



NSW Health
Western NSW Local Health District
Palliative Care Regional Workshop – Orange
1 May 2017



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1. Introduction

On Monday 1 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Orange with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

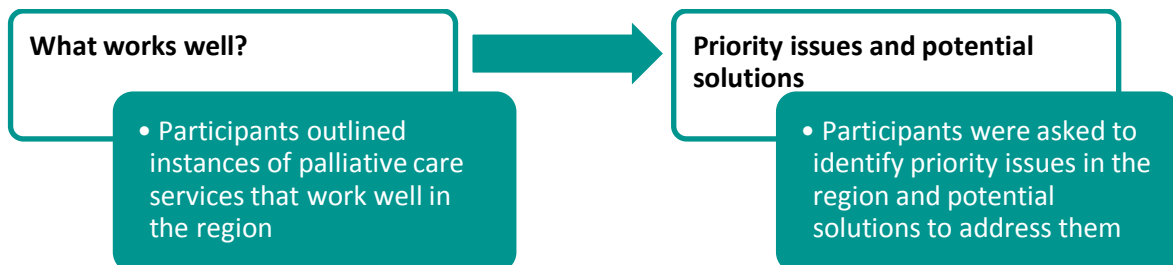
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Orange session, the first 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 Scott McLachlan, Chief Executive at Western 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.

Consumer	<ul style="list-style-type: none">• Consumer cared for his wife for six years before she died• She died a calm, pain-free death because the family recorded her wishes and were advised of their options• Orange health services need to prepare for "baby boomers" who are approaching the age where they will need end of life care• Communities need to talk more about death and dying
Medical practitioner	<ul style="list-style-type: none">• General Practitioners (GPs) have varying levels of involvement in end of life care• Research has found that, generally, people in major rural towns were more interested in new after-hours services than in smaller towns, where General Practitioners (GPs) are meeting this need• Some GPs provide cradle -to-grave support but younger doctors may have different approaches
Not-for-profit representative	<ul style="list-style-type: none">• Every community has different needs and wants but some solutions can be delivered across the state• There is a need to find commonalities while still addressing the needs of specific communities (e.g. smaller towns)
Nurse	<ul style="list-style-type: none">• There have been advances in technology in palliative care nursing• Geography is a barrier to equal access (e.g. long trips to and from hospital for people in rural areas)• This issue can be addressed, in part, by supplementing face-to-face support for patients and medical staff with tele-health services• A multidisciplinary approach is needed
Local government representative	<ul style="list-style-type: none">• Community looks to local government to lobby for necessary services, staff and facilities• Inexperienced and/or rotating doctors do not always have the level of understanding or ability needed to communicate effectively with diverse community groups (e.g. Aboriginal Australians, middle-European)
Pharmacist	<ul style="list-style-type: none">• Required medications for palliative care are not always readily available, which makes it difficult to provide good pharmaceutical service to patients at home



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
Access to support	<ul style="list-style-type: none"> • Access to support services, including respite and home care • Constant care to keep the patient and family comfortable • Fly in fly out services, providing regional staff and patients with expert support from metropolitan areas. Works well because: <ul style="list-style-type: none"> ○ Incoming staff work with local staff ○ Staff trust each other, provide feedback and coordinate services ○ The services provide extra support and ongoing education • After-hours services (including phone support) for staff and the community • An on-call service is being trialled in the Central West (it operates after hours and weekends), to support Residential Aged Care Facilities (RACFs) and other facilities – the trial will soon expand into Dubbo • Better outcomes when the palliative care team is contacted early, at the point of diagnosis.
Continuity of care and multi-disciplinary support	<ul style="list-style-type: none"> • Continuity of care when available (e.g. local GP supporting patient through nursing home care and then to end of life care) • Small communities provide continuity of care by sharing access to records and communicating and collaborating across disciplines • Referral pathways • Offering care from a broad range of health professionals (including allied health, pharmacists, GPs, community health staff) • Networked model of care, utilising different clinicians who support each other • Access to someone (e.g. a palliative care nurse) who can offer advice and support (e.g. for a GP) • Decision Assist service, which is funded by Commonwealth Government, supports staff in Residential Aged Care Facilities • Structures to support multi-disciplinary consultations • GPs leading the decision-making for a more efficient process • Working as a health district to deliver compassionate care that addresses the suffering of patients.
Communication and education	<ul style="list-style-type: none"> • Localised communication, including informing the community about services that are working well • A dementia care support group in Dubbo provided education (including in relation to power of attorney and creative ways to cope and care)



	<ul style="list-style-type: none"> • GP induction, with more information about palliative care and Advanced Care Directives • Palliative care works well when GPs are engaged and know the family • GP training evenings and weekend sessions (e.g. in the Central West Division/Western NSW Local Health District) • Educational opportunities, to improve confidence among staff and enable them to have conversations about palliative care with families. • In Bathurst, a 'trip planner' has been produced to sit on front desk at GP offices
Workforce	<ul style="list-style-type: none"> • Highly supportive nursing staff and doctors • Staff ordering food for family and carers in hospitals • Quality Nurse Practitioners who are involved in integrated support networks • Skilled and supported volunteers • Highly committed generalist/district community nursing staff, who go above and beyond what is expected of them to support patients and their families.
Infrastructure, equipment and other resources	<ul style="list-style-type: none"> • Rooms designed to be peaceful (e.g. with fresh flowers, incense and music chosen by the family) • Family and carer rooms equipped with sofa beds for resting and staying overnight if needed • Designated palliative care beds and clustered services (e.g. Sacred Heart Camden Health Service) • Resources in Bathurst and Orange (opportunity to better coordinate these existing resources) • HammondCare home support packages complement the services that are available (i.e. for primary health care teams, GPs, RACFs).
Culturally appropriate care	<ul style="list-style-type: none"> • Culturally appropriate care and referral pathways • Involvement of Indigenous nurses and doctors • Cultural awareness as a training component for all health staff • Addressing and/or challenging barriers to accessing care (e.g. cultural barriers).
Patient-centred care	<ul style="list-style-type: none"> • Focus is on the person and their personal journey, with community resources 'wrapped' around them. This requires: <ul style="list-style-type: none"> ○ Collaboration ○ Communication (including with families and patients) ○ Integrated support between hospital and the home ○ Considering spiritual needs ○ Addressing related family disputes • Making it possible for people to remain at home if that is their wish, and/or creating home-like environments in RACFs • Nurses caring for patients in the patient's home • Flexible, seamless delivery of palliative care (e.g. home and hospital care in Orange).



Supportive technologies	<ul style="list-style-type: none">• Telehealth and new technologies are working well, though require more champions, and support and education for users• IT platforms (e.g. telehealth and Healthdirect), including texting, telephone calls and video links, are supplementing face-to-face support and advice• Local communities are all becoming more familiar with these technologies and the younger generation is helping their family members use technology• Families are realising that technology can reduce the need for travel, which can be a burden in rural areas• Technology is helping to connect patients and their families with services by tracking the patient journey and mapping available services.
Planning for quality care	<ul style="list-style-type: none">• Palliative care plans include:<ul style="list-style-type: none">○ Ambulance palliative care plans○ Advanced Care plans, which can help overcome barriers to care by giving authority to carers○ Home death planning (involving funeral director, GP, nurses)○ Dedicated plans for palliative/end of life clinical streams (established by Western NSW Local Health District)• Palliative care planning enables staff to:<ul style="list-style-type: none">○ Constructively identify gaps in care and support○ Prioritise resources○ Transparently communicate with communities re: decision making around resources○ Engage and involve patient and family in planning care and information○ Build the family's trust with the medical team○ Respect the patient's wishes.



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.

Workforce	
Priorities	Possible Solutions
<p>Support, upskill and expand the palliative care workforce</p>	<ul style="list-style-type: none"> • Use Multi-disciplinary Team Care approach to palliative care • Upskill and support primary care, acute care, GP and aged care workforces • Provide funding for the development of volunteer programs for palliative care in aged, acute and home care settings • Coordinate more conversations and educational opportunities for general staff, as well as pointing them toward information on palliative care, to build their confidence and willingness to initiate conversations with patients • Introduce mandatory training around palliative care (including for nurses, allied health staff and new graduates) • Establish team to organise events and workshops and coordinate work to make education easier for trainees • Introduce an education calendar, so that staff are aware of opportunities • Make use of existing funding for education, which also produces revenue from registrations • Attract and retain staff to regional areas, including by providing accommodation and positioning as an opportunity to ‘have a break’ away from metropolitan areas • Provide adequate resources to avoid burnout among staff, especially in small country towns where there may be a small number of staff • Develop a strategy for supporting younger GPs, who lack confidence and are reliant on specialists; provide opportunities for them to work in palliative care teams, with specialist support for accreditation • Provide rural generalist training that includes palliative care modules (i.e. Health Education and Training Institute - HETI) • Develop an education plan that takes into account who can provide what training and how it should be done • Introduce a Community End Of Life (EOL) Coordinator • Have practice nurses take on coordination roles.



	<ul style="list-style-type: none"> • Provide a 24/7 registered nurse in every Residential Aged Care Facilities so that palliative patients do not have to leave the facility • Extend provision of community nursing staff • Consider ways of linking education in Residential Aged Care Facilities (e.g. linking HETI with Alzheimer’s Australia etc.).
Providing specialist care	<ul style="list-style-type: none"> • Place palliative care nurses into Multipurpose Service Centres and aged care services • Offer fly in/fly out support from metropolitan areas, including doctors and nurses participating in discussions with multi-disciplinary teams • Provide a dedicated palliative care specialist for Dubbo/North West.

Access to Resources	
Priorities	Possible Solutions
Access to appropriate infrastructure, equipment and medications, especially in rural areas	<ul style="list-style-type: none"> • Flexible solutions required around rural transport, including possibly providing financial assistance for patients and families • Make spaces/beds/units available for end of life care • Provide timely access to appropriate medications and equipment • Districts could identify minimum standards for equipment, with potential for state-wide review • Establish minimum medication standards for palliative care (i.e. ‘care packages’ aged care facilities with dosage guidelines etc.) • Assign designated areas for palliative care • Provide adequate numbers of ‘slow stream’ beds to prevent the need to move palliative patients.
Hub and spoke resourcing model	<ul style="list-style-type: none"> • Achieve critical mass in regional centres so that new innovations in palliative care are adopted and provided with flexibility, and training does not always have to be sourced from Sydney • Connect ‘spokes’ (i.e. regional areas) with ‘hubs’ (i.e. metropolitan areas) for education, mentoring and support • Establish minimum standards for ‘hubs’, including strong workforces, multidisciplinary teams, IT support and equipment



	<ul style="list-style-type: none"> • Utilise population planning tools • Improve coordination of resources that are already available.
Access to support, including through technological solutions	<ul style="list-style-type: none"> • Offer after-hours support • Establish and promote carer support groups, to provide families and carers with palliative care education and support • Employ a combination of telephone, iPads and home visits/consultations • Use telehealth as a means of keeping patients linked to appropriate services • Use iPads to engage families in remote areas in palliative care • Supplement face-to-face consultations and training with use of telehealth technologies, particularly where geographical distance is a challenge.

Integrated Support	
Priorities	Possible Solutions
<p>Address silos in the health professional workforce;</p> <p>Integrate support and information and resources sharing;</p> <p>Forging strong and productive partnerships</p>	<ul style="list-style-type: none"> • Encourage more networking, collaboration and cross-agency teams • Provide better data by improving coding, particularly in settings without many specialists • Improve data linkages and exchanges • Support consultation arrangements and/or shared caring, including through appropriate payment arrangements • Consider implications of National Disability Insurance Scheme (NDIS) for palliative care • Establish clear metro/regional arrangements around palliative care specialists, to address current gaps in professional relationships • Improve palliative care in hospitals by establishing standards around roles and delineation of responsibilities • Map the palliative care services that are currently being delivered in the region, and how well they are performing • Explore opportunities for partnerships in providing education (e.g. with Cancer Council NSW) • Organise more round-table discussions • Explore partnerships to assist with providing accommodation to staff who are new to the region



- Provide **increased support to allied health professionals**, including social support and equipment so that they can help keep patients at home rather than ‘calling’ on doctors for assistance
- Register patients with **ambulance services**
- Support **palliative care in the home** to relieve some of the pressure on Residential Aged Care Facilities
- Improve communication **at point of transferring care** (e.g. from hospital to hospital, hospital to GP etc.)
- Value **carers as partners** in healthcare.

Patient-Centred Care	
Priorities	Possible Solutions
Continuity of care	<ul style="list-style-type: none"> • Improve awareness and uptake of Advanced Care planning • Explore other examples of structures/guidelines around connected patient flow (e.g. in child health) to identify good practice • Communicate choices that are available to a patient • Offer bereavement support for families and carers • Resolve a plan/directive that aligns with a patient’s journey (i.e. involving ambulance team, acute care services and the community) • Attract and retain staff to regional areas so that doctors have knowledge of a patient’s history • Local Health District could consider providing an after-hours service with palliative care nurses • Leverage local community knowledge to ensure services are suitable for the patient • Provide clearer information and communications points for families (e.g. brochures, website, letters sent out by GPs) • Treat patients and their families as a unit • Keep a patient’s GP in the loop, to help maintain continuity of care • Prevent, where possible, palliative care patients from having to move to facilities outside of the town they live in • Recognise that ‘one size doesn’t fit all’ patients • Establish patient-centred pathways to palliative care • Establish robust measures and processes (e.g. patient and carer reports) to achieve consistent outcomes.



Culturally-appropriate support

- Identify what **Indigenous and CALD** needs are
 - Use **culturally appropriate language** when providing education and care
 - **Consider resource limitations** in Indigenous communities
 - Consider the **needs of other ethnic groups** (e.g. Sudanese and Islamic)
 - Provide a 'toolkit' for ethnic groups, including appropriate **translations of key documents**
 - Provide **culturally appropriate resources** (e.g. booklets) and spaces in health facilities
 - Provide families with information and support on **dying at home**, particularly Aboriginal families so that they can perform smoking ceremonies etc.
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