginal and Torres Strait Islander people

Best practice palliative and end-of-life care involves tailoring 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[23]:

- 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.

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

Palliative care in Illawarra Shoalhaven is delivered across almost all health settings, from general practice, residential aged care facilities, community settings, designated in-patient palliative care beds and units and acute public, private and regional hospitals.

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.

Summary of roles in palliative and end-of-life care delivery for Illawarra Shoalhaven[24]

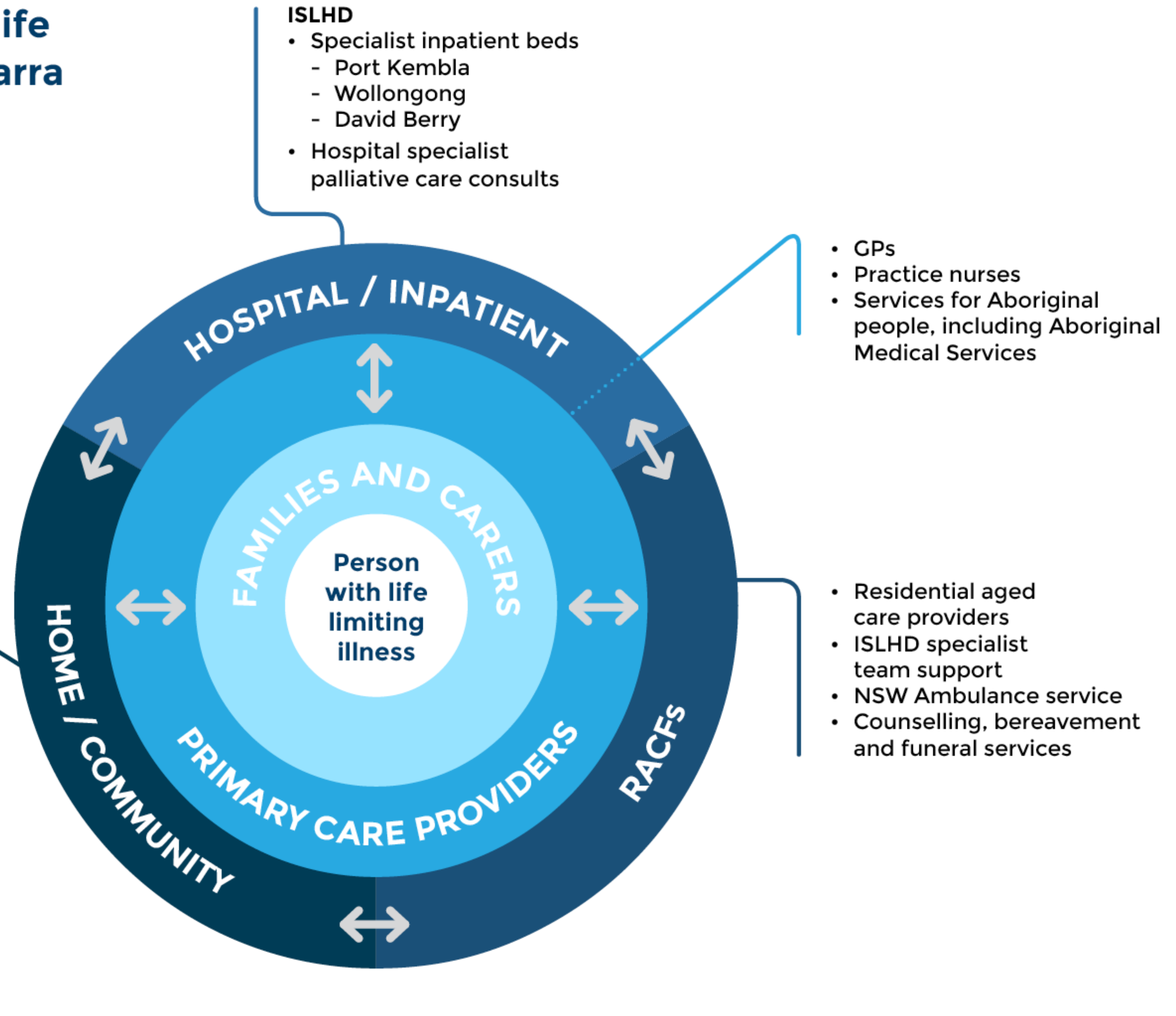
Provider	Role
Patients	Actively participate in their care and ongoing decision-making.
Families and carers	Are supported throughout the care process, including bereavement support, and included in care planning and ongoing decision-making.
General practitioners	Provide the first line of care to people approaching and reaching end of life.
General practice nurses	Also known as practice nurses, provide a range of patient care, coordination and education activities in conjunction with GPs.
Primary health nurses (LHD)	Also known as community nurses; employed through LHD Community Health Centres. Provide care in conjunction with general practitioners and specialist palliative care service.
Residential Aged Care Facility (RACF) staff	Provide care for aged care residents in conjunction with general practitioners and/or local palliative care service.
NSW Ambulance	Can provide palliative care to patients in their residence if a NSW Ambulance Authorised Palliative Care Plan is in place.
Other medical specialists and services	End-of-life care provided by specialists whose substantive work is not in palliative care. For example, oncologists, geriatricians, staff in intensive care units, emergency departments and Aboriginal Medical Service (AMS) treating teams.
Palliative care services, including specialist team	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 (including private providers) and on-call specialist advice. Includes Specialist Medical Officers, Clinical Nurse Consultants and allied health professionals.

The diagram overleaf provides a visual overview of palliative and end-of-life care providers in Illawarra Shoalhaven.

Palliative and end-of-life care provision in Illawarra Shoalhaven

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.

- ISLHD specialist team outreach
- ISLHD primary health nursing
- ISLHD after hours support
- Ambulatory care services
- NSW Ambulance service
- NGO providers
- Allied health providers
- My Aged Care providers
- Hospice Care providers
- Palliative Care Home Support Package (PEACH) provider
- Counselling, bereavement and funeral services



3. A model of care for Illawarra Shoalhaven

Palliative and end-of-life care is delivered in Illawarra Shoalhaven through the dedicated work of GPs, specialist palliative care teams, primary health nurses, RACF staff and other care providers.

This 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 experiences their palliative and end-of-life care. It provides key principles, clarity on the way palliative and end-of-life care is delivered in Illawarra Shoalhaven NSW, and defines care arrangements for three levels of patient complexity at different stages of care. While the 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 Illawarra Shoalhaven:

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*[25].

Stepped care

The model for palliative and end-of-life care in Illawarra Shoalhaven 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 model also supports a **shared approach to care**. This involves the joint participation of primary care providers and specialist palliative 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 teams 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 palliative and end-of-life care for Illawarra Shoalhaven

	LEVEL 1 NON-COMPLEX	**LEVEL 2** MODERATE/EPISODIC	**LEVEL 3** COMPLEX

Patients' palliative care needs may change over time

	LEVEL 1 NON-COMPLEX	LEVEL 2 MODERATE/EPISODIC	LEVEL 3 COMPLEX
OVERVIEW OF PATIENT NEED[1]	Patients with non-complex needs • Largest patient cohort • Mostly 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 standard care protocols • Requires highly individualised care plan Includes most patients at or near end of life.
KEY CARE PROVIDERS	GP +/- specialist palliative care advice +/- RACF staff (if applicable) +/- Support from GP practice nurse +/- Carers and families	As per Level 1, +/-: • Specialist palliative care team (episodic involvement) • Primary health nursing and/or RACF staff, allied health, social workers and AMS care team	As per Level 2, +/-: • Specialist palliative care team (regular/active involvement) • Episodes of inpatient care for symptom control/terminal care
OVERVIEW OF CARE ARRANGEMENTS	GP is the primary coordinator of care, responsible for early conversations (such as advance care directives, 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 possible home/RACF visits. On-call specialist palliative care advice available. Other medical specialists (e.g. oncologist, geriatrician) also responsible for early conversations with patient.	GP is the primary coordinator of care; responsible for pre-emptive script writing and coordinating care with primary health nurses/RACF staff. Referral to specialist palliative care service if required for physical and/or psychosocial review. On request from GP, episodic care from specialist palliative care team may occur.	Formalised/documented care arrangement shared between GP, specialist palliative care team and other care providers may be required. Coordinator of care to be determined in initial case conference/multidisciplinary team (MDT) meeting. May include ongoing case conferencing.
KEY SERVICES AVAILABLE FOR COMMUNITY PATIENTS	• On-call specialist palliative care advice • NSW Palliative Care After Hours Helpline; • DecisionAssist telephone advice • Care in the home packages • Medications in the home project	As per Level 1, plus: • ISLHD equipment loan pool • Specialist palliative care team home visits (as required) • Radio Doctor (Illawarra only) • Assessment for inpatient stay • PEACH (palliative care home support) packages	As per Level 2, plus: • Tele/video conferencing with specialist team • Home visits by specialist team
KEY SERVICES AVAILABLE FOR RACF PATIENTS	• On-call specialist palliative care advice • NSW Palliative Care After Hours Helpline • DecisionAssist telephone advice	As per Level 1, plus: • Specialist palliative care service RACF visits (as required) • Radio Doctor (Illawarra only) • Assessment for inpatient stay[3]	As per Level 2, plus: • Tele/video conferencing with specialist team • Residence visits by specialist team
IMPORTANT PROTOCOLS AND TOOLS	• NSW Health Advance Care Directive • NSW Ambulance Authorised Palliative Care Plan (Paediatric, Adult) • HealthPathways • ISLHD symptom control guidelines • ISLHD medications in the home protocol (pre-emptive prescribing) • Specialist palliative care 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 could impact on a decision to initiate higher levels of care and/or referral to the palliative care service, including an identified need to access the ISLHD equipment loan pool or other support services, and family/carers' capability and/or willingness to play an active role in care

[2] Includes My Aged Care packages and the NSW-wide Palliative Care Home Support Program administered by HammondCare

[3] For management of complex symptoms, respite for carers, or care in the terminal phase.

An expanded role for general practice nurses in palliative care

A general practice nurse is an enrolled nurse or registered nurse or who works within a general practice clinic. There are over 12,000 nurses working within general practice in Australia[26] with around 65% of general practices employing at least one nurse.[27] 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 Illawarra Shoalhaven, including to:

- Develop and implement a comprehensive stakeholder engagement strategy to support model rollout
- Update existing resources such as HealthPathways to align with model of care and to profile available palliative and end-of-life care services
- Review and where appropriate, amend referral procedures for ISLHD specialist palliative care and primary health nursing services
- Explore and expand use of communication and information platforms/approaches (e.g. case conferencing, secure messaging, 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 feasibility of establishing a register of GPs with interest in receiving palliative care referrals and able to undertake home visits
- Support increased uptake of advance care directives and NSW Ambulance Authorised Palliative Care Plans (see case study overleaf)
- Advocate for expanded resourcing and improved delivery of palliative and end-of-life care in Illawarra Shoalhaven

Specific considerations for implementing these system changes are described in Section 0.

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 8 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 (ACP) 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.

Key roles of care providers

The table below details roles for GPs, the specialist palliative care team, and the primary health nursing team. Care will often be provided in collaboration with a wider range of care partners, including the patient's treating medical team, 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 • Symptoms • Palliative care emergencies • Psychological, social, cultural and spiritual needs Initiate conversation around death and dying with patients, families and carers (such as advance care directives, active treatment options and role of palliative care) Consult with specialist team if needed Early referral to specialist team may be appropriate[1]	*As per Level 1, plus:* • Refer patient to specialist team as determined by patient need	*As per Level 2*
	Specialist 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 in-home/RACF or clinic review upon patient's referral to service • Assessment for inpatient stay if required	*As per Level 2*
Care planning	**General practitioner**	• Complete advance care directive with patient, their family and carers • Develop care plans with patient, their family and carers, and other care providers if relevant, including NSW Ambulance Authorised Palliative Care Plan (Paediatric, Adult)	*As per Level 1, plus:* • Directly after referral to specialist palliative care service, consult with specialist team (e.g. through case conference or phone call) to agree 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 team, defining clear role of each care provider (if required)
	Specialist 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 a care arrangement shared between GP and specialist team, defining clear role of each care provider (if required)

[1] 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**
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 • 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 team if care deviates from standard care protocols • Review the care plan with patient, carer and family and specialist as required	*As per Level 1, plus:* • Consult with the specialist team and provide care to the patient, carer and family as agreed • Review the care plan with patient, carer and family and specialist as required
	Specialist 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 specialist assessment and treatment recommendations and (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)
	Primary health nursing team	*n/a*	*Referral through palliative care service* • Support care in patient's place of residence, including monitoring patient status, administrating medications, working with care coordinator to determine changes to care plan, support access to resource available through palliative care service	*As per Level 2*
Communication and information sharing	**General practitioner**	• Liaise with the patient, their family and carers • Two-way communication with other care providers (e.g. allied health, counselling services etc.)	*As per Level 1, plus:* • Regular two way communication with specialist palliative care team, primary health nursing team and/or other care providers as required	*As per Level 2*

Stage of care	Care provider	Usual activities		
		Level 1: Non-complex	**Level 2: Moderate/ episodic**	**Level 3: Complex**
	Specialist team	• Provide 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, primary health nursing team and other care providers as required	*As per Level 2*
	Primary health nursing team	• Two-way communication and coordination with GP/ care coordinator	*As per Level 1*	*As per Level 1*

4. Putting the model into practice

A range of local system changes will support implementation of the model of care across Illawarra Shoalhaven. 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 involved
Develop and implement comprehensive stakeholder engagement strategy to support model 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 • ISLHD • Other(s) as identified
Update existing resources such as HealthPathways to align with model of care and to profile available palliative and end-of-life care services	• Resources (including HealthPathways) are aligned with 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
Review and where appropriate, amend referral procedures for ISLHD specialist palliative care and primary health nursing services	• Strengthens specialist palliative care referral processes and supports early two-way communication between specialist and GP	• Map current variations in referral procedures for palliative care services across Illawarra Shoalhaven • For non-complex patients, explore feasibility of region-wide access to primary health nursing support without referral to specialist service • For less complex patients (e.g. early referrals), explore opportunity for palliative care CNC to conduct initial assessment • Review and amend referral form, particularly to allow GP to specify level of patient need and/or request for direct GP contact • Explore opportunities to support two-way discussion between specialist team and GP (e.g. through case conferencing) following initial specialist consult to allow discussion/agreement on care arrangements	• ISLHD palliative care service • COORDINARE • Project Advisory Group members

Proposed initiatives	Purpose	Possible activities	Possible stakeholders involved
Explore and expand use of communication and information platforms/approaches (e.g. case conferencing, secure messaging, patient held records) to support coordination between care providers	• Strengthens ongoing and timely communication and care coordination between primary health nurses, GPs and specialist team, including increased use of case conferences/MDTs and phone conversations • Supports formalised shared care arrangements, including case conferencing/MDTs	• Explore most appropriate platforms/approaches to support strengthened communication and coordination, e.g.: o Telehealth/case conferencing o Patient held records o Argus secure messaging o Encrypted email o Palliative care plan templates to support sharing of care between GP, specialist team and other providers (Level 3) o Phone directory of GP practice managers or other mechanism to facilitate efficient specialist communication with GP • Establish protocols, implement, promote, and monitor and evaluate use of identified platforms/approaches	• COORDINARE • ISLHD palliative care service
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 and other palliative care providers	• Build awareness of available educational services[2], resources and initiatives[3] • 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 • ISLHD • 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 team • 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, ISLHD 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

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

Proposed initiatives	Purpose	Possible activities	Possible stakeholders involved
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
Support increased uptake of advance care directives and NSW Ambulance Authorised Palliative Care Plans	• Ensures patient wishes on treatment are documented • Supports paramedics to provide palliative care in the home, potentially avoiding unnecessary hospitalisation	• Agree on standardised advance care directive tool for Illawarra Shoalhaven across different care settings • Actively promote use of standardised advance care directives and NSW Ambulance Authorised Palliative Care Plans to GPs, Aboriginal Health Workers and other key service providers • Work with RACFs to embed advance care directives in resident admission process	• COORDINARE • GPs • RACFs
Advocate for expanded resourcing and improved delivery of palliative and end-of-life care in Illawarra Shoalhaven	• Influences decision-makers to support different care and funding models and support expanded access to palliative and end-of-life care	• Advocate for expanded access to PEACH packages for Level 1 and 2 patients (not just in the last days of life) • Consider a strategic approach to influencing palliative care funding models (including Medicare items) that support greater involvement of GPs, including to undertake home/residence visits • Develop proposal for hospice-type service(s) within the region • Advocate for resourcing to address constraints in specialist palliative care service, including to ensure equity of access for patients in more remote areas	• COORDINARE • ISLHD • 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[28], 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[29]. 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 Illawarra Shoalhaven 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 Illawarra Shoalhaven 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 Illawarra Shoalhaven into the future, including a number described below.

Reform	Relevance to Illawarra Shoalhaven
Health Care Homes (HCHs) and medical home models	The Australian Government is 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.

NSW Health funding for specialist palliative care medical positions, including locum positions specifically to support GPs, may also have implications for the delivery of care in Illawarra Shoalhaven. 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 Illawarra Shoalhaven. 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:

COORDINARE

1300 069 002

PO Box 325, Fairy Meadow NSW 2519

info@coordinare.org.au

Appendices

I. Tools and resources

A wealth of resources are available to support palliative and end-of-life care and learning and education. Key resources are presented below.

Summary	Resource	Author	Description	URL
Guidelines, handbooks and tools				
Comprehensive clinical guidance and information	**HealthPathways – Illawarra Shoalhaven**	COORDINARE/ ISLHD	Comprehensive **guidance and information** on palliative care. Includes key resources, referral information, and care plan forms	https://illawarrashoalhaven.healthpathways.org.au/index.htm
Symptom control	**Symptom Control in Palliative Care for the Illawarra Shoalhaven Local Health District (5th ed., 2013)**	Roger Cole/ISLHD	**Therapeutic approaches** to common symptoms in palliative care for Illawarra Shoalhaven	http://www.coordinare.org.au/assets/Uploads/Resources/Addressing-health-priorites/Palliative-care-Symptom-control-booklet.pdf
Medication information	**Medication in the home project (*Driven to change: Making medications work*)**	ISLHD	Provides **advice about standard medications** for end-of-life care. Invites GPs to pre-write scripts and crisis medication orders	http://www.coordinare.org.au/news/palliative-care-project-driven-to-change-making-medications-work/
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 ISLHD specialist palliative care services, as well as the GPs, specialists, other care providers and consumers who shared their insights to provide insights and help shape this model.

Expert Advisory Group

Name	Position
Dr Bronwen Spalding	GP, Nowra
Dr Julie Blaze	GP, Bulli area
Dr Katie Macartney	GP, Milton
Dr Carl Mahfouz	GP, Shoalhaven area
Dr Laura Pearce	Palliative Care Specialist, ISLHD
Kay Cope	Palliative Care Clinical Service Manager, Palliative Care Service
Linda Livingstone	Regional Director, Engagement and Coordination, COORDINARE
Kim Barry	Health Coordination Consultant, COORDINARE
Sue Sinclair	Director, ZEST Health Strategies
Rob Sutherland	Associate Director, ZEST Health Strategies
Hayden Jose	Consultant, ZEST Health Strategies

Formative stakeholder interviews

Stakeholder type	Location/service	Number
General practitioner	Illawarra area	9
General practitioner	Shoalhaven	6
Clinician	Palliative care services	5
Clinician	Community Health Centre (Illawarra)	1
Private palliative care consultant	Multiple services	1
Senior clinician/health service manager	ISLHD	1
Home-based care provider	Multiple services	3
Residential aged care facility (RACF)	Multiple locations	1
Consumer	Various	3
	Total	**30**

III. Key definitions and glossary of terms

Term	Definition
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[30].
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[31].

IV. References

[1] ACI, "Framework for the Statewide Model for Palliative and End of Life Care Service Provision" (Chatswood: Agency for Clinical Innovation, 2013).

[2] Tasmanian Health Service, "Palliative Care Service Delivery Model," 2007, http://www.dhhs.tas.gov.au/palliativecare/health_professionals/model_of_care. Accessed October 2017.

[3] Department of Health, State of Western Australia, "Rural Palliative Care Model in Western Australia" (Perth, WA: WA Cancer and Palliative Care Network, Department of Health, State of Western Australia, 2008).

[4] Doris Howell et al., "A Shared Care Model Pilot for Palliative Home Care in A Rural Area: Impact on Symptoms, Distress, and Place of Death," *Journal of Pain and Symptom Management* 42, no. 1 (July 1, 2011): 60–75.

[5] Denise Marshall et al., "Enhancing Family Physician Capacity to Deliver Quality Palliative Home Care," *Canadian Family Physician* 54, no. 12 (December 1, 2008), http://www.cfp.ca/content/54/12/1703.

[6] World Health Organisation, "Palliative Care," WHO, 2015, http://www.who.int/mediacentre/factsheets/fs402/en/.

[7] Palliative Care Australia, "What Is Palliative Care?," Palliative Care, n.d., http://palliativecare.org.au/understanding-palliative-care-parent-menu/what-is-palliative-care/. Accessed October 2017. Accessed October 2017.

[8] NSW Health, "The NSW Government Plan to Increase Access to Palliative Care 2012-2016" (Sydney: NSW Health, 2012).

[9] ACI, "Framework for the Statewide Model for Palliative and End of Life Care Service Provision."

[10] Australian Bureau of Statistics. Population Projections Australia 2004-2101, Catalogue No. 3222.0 (2005).

[11] Cancer Institute NSW, based on 2013 estimates. Provided by COORDINARE Population Health Information Manager (August 2017).

[12] Torrens University of Australia, based on 2011-12 modelling estimates. Provided by COORDINARE Population Health Information Manager, August 2017.

[13] NSW Ministry of Health and Torrens University of Australia, based on 2011-12 modelled estimates. Provided by COORDINARE Population Health Information Manager (August 2017).

[14] Australian Kidney Foundation, 2016. Provided by COORDINARE Population Health Information Manager (August 2017).

[15] Alzheimer's Australia NSW, based on Deloitte Access Economics modelling, 2006. Provided by COORDINARE Population Health Information Manager (August 2017).

[16] ISLHD, "Key messages from our data: Palliative care service planning workshop June 2017", Illawarra Shoalhaven Local Health District, unpublished (June 2017).

[17] Geoffrey Keith Mitchell, "Palliative Care in Australia," *The Ochsner Journal* 11, no. 4 (2011): 336.

[18] Sion L. Kim and Derjung M. Tarn, "Effect of Primary Care Involvement on End-of-Life Care Outcomes: A Systematic Review," *Journal of the American Geriatrics Society* 64, no. 10 (October 2016): 1968–74.

[19] Department of Health. Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice (Canberra, March 2017).

[20] Productivity Commission, "Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services (Draft Report)" (Canberra: Productivity Commission, June 2017).

[21] Queensland Health, "Statewide Strategy for End-of-Life Care" (Brisbane: State of Queensland/Queensland Health, May 2015).

[22] ISLHD, "Key messages from our data: Palliative care service planning workshop June 2017", Illawarra Shoalhaven Local Health District, unpublished (June 2017).

[23] Points adapted from Palliative Care Australia. (n.d.). *"Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians":* position paper.

[24] Adapted from NSW Health, "NSW Health Guide to the Role Delineation of Clinical Services" (Sydney, 2016).

[25] ACI, "Framework for the Statewide Model for Palliative and End of Life Care Service Provision."

[26] Australian Institute of Health and Welfare. "Nursing and Midwifery Workforce Report", 2014.

[27] Australian Medicare Local Alliance General Practice Nurse National Survey Report, 2012

[28] Department of Health, "Chronic disease management provider information" (Australian Government, Canberra: 2014).

[29] Department of Health, "Chronic disease management: Multidisciplinary case conference Medicare items for GPs" (Australian Government, Canberra: 2013).

[30] Adapted from Australian Department of Health. "PHN Primary mental health care flexible funding pool implementation guidance: Stepped care", (Canberra, 2016).

[31] Hickmann M, Drummond N, Grimshar J: A taxonomy of shared care for *chronic disease*. *Journal of Public Health Medicine* 16:4, 1994.