NSW Health
Far West Local Health District
Palliative Care Regional Workshop – Broken Hill
16 May 2017

Report
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1. Introduction

On Friday 16 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Broken Hill 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 Broken Hill session, the third 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 Melissa Cumming Director Palliative Care Far West Local Health District and Tom Hynes, Chair, Far West Local Health District Board. Mrs Leslie Williams, Parliamentary Secretary for Regional and Rural Health also gave a welcome and updated participants on the roundtable process so far. 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:

- Participants outlined instances of palliative care services that work well in the region
- Participants were asked to identify priority issues in the region and potential solutions to address them

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.

**Physician**
- If palliative care services are provided well, the skills transfer across all other areas of health
- In the past, models of care have been implemented but not embedded, and were then discontinued for other reasons
- 50% of patients who are expected to die in FWLHD are known to Specialist Palliative Care services. Our model of care is working on embedding quality palliative and end of life care principles to the remaining 50% of expected deaths of people who are cared for by PHC providers using a palliative approach to care, as specialist palliative care may not be required.
- Advance care planning, discussions with patients and families, and case conferencing with all carers are all implemented and work well.

**Consumer**
- Has accessed palliative care services for several family members over a 30 year period
- Both their mother-in-law and father-in-law wanted to die at home
- The palliative care team cared for these patients at home for three weeks, so they could be surrounded by family
- Both of these family members had their wishes met due to the excellent services received.

**Health Service Manager (Remote)**
- It is very important to talk about a person's choices. A person's 'preferred place of death' is a very personal decision.
- Generalist community care providers have 24-hour access to a specialist palliative care team whose advice and support make caring for patients at the end of their life so much easier.
- Specialist palliative care providers hold education days to further enhance the palliative care skills of generalist care providers
- For Aboriginal patients, shared management involving Aboriginal Health Workers is the right model. Aboriginal Health Workers in the community know everyone, and are trusted
- Aboriginal patients receive exactly the same care as everyone else, thanks to having good relationships and trust established with local palliative care services.
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.

<table>
<thead>
<tr>
<th>Key themes</th>
<th>What works well</th>
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| **Strong local leadership  **| • LHD leaders have a palliative care background and provide clear direction for palliative care  
  • Leadership drives an effective model of care based on international best practice  
  • A broader strategic plan is implemented across the entire district  
  • The service director is dedicated and engaged in the local area. They know all the stakeholders and have developed working relationships  
  • A strong team of specialists is established, with clear roles and responsibilities defined for all care providers  
  • Team members are ‘at the top of their clinical game’, and offer flexible and creative solutions. They have an established record of supporting GPs, carers and anyone needing assistance  
  • The specialist palliative care team is available to provide instant support for generalist care providers  
  • Clinicians are passionate about their work, and staff turnover is low – the team’s reputation attracts good people and staff feel valued. |
| **Resourcefulness in remote areas** | • A process for accessing the specialist palliative care team’s Clinical Nurse Consultant (CNC) is established to provide support for smaller communities in remote areas  
  • Remote hospitals are staffed by service managers and generalist nurses (at times graduates) who are supported by the specialist palliative care team to provide excellent care  
  • The Royal Flying Doctor Service is good at accessing specialist services across the district  
  • Maari Ma Health (Aboriginal community controlled health organisation) have their own generalist community care providers and are also very good at using the resources available to them  
  • There are additional challenges for people living on remote properties who often rely on family members to provide care with the support and assistance of the specialist team and generalist care providers. |
| Best practice care, delivered by well trained staff | • **A model of care based on best practice** is established  
• The specialist palliative care team use **anticipatory planning** to ensure that even in small sites, the necessary drugs and medications are available and ready for use at any time  
• **Residential Aged Care Facilities** implement a palliative care framework and have access to Decision Assist, a Commonwealth-funded program that provides education, resources and advisory services to aged care staff and GPs  
• The **Palliative Care Nurse Link Program** is beneficial and resulted in fewer referrals, with staff more confident to undertake palliative care work  
• A Clinical Nurse Specialist (CNS) is seconded to a residential aged care facility for two days per week over a one year project, working with the facility’s experienced Registered Nurses to provide palliative care support  
• It is important for **specialist palliative care services to provide education, mentoring and clinical supervision to generalist care providers, including GPs.** |
| Community engagement, understanding and establishing trust | • The specialist palliative care team is **engaged with the community and has established credibility and trust**  
• The specialist palliative care team provides **empathy, stability of staff, familiarity** with communities and settings, and **knowledge** of available services and support mechanisms  
• The palliative care team is the **focal point** for many local organisations and GPs requiring access to specialist knowledge  
• An element of ‘**caring for our own**’ leads to people going ‘above and beyond’ to provide assistance  
• The local community is very aware of the service. This has led to much **generosity and donations to the service from community members**  
• Services need to be aware of the **different interpretations that a patient may have of ‘home’**  
• From a patient’s perspective, because of the stable workforce, **trust and respect** are established with the specialist palliative care team, and there is familiarity between providers  
• Support is provided to Aboriginal communities where people may have a **cultural desire to die in country**. Getting home to country is important and if a patient is sent to Adelaide, the service works to get them home and back to country (for example, this has been done in Wilcannia). |
| Patient choice and service flexibility | • The service provides **patient-focused care**, allowing the patient to stay in their location of choice for as long as possible  
• The service provides **24-hour in-home support**, with an instant response when needed  
• An in-home respite service delivered by the same volunteer at the same time is not currently available in Far West Local Health District  
• **Support services** such as showering, cleaning and personal care are accompanied by the timely availability and delivery (same day) of equipment to be put into the home. The specialist palliative care team provides an assessment to determine the patient’s equipment needs |
98% of specialist palliative care team patients have a written **Advance Care Plan**, and 98% have their wishes respected, including dying in their preferred place.

- Services all **work together** to address patient needs, they don’t dictate which services a patient should receive.
- The **community works together** to provide a home death for a patient.
- **Care is provided in the place of the person’s choosing** with good rapport with the specialist service and continuity of care.

### Multi-disciplinary cooperation

- **Inter-disciplinary team meetings** focus on supporting individual cases with no demarcation between services.
- In smaller settings, there is **reliance on the primary health team** to deliver palliative care, with regular communication with the community nursing team.
- A number of local **care providers are multi-skilled** and cover a broad spectrum of disciplines.
- There is a **good connection between care providers and services**, and these service links are starting to become seamless.
- **Residential Aged Care Registered Nurses are now connected to Health** and feel part of the team and the patient’s journey, handing over care to the relevant staff at the right time.
- A truly **multi-disciplinary team** offers 24-hour care with connected, coordinated and collaborative services (encompassing oncologist, GP, Primary Care and specialist palliative care, doctors, nurses, allied health professionals, Enrolled Nurses, Aboriginal Health Workers).
- **Consistent and coordinated palliative care is delivered across all care settings**, for example: in the community, at home, in Residential Aged Care Facilities, and in hospital.
- **Close working relationships** are established with other providers and shared case management provides flexibility.
- A **truly collaborative approach** allows palliative care knowledge to be included in other organisations’ policies on end of life.

### Good communication skills at all levels

- **Clear communication between services** is vital to delivering person-centred care.
- Establishing ‘journey boards’ and engagement with Residential Aged Care Facilities means that **‘conversations’ can commence earlier**. Facility care providers can have conversations with families about the options for their family member at an early stage, without relying on specialist palliative care services to manage this.
- There is **good communication at a clinical level** in Far West Local Health District.
- **Good communication with patients around Advance Care planning** has led to an increase from 40% of patients with an Advance Care plan to 80%.
- **Better communication with GPs** has led to more GPs being supportive of Advance Care planning and many are now prescribing palliative care medications, where in the past they often refused.
- **Emotional and psychological support** for the patient and their carer or family during their illness and into bereavement is most effective when care providers are trained around having these discussions.
### 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.

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<th>Better Collaboration and Integration</th>
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<td><strong>Priorities</strong></td>
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| Integrate palliative care staff into multi-disciplinary team | • Ensure the sustainability and resilience of a 24-hour specialist palliative care medical specialist  
• Consider a ‘hub and spoke model’ (similar to the nursing model) to educate and support specialists, registrars and Junior Medical Officers in rural and remote areas  
• Ensure Junior Medical Officer and clinical administration support to the specialist palliative care team  
• Provide incentives for medical specialists working in rural and remote areas (the only profession that currently don’t receive any incentive)  
• Ensure patients are identified early to access the palliative and end of life services that they need  
• Continue to use and roll out the Far West NSW Local Health District model of care and framework across the district and beyond. Translation of this approach is currently being demonstrated through a Translational Research Grant Scheme project. Elements of the model include a ‘palliative approach’, co-ordinators/champions, framework, clinical documentation, medication management, education, mentoring, training and clinical supervision  
• Establish a health alliance for the region based on the Canterbury Clinical Network model of teams to work on priority areas  
• Work together as a team so that all care providers involved in a patient’s care can refer them to specialist palliative care, not only the doctor. |
| Data sharing and Electronic Medical Records (eMR) | • Real-time sharing of records needs to be established. Lobby for changes to the legislation to be able to share medical records between Health and non-government providers  
• Make the patient the owner of their health records, not the individual health organisation  
• Continue work to progress the development of forms, clinical documentation and tools (e.g. Between the Flags) |
• **Integrate pathways into the software** (e.g. chronic disease pathway). Work with practice support teams and digital managers to support this translation.

### Better trained staff and community awareness

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<th>Priorities</th>
<th>Possible Solutions</th>
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| Need specific palliative care training for staff | • Provide **training opportunities** for staff and students in palliative care  
• Offer **palliative care education** at graduate level for clinicians  
• Include **training in palliative care in undergraduate degrees and as part of rural clinician training**, including how to have conversations around end of life and bereavement  
• **Enhance the palliative care skills** of interdisciplinary allied health team members. |
| Some GPs either resistant or lacking resources | • Some GPs may be reluctant to work with the multidisciplinary team in patient management  
• Some GP practices may not be sufficiently resourced to manage and respond to chronic disease managers and clinic nurses along with supporting the many needs of their clients  
• **Resources need to be provided to support the services needed** including access to social workers, mental health, clinical coordinators and care navigators for preventative care  
• Need to **improve the health literacy** of GPs and through them, their patients and carers  
• Ensure that **GPs know how to find and access** the range of services available. Local service websites need to be kept up to date  
• **New GPs** should be trained in end of life care. |
| Increase public awareness of palliative care | • Ensure that **families are made aware of links and connections** and know which services are available and what these can provide  
• Ensure that community members and care providers are **aware of and educated about palliative care**. The more people are aware of palliative care, the more comfortable people are with dying  
• **People are not always aware** of what palliative care is about and what services are available. |
## Ensure sufficient local resources are available

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<th>Priorities</th>
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| Lack of hospice facilities/beds in acute facilities                       | - There is a need for a **designated hospice that provides emergency respite**  
- Need to provide a dedicated place for palliative care for **people under 65**  
- Confirm that funding commitments for community end of life care and bereavement care are ongoing  
- **Need appropriate staffing for hospice care** (including medical, nursing, allied health and clinical administration staff)  
- **Provide opportunities for training medical, nursing and allied health junior staff**. Provide opportunities for exposure of medical, nursing and allied health students, including compulsory inclusion of palliative care placements in medical school training and nursing training  
- **Adequate staffing** avoids potential conflict for staff, especially after hours, as sufficient cover is available.                                                                                                                                                                                                 |
| Need for flexible funding for in home care packages                        | - **Ease the restrictions around in-home care packages**. Currently HammondCare (a non-government organisation) provides 48-hour packages but this is often not enough  
- The current care packages available through HammondCare are fantastic, but time-specific. If the care package is for only 48 hours, this adds stress to the family on when to make the call and commence the care package, but also uncertainty if their loved one doesn’t pass in the allocated time. |
| Uptake of telehealth is slow                                               | - **Clinician participation in telehealth is low**. The Medicare Benefits Schedule (MBS) needs to be updated as currently it does not include an item for telehealth consultations  
- **Regional NSW needs better internet service** as bandwidth often low or missing.                                                                                                                                                                                                                                                                       |
## Supporting the Patient and their Families

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<th>Possible Solutions</th>
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| **Aboriginal health**                        | • **Further engagement with Aboriginal communities about death** is needed, as many Aboriginal people are fearful of death  
  ○ The more health workers discuss this in the community, the more normal the idea will become - similar to normalising mental health  
  • Maintain **support for Aboriginal Health Workers** in the community. Their cultural understanding and community trust is invaluable. |
| **Support bereavement process**              | • **Build better family support** through the process of palliative care and bereavement. There is the possibility for volunteers and social workers to be involved here  
  • Need to provide **general bereavement services for the community**, so grief isn’t medicalised as a mental health issue.  
  ○ Referral to a psychologist medicalises the normal grief process, and usually there is a long wait time to receive services  
  • Have **all staff trained in end of life conversations**, because it is ‘everyone’s business’. |
| **Earlier engagement with palliative care team** | • **Aim to reduce the frequency of late referrals to palliative care**  
  ○ ‘bushies’ and older generations are more stoic about their health and healthcare, this leads to late diagnoses  
  ○ Desire to die on land  
  • Need to **have more conversations around end of life** with the community at large  
  • There is a **gap in services for patients with dementia or acquired brain injury** with limited specialty services available  
  ○ Need to work with practitioners who understand the patient’s condition  
  • **People in remote and isolated areas need to have conversations** about what is important to them and what needs care providers can try to fulfil (e.g. having their pet with them when dying). |
| **Support for carers**                       | • Be aware of **changing family dynamics** in the region  
  ○ Children are moving away from their parents  
  • **Show sensitivity to a patient’s needs and wishes**, particularly when coming in to their home. |
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