



**NSW Health**  
**Hunter New England Local Health District**  
Palliative Care Regional Workshop – Tamworth  
22 May 2017

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# 1. Introduction

**On Monday 22 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Tamworth with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.**

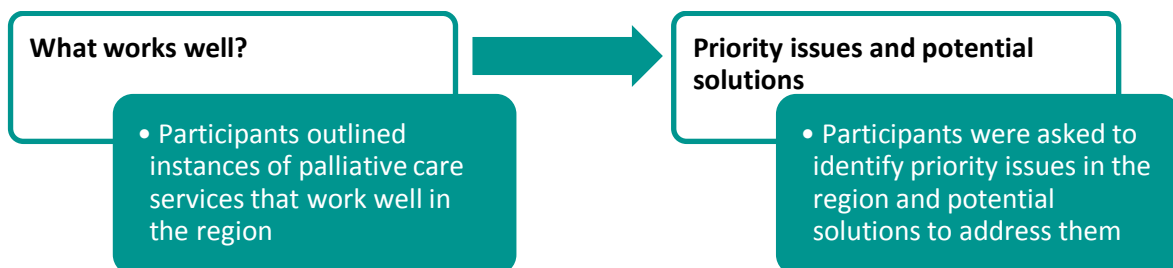
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Tamworth 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 Ms Susan Heyman, Executive Director of Rural and Regional Health Services, and Mrs Leslie Williams, Parliamentary Secretary for Regional and Rural Health. A number of participants, selected at random, 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.

Carer	}	<ul style="list-style-type: none"> <li>• Carer lost her husband to terminal lung cancer</li> <li>• Her husband was still racing cars three weeks before he died</li> <li>• The palliative care team helped to make that possible.</li> </ul>
General Practitioner (GP)	}	<ul style="list-style-type: none"> <li>• Good experiences are possible when "all the stars align" and the right medical staff are available</li> <li>• Developing telehealth and telephone services to support nurses and GPs in surrounding towns</li> <li>• New technologies are part of the solution.</li> </ul>
Academic/GP	}	<ul style="list-style-type: none"> <li>• University has been working with GPs to address gaps in palliative care knowledge</li> <li>• Stakeholders need to know what resources are available</li> <li>• 50% of deaths occur in Residential Aged Care Facilities (RACFs), so palliative care needs to be linked to RACFs, hospitals and homes.</li> </ul>
Clinical Nurse Consultant	}	<ul style="list-style-type: none"> <li>• Clinical Nurse Consultant responds to referrals, performs assessments in the home, and helps to educate medical staff</li> <li>• A good proportion of people want to live and die in their own home</li> <li>• There is a symbiotic relationship between the palliative care unit and the local community in Tamworth</li> <li>• Palliative care unit helps manage symptoms so that, ideally, patients can return to their homes.</li> </ul>

## 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 information about 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
<b>GP involvement</b>	<ul style="list-style-type: none"> <li>• <b>GP-driven model of palliative care</b>, with the patient’s GP at centre and with access to expert, timely advice and support (i.e. from skilled community nurses and palliative care specialists)</li> <li>• GPs willing to be involved in the <b>care of the patient at home</b>, including providing home visits when needed (with and/or without nurses)</li> <li>• GPs acting as a <b>link between primary health and acute services</b>, particularly in rural communities</li> <li>• In many cases the <b>GP has a good overview</b> of the patient and their family’s situation and/or health background</li> <li>• <b>GPs admitting patients</b> to hospital</li> <li>• <b>GPs supporting Residential Aged Care Facilities (RACFs)</b></li> <li>• <b>Ongoing learning opportunities</b> for GPs</li> </ul>
<b>Open communication</b>	<ul style="list-style-type: none"> <li>• Resources for following up with patients and offering <b>integrated and coordinated services</b>, so that patients and carers feel they can ask for help</li> <li>• <b>Good communication</b> between treating clinicians (e.g. GP, palliative care Clinical Nurse Consultant (CNC) and/or palliative care nurses), hospital teams and patient, to build rapport and trust</li> <li>• Good <b>communication between primary and tertiary care partners</b>, to share knowledge across different specialties</li> <li>• <b>Documents, processes and programs</b> that encourage communication, including ‘dying at home’ forms, ambulance programs and escalation plans/coordination.</li> </ul>
<b>Early engagement and planning</b>	<ul style="list-style-type: none"> <li>• <b>Planned care</b>, beginning with a coordinated meeting between the patient and end of life care staff</li> <li>• <b>Early engagement</b> with skilled staff, to set clear expectations around a patient’s prognosis and available palliative care pathways</li> <li>• Care plans and structured support <b>built around the patient</b> and their needs</li> <li>• Patients and family <b>awareness of the need for wills</b>, advanced care plans and the opportunity to choose where they will receive</li> </ul>

	<p>palliative care</p> <ul style="list-style-type: none"> <li>● <b>Education for staff</b> to enable them to achieve consistent, agreed plans (e.g. for night-time assistance)</li> <li>● <b>Evaluating pathways</b>, and identifying ‘red flags’ and/or those elements that could be improved</li> </ul>
<p><b>Patient and family-centred care and support</b></p>	<ul style="list-style-type: none"> <li>● Staff have empathy towards, and <b>commitment to, the patient and their family</b> (families in the district have voiced their appreciation of this)</li> <li>● <b>‘Wrap-around’ services</b> provided in the patient’s last few weeks or days</li> <li>● Regular <b>home visiting service</b>, especially where adequate resources are available</li> <li>● <b>Flexible access</b> in facilities (e.g. to chapels and/or pets)</li> <li>● Recognising the <b>family as the ‘unit of care,’</b> and assisting in helping family members to be resilient</li> <li>● Appropriate <b>psycho-social support</b> in place for patients and their families</li> <li>● Patients not ‘pushed’ to mortuary but rather left with the family for as long as the family wish</li> <li>● ‘Moses cribs’ provided for stillborn babies so they are warm when held, not cold</li> <li>● <b>Bereavement Coordinator</b> involved with families, especially for children and young people</li> <li>● <b>Education of families</b> and/or carers as a key component of care, so that families understand what is happening and why</li> <li>● <b>Follow-up</b> by palliative care nurses for as long as family require</li> <li>● <b>Informal systems</b> for providing food to families, particularly in rural areas</li> <li>● <b>No attempt to ‘rush’ people</b> out of a public aged care facility following the death of a family member</li> <li>● <b>People with a disability, including children in out-of-home care</b>, provided with calming, dignified experiences, due to: <ul style="list-style-type: none"> <li>○ Key people working well collaboratively</li> <li>○ Well-resourced and trained staff, particularly in metropolitan areas</li> <li>○ Support structures, including for disability accommodation staff who may be unprepared to respond to a resident who is palliative</li> <li>○ Internal staff involvement (e.g. clinical psychologist)</li> <li>○ Clear communication and rigorous documentation</li> <li>○ Clear lines of authority and escalation processes.</li> </ul> </li> </ul>
<p><b>Skilled staff delivering integrated care</b></p>	<ul style="list-style-type: none"> <li>● <b>Palliative care for inpatients</b> (e.g. NIOKA Palliative Care Team in Tamworth), where families are supported by staff who are well trained and sensitive to their needs</li> <li>● <b>Aged Care Emergency Nurses</b> acting as a conduit between the patient, RACF staff and acute-based palliative care clinicians</li> <li>● <b>Linking resources</b>, clinicians and referrals, including for palliative care patients with conditions other than cancer</li> <li>● <b>Specialist palliative care services</b> in hospital settings, supported by a primary GP and community nurse</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>‘Hub and spoke’ model</b> of service and program delivery (e.g. Calvary Mater Hospital supporting Hunter New England Local Health District)</li> <li>• <b>Smooth handovers</b> and patient transfers, including between acute care and cancer services</li> <li>• <b>Multi-disciplinary care</b>, including specialist medical/nursing staff, allied health, spiritual care and more</li> <li>• <b>‘Champion’ staff</b>, who are well-trained, educated and have connections to the community</li> <li>• Integrated model of care, including <b>Non-Government Organisations (NGOs)</b> (e.g. Silver Chain)</li> <li>• Local Health Committee and aged care group who are consulted and educated by specialists, including on end-of-life plans</li> <li>• There needs to be a push around <b>Advanced Care Directives</b> in each town, involving GPs and Multipurpose Service Sites (MPSs)</li> <li>• Good relationships between GPs and palliative care staff to allow for <b>medications</b> to be reviewed and/or updated in a very timely manner</li> <li>• <b>Adaptable and flexible services</b>, where staff will take an innovative approach to the solution for a patient, especially in smaller and more remote towns</li> <li>• <b>Registered Nurses (RNs)</b> need to be available in RACFs</li> <li>• <b>Aged Care Emergency program</b> assisting aged care services in delivering plans, providing medication and managing pain.</li> </ul>
<p><b>Continuity of care; Tailored spaces</b></p>	<ul style="list-style-type: none"> <li>• Patients picked up by palliative care clinicians soon after they are referred to acute care for symptom management</li> <li>• Regular <b>access to experienced people</b> who became familiar with, and trusted by, the patient and their carers</li> <li>• Palliative care <b>clinician with knowledge</b> and ability to guide patient through the process and provide factual information and advice to the patient’s family</li> <li>• Taking time to <b>build a relationship</b> with a patient if and when they transition between tertiary, community-based and private services and facilities</li> <li>• <b>Forward planning skills</b>, particularly in RACFs and other settings, where staff think ahead to line up services and care</li> <li>• <b>Dedicated, appropriately designed palliative care rooms/suites</b> and staffing in facilities</li> <li>• <b>Facility layout</b>, designed so that mortuary is not underneath the palliative care rooms</li> <li>• Consultation with consumers to inform layout of facilities.</li> </ul>
<p><b>Access to support</b></p>	<ul style="list-style-type: none"> <li>• <b>Support available 7 days per week</b>, including 9am-5pm opening hours and 24/7 out-of-hours phone support for patients, families and staff, to provide urgent care and ensure that ‘the wheels don’t fall off’ on the weekends</li> <li>• 7 days per week <b>support from palliative care nurses</b> and, in smaller towns, from specially-trained RNs and community nurses</li> <li>• <b>Provision of equipment</b> in a timely manner to support someone to remain at home, including through access to specialist or combined pools, funded by charities or by other means</li> <li>• <b>Resources are needed</b> to increase hours of work for nurses and social workers, to support patients out-of-hours</li> </ul>



	<ul style="list-style-type: none"> <li>• <b>Caring for the carer</b> <ul style="list-style-type: none"> <li>○ Providing carers with access to clinicians when the carer needs help managing the patient at home</li> <li>○ Someone available for carers to talk to, share facts with and receive education and support from</li> </ul> </li> <li>• Providing people with the opportunity to access services without having to relocate</li> <li>• Systems in place that incorporate support from <b>volunteers</b></li> <li>• Accessible and available Silver Chain <b>support packages</b> and syringe drivers</li> <li>• Smaller community <b>Multipurpose Service Sites (MPSs)</b> so that patients can find comfort in familiar facilities and staff</li> <li>• <b>Clear pathways</b> for families to seek help</li> <li>• Last Days of Life <b>toolkit</b></li> <li>• <b>Ambulance</b> as earlier point of contact for 24hr acute support</li> <li>• Balancing access to support with the need to <b>prevent burnout</b> among staff</li> <li>• Multifaceted, personalised and timely <b>education for patients, families and carers</b></li> <li>• Good <b>access to pharmacies</b>, with staff who acknowledge impacts of their advice on decisions made by families (e.g. as in Tamworth)</li> <li>• <b>Medication ‘rescue pack’</b> that is easily accessible</li> <li>• <b>Aged Care Emergency program</b> as a point of contact for advice rather than admitting patients to hospital.</li> </ul>
<p><b>Cultural considerations</b></p>	<ul style="list-style-type: none"> <li>• Awareness of the <b>Aboriginal</b> person and their <b>cultural needs</b>, with skilled care teams who are able to engage with people on a ‘human’ level</li> <li>• Family and patient access to an <b>Aboriginal Health Worker</b>, including when the patient is in hospital</li> <li>• <b>Communication</b> between Aboriginal Health Worker and palliative care clinicians</li> <li>• High number of Aboriginal staff available to assist with engagement</li> <li>• <b>Continued connection to services</b> during and after person’s passing (e.g. as in Taree)</li> <li>• <b>Specialist rooms</b> to accommodate the extended families of palliative patients</li> <li>• <b>Culturally appropriate resources for Aboriginal communities</b> and other groups that may need them</li> <li>• Consideration of how/where Aboriginal families can complete smoking ceremonies</li> <li>• <b>Available rooms</b> that are adjacent to ‘outside areas’.</li> </ul>
<p><b>Technological assistance</b></p>	<ul style="list-style-type: none"> <li>• <b>Technology-assisted communication</b> (e.g. Skype) with staff, patients and/or families, enabling patients to remain in the home</li> <li>• Clinical care updates <b>to identify useful points of contact</b> for phone support, both locally and in metropolitan areas</li> <li>• Clinical <b>telehealth services</b> (e.g. iPads) to spread expertise and minimise out-of-hours presentations.</li> </ul>



### 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.

Developing Workforce	
Priorities	Possible Solutions
<p><b>Supporting and upskilling the workforce</b></p>	<ul style="list-style-type: none"> <li>• Provide <b>increased support for GPs</b>, with access to specialist clinicians for advice and guidance</li> <li>• <b>Educate GPs</b> on the End of Life Plan, analgesia, pain management and the care and conversation with patients and carers</li> <li>• Employ <b>skilled and educated</b> nurses and doctors</li> <li>• Explore how <b>volunteers</b> may support clients, families and carers</li> <li>• <b>Educate the community</b>, staff and clients/families about services, available resources and skills that need to be developed</li> <li>• Increase <b>commitment to education</b> by providing more undergraduate training in End Of Life (EOL) and palliative care, placements in palliative care, exposure to death for new workers and mentoring arrangements</li> <li>• Increase the skills of the current care team by encouraging clinical leadership and engaging social workers and nurses.</li> </ul>
<p><b>Expanding and restructuring the workforce</b></p>	<ul style="list-style-type: none"> <li>• <b>Provide funds to enable recruitment</b> of dedicated palliative care health professionals and specialists, including medical, allied health, palliative care Nurse Practitioners, dedicated palliative care nurses, Bereavement Coordinators and Aboriginal Health Workers/practitioners</li> <li>• Deliver <b>allied health services</b> that include social work, occupational therapy, physiotherapy, dietitian, spiritual care and Aboriginal Health Workers as a ‘Hub &amp; Spoke’ model</li> <li>• <b>Distribute resources equally</b> to all sites for consistent training and support; for example, two additional palliative care Specialists/Doctors across the region with a minimum of two palliative care nurses available across the Hunter New England region</li> <li>• <b>Target positions</b> when recruiting, while acknowledging differences between metropolitan, regional, rural and remote areas</li> <li>• Implement a clinical team based on <b>tiered service</b>.</li> </ul>

	<ul style="list-style-type: none"> <li>• <b>Workforce models</b> could include:             <ul style="list-style-type: none"> <li>○ Palliative Care Specialist Clinician (Clinical Leader &amp; Clinician, educating GPs) supported by Palliative Care Nurses and generalist CH Nurses</li> <li>○ 2 FTE Specialist Palliative Doctors, supported by 4 FTE Palliative Care Nurses.</li> </ul> </li> </ul>
<b>Providing access to care</b>	<ul style="list-style-type: none"> <li>• Offer <b>24 hour, 7 days per week service</b></li> <li>• Provide access to a single local point of contact for escalation processes</li> <li>• <b>Enhance existing nursing services</b> with additional Registered Nurse positions to provide 7 days per week service, and build on existing infrastructure, knowledge and networks</li> <li>• <b>Facilitate liaison</b> between nurses and GPs, NIOKA and other service providers to deliver prompt nursing responses and address urgent palliative care needs.</li> </ul>

Planning & Integrating Care	
Priorities	Possible Solutions
<b>Coordination and integration of care</b>	<ul style="list-style-type: none"> <li>• Coordinate a <b>Multi-Disciplinary Team (MDT) approach</b> when providing palliative care</li> <li>• Acknowledge that an MDT approach may look different across metropolitan, regional, rural and remote areas</li> <li>• Coordinate the clinical team through <b>quality leadership</b>, governance and communication</li> <li>• <b>Improve flexibility</b> of staff and resources, allowing them to increase and decrease as activity fluctuates</li> <li>• <b>Manage local service agreements</b> between key stakeholders to include education and shared documentation of client information so that care can be timely, efficient and holistic; for example, provide access to My Health Records</li> <li>• Specify in job descriptions that palliative care services are holistic, extending across acute and community care</li> <li>• Consider new roles, such as <b>Nurse Practitioners</b>, that have prescribing abilities and can work with GPs, hospitals and other facilities/services</li> <li>• Consider best placement of staff and a <b>Community of Practice</b> to support these roles</li> <li>• Support <b>Clinical Nurse Consultant (CNC)</b> roles, because they provide flexibility in regional areas</li> <li>• Ensure that <b>palliative care is everyone's business</b></li> </ul>

<p><b>Planning and management of care</b></p>	<ul style="list-style-type: none"> <li>• Enable timely and efficient <b>Advanced Care planning</b></li> <li>• <b>Implement a single clinical record/care plan</b> (like a maternity card) that can be accessible outside of the public system, as an interim solution until systems are integrated</li> <li>• Utilise <b>community pharmacy support</b> in medication management</li> <li>• Ensure <b>effective communication</b> between internal and external stakeholders, clients and families in order to facilitate planning and sharing of skills, knowledge, resources and education.</li> </ul>
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Patient-Centred Care	
Priorities	Possible Solutions
<p><b>Providing continuous, quality care</b></p>	<ul style="list-style-type: none"> <li>• <b>Patient-centred</b> palliative care is essential</li> <li>• <b>Provide home visiting nursing services</b> with regular face-to-face contact</li> <li>• Consider remuneration and incentives for GPs who undertake palliative care <b>home visits after hours</b></li> <li>• Use <b>Telehealth</b> (e.g. through iPads and Scopia) in a planned and scheduled manner, to assist in providing tailored support</li> <li>• Provide a <b>telephone support service</b> for advice after-hours, which may be sector-based.</li> </ul>
<p><b>Ensure timely access to equipment and medications</b></p>	<ul style="list-style-type: none"> <li>• <b>Improve infrastructure</b> and <b>review policy and legislation</b> to enable use of syringe drivers within the home in a broader range of situations</li> <li>• <b>Increase nursing staff</b>, education, and availability of equipment</li> <li>• <b>Decentralise equipment</b> from current location to allow timely access to equipment in the home.</li> </ul>
<p><b>Addressing legislative barriers to care</b></p>	<ul style="list-style-type: none"> <li>• Address legislative <b>barriers</b>, especially in regard to keeping drugs in stock</li> <li>• Address the provisions in the <b>Aged Care Act</b> that exclude palliation and function as a disincentive to providing good palliative care and appropriately diagnosing palliative situations</li> <li>• Consider a Palliative Care Act that covers the key principles of care, possibly with links to the Palliative Care Quality Standards.</li> </ul>
<p><b>Consider cultural sensitivities</b></p>	<ul style="list-style-type: none"> <li>• Ensure <b>appropriate consultation</b> with local Culturally and Linguistically Diverse (CALD) and Aboriginal communities</li> </ul>

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- Educate and support GPs and nursing staff in cultural appropriateness training.
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