

NSW Health
Palliative Care Metropolitan Workshop
26 April 2017

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1. Introduction

On Wednesday 26 April 2017, as part of a broader process of developing its strategic directions for palliative care services, NSW Health hosted a workshop in Sydney with consumers, health sector representatives, and academics to discuss the future of palliative care in the State.

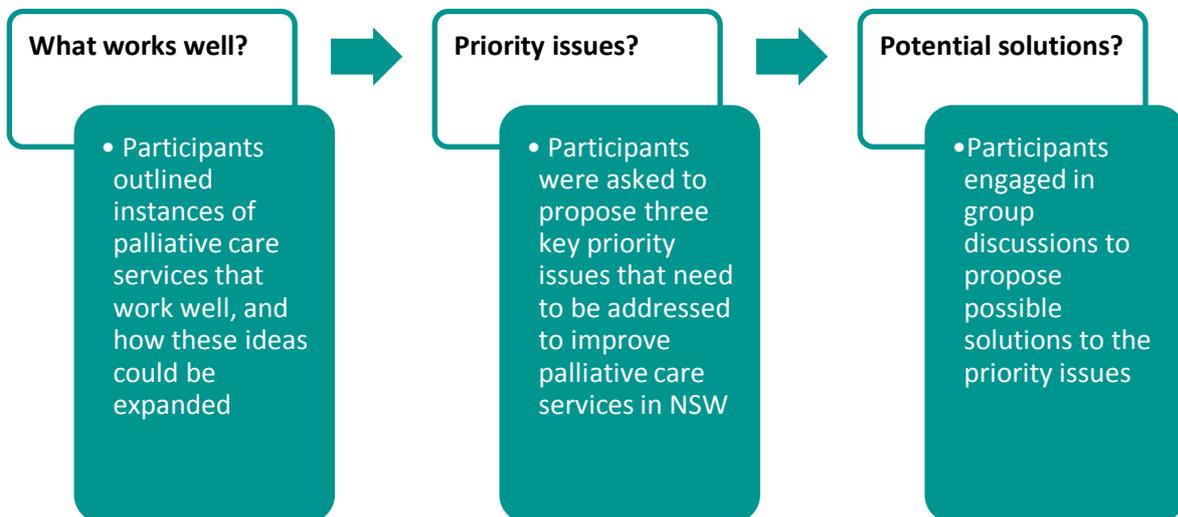
Approximately 50,000 people die each year in NSW and this number is expected to more than double by 2056. With a growing ageing population and an increase in chronic illnesses, the need to provide quality palliative and end of life care will also increase.

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 metropolitan meeting and the regional roundtables to follow, is to listen to stakeholders about what they see as the priorities for palliative care, identify and prioritise gaps in service planning and delivery, and propose solutions.

The workshop was facilitated by Dr Norman Swan and commenced with a welcome address from Hon Brad Hazzard MP, Minister for Health and Minister for Medical Research. Three stakeholders were then invited to speak about their personal experience with palliative care services in NSW, from the perspective of a consumer, a health professional, and an academic. Approximately 70 people attended, and these were clinicians, carers, service providers and community groups.

Following this, workshop participants undertook three targeted, small-group discussions:



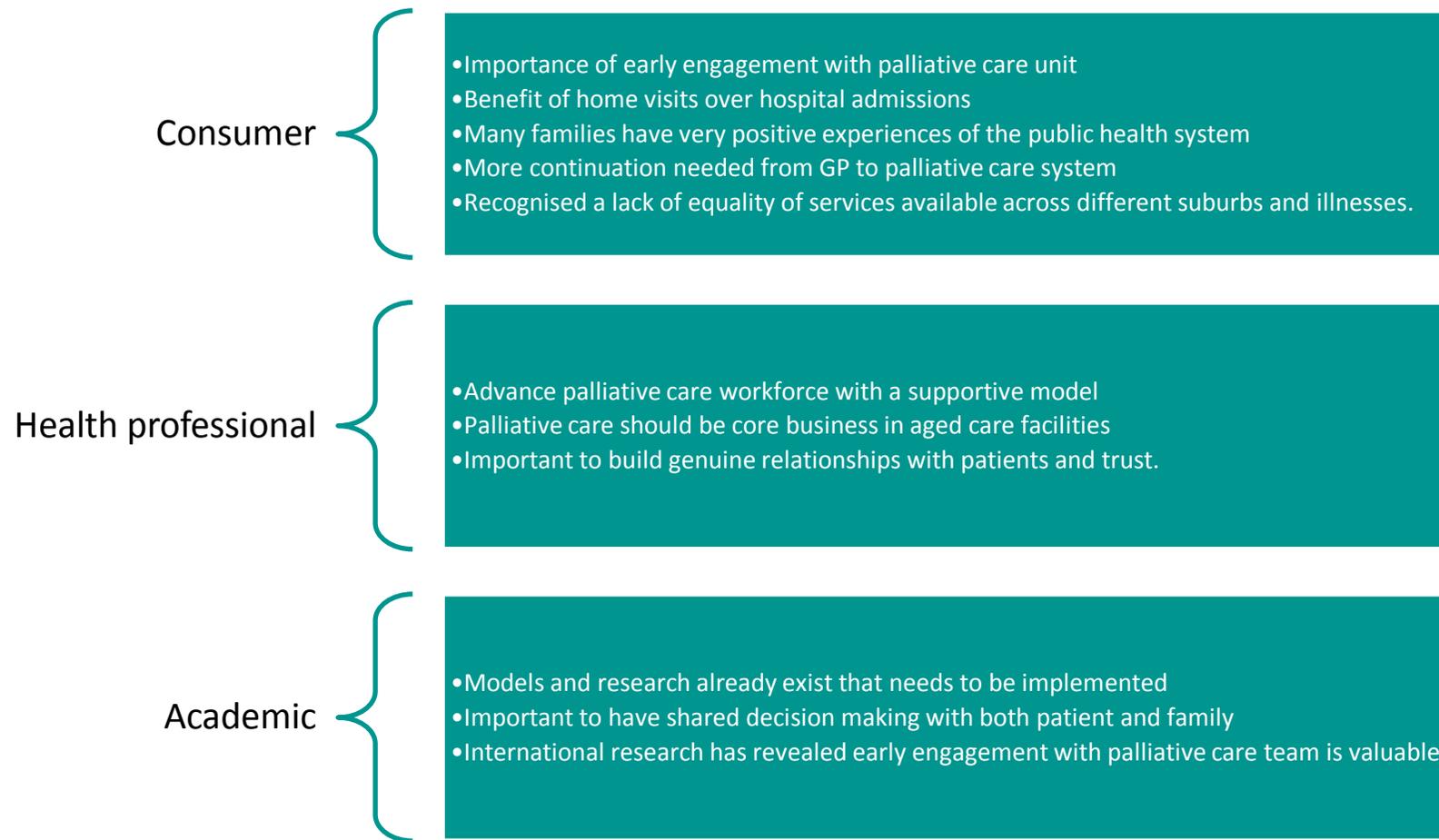
The results of these discussions are summarised in the following sections of this report.

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

3.1 Three Perspectives – Palliative Care

Three people presented their experience with palliative care services in NSW, including perspectives of a consumer, a health professional, and an academic. The key points from their presentations are captured below, with more detailed notes included in the Appendices.



3.2 Three Perspectives – Q&A Discussion

Workshop participants were then invited to ask questions of the three presenters. The key questions and responses are captured in the table below.

Perspective	Comments
Consumer	<p><i>How to achieve a patient-centred process?</i></p> <ul style="list-style-type: none"> • Need to integrate palliative care services to be patient-focused • Need to improve case management • Patients need to make initial contact with palliative care services early • Educate families about services and what to expect.
Health Professional	<p><i>What solutions will help transition from acute to palliative care teams?</i></p> <ul style="list-style-type: none"> • Palliative care teams need to maintain an ongoing presence, so that they can be called early (e.g. a colleague is embedded in renal service in Nepean District) • Disease trajectories of people with non-malignant diseases are different to those with cancer. Person-centred engagement strategies are needed to support the transition of patients from acute to palliative care teams.
Academic	<p><i>What do we know from research that we should be doing?</i></p> <ul style="list-style-type: none"> • Research indicates that it is essential to engage with residential care staff • Work with Residential Aged Care Facilities (RACFs) and hospitals • The staff are passionate and engaged and are crying out for training and mentorship in this area • Some staff are unaware of what they can do and service options that are available. They need alternatives to sending people to the Emergency Department • Give the health workforce the skills to work with families earlier • Earlier engagement means an ongoing conversation, and not just reacting to crises.

3.3 What Works Well?

“Where have you seen palliative care services that work well, and what did they look like? How could we expand these ideas into other areas?”

Small group responses to these questions are collated and summarised in the table below.

Key themes	What works well
Whole-of-person approach	<ul style="list-style-type: none"> • Setting based on the home (i.e. increasing the comfort level for families with blankets, coffee shop; less sterile environments) • Not-for-profit organisations using a whole-of-person approach to care (e.g. St Vincent’s Hospital providing ‘Palliative and Supportive Care’, where people come in and out throughout process) • Connecting centres of care to care in the home, recognising that person doesn’t need specialist care all of the time • This quality integrated approach makes it possible for patient to remain in the home • Providing the right care in the right place.
Multi-disciplinary approach, including educating those in acute care settings	<ul style="list-style-type: none"> • Well-educated and resourced community nursing model, with nurses as primary providers, supported by multi-disciplinary team (e.g. experts in allied health, bereavement, pastoral care) • Social worker model of care (e.g. Can Revive) • Residential Aged Care Facilities (RACFs) doing palliative care well • Dedicated hospices and allocated palliative care beds in acute health care settings • Good models of palliative care (e.g. renal supportive model), including those that: <ul style="list-style-type: none"> ○ Offer the patient a supported pathway ○ Provide palliative care as an alternative to traditional acute care, when and where appropriate ○ Maintain links with GPs and families throughout the process • Education units (e.g. in HETI – the Health Education and Training Institute), that inform people of end-of-life care and communications, as well as the trigger points at which palliative care teams should be invited to speak with acute care patients.
Early engagement	<ul style="list-style-type: none"> • Early involvement of palliative care in care for patients with diseases other than cancer (e.g. Motor Neurone Disease in Victoria, Huntington’s Disease at St Joseph’s).
Engaging and upskilling key stakeholders	<ul style="list-style-type: none"> • Encourage collaboration between specialists, primary health carers, community and volunteers • Engage families, which is typically done better in regional areas than in metropolitan centres • Processes for upskilling General Practitioners (GPs) and increasing their engagement with palliative care (e.g. HammondCare in Northern Beaches).

Palliative care funding and research	<ul style="list-style-type: none"> • Funding to enhance pathways to palliative care (i.e. to improve support for those with high needs) • KPIs for service agreements to empower funding in palliative care • Identifying and documenting best practice to share throughout the sector • Principles from the Agency for Clinical Innovation (ACI) Blueprint are sound.
Local and regional champions	<ul style="list-style-type: none"> • Good models emerging from areas where individuals are championing palliative care • Nurse Care Coordinators as advocates for palliative care.
Quality equipment and services	<ul style="list-style-type: none"> • Quality equipment and supportive services • Good coordination of services, including: <ul style="list-style-type: none"> ○ GPs and palliative care champions supporting coordination in the community ○ Advanced care planning and identification of triggers for engaging appropriate services ○ Connecting acute care, aged care and palliative care ○ Informing patients of services available ○ Information sharing between agencies ○ Tailoring coordination depending on where the patient is based.
Innovative technologies	<ul style="list-style-type: none"> • E-health to enable a safe patient journey (e.g. St Vincent’s Hospital).

3.4 Priority Issues and Potential Solutions

“What are the three priority issues that we need to address to continue to improve palliative care services in NSW? What could be the solutions to address these issues?”

Small group responses to these questions are collated and summarised in the table below.

Equity of access	
Priority Issues	Possible Solutions
<p>In-home care can be difficult to resource, especially in regional areas.</p> <p>Inconsistent means of reporting can be a barrier to information sharing across multi-disciplinary teams.</p>	<ul style="list-style-type: none"> • IT solutions to aid sector and patient engagement – Use IT services (e.g. Skype) to work as a team to provide services and engage the patient in their home • IT systems – Ensure IT systems ‘talk’ to each other (e.g. digitising at-home patient reports so ambulance officers have information in advance of arriving at house) to aid information flow, including after-hours • MyHealth record – Include palliative care plans in all records as they are rolled out • E-health models – Explore and replicate good examples of e-health models • Appropriate funding allocation – Use evaluative tools for identifying patients in need of palliative care (including patients in aged care facilities) and prevent wastage on ‘futile’ services • Disability sector – Include disability sector in conversations, policy and service development.

Workforce upskilling and integration

Priority Issues	Possible Solutions
<p>Ageing palliative care workforce means that the sector is losing expertise</p> <p>Integrated approach to palliative care requires broader knowledge base and shared resources</p> <p>Lack of engagement from medical practitioners (e.g. GPs)</p> <p>Aged care and acute care facilities require the most work</p>	<ul style="list-style-type: none"> • Education and training – Education and training for health care professionals, those working in RACFs, carers, the community and more (including mandatory training for health care professionals, such as the way CPR is taught now) • Supporting systems – Engage agencies and primary health care networks in the process of providing education and training • Workforce planning – Plan needs to be prepared by service providers and NSW Health, for workforces across all disciplines • Palliative care as core business – Palliative care needs to be core business of all health care professions • Embedded palliative care – Embed palliative care in acute and aged care facilities • Resource allocation – Improve resource allocation for palliative team care approach (incl. specialist nurses) and out of hours services • Communication – Good communication between disciplines (including GPs) to provide integrated services to consumer • Champions – Identify a champion in aged care within each service provider, who can deal with day-to-day care and connect with palliative specialists where necessary • Sustainable approach – Fewer one-off project approaches • Dedicated funding for education – Need dedicated funding for education, from university right through a person’s career • Incentives – Incentives for medical staff to learn about palliative care • Infrastructure to support conversations – Provide spaces (e.g. rooms in acute care facilities) where family members can gather • Identified triggers – Train all health care staff to identify points at which palliative care specialists should engage patient • Early engagement – Offer earlier access to palliative care through a patient’s care plan • Mobile workforce – Mobilise palliative care workforce so that they can follow patients as they transition in and out of acute care settings • Assisting GPs – Provide means for GPs to access specialised palliative advice, recognising that it is a hugely varied workforce (i.e. corporate vs family-focused) • Volunteers – Increase use of volunteers as part of the system • Map existing services – Identify who is doing what, where, and identify learnings that can be mirrored elsewhere.

Leadership in quality care

Priority Issues	Possible Solutions
<p>Need to foster leadership in palliative care</p>	<ul style="list-style-type: none"> • Leadership body – Establish a leadership body, similar to the Cancer Institute, to drive a universal approach to palliative care • Evidence-based care – Fund and gather insights from research, using evidence as the basis for future decisions • Position palliative care as mainstream – Identify solutions that transcend silos and position palliative care as mainstream care • Encourage integration – Assist in developing processes for smooth handovers between services • Standardised care – Push for standardised palliative care, including agreed referral criteria, in and across Local Health Districts • Central depository – Provide central, IT-supported depository for palliative care-related information • Palliative care promoted as preventative approach – Palliative care needs to be promoted as a preventative approach, including that it decreases strain on community services and taxpayer dollars in the long term • Understand local service needs – Identify training and resourcing requirements by area and leverage off existing workforce facilities (e.g. a phone line for staff) • Reduction in duplication of services – Identify where duplication of services has been reduced and mirror this elsewhere to assist providing equitable access • Clear processes - Put processes in place for how care should be delivered (e.g. NSW-wide push for evidence-based care) • Recommendations to service providers – Palliative Care Australia should provide recommendations for acute care, aged care and other services providers to respond to • Evaluative measures – Establish and maintain means of evaluating palliative care to determine which facilities are doing a better job • Defined responsibilities across the sector – Establish clear policy and/or arrangements for RACFs and GPs, including the depth and level of palliative care specialist involvement in these facilities (i.e. avoid too little or too much); these service providers should drive their own improvement • Advocate for funding model improvements – Invert funding model so that community is funded as a priority over institutions, as those are the services patients want to use.

Patient-centred approach	
Priority Issues	Possible Solutions
<p>Patients and their families do not always have the knowledge and resources to support home-based care</p> <p>For example, some medications are only available or affordable in hospital system, not in residential aged care or in the community</p>	<ul style="list-style-type: none"> • Case managers and/or home care workers – Palliative care ‘navigator’ can guide patients and families through the process of approaching agencies for services (this could be the patient’s GP or someone in their office) • Empowered customers with information for decision-making – Provide patients and their families with information about their situation and rights (e.g. of the risk of death in a hip replacement) • Remuneration based on conversations not procedures – To encourage health providers to recommend palliative approaches when acute care approaches are not appropriate, and ensure they are remunerated for the alternative approach (including GPs and acute care facilities) • Information and access – Provide customers with choice by directing them to appropriate services, equipment and specialists • Affordable medication – Provide affordable medication for patients being cared for at home • Streamlined movements – Streamline movements between home, hospital and aged care facilities • Culturally appropriate care – Ensure patients are provided with flexible options to cater for cultural preferences and sensitivities • Age-appropriate care - Provide appropriate services regardless of the patient’s age, including in various environments • Conversations about death – Ensure healthy conversations are taking place about death, including improving the community’s knowledge and providing training for people in the health sector • Clear goal of care – Determine the goal of care at the point of diagnosis and at every point of contact with the patient; communicate this goal to other care providers (e.g. GP).

3.5 Principles of Care

In the workshop background paper, participants were presented with Principles of Care that form part of the Palliative and End of Life Care Blueprint for Improvement. Participants were invited to provide feedback on the principles, in order to test whether they provide an adequate, guiding framework for NSW's palliative care strategy moving forward. The principles and corresponding feedback from workshop participants is included below.

Principles	Participant feedback
Principle 1: Care is patient, carer and family centred	<ul style="list-style-type: none"> • Add 'cultural needs' (e.g. Aboriginal Liaison Officers) • Include Advanced Care planning in this principle
Principle 2: Care is provided on the basis of need	<ul style="list-style-type: none"> • Add 'timely' • Provide further clarity regarding what the basis of 'need' is
Principle 3: Patients, carers and families have access to local and networked services to meet their needs	<ul style="list-style-type: none"> • None specified
Principle 4: Care is evidence-based, safe and effective	<ul style="list-style-type: none"> • None specified
Principle 5: Care is integrated and co-ordinated	<ul style="list-style-type: none"> • Include that palliative care needs to be better integrated and coordinated • Include advanced care planning in this principle
Principle 6: Access to care is equitable	<ul style="list-style-type: none"> • None specified
<i>Additional principles</i>	<ul style="list-style-type: none"> • Add principle on local flexibility • Add principle on workforce (i.e. palliative care as core business for everyone, creating better connections with a range of services).

3. Appendices

Palliative Care – Three Perspectives (Detailed Summary)

Perspective	Comments
<p>Carer</p>	<p>Presenting the individual experience of a consumer of palliative care services, the first speaker outlined their interactions with the NSW Health system after her mother was diagnosed with breast cancer.</p> <ul style="list-style-type: none"> • Following diagnosis, her mother lived at home by herself (for approximately 12 months), then moved in with daughter for the next 6-8 months, and was unable to walk for the last 3-4 months • Early engagement with palliative care unit meant the patient had “a good death” and was able to see and spend time with family • Palliative care nurses allowed the family to cease being nurses and resume being daughters • Mother’s first reaction to introducing her to palliative care unit was “I don’t want to die yet” • Nurses performed visits to the home, which minimised the distress arising from visits to the Emergency Department. Arguably, home visits are also cheaper for the tax payer than admitting a patient to hospital each time • Patient experienced a seamless transition between treatment and palliative care with the respective doctors talking to each other, however this is unusual • Palliative care nurses with expertise were able to provide reassurance and expert advice to reassure mother and allay fears • Nurses recorded conversations with her mother • The volunteer came at the same time, every day (which meant that her sister could maintain routine for herself e.g. shopping, drinks with friends) • Occupational therapist helped redesign her sister’s house to make it suitable for caring for a very sick person • Equipment was provided including a bed, oxygen, wheelchair etc. • “We live in a great country that my mum, a broke pensioner, could get access to all of that.” • Electricity subsidies assisted with financial challenges • All of these services helped in providing a ‘good death’ • Mother had the ‘right illness’ and the ‘right postcode’ to get access to all of these services. She also had two daughters who were willing and able to care for her, were from an English-speaking background, and a bureaucrat daughter who could advocate for her • The ultimate outcome was that the patient “died surrounded by her family”.

	<p>Criticisms:</p> <ul style="list-style-type: none"> • GP “dropped her like a hot cake” when she was diagnosed • The family had to seek out information - they weren’t sought out by the system • There were arguments between nurses re: record keeping in for home visits • These criticisms were minor, in the context of the family’s whole journey.
<p>Health professional</p>	<p>The second speaker spoke about her 17 years of professional experience in both the public and private sectors, and now working as a Clinical Nurse Consultant in palliative care. The speaker also had experience in hospice care in London, and was awarded a scholarship to travel to Canada and research palliative care services there.</p> <ul style="list-style-type: none"> • Need to create genuine relationships with patients. This requires experience, skill and time • Try to normalise death with the patient and their family, but this is difficult in a “death-phobic” culture • Works best when genuine relationships are built with the patient and their family, in an environment that supports this (e.g. home environment) • Acute care environment is not ideal. Palliative patients need home-like environments (e.g. hospices) • The lack of dedicated palliative care beds in some hospitals presents a challenge • In Canada, work was undertaken to partner with aged care facilities to get dedicated palliative care facilities and staff - infrastructure was already there • Canada provides longer term support (up to 3 months). In Australia, patients do not stay as long in palliative care and hence feel they are being moved on if they don’t die quickly enough • The rate of home deaths has increased in the Local Health District, which is a good thing • Those living alone with no constant care giver don’t have the option to die at home. Longer term hospice care might help in these cases • Need to support carers, including financial, information, emotional needs etc. • UK has “twilight nurses” that visit outside of business hours to support carers, which helps to give carers the sleep they need • After-hours phone service requires further improvement to provide more effective service at local level • Need trusted networks around phone service • GPs will not conduct home visits in many areas • Registered Nurses are often stretched over large areas and may have little knowledge or experience in palliative care • Palliative care should be core business in aged care facilities. There are under-utilised training materials and often facilities are lacking dedicated staff

	<ul style="list-style-type: none"> • Services need to advocate for the patient. Need to ask about the patient’s suffering, views about death, preferences etc. People often don’t have these conversations in most facilities • Need to embed palliative staff in other teams to build a supportive care model <i>priority: advance palliative care workforce with supportive model!</i>
<p>Academic</p>	<p>The third speaker is a Professor of Palliative Medicine, and spoke about how research can inform palliative care services and government policy.</p> <ul style="list-style-type: none"> • Services should be underpinned by research, and the health system needs to be able to implement findings of research in a scaleable way • Need to consider benefits and harms, alignment with consumer preferences, cost-effectiveness etc. to deliver right care, at the right time, in the right place, every time • Need to be ambitious and build on palliative care research community • Consumers and academics need to be brought to the same table to consider solutions (to both past and future challenges) • Data already suggests critical areas - over half of deaths occur in an admitted-patient setting. Evidence indicates that consumers have preference for receiving care at home and dying at home • Simultaneously, end of life care in hospitals needs to be addressed • Important to have shared decision making with both patient and family • Everything matters - how you touch the patient, whether you matter to them etc. • Dementia is the second leading cause of death. Most people with dementia are supported in Residential Aged Care Facilities (RACFs) • Models have already been developed to provide palliative care to this group • We need to provide care for increasingly older population, both with cancer and other conditions • Important to respond to international research, which has revealed early engagement with palliative care team is valuable • Solutions lie in readily available research that needs to be implemented into policy • Will need to move to different ways of doing things in some ways • Need to have consumer-directed conversations and provide support for informal care givers.



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