



NSW Health
Murrumbidgee Local Health District
Palliative Care Regional Workshop – Griffith
26 May 2017

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1. Introduction

On Friday 26 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Griffith with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

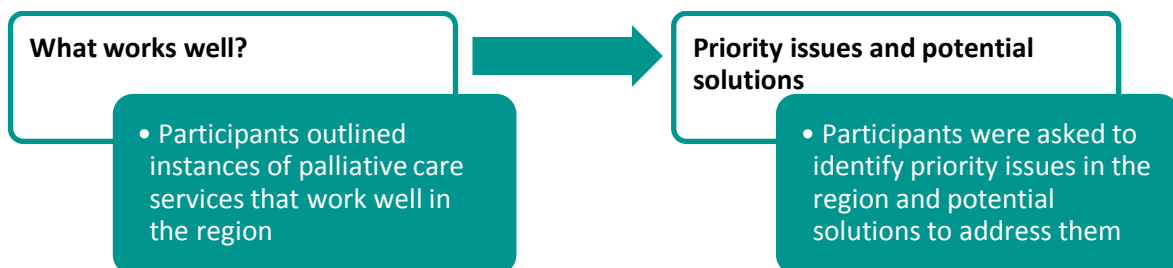
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

High quality palliative care and end of life care is presently provided by a range of health practitioners, both specialist and generalist, working together to ensure the broadest possible access to care. General Practitioners (GPs) and community-based services also have an important role to play. At present, more than half of all deaths in Australia occur in hospitals, though most people indicate that they would prefer to die at home.

The purpose of the Griffith session, one in a series of regional roundtables on the subject, was to hear what local stakeholders felt was working best in the region, what their priorities were for palliative care, and what solutions they proposed to the priorities identified.

The workshop was facilitated by Ian Colley from independent communications and engagement agency, KJA, and commenced with a welcome address from Mr Brett Thompson, Director Operations Murrumbidgee Local Health District, and Mrs Leslie Williams, Parliamentary Secretary for Regional and Rural Health. A number of participants spoke about their personal experience and expertise with palliative care services in the region.

Following this, workshop participants undertook two targeted, small-group discussions:



The results of these discussions are summarised in the following sections of this report.

Upon completion of the workshop series, an overarching summary paper will be prepared for NSW Health. This summary paper will inform NSW Health's development of strategic directions for delivering services to best support people facing a life-threatening illness.

2. Workshop Outcomes

2.1 Palliative Care Perspectives

Participants spoke about their personal experience and expertise with palliative care services in the region. Key comments appear below.

General Practitioner (GP)

- Main aim of palliative care delivery is to develop a model for a country town to provide necessary care to a patient who wishes to receive palliative care at home
- The model is working well and has been rewarding opportunity for the patient and their family

Private Hospital Representative

- Hospital houses a relatively new specialist palliative care unit
- The unit provides services to public and private patients
- The unit works closely with GPs and with the LHD palliative care team, who are "fantastic"
- A lot of education is needed for clinicians, frontline people and medical practitioners
- Focused on patient-centred care (i.e. what is important for the patient and what do they want)
- As a Catholic organisation, the focus is on mitigating suffering of patients

Cancer Council Representative

- Cancer Council provides a grassroots, advocacy-based perspective on palliative care
- People sometimes refer to home care as 'free range palliative care'; it's great for the patient and the families
- Found that the community is aware of the benefits of early engagement with palliative care
- Found that the community is appreciative of these services and recognise the challenges

Not-For-Profit Representative

- Works closely with GPs
- Solutions should focus on how to best use existing resources
- Supports a model of early intervention
- Looking at mental health in palliative care, from initial engagement through to bereavement care
- Rolling out training for health workers to help perform mental health work in communities

2.2 What Works Well?

“Where have you seen palliative care services in the region that work well and what did they look like?”

Note: In addition to sharing palliative care services they felt were working well, participants suggested what was required for palliative care services to work well. This is reflected in the summary table below.

Key themes	What works well
Planned care and public awareness	<ul style="list-style-type: none"> • Use of Commonwealth-funded GP management plans to access mental health and allied health • Palliative care stream within the Local Health District (LHD) to provide an independent voice and strategic view of palliative care across the LHD • Pre-planning and anticipatory care in facilities (e.g. providing weekend cover) • NSW Ambulance care plans and the provision of pain relief without transportation to a hospital • Agency for Clinical Innovation (ACI) Model of Care providing research, foundations and a framework to work with (e.g. Blueprint for pursuing equity of access to care) • Pre-organised planning throughout the sector has reduced non-productive time • Discussions within families about Care Plans, which is providing clearer directions and facilitating earlier introductions to services • The LHD is good at looking at the whole palliative care picture • Through strong communication and education of health care professionals, the LHD is moving from a medical model to a palliative model of care • Client level explanations of what palliative care has to offer.
Mental health support	<ul style="list-style-type: none"> • Non-Government Organisations and mental health social workers offering therapy for patients, carers and families, including 10 sessions per year Commonwealth-funding (bulk billed) • Current training for clinicians, including around narrative, family dignity and cognitive therapies, so that they can assist in operating this model • Early referral and follow-up for patients and families that have been delivered ‘bad news’ • Psychosocial aspect of care is dealt with well in the District.
Volunteer assistance	<ul style="list-style-type: none"> • Volunteer programs (approx. 4 year stints) where volunteers are well supported by coordinator and treated as employees (i.e. well trained) • Diverse volunteer role, including in the areas of entertainment, respite, feeding and transport • Volunteers screened so that they can be given work that aligns with their strengths.

<p>A capable and supported workforce</p>	<ul style="list-style-type: none"> • Specialist service providers who are proud of their services, respectful and passionate about delivering care • Support for palliative care staff • Nurses who are very good at navigating the system • Enhancement of full time equivalent positions, including two Clinical Nurse Specialists (CNSs) from Nursing and Midwifery Office (NAMO) to provide specialist services in rural communities • Metro services such as the provision of social worker and allied health services, which can be implemented in regional areas • GP education, support and training, as provided by the Primary Health Network (PHN) • GP education around advanced care planning, care coordination, palliative care planning, administration and prescribing of drugs, which is awaiting funding • ‘Train the trainer’, where nursing staff build skill levels to deliver messages to the general public • University medical students supervision by a hospital GP • Increased awareness of stages and opportunities for referrals to palliative care.
<p>Patient and family-centred care and choice</p>	<ul style="list-style-type: none"> • Palliative Care Outcomes Collaboration (PCOC) measure of patient experience is used to identify impacts of care measures and enable growth for clinicians • GPs deeply engaged in care, making use of their good, long-standing relationships with patients and their families, leads to improved end of life choices and outcomes • Hospitals as an option for patients who may view those facilities as ‘their home in the community’ • Pastoral care within facilities to support patients and families when they are in need • Not-for-profit organisations providing family members with support in the home (e.g. Baptist Care) • Basic accommodation for families who are supporting palliative care patients • Understanding the family’s community, cultural and spiritual needs in order to deal with diverse needs.
<p>Localised community care</p>	<ul style="list-style-type: none"> • Communities engaging in more meaningful conversations, including about advanced care planning • Great sense of community and community values demonstrated by community palliative care services mean that home deaths arguably work better in rural areas than in city environments • Families and migrants in multicultural communities adding value to palliative care for the patient • Strong sense of community, with confidence rising as a result of ‘everyone knowing each other’ and providing support • Cancer support groups doing a great job in smaller communities to create a greater sense of community • Local people delivering local services to their community • Network approach to care, including improved communication and development of relationships for seamless patient transitions (e.g. Cootamundra providing drivers who were local service providers and are often known to families) • Locally based, on-call staff • Encouraging local ownership by working with local communities to generate local solutions.

<p>Integrated and coordinated care</p>	<ul style="list-style-type: none"> • Guidance at the Ministry of Health level with action and flexibility at the local level • Nurse Practitioners working closely with GPs, including in planning care and symptom management • Enhanced communication between services means improved outcomes and enables patients and families to feel safe • Linkages to tertiary palliative care services for specialist staff and volunteers • Flexible care delivered by multiple, linked organisations, with patients at the centre (e.g. a GP hands over to MLHD staff, who hand over to NSW Ambulance who hand over to an NGO such as HammondCare) • Smaller facilities with palliative care rooms to place families and carers in an environment of togetherness • Collaboration with acute and specialist palliative care teams despite limited staffing hours and resources • NSW Ambulance collaborating with primary health providers (e.g. GPs) to identify what services exist in the District • NSW Ambulance involved in limited palliative care plans/authorised care plans and working well with community and community services • Small community consortia (e.g. Cootamundra), where all stakeholders have a commitment to coordinating all their services • Interstate partnerships with cross-border relationships, which are especially important given the touch points between Victoria and NSW across the southern region of the State • Panel consulting with Medical Officers for administration of medication/drugs • Programs and projects focused on care coordination to link services and educate GPs • Collaboration between PHN and LHD to run community forums, which were well received by the community • Renal care supporting palliative care teams • Good working relationships with other staff across different facilities • Facilitated flow strategy to seamlessly move patients in to hospital or back home • Communication between palliative care team and Aboriginal health groups is very good • The oncology team works well with the palliative care team • Collaboration between public and private facilities is good • Pre-admission organised between NSW Ambulance and hospitals to decrease waiting times for patients being admitted • In Melbourne, referral pathways work well when organised through allied health staff and social workers.
<p>Access to resources, facilities and support</p>	<ul style="list-style-type: none"> • Introduction of end of life resources from the Clinical Excellence Commission (CEC), including a medication ‘toolkit’ for GPs • End of Life toolkit, which has a good focus and level of guidance, data collection and gathering, and investment in knowledge and information • 24-hour service (e.g. in Griffith, Wagga and Deniliquin), which is slowly improving and needs further implementation, including encouraging older generations to use • Inpatient facility at Calvary Riverina Hospital • HammondCare packages to aid in home support.

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| | <ul style="list-style-type: none">• Flexible funding options to support nurses who are providing care without payment (e.g. seeing patients in smaller communities on their own time), to assist in avoiding hospital admissions• Increase in outreach services• Nursing staff on site at Residential Aged Care Facilities (RACFs), which is helping to reduce ambulance calls• Expansion of networks to utilise community skills and package providers• Using technology appropriately (i.e. Telehealth) to improve access to specialists (e.g. bedside iPad)• Sharing of, and crowd-funding for necessary equipment. |
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2.3 Priority Issues and Potential Solutions

“What are the priority issues that we need to address to continue to improve palliative care services in the region? What could be the solutions to address these issues?”

Small group responses to these questions are collated and summarised in the table below.

Integrated and Accessible Care	
Priorities	Possible Solutions
<p>Operating as a single network</p>	<ul style="list-style-type: none"> • Form a network of available service providers • Assign a Care Coordinator, who can help people navigate the system • Provide broader allied health coverage • Establish a Transitional Palliative Care Program, including a coordinator, dietitian, physiotherapist, occupational therapist and so on, who can work with a palliative care specialist to broker solutions • Encourage staff to enter into open communication and to collaborate with a shared passion and drive for change • Develop Multi-disciplinary Team (MDT) model of care to improve communication across and in/out of facilities • Create forums and platforms for conversations about palliative care • Link facilities with services in the home • Assign designated staff to each facility, who can be easily accessed by patients.
<p>Providing equity of access to care</p>	<ul style="list-style-type: none"> • Use telehealth as a means of providing service access and review telehealth funding • Establish a central pool of funding to hire and provide equipment and educate people on the use of equipment • Collaborate at the local level to provide public access to hospice beds • Address limited access for those under 65 by increasing education around the best means of accessing the system and by reviewing Centrelink requirements for terminally ill patients • Improve access to financial support early in diagnosis by reviewing Centrelink funding arrangements • Improve communications, including through interpreters, by encouraging health staff to use the Health Interpreter Service and by ensuring interpreters are attuned to a person’s communication ‘level’ • Support smaller communities by identifying and filling gaps in their care, and by better utilising their existing GP, aged care and community nurse facilities.

Patient-Centred, Community Care	
Priorities	Possible Solutions
Placing patient at the centre and providing options	<ul style="list-style-type: none"> Establish 'horizontal' partnerships so that patient can remain 'at the centre' and providers can act as the 'spokes', integrating their services Share resources to create 'one stop shops' for patients Coordinate clinical journeys of patients Identify services that exist in each community and share the limited resources available for palliative care Support choice of location of care via telehealth, care coordination and equipment provision Provide sub-acute, 'step down' facilities, improve regional/rural transportation and provide live-in carers so that patients do not need to go to RACFs outside of their community.
Providing funding that reflects diversity of patient needs	<ul style="list-style-type: none"> Review funding models Change language from 'mental health' to 'wellness' plans in an effort to increase uptake of services provided by professionals such as mental health social workers, psychologists and occupational therapists Provide social ventures funding by considering philanthropy as a funding stream Extend three year provision of funding to allow for more flexible thinking Develop a pop up model of funding so that services can be taken to the patient, rather than being housed in one central place Purchase services privately where public providers are not available Allocate more mobile funding to be spent on client homes to provide physical resources (e.g. powered beds to prevent pressure ulcers) Increase, and simplify the system for, travel reimbursements to families and carers.
Increasing the community's awareness	<ul style="list-style-type: none"> Provide training, education and tools for a change manager to engage the community in conversations about palliative care Identify community services where capacity could be increased for the benefit of the community.
Encouraging quality volunteer work	<ul style="list-style-type: none"> Identify people with the right motivations and commitment to get involved in palliative care Engage the Local Health Advisory Committee to encourage community ownership of palliative care

	<ul style="list-style-type: none"> • Develop a program and resourcing strategy to increase volunteer numbers.
Expanding support to earlier engagement/ bereavement care	<ul style="list-style-type: none"> • Increase outreach into facilities and wards to identify additional opportunities for early identification and intervention • Provide comfort for families in times of need • Change the use of language around concepts of ‘death’ and ‘dying’.
Promoting localised care	<ul style="list-style-type: none"> • Engage and provide funding for local medical officers who have the skillset, passion for and/or special interest in palliative care so as to encourage localised service delivery • Assign locally trained staff the task of meeting service gaps and tailoring care to patients.

Supporting the Workforce	
Priorities	Possible Solutions
Providing additional palliative resources	<ul style="list-style-type: none"> • Providing additional resources to address gap in social worker availability (allied health) and avoid staff burnout • Maintain the number of Registered Nurses (RNs) in Residential Aged Care Facilities (RACFs) to enable the provision of 24-hour pain and comfort medication • Supply dedicated positions, including training positions, for local medical staff (GPs and Registrars) to increase patient access to specialist palliative care physicians • Support development of targeted Aboriginal health clinician positions in palliative care to develop expertise • Increase funding and positions for nurse practitioners in palliative care across the District.
Improving efficiencies through technology	<ul style="list-style-type: none"> • Assign laptops for recording notes in patient’s homes so that they do not need to be written up when staff return to hospital • Provide good state-wide infrastructure to support telehealth (e.g. fast and reliable internet access) • Select technology that is suitable for the LHD geography (i.e. in rural locations) • Provide Nurse Practitioners with laptops/iPads and designed care plans.
Educating prospective and current staff	<ul style="list-style-type: none"> • Develop palliative care education framework that begins at University, including orientation packages • Educate GPs on supplement CEC toolkit (i.e. medications), end of life conversations and disease progression conversations • Share successes across the sector when services and initiatives work well • Expand the perception of palliative care so it is considered part of positive health management.



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