



NSW Health
Southern NSW Local Health District
Palliative Care Regional Workshop – Queanbeyan
29 May 2017

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1. Introduction

On Monday 29 May 2017, as part of a broader process of developing its strategic directions for palliative care services into the future, NSW Health hosted a workshop in Queanbeyan with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

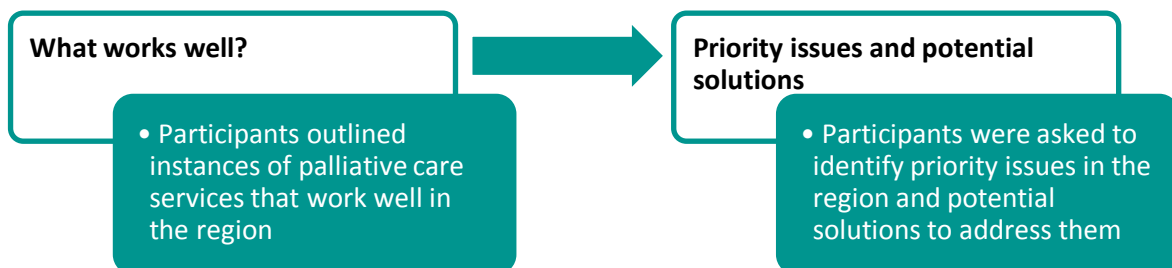
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Queanbeyan 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 Deborah Cameron from independent communications and engagement agency, KJA, and commenced with a welcome address from Janet Compton, Chief Executive of the Southern NSW Local Health District, and Ms Bronwyn Taylor, Parliamentary Secretary for the Deputy Premier and Southern NSW. 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), Palliative Care Specialist and Doctoral Student

- Interested in the meaning of home and place, the experience of patients and families from palliative care through to bereavement, and the role of nurses and GPs in this process
- Believes that palliative care data that shows an emphasis on home care needs careful interpretation because the question is being asked of healthy people, who are less likely to see value of a hospital setting, until they are sick
- Hospitals may be perceived a part of the community more in regional communities than in metro areas
- Local research underway on the dying experience in the Snowy Mountains region

Clinical Nurse Specialist

- Is focused, to some degree, on palliative care and on moving people to proper end of life care
- Often feels 'spread thin' and feels multidisciplinary team would help
- Placing community health under one roof has increased visibility and enabled early referrals, but increased workload as a result
- Seeks to balance care for those in hospital with those at home, who can be kept from being hospitalised
- Clinical Nurse Educator has been funded for Bega but the position has not been filled yet

Consumer and Palliative Care Nurse

- Husband had motor-neurone disease so has seen palliative care from 'both sides'
- Dealt with extra bureaucracy because husband did not fit the mould of an elderly palliative patient
- Aware of existing services, how to advocate for her husband and how to support him at home due to her nursing background
- Important to connect staff and services to patient before symptom control is required
- Navigating lots of new systems keeps people from giving and receiving hands-on care

Community Volunteer

- Felt that she was not provided with sufficient mental support after her father died and so took up volunteer work to have rich conversations with patients/carers that health professionals don't always have time for
- Volunteers help determine the needs of the patient and carer and support them on a weekly basis (e.g. freeing the carer up so they can go and play a game of golf)
- Would appreciate being trained in physically handling patient so can provide support over longer periods
- Palliative care specialists need more time to manage volunteers
- Volunteers need earlier access to patients and their carers

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
Access to quality care	<ul style="list-style-type: none"> • After hours services and 24hr support make a significant difference to the available support for the patient, carers and health staff • Palliative care-specific rooms at hospitals, for the patient and their family • Small country hospitals can be good places for patients depending on their needs at the end of their life • Flexible funding provided by NSW Health helps enable Local Health District to meet its priorities • The palliative care team works well to offer all services and manage symptoms (e.g. pain and shortness of breath).
Planning for care	<ul style="list-style-type: none"> • Ambulance care plans are very useful, especially for after-hours support, though could be used by more patients and be better supported by IT systems • Early referrals provide smoother experience for patient ahead of symptom management and other considerations • Conversations with patients and their family about end of life care and Advanced Care Directives • Developing good rapport with patient to facilitate conversations about their end of life wishes • End of life care pathway conversations at Residential Aged Care Facilities (RACFs), with annual reviews by GP and staff • Plain, direct, honest and simple language in communications with patients regarding illness trajectory to create opportunities for discussion about end of life care, as well as allowing time for the patient and their families to process that information • Supporting patients to weigh-up options, including between active treatment and supportive care.
Tailored support, including at-home support	<ul style="list-style-type: none"> • Palliative Care Home Support Program helps give patients the option to remain at home • GPs have a good understanding of palliative care and rapport with the patient, especially in smaller communities • GPs in smaller communities will visit homes, often after hours • Palliative care medical specialist visits, including home visits

	<ul style="list-style-type: none"> • In-home child care, funded by Centrelink (e.g. Zest Care Australia in Sydney Metropolitan area) • HammondCare package to assist with end of life care • Bereavement support program, which is currently undergoing a needs assessment • Advocating on the patient's behalf when they are not well enough to advocate for themselves.
<p>Communication and collaboration</p>	<ul style="list-style-type: none"> • Collaboration between those involved in palliative care to meet holistic needs of patients and carers • Good communication (e.g. between GPs, Community Health Nurses (CHNs), allied health staff, hospital staff), including when reviewing palliative patients • Swift communications (e.g. between a Specialist Oncologist and a GP) • Direct admission, including where GPs have admitting rights to hospitals, results in a smoother process for the patient • Cancer Care Coordinator involvement and communications • Support from Palliative Care Community Nurse Consultants (CNCs) • Allied health involvement in palliative care • Support from the Children's Hospital tertiary referring team • Collaborative prescription capability, involving GPs and aged care providers • Multi-disciplinary meetings, supported by specialist medical staff • Volunteer programs to provide support for health professionals and carers • Assistants in Nursing (AINs) sitting within teams rather than being contracted by a non-government organisation • Coordinating care to provide central point of contact for patients, families, carers and staff • Communication between intercity and state services • Smooth transitions between home and hospital for patients in end of life care • Highly visible palliative care team in the hospital setting.
<p>Equipment and technologies</p>	<ul style="list-style-type: none"> • Secure text messaging for time-efficient communications between doctors, nurses and carers • Interactive palliative care database for clinical staff, where referrals can be sent and staff can liaise with GPs and others • Community groups providing equipment and funding to hire end of life equipment.
<p>Staff training and mentoring</p>	<ul style="list-style-type: none"> • Online modules to assist staff and carers in preparing for end of life care and symptoms for deteriorating patients • Team approach to palliative care is beneficial, especially where mentoring opportunities exist, and should be rolled out across the Local Health District within each cluster • Nurse led models of palliative care, which enable succession planning and education • Supervision, support and development of staff, including those in RACFs • Education of generalist nursing staff so that they can take a palliative approach in hospital, and know when to make contact with the specialist palliative care team.

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.

Coordinated Services	
Priorities	Possible Solutions
<p>Establishing a multidisciplinary palliative care team</p>	<ul style="list-style-type: none"> • Nursing led models of palliative care supported by appropriate governance model (i.e. multi-disciplinary governance), with collaborative support from appropriate allied health and medical staff • Establish formal model of multidisciplinary meetings that are supported by specialist medical staff • Multidisciplinary team dedicated to palliative care, including: <ul style="list-style-type: none"> ○ Palliative Care Physician, with agreement to offer after-hours contact ○ Social Worker ○ Occupational Therapist ○ Clinical Nurse Specialist (additional) ○ Nurse Practitioner.
<p>Integrating communication and patient pathways</p>	<ul style="list-style-type: none"> • Employ software and system mechanisms to better link people (e.g. share electronic medical records between departments and specialities; expand telehealth services) • Raise awareness of available health pathways in patients, families and service staff • Develop a template to guide GPs in anticipating a patient’s need for end of life care, identifying available local services, and staying connected during the patient’s care • Fast track patient’s transition into end of life hospital care by: <ul style="list-style-type: none"> ○ Developing process for direct admission

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- Ensuring patient's palliative care plan is included in their medical record.
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Certainty of Care	
Priorities	Possible Solutions
Mapping existing palliative care resources	<ul style="list-style-type: none"> • Fund scoping project to compile a portal containing details of palliative care resources, including associated services such as Centrelink • Promote the portal to patients, carers and health care workers.
Committing ongoing funding to palliative care resources	<ul style="list-style-type: none"> • Commit ongoing funding to palliative care resources, including: <ul style="list-style-type: none"> ○ Staff (e.g. Physician, Nurse Practitioner, Clinical Nurse Specialist) ○ Equipment and services (e.g. Hammond Care packages, volunteer coordination, bereavement support program)
Coordinating equitable access across the LHD	<ul style="list-style-type: none"> • Conduct operational management of palliative care services at a Local Health District-wide level • Articulate, through service level agreements, a metropolitan/rural relationship that will enable support of specialist palliative care services in rural areas • Take a standardised approach to care within the LHD, utilising existing services and systems in the District • Employ model of care that enables a nurse practitioner to support rural and remote areas without duplicating services
Providing 24hr support	<ul style="list-style-type: none"> • Employ telehealth services as a means of supporting patients in the home • Learn from other statewide programs when identifying and implementing out-of-hours support mechanisms • Embed 24hr support structures in the NSW Health/LHD Services Level Agreement • Assign a dedicated team to providing this 24hr care

Human Resources & Management

Priorities	Possible Solutions
<p>Building workforce capacity through education</p>	<ul style="list-style-type: none"> • Planning for succession of staff so that palliative care expertise is continually available throughout LHD • Support supervision and education within the NSW Health/LHD Services Level Agreement • Expand clinical supervision model, including mentoring opportunities, for all palliative care staff • Provide educational support, available in the person’s local area, including for: <ul style="list-style-type: none"> ○ Consumers and the community ○ Primary providers (e.g. Medical, Nursing, Allied, Oncology, Renal and Rural staff) ○ Residential Aged Care Facility staff ○ Specialist clinicians (i.e. formal transition training and regular clinical placements) ○ Volunteers • Identify mentors and champions for palliative care across the District
<p>Identifying and addressing gaps in the workforce</p>	<ul style="list-style-type: none"> • Conduct a statewide review of the workforce to identify gaps and equity issues • Consult people in each local area to identify solutions and recruitment opportunities • Address these gaps, including by funding dedicated palliative care allied health services that could be shared with other chronic condition groups



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