

NSW Health
Illawarra Shoalhaven Local Health District
Palliative Care Regional Workshop – Kiama
2 June 2017

Report

Table of Contents

1.	Introduction	3
2.	Workshop Outcomes	4
2.1	Palliative Care Perspectives	4
2.2	What Works Well?	5
2.3	Priority Issues and Potential Solutions	9

1. Introduction

On Friday 2 June 2017, as part of a broader process of developing its strategic directions for palliative care services into the future, NSW Health hosted a workshop in Kiama with consumers, health sector representatives, and academics to discuss the future of palliative care in the region.

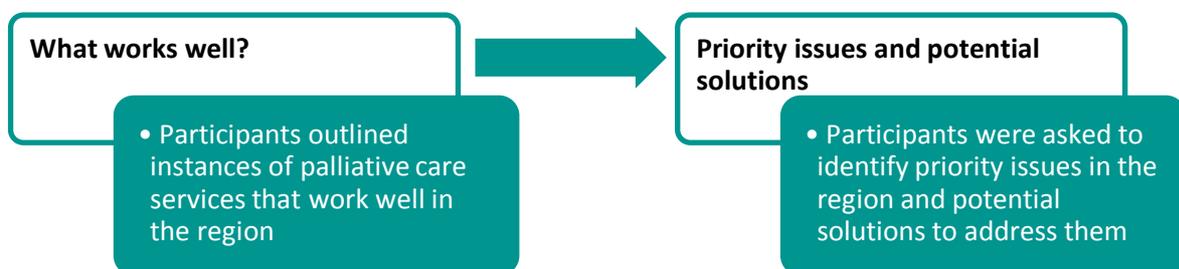
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 Kiama 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 Sara Harris, Executive Director, Clinical Operations, on behalf of Ms Margot Mains, Chief Executive of the Illawarra Shoalhaven Local Health District, and Mr Lee Evans MP, Member for Heathcote, on behalf of NSW Health Minister, Mr Brad Hazzard. 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.

Palliative Care Specialist

- Worked in palliative care for 12 years and in the region for 2 years
- Attracted to palliative care because it is patient-centred and tailored case by case as there is no consistent pattern for how people want to die
- People generally prefer to be at home for as long as possible but support services are not always adequate or robust enough to support this
- After -hours equates to about 75% of the week so services need to address this gap in support
- Patients should not bounce in and out of hospital.

Carer and Cancer Council Advocate

- Illawarra/Shoalhaven is fortunate to have good palliative care services in the region but opportunities exist for improvement
- Was surprised how difficult the palliative period was when husband became ill
- Left hospital when treatment finished for husband because he wished to die at home with friends and family
- Family waited 12hrs on one day to get a piece of equipment, and was unsure whether to just call an ambulance
- Became Cancer Council Advocate after husband's death, to support the cause and improve others' experience.

Quality Improvement Facilitator (Palliative Care Outcomes Collaboration)

- Worked in partnership with palliative care services in the area for approximately 10 years
- Found that every service in the area strives for excellence; for the patients, carers and families, and that they care about how they can do better
- PCOC collates quantitative-data from a suite of patient reported symptoms and clinician rated assessment tools.
- It is important to keep research as part of the palliative care agenda.

Volunteer (Palliative Care in Ulladulla)

- Just trained up 16 volunteers; now need to support them
- Two new beds just opened in a local hospital
- Not medically trained so does not perform any medical tasks
- Advocate for patients and journeys, helping them access available resources as it is not easy to navigate
- Need more staff to assist, including access to a trained doctor once a week.

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
<p>Principles of care, including emphasis on patient-centred care</p>	<ul style="list-style-type: none"> • National and international principles and standards for palliative care • Good specialists with a broad range of palliative skills, focusing on the patient as the centre of care • Placing the patient at the centre of the care process, including through patient journey work and case conferences • Palliative care team in Nowra is getting involved in the patient’s early stages of renal failure to ensure they die more comfortably at home with a familiar care team • Providing options to patients, for example renal patients can: <ul style="list-style-type: none"> ○ Receive symptom management support at home from palliative care and allied health teams ○ Provide medication assistance from a palliative care doctor in hospital • Care coordination, ensuring that families have one contact who coordinates care across the continuum.
<p>Integrated and enabled workforce, with GP involvement</p>	<ul style="list-style-type: none"> • Effective liaison between Primary Health Nurses, Specialists and Silver Chain (a non-government service) to help patients who choose to stay at home to do so for as long as possible • Expanded community allied health team in the Shoalhaven, which is providing valuable care through the provision of equipment and support services • Allied services improving quality of life for patients and carers by assisting their safety and providing education • General nurses in the Local Health District (LHD) who are knowledgeable about palliative care • Good multi-disciplinary specialist input “up and down the coast” • Approachable palliative care team that is always willing to provide support, no matter which location the request comes from • Good spread of public and private hospitals, where specialists are contributing as appropriate, “up and down the coast” • Oncology specialists receiving valuable input from palliative care specialists • Small consultative services addressing service delivery gaps (e.g. working with those that need palliative care in corrective services)

	<ul style="list-style-type: none"> • Environments that enable staff through supportive leadership, IT inter-operability, anticipatory planning and strong communication between different providers (from care workers to specialists) • Involvement of palliative care Clinical Nurse Consultants (CNCs) • Palliative care provided by staff in the community, including primary health nurses, specialist palliative care nurses, GPs and allied health teams that are working together • Allied health-led collaboration between rehabilitation and palliative care (including volunteers) as part of motor-neurone service, with outreach to the patient's home • Support for service-level research, to encourage staff to be engaged in research and service improvement • Use of case conferencing to facilitate care and communication across teams • Involvement of Primary Health Network (PHN), with specialist and other services (e.g. GPs) working together to provide palliative care in the community • Engagement with GPs, including communication with non-palliative doctors • Referral processes to palliative care included as part of Health Pathways, with ideas and guidelines for GPs to follow • Collaboration with the family GP, to keep them involved throughout the patient's palliative care journey.
<p>Education and awareness for staff and community</p>	<ul style="list-style-type: none"> • 'Tapestry' education day; a palliative care open day to talk to community members about Advance Care planning and how to have difficult conversations around palliative care • Video created in Port Kembla to develop awareness and demonstrate how well care can be provided at home • Provision of intensive palliative care training within individual facilities, to upskill generalist staff • Specialist education support provided through St George Hospital in Sydney • PEPA (Program of Experience in the Palliative Approach) program, which provides placements for staff in aged care services to learn about palliative care • Supporting services with professional supervision and professional development • Education and support for GPs from specialist palliative care staff • Education models rolled out by Coordinare and Primary Health Networks to support GPs providing palliative care • Educating carers in various aspects of care, including administration of medications so that patients can be managed well after hours.
<p>Access to equipment, medication and supporting tools/systems</p>	<ul style="list-style-type: none"> • Improved equipment access due to funding to increase loan pool and improved delivery services • Standard medications available in the home to avert crises and improve symptom management • Suite of assessment tools from Palliative Care Outcomes Collaboration (PCOC) to facilitate a common language and provide a consistent clinical picture that can support patients and clinicians when there are multiple providers involved • Screening tools that identify patients in need of care.

<p>Community care</p>	<ul style="list-style-type: none"> • Patients linked to accessible community nursing specialists (CNSs) early in their palliative care journey • Community care helping to cater for a patient’s needs, especially in the last days of life • High usage of Palliative Extended Care at Home (PEACH - i.e. Palliative Care Home Support Packages) packages for patients nearing their last days of life at home • PEACH provides responsive respite care, with twice daily visits and telehealth support • Medications made available as part of the Community Project.
<p>Care in Residential Aged Care Facilities</p>	<ul style="list-style-type: none"> • PEPA helping Registered Nurses (RNs) to provide palliative care in Residential Aged Care Facilities (RACFs) • Changed model of aged care allowing for a more patient-centred approach to care, with improved communication • Improved access to the community CNC (Clinical Nurse Consultant), so that aged care residents can be linked to palliative care services earlier and receive support in the facility, which they consider to be their ‘home’ • Application of ‘journey of care’ concept in aged care, where patients’ wishes are accommodated and services are tailored to personal needs, with enhanced communication with families to improve quality of life • Palliative Care Consultant (Private Facility-Funded Nursing service) available to visit RACFs, to: <ul style="list-style-type: none"> ○ Build relationships with patients ○ Hold case conferences ○ Meet with families ○ Talk to staff about the patient’s condition ○ Offer early intervention for symptom management.
<p>Hospital care</p>	<ul style="list-style-type: none"> • Successful symptom control, enabling patients to be discharged back home rather than being admitted to hospital for longer periods • Early referrals to the specialist care units • Involving patients in decisions about their care • Electronic medical record is improving communication • Palliative-care trained nurses in the facility, including after-hours services.
<p>Primary care</p>	<ul style="list-style-type: none"> • Single referral to community specialist services helps to trigger referrals to follow-up services, with the community specialist acting as a central access point • GPs demonstrating increased support for, and understanding of, the patient’s needs • Increased focus on Advance Care planning.
<p>Volunteer services</p>	<ul style="list-style-type: none"> • Palliative care volunteers with the capacity to visit patients at home and provide respite for carers • Volunteers help keep patients company and have morning tea with them • Volunteer programs that are supported locally as well as by Palliative Care NSW, who assist with the networking, advocacy and progression towards a sustainable model for palliative care volunteers.

After-hours services

- **After-hours service** in the Illawarra is helping to keep people at home and preventing unnecessary hospitalisations
- **Primary health nurses** doing initial assessments and interventions during the day, with the back-up of the specialist team and on-call doctor after-hours service
- **24hr support** from a geriatrician, nurse practitioner and aged care CNC to prevent admissions to hospital where possible
- **After-hours nurses**, from 3pm-11pm and from 11pm-7am, for home visits and over-the-phone triage
- **Shared model** with primary health care nurses and specialist palliative care nurses doing after-hours work
- After-hours service helping to **facilitate both patient care and advocacy.**

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.

Education and choice	
Priorities	Possible Solutions
Increasing choices for patients	<ul style="list-style-type: none"> • Support patients to enable them to die in their preferred location • Deliver palliative care packages for patients at home • Increase hours of care in the community and business hours (to support after-hours service) • Provide after-hours GP and specialist palliative care services, especially in the Shoalhaven area • Increase awareness of specialist services other than palliative care and primary care, to help support patient • Provide adequate resources to support these services.
Reducing the stigma around death and palliative care	<ul style="list-style-type: none"> • Educate the community about palliative care, including the different stages of care • Encourage people to talk about death and palliation • Use media outlets and community functions as avenues for spreading the message • Primary care and Primary Health Networks (PHNs) could help educate healthcare professionals about palliative care • Establish a register of Advance Care Plans.
Educating and developing the workforce	<ul style="list-style-type: none"> • Increase research capacity of the workforce and encourage a research culture across palliative care services in NSW • Increase literacy around death and dying within the community and palliative care services through a mixed method of education that includes forums, educational modules and other methods • Ensure that end-of-life is a mandatory competency unit for all medical and nursing undergraduate training • Implement a palliative care volunteer framework across NSW • Increase advocacy services for palliative care patients • Provide additional specialist palliative care staff across NSW • Expand knowledge within the general community and build workforce by:

	<ul style="list-style-type: none"> ○ Building capacity of the broader workforce, including families and carers, the general population, other specialists within the Local Health District, GPs, practice nurses, registered nurses and allied health providers ○ Use a variety of methods, including building palliative care into the undergraduate curriculum, providing on-the-job coaching and specialised training, offering incentives to increase qualifications, using social media and videos, providing telephone support lines and creating opportunities for work experience ○ Use regional governance committees to support this capacity building by linking it to broader planning (i.e. using demographic info, conducting needs assessments, analysing service gaps and auditing the workforce) ○ Adopt a creative approach and challenge existing structures and staffing models (e.g. increasing number of geriatricians and reduce staffing in other areas to better cater for ageing population).
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Accessible and Integrated Care	
Priorities	Possible Solutions
Extending access to support	<ul style="list-style-type: none"> ● Provide 7-days a week services, including provisions for leave relief for key staff ● Match resources with requirements so that the sector has the capacity to cover staff on leave and provide continuous care ● Prioritise palliative care across all Local Health Districts ● Support requirement for RACFs to have Registered Nurses available 24/7 ● Provide the same level of access to after-hours support for people in the Shoalhaven region that is available in the Illawarra region, by: <ul style="list-style-type: none"> ○ Bringing in the new model of care for an after-hours nurse at Port Kembla Hospital, situated on site and conducting call-outs in the Illawarra throughout their shift as well as providing telephone support to the Shoalhaven ○ Utilising Ambulance plans ● Progress with the current project that is designed to teach targeted family members how to give injections in the home.
Integrating care	<ul style="list-style-type: none"> ● Streamline funding models between services that are funded by the State and Commonwealth governments, including services that provide palliative care packages ● Improve links between local hospital(s) and the community ● Integrate primary care and specialist services ● Provide clarity about the different patient and carer roles ● Employ e-health tools and initiatives

	<ul style="list-style-type: none"> • Integrate a grief and bereavement service within every specialist palliative care service across NSW.
Intervening early	<ul style="list-style-type: none"> • Intervene early to engage patients and their families before end-of-life care begins • Provide patients and families with access to support services and allied health services through tailored packages • Ensure that support packages are easy and quick to access • Address funding issues so that palliative patients who are not aged or disabled can access support packages – this will enable early intervention.
Improving case management	<ul style="list-style-type: none"> • Create a single point of contact for key information and equipment, which would replace the current combination of smaller, discrete systems • Assign resources to roles and teams rather than to individuals by developing standardised policies and procedures • Document clinical referral pathways to better utilise Health Pathways • Improve digital health records inter-operability between the records of the Local Health District, GPs, and RACFs • Ensure case management is available 24hrs • Improve service models to ensure they meet the changing expectations of ageing “baby boomers” • Explore opportunities to engage the community and attract volunteers in palliative care (e.g. Compassionate Communities).

Quality Infrastructure with Supported Staff	
Priorities	Possible Solutions
Supporting staff and carers	<ul style="list-style-type: none"> • Support clinicians by: <ul style="list-style-type: none"> ○ Providing ‘action learning’ opportunities for GPs ○ Supporting primary care teams ○ Educating all staff ○ Standardising care plans ○ Offer scalable, phase-dependent supportive care ○ Establish one point of contact for communication • Support Residential Aged Care Facilities by:

	<ul style="list-style-type: none"> ○ Employing nurse-led models of care ○ Offering financial incentives for GPs to deliver palliative care ○ Ensuring organisations take responsibility for educating staff ○ Providing access to after-hours services ○ Reviewing funding models to ensure greater flexibility across sectors ○ Increasing accessibility of after-hours services ○ Changing legislation to require Registered Nurses in RACFs ○ Implementing and monitoring standards of palliative care in RACFs ○ Increasing promotion of Advance Care planning ○ Reviewing the Medicare Benefits Schedule (MBS) to provide more incentives for GPs to provide palliative care services to RACFs ● Support carers by: <ul style="list-style-type: none"> ○ Offering flexible, ongoing palliative care packages that are not dependent on a patient’s age and have the capacity to provide extensive respite for carers.
<p>Updating infrastructure</p>	<ul style="list-style-type: none"> ○ The in-patient unit at David Berry Hospital needs improvement, as the facility is old and was not purpose-built. It is also geographically isolated. It may be more appropriate to transfer palliative care services to the Shoalhaven District Memorial Hospital Campus, which would also allow cross-pollination of palliative care and general medical knowledge ○ Allocate an additional staff specialist at Shoalhaven to help take pressure off in the large geographical area.



Sydney office

Level 9, 2 Elizabeth Plaza, North Sydney NSW 2060
PO Box 302, North Sydney NSW 2059
T 02 9955 5040 F 02 9955 5901

Melbourne office

Suite 1102, 530 Little Collins Street Melbourne VIC 3000
PO Box 16215, Collins Street West VIC 8007
T 03 9005 2030

E info@kjassoc.com.au | www.kjassoc.com.au