

NSW Health
Mid North Coast Local Health District
Palliative Care Regional Workshop – Kempsey
15 May 2017

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1. Introduction

On Monday 15 May 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Kempsey with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

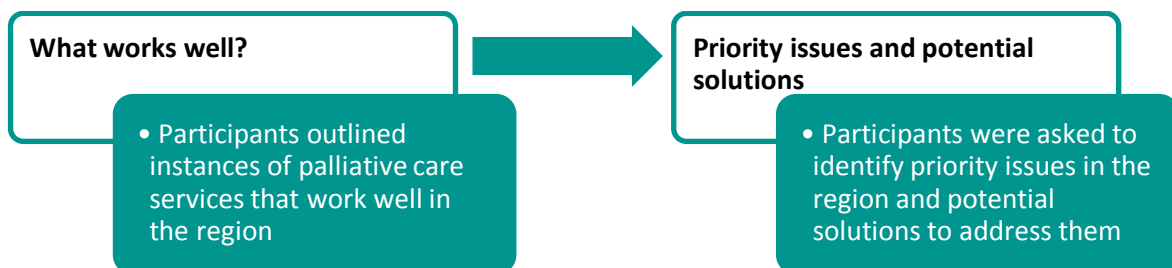
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Kempsey 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 Deborah Cameron from an independent communications and engagement agency, KJA, and commenced with a welcome address from Stewart Dowrick, Chief Executive of the Mid North Coast 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:



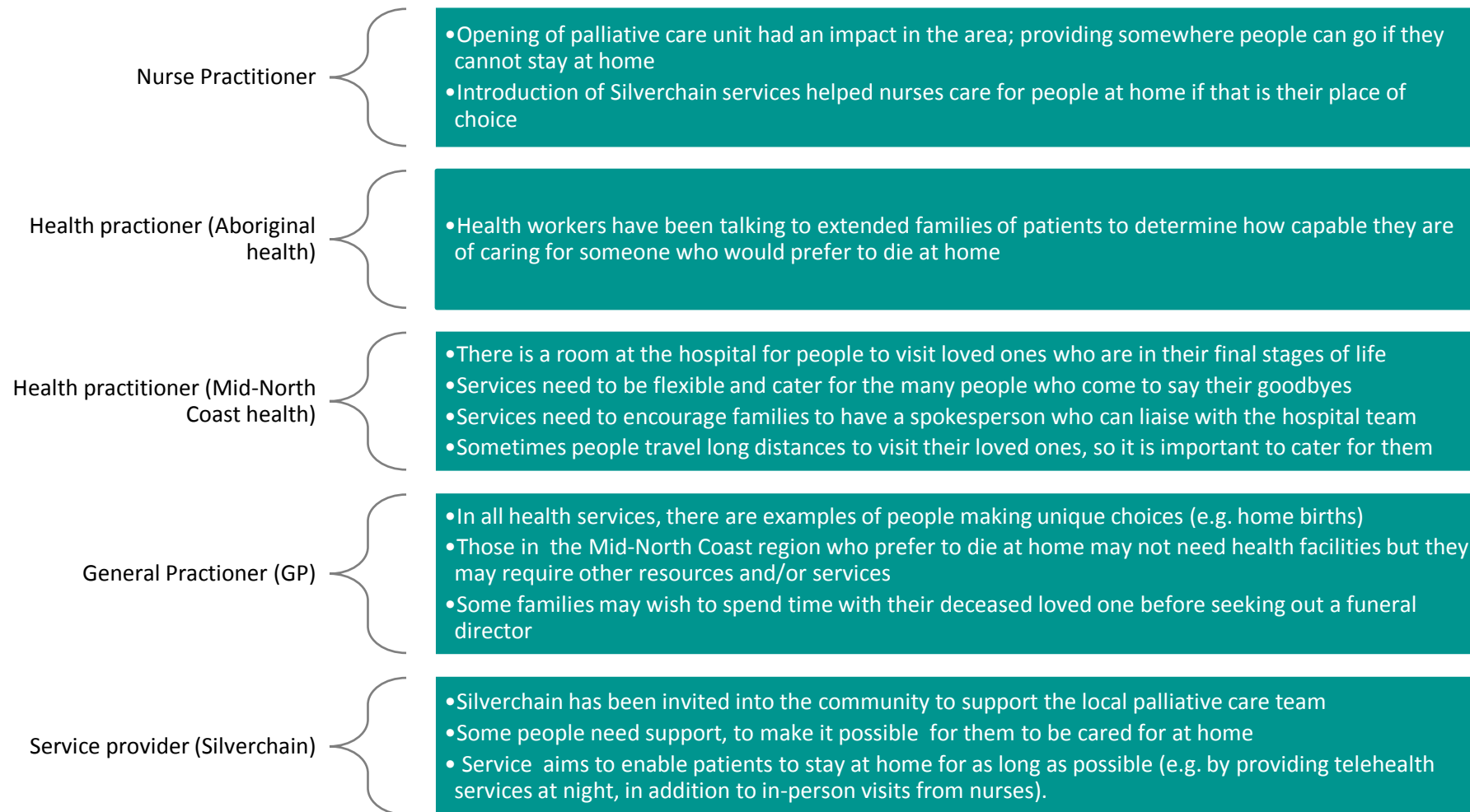
The results of these discussions are summarised in the following sections of this report.

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.



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>Specialised staff supporting other medical professionals</p>	<ul style="list-style-type: none"> • Specialised palliative care units: <ul style="list-style-type: none"> ○ Providing knowledge and resources to support surrounding nearby facilities (e.g. Residential Aged Care Facilities) ○ Training medical professionals to increase their awareness of existing services and develop their knowledge of palliative care more generally ○ Working closely with General Practitioners (GPs) and nurses to encourage them to engage in conversations about palliative care ○ Working within health care centres ○ Assisting patient flow and capacity of medical centres to meet ‘goals of care’ • Dedicated service providers • GPs identified to play specific role in servicing Residential Aged Care Facilities (RACFs) • Some GPs specialised in palliative care due to GP Palliative Shared Care programme • Clinical Nurse Consultants (CNCs) educating and supporting RACF nurses • Funding for a Clinical Nurse Specialist (CNS2) in the Coffs Harbour network • Nurses leading palliative care advocacy, support and expertise where there is an absence of medical specialists in palliative care (e.g. in the Manning region).
<p>Sector-wide efforts to enable smooth palliative care pathways</p>	<ul style="list-style-type: none"> • GPs specialising in palliative care and helping patients through the transition into palliative care <ul style="list-style-type: none"> ○ GPs with an interest in palliative care ○ Working with supportive network (e.g. nurses) ○ Acting as the common thread for a patient ○ Connected to physicians (either officially or informally) ○ Introducing patient to other services and social supports • Collaboration between Local Health District (LHD) services and other services (e.g. residential aged care) to provide smooth end-of-life pathways for patients

	<ul style="list-style-type: none"> • Clear documentation (i.e. what patients have gone to hospital for, what their preferences are in relation to the facilities they use) working well, including when combined with follow-up phone calls • Approach to palliative care for people with non-malignant conditions is improving, including improved links between chronic care and palliative care teams • Great community nurses, who are working together to transition to a whole-of-service approach to care • Allied health services working well together and communicate well • RACF model for GPs, where they are dedicated to RACF patients • Nursing mentor model • Use of volunteers in palliative care (e.g. for home visits, social outings, bereavement) • Designated palliative care areas in health facilities • Model of care evolving from primary nurse model to an IT-centred, whole-of-services approach • End-of-life pathway is working well across the Mid North Coast Local Health District and Nambucca Valley Care • Links between oncology services and palliative care, including joint discussions and shared care • Building links between chronic care team and palliative care team • Hub and spoke model working well, including where smaller sites are taking palliative patients from Port Macquarie Base Hospital so that they can spend their last days of life in a more friendly environment and/or in accordance with their wishes • Current focus on education and training to build a robust multi-disciplinary palliative care workforce (e.g. physiotherapy assistance with respiratory function) • Community team providing support to families of a patient in a hospice, including checking equipment, answering questions and liaising with on-call doctor (e.g. Newcastle unit).
<p>Palliative care planning</p>	<ul style="list-style-type: none"> • District workshops involving solicitors, to discuss planning ahead (opportunity to expand these further) • NSW Ambulance services helping support those at home, including the use of ambulance palliative plans • Taking an holistic approach to planning, in which psychosocial, medical and spiritual factors and the impact on a person's functioning are all considered • Collaboration with the Primary Health Network (PHN) and other organisations to identify gaps and opportunities to adapt for the future (e.g. responding to a growing and increasingly diverse population) • Improved awareness in the healthcare workforce and community about Advanced Care planning.
<p>Providing options (including at-home care)</p>	<ul style="list-style-type: none"> • Providing choices for families in terms of what facilities they use • Providing alternative options for palliative care patients • Improved support for patients dying at home, as well as symptom management (e.g. Coffs Harbour Clinical Network)

	<ul style="list-style-type: none"> • Service providers adapting to the needs of the community • Keeping more patients in RACFs during their final days, rather than sending them to hospitals.
Cultural and age considerations	<ul style="list-style-type: none"> • Aboriginal Medical Services and clinicians, in partnership with GPs, supporting the Indigenous community's wishes, taking into account how and where patients want to spend their last days • Providing care for patients of all ages, including young children • Initiating conversations about palliative care early, which helps to reduce grieving afterwards (including in Aboriginal communities).
Tools, technologies, equipment, physical spaces and data collection	<ul style="list-style-type: none"> • Developing new tools (e.g. 1800 numbers) to build the confidence among medical professionals who work with palliative patients • Silverchain's out-of-hours support, including for GPs • Advanced Care Directives providing a range of medical professionals with timely information about the patient's wishes so that they can respect these • End-of-life toolkit (trialled in Kempsey), which includes all staff and families and encourages transparency • Local pool of equipment that is shared with surrounding areas • Special, larger rooms with opening windows where family can gather when someone in hospital is dying (e.g. Kempsey District Hospital) • Improved data collection • The development of a service directory; an online service linking the community with information about care providers.
Open dialogue with, and support for, families, patients and the community	<ul style="list-style-type: none"> • Early engagement to develop a patient's relationship with palliative care services • Nurse Practitioners are in a good position to have conversations with patients about Advanced Care Directives • Facilities improving communication by providing lists of the best ways to contact different service providers • Holistic approach to care in Residential Aged Care Facilities (RACFs), where information about palliative care is provided up-front • Greater understanding of, and comfort around, palliative care in the community, as well as assistance (e.g. support groups, fundraising) • Establishing guardianship to make process easier for GPs • Providing accommodation for families during patient treatment (though transport can be an issue).

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.

Supporting the Workforce	
Priorities	Possible Solutions
Additional staff	<ul style="list-style-type: none"> • Provide ongoing support to continue the End Of Life (EOL) Coordinator position, as evidence indicates that early intervention by EOL coordinator reduces costs over timeline of care • Appointment of Palliative Care Medical Specialists (e.g. in the Hastings Macleay Clinical Network) to provide an adequate medical structure where these specialists are developing and advocating for the services they represent.
Succession planning and capacity building	<ul style="list-style-type: none"> • Offer specialty promotions to encourage staff to get into palliative care • Include a district management role to coordinate and promote palliative care • Expand the palliative care workforce, especially GPs, palliative care specialists, palliative care nurses, Aboriginal palliative care specialists.
Expanding multi-disciplinary, collaborative approach to palliative care	<ul style="list-style-type: none"> • Develop multi-disciplinary teams to include: <ul style="list-style-type: none"> ○ Medical Specialists ○ Occupational Therapists ○ Physiotherapists ○ Psychologists ○ Social Workers ○ Bereavement counselling services ○ GPs ○ Public/private providers ○ NGO sector.

Providing emotional support for staff	<ul style="list-style-type: none"> • Look after staff who provide end of life care (e.g. palliative care nurses), particularly in rural areas where staff are more likely to have a close connection with patients and the community.
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Integrated Resources and Support	
Priorities	Possible Solutions
Shared data	<ul style="list-style-type: none"> • Improve data collection in palliative care (e.g. add palliative care as a category in Electronic Medical Record (EMR)) • Maintain database for palliative care resources, to help improve awareness of available health pathways.
Improvements in allied health support	<ul style="list-style-type: none"> • Promote palliative care in allied health.
Availability of, and adherence to, Advanced Care Directives	<ul style="list-style-type: none"> • Develop a national, one-page standardised process for Advanced Care Directives • Make available and accessible (e.g. through mobile apps or in the My Health Record, and across all facilities) • Recognise good practice (e.g. provide incentives for GPs to develop management plans) • Provide related training and support.
Consistent communication and documentation	<ul style="list-style-type: none"> • Consider existing IT requirements when setting up projects and services • Provide secure messaging options, including between people and agencies • Standardise forms and roll out preferred format • Prepare communication plans for interactions between GPs and palliative care teams.
Incentives for staff	<ul style="list-style-type: none"> • Provide funding, payment or other incentives for staff in regional and remote areas, including GPs, for time spent on palliative care communications.
Expertise in palliative care	<ul style="list-style-type: none"> • Incorporate nurses or GPs trained in palliative care into the super-clinic structure • Upskill existing staff • Raise awareness of existing palliative care funding, including educational opportunities for clinicians • Provide support and training to GPs and other health professionals who support RACFs (Primary Health Network should

	coordinate this if funding is provided).
Identifying gaps in palliative care services	<ul style="list-style-type: none"> • Conduct forums and/or develop a strategy to identify gaps and implement changes required • Engage service providers, GPs, and other relevant health practitioners in the process • Local Primary Health Network should play a pivotal role • Build confidence and share organisational information, including what role each service plays, so that service coordination can be improved • Formalise the Palliative Care Alliance.
Using integrated modelling in the future	<ul style="list-style-type: none"> • Ensure the model is sustainable by building team capacity to provide after-hours care • Offer supportive tools (e.g. Advanced Care Directives, health pathways) • Provide 24hr telehealth services, where GPs and/or palliative care specialists can be contacted for advice and/or coordination of prescriptions • Provide access to drugs and medications in RACFs, as well as protocols to govern this process • Develop links with aged care projects and services.
Offering Advance Care planning support	<ul style="list-style-type: none"> • Embed Advance Care planning in practice • Set 'goals of care' for all palliative care patients.
Addressing carer fatigue	<ul style="list-style-type: none"> • Provide more basic care support and respite services • Provide social work support to carers • Identify equipment, through allied health assessments, which may make caring easier or less physically taxing.
Providing specialist palliative care support to all services and organisations that provide end of life care	<ul style="list-style-type: none"> • Establish a specialist palliative care unit in all larger centres that provides outreach to smaller centres, providing specialised support for all services and organisations that provide any level of palliative care.

Patient Choice and Access	
Priorities	Possible Solutions
Facilitating more palliative and end of life care at home	<ul style="list-style-type: none"> • Adopt the fundamental concepts of the Ottawa Charter (i.e. a compassionate community) • Transform community engagement around dying and related care.
Providing an ageing population with access to palliative care	<ul style="list-style-type: none"> • Establish easier pathways for community and service providers to let them know what services can be provided, where, how and by whom • Build up the current palliative care workforce • Ensure end of life pathways are consistent and that patients and their families know how to use them • Provide training to address key gaps in palliative care (e.g. training for GPs, practice nurses, RACF staff) • Allocate funding for earlier access to care packages.
Early referrals to palliative care	<ul style="list-style-type: none"> • Increase participation of multi-disciplinary teams, including early identification of patients who may need palliative care • Improved links between GPs, Ambulance staff, Aboriginal Medical Services and RACF staff to prevent avoidable hospital admissions.
Addressing the gap in provision of service between initial diagnosis/admission and end of life	<ul style="list-style-type: none"> • Offer pre-end of life care and services to help patients remain at home if they wish • Provide additional home care • Prepare families and support them through these final stages.

Community Awareness and Support	
Priorities	Possible Solutions
Raising awareness in the community	<ul style="list-style-type: none"> • Establish a common language and common understanding about palliative and end-of-life care across healthcare services and the wider community • Normalise death and dying as part of life’s continuum (e.g. by including as part of the school curriculum with video resources) • Use different media types to their full extent (e.g. mobile apps to assist with Advanced Care Directives) • Develop a one-stop-shop for palliative care resources • Primary Health Network to map palliative care opportunities, as it has done for dementia services • Clearly position palliative care as a speciality, to promote greater awareness.
Integrating the palliative approach within the healthcare sector and wider community	<ul style="list-style-type: none"> • Have spaces in hospitals that facilitate positive experiences of palliative care (e.g. support rooms for families and carers) • Make training in palliative care mandatory for health professionals (i.e. for undergraduates and those in medical placements) • Create more opportunities for conversations around palliative care, for example: <ul style="list-style-type: none"> ○ Campaigns ○ Awareness days ○ Schools curriculum ○ Workshops ○ Elder days • Provide incentives around palliative care (e.g. incentives within the Medicare Benefits Schedule).
Consulting Aboriginal communities	<ul style="list-style-type: none"> • Engage Aboriginal communities to start discussions about palliative care and what it should look like for their communities • Develop a culturally appropriate toolkit with information designed in a way that will engage Aboriginal people.
Providing quality care for the patient, the family and community that surround them	<ul style="list-style-type: none"> • Provide holistic care to the patient, family and community that includes various services such as social work, allied health, and psychological support • Follow up with carers and families to provide grief and bereavement support • Make a broad range of clinicians and services available to not only patients, but their families and communities as well.



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