



NSW Health
Northern NSW Local Health District
Palliative Care Regional Workshop – Lismore
12 May 2017

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1. Introduction

On Friday 12 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Lismore with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

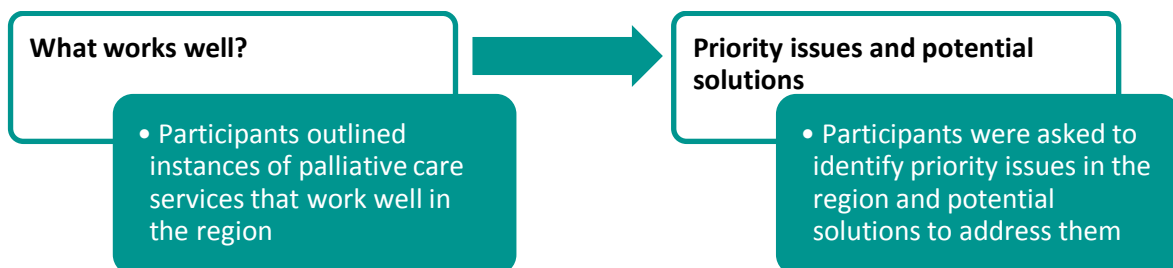
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Lismore session, the second 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 Wayne Jones, Chief Executive of the Northern NSW 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.

Academic

- Has witnessed the incredible improvements in quality of life and a patient's personality that good end of life care can offer as a young doctor overseas
- One patient came into a clinic and was a shadow of her former "larger than life" persona. Saw her old personality return when she was given medical assistance and prescribed appropriate medications
- Important that these considerations are central when considering how to deliver palliative care services.

Health Care Practitioner

- The community wants to have conversations about end of life care
- Recently attended a talk in Ballina about palliative care, where 100 people attended
- Important that carers and medical staff meet regularly to revisit cases and identify what has gone well and what needs to be improved for the patient.

Carer

- Carer's father went through palliative care and was cared for by a private, not-for-profit care provider
- The experience and quality of care had a positive effect on her father
- Carer had the feeling that the staff genuinely cared: her father would tell stories and they would listen attentively and he never felt like he was a burden
- Everyone should have access to the same service and experience.

Chief Executive, Northern NSW Local Health District

- Supporting someone at the end of their life to ensure that they die well doesn't just support the patient, but also supports the patient's family.

2.2 What Works Well?

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

Small group responses to this question are collated and summarised in the table below.

Key themes	What works well
<p>Communication and coordination between different services and carers</p>	<ul style="list-style-type: none"> • A multi-disciplinary and collaborative approach to care. <ul style="list-style-type: none"> ○ A pilot program being run with meetings held every 2 months with different care providers and services to study cases, including the General Practitioner (GP) and Primary Health Networks (PHNs) • Having an Admission and Discharge Notifications (ADN) system in place, where a phone alert is sent to palliative care clinicians for hospital admissions <ul style="list-style-type: none"> ○ Local GPs also advised of discharge and admission of their patients • The success of truly integrated care across departments and sectors is due to the commitment of all partners, starting with Hospitals and then drawing in the GP, Ambulance, and consumers • A Palliative Care Governance Committee is being established across the Local Health District (LHD), with representation from decision-makers to ensure there is a consistent approach • There is a patchwork of services working well individually in the Northern Rivers region, but they need more coordination • Best results come from strong working relationships between services <ul style="list-style-type: none"> ○ Individual silos in palliative care are working well, but services are not always coordinating well • South East Queensland has a successful palliative care service model: <ul style="list-style-type: none"> ○ A holistic service, with input, output and community services which are well funded ○ Community services cover the patient throughout broader process, not just the last few days of life ○ Key difference is that the community services were available for GP referrals • Capacity to add any Advanced Care Directive (ACD) to the patient’s Electronic Medical Record (eMR), which will assist services in honouring patient’s wishes • GP Registrar project operating in the Ballina area, where all patients are reviewed on admission, on a quarterly basis, and at any time they become unstable • St Vincent's Private Hospital provides palliative care services in a hospital setting, and there is a contract between the private hospital and the LHD to provide this.

<p>Empathic and culturally aware engagement with family</p>	<ul style="list-style-type: none"> • Developing a collaborative care plan including cultural competencies and considerations, and good communication with palliative care service and staff in Aboriginal Medical Service (AMS) • Aboriginal services in Queensland has a ‘dying at home’ policy that provides appropriate services. <ul style="list-style-type: none"> ○ Northern NSW LHD (NNSWLHD) has encouraged the Ministry of Health to adopt this policy • Cultural awareness is needed to provide appropriate palliative care to different communities • Staff are educated around how to have “difficult conversations” with families. Staff trainers have now been trained, so gaining the skills needed to have these conversations is now embedded in regular staff training • Grief packages are provided to families and carers.
<p>Specialised palliative care staff and training</p>	<ul style="list-style-type: none"> • Palliative care volunteers in Port Macquarie and Coffs Harbour who are specifically trained in palliative care to assist in the home with basic needs such as shopping, assisting carers etc. <ul style="list-style-type: none"> ○ Some of these volunteers are specifically trained in the bereavement process as well as end of life ○ A Registered Nurse coordinates the volunteering through the LHD to provide this service in the community • Palliative Care hub and spoke model for Nurse Practitioners, which provides: <ul style="list-style-type: none"> ○ Level of expertise that can be brought by a Nurse Practitioner with higher level of knowledge, assessment and ability to prescribe and refer ○ More accessible person-centred care, longitudinal care, and collaborative relationship with a medical practitioner • Involvement of passionate GPs who have been involved in the patient’s long term care, and passionate nurses - both with an understanding of palliative care • A whole-team approach, with nurses working with families in communication with GPs, Aboriginal Medical Services (AMS) and other services • Having back-up from specialists gives GPs the support they need to provide the best care • An End of Life Committee that has been introduced in the Lismore Base Hospital • A new palliative care nurse has been appointed and this nurse is alerted to all new palliative care referrals <ul style="list-style-type: none"> ○ Provides support and will refer patient to community services and/or Silver Chain (a non-government service provider) as needed • Having a palliative care specialist supervising a registrar who would work directly with patients in the home, and report back to the specialist <ul style="list-style-type: none"> ○ This was a two year research project that was run by Sydney University ○ Statistics showed improvements, but funding ran out after two years, though funding was recently reinstated.

<p>Flexibility of services</p>	<ul style="list-style-type: none"> • Having a service that is flexible, not structured and tailored to meet individual needs over 7 days a week, and 24 hours a day e.g. Silver Chain <ul style="list-style-type: none"> ○ Services provided in the home over a 24-hour period, flexibility is paramount • Monday to Friday services work well with lots of support from GPs, Registered Nurse on duty, the service is well resourced and has good relationships with GPs <ul style="list-style-type: none"> ○ After hours is when problems tend to occur and coordination is more difficult at these times • The capacity to admit a patient after hours to St Vincent’s palliative care • A 24-hour local palliative care phone service used to work well, but this service is no longer available • When services are expanded, it is important to ensure capacity and resources are also provided to improve resource management redesign of services • Telehealth solutions have made a positive difference as patients are able to videoconference nursing staff (Silver Chain).
<p>Providing options (including in-home care)</p>	<ul style="list-style-type: none"> • Providing choices for families, in terms of what facilities they use • Providing options for palliative care patients, such as being cared for at home • Improved support for dying at home, as well as symptom management (e.g. Coffs Harbour Clinical Network) • Service providers adapting to the needs of the community • Keeping more patients in Residential Aged Care Facilities (RACFs) during their final days, rather than admitting them to hospital.
<p>Cultural and age considerations</p>	<ul style="list-style-type: none"> • Aboriginal Medical Services (AMS) and clinicians, in partnership with GPs, supporting the Indigenous community’s wishes, including how and where people want to spend their last days • Providing care for palliative patients of all ages, including young children • Initiating conversations about palliative care early, which helps reduce grieving afterwards (including in Aboriginal communities).
<p>Non-Government service providers</p>	<ul style="list-style-type: none"> • Silver Chain operates in the Northern NSW Local Health District, and this organisation is an excellent service provider • Local Health District staff refer directly to Silver Chain, which is funded by the Ministry of Health. Silver Chain staff work with LHD staff and doctors • Silver Chain service allows patients to feel comfortable and they feel like they are less of a burden on people <ul style="list-style-type: none"> ○ Staff don’t hurry care and patients are given personalised attention ○ Carers and family are more comfortable at home ○ Tailored service to patient’s needs and provide a sense of normalcy around death • Telehealth service is very user-friendly, and patients who aren’t tech-savvy able to navigate it easily. This offers a sense of security to

	<p>carers and families and prevents unnecessary hospital admissions</p> <ul style="list-style-type: none"> • Wedgetail Hospice is a good, community-funded service, run primarily by trained palliative care volunteers • 'Amyteus' in Byron Bay is a service generated by GPs in Byron Bay, providing similar respite services.
<p>Early engagement with palliative care team and normalising End of Life</p>	<ul style="list-style-type: none"> • Early contact between the patient and the palliative care team encourages planning, conversations with the patient, family support, awareness of services, etc. • Best when dying isn't seen just as the end of life, and more about preparing to 'die well', quality of life etc. • Breast Screening campaign worked very well – it included advertising, coordinated program - everyone knows about this service • Marketing campaign similar to other health campaigns: <ul style="list-style-type: none"> ○ Demystify palliative care and normalise conversations around death and dying ○ Expand perceptions of palliative care rather than just focusing on oncology • The community is keen to have the discussion about death and dying, which is demonstrated by strong attendance at community forums.
<p>Community and home based care options</p>	<ul style="list-style-type: none"> • In the USA there is a service provided to accommodate people dying at home where a backpack is provided by the GP with care information and emergency services details to minimise the likelihood of a person having to be hospitalised • Last Days of Life Toolkit developed by Clinical Excellence Commission places patients on a comfort chart, with an accelerated discharge-to die-at-home plan • Arrangements for Expected Home Death form that informs everyone that a GP doesn't have to certify death, and allows timely removal of the body, which improves the process for the carers and families • Community-based services enabling patients to stay at home <ul style="list-style-type: none"> ○ A decision to go to hospital or hospice may still occur, but patient/carer choice is important ○ Having options works well need to be informed of different choices • Support from palliative care service, community palliative care NGOs and volunteer organisations, all working to assist carers and patients in their home • Volunteer service in the Tweed is outstanding and provides transport and equipment • Utilising technology for patient symptom management and communication with carers • Health Care Homes (HCH) model, shifting services to the community e.g. after hours GP <ul style="list-style-type: none"> ○ Feedback loop needs to be structured, and good communication between different services, specialists and carers • 24/7 service at home like 'Hospital in the home' (HITH) • Having the back-up from specialists gives GPs the support they need to provide the best care.

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.

Providing Flexible Care	
Priorities	Possible Solutions
Providing patients with options	<ul style="list-style-type: none"> Support for local resources, NGOs, Aboriginal Medical Services, and other community organisations Provide patients and carers with access to options and communicate them clearly Empower patients to be in control of their care with at-home services.
Provide enough staff and support staff for flexible services	<ul style="list-style-type: none"> Provide a minimum standard number of staff specialists, nurses and allied health professionals Provide a 7-days-a-week service that could dovetail into GP services, which would give the patient and their family choices.
24/7 care with access to acute care beds	<ul style="list-style-type: none"> Increase the workforce for palliative care, and include succession planning for this workforce.
GPs not offering home visits or after-hours services	<ul style="list-style-type: none"> New palliative care positions to supplement the shortfall in home visits by GPs, as many GPs will not do home visits Available carer needs to have had good clinical handover from palliative care service Medications could be prescribed electronically, with e-links to local pharmacies Provide after-hours pharmacy and GP services Patients/carers/families need more information about where to obtain equipment necessary for providing palliative care at home.

Better coordinated resources and services	
Priorities	Possible Solutions
A district-specific approach to palliative care	<ul style="list-style-type: none"> • Linking all the local services would best utilise the funding allocated to address specific needs • Create a unified approach that supports the process locally and ensures a minimum standard of care.
Review and redesign of entire system	<ul style="list-style-type: none"> • Conduct a “root-and-branch” review, to map and connect services in the LHD and identify gaps • Review other jurisdictions and models, and liaise with GPs/Primary Health Network Case Coordinators or others who navigate the system • Coordinate the resulting map of all services into a working model as per identified best practice, and regularly review this model • Replicate best practice from other states where it is applicable to our region, and develop strategies to align with these models • Establish outpatient clinics, to provide palliation in the community, with engagement with GPs • Coordinate resources across local areas where resources can be shared across identical services • Standardise palliative care within the hospitals, and create a single identity • Better communication mechanisms across the whole care team, and including patients • Multi-disciplinary team could be expanded to involve more stakeholders in the hospital setting • Improved planning around the discharge process, and ensure follow-up with the patient and carers before discharge and also once at home • Early planning for transitions between the various stages and locations.
Gaps in service	<ul style="list-style-type: none"> • Ensure LHD-level services have sufficient administrative support to be able to work effectively • Utilise consumers to identify gaps in service, considering their view of shortfalls, what works well, and what is missing • Use of a broader range of community service providers to ensure comprehensive coverage.

Ensure sufficient local resource availability

Priorities	Possible Solutions
<p>General lack of resources</p>	<ul style="list-style-type: none"> • Ensure both clinicians and the local community are informed about palliative care services • Expand and harness the capacity of the workforce, and tap into primary and community services • Offer a palliative care support phone line and resource package, available to everyone, and include after-hours access for specialist palliative care services • Introduce more allied health staff, more technology solutions, and more staff and services • Need to focus on more than just end of life and be adaptable in care • In cases such as cancer, services need to work on the patient’s journey from treatment through to palliative care • Palliative care process could include a broader range of services, including social workers, physiotherapists, speech pathologists, dietitian, grief counselling, and volunteer services • More community-based specialised services focused on palliative care to work alongside existing services • Need to consult with local Indigenous communities around what is needed and suitable for their communities • Design a structured, planned education program on palliative care for medical and allied health, community and acute residential aged care • More specialist nursing training and Aboriginal Health Worker training.

Integrated Care and Support

Priorities	Possible Solutions
<p>Consistent, coordinated and integrated palliative care for the Northern NSW region</p>	<ul style="list-style-type: none"> • Establish a strategic-level committee consisting of senior leaders, palliative care clinicians and so on that oversees the entire service and is tasked to develop a plan for the LHD and make decisions about how to best spend the available funds • Establish a management structure across the LHD, which would be allocated the central pool of palliative care funding and be accountable to the Executive • Designate central hubs (e.g. in Tweed, Richmond, Clarence) to provide medication, support, clinics, education rooms, bereavement services, workshops and administrative support • Palliative care services across the continuum of outpatients services, inpatient services, community services • Adaptable services that meet local needs in a culturally inclusive manner.
<p>Advance Care Directives</p>	<ul style="list-style-type: none"> • More streamlining of what is included in an Advance Care Directive form and adoption of Advanced Care Directives across different agencies with better definitions • Introduction of legislation to support Advance Care Directives • High-level discussions need to be held between NSW Ambulance, the Ministry of Health, Local Health Districts, and the Agency for Clinical Innovation to achieve consensus and common understanding about Advanced Care Directives • Community education and pre-emptive engagement.
<p>Standardised processes and guidelines</p>	<ul style="list-style-type: none"> • Hold focus groups with relevant stakeholders to establish best practice • Promote improved communication between service providers • Offer palliative care help/information line to facilitate knowledge sharing.

Community Awareness and Support

Priorities

Possible Solutions

Improve community understanding of palliative care and combat stigma

- **Develop information** and provide information via GP clinics
- Develop a **social media presence** with an educational focus
- **Marketing** is a focus for getting the message out there and starting the conversation within communities
- Need to address the **stigma** around palliative care in the community
- Palliative care is connected with cancer in community's view, but many other illnesses are palliative
- Important to **provide information on planning** through advertising, promotion, and other forums for education.



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