



Government of **Western Australia**
Department of **Health**



Executive Summary Report and Recommendations

Great Expectations – Planning for expected deaths in acute health settings

Clinical Senate of Western Australia
6 March 2015

Executive Summary

The first meeting of the Clinical Senate of Western Australia for 2015 was held on 6 March at the University Club of WA. The topic for debate was Great Expectations – Planning for expected deaths in acute health settings.

The Clinical Senate first debated this topic in 2008 prior to the enactment of the legislation supporting advance care planning. At the request of the Chief Medical Officer the topic was brought back to the senate as it was his view and that of the WA Cancer and Palliative Care Network (WACPCN) that there was more work to be done, particularly in our hospitals, to support people to die as they wish. Professor Gary Geelhoed (represented by Professor Geoffrey Dobb) partnered with the WACPN as executive sponsor of the debate.

The focus for debate was on what needs to be done in acute health settings to support all patients to have a good death.

The mandate for clinicians was to consider the need to identify patients with chronic and life-limiting illnesses, the importance of initiating discussions around end of life care and the response to clinical deterioration.

In planning for the debate experts included geriatricians, researchers, educators, lead clinicians in acute health, palliative care clinicians, experts in Advance Care Planning and Advance Health Directives as well as consumer and carer representatives. Experts were multidisciplinary and came from both the public and private sectors.

In offering the Welcome to Country for this debate, Nyungar Elder, Ms Marie Taylor shared stories of ancestors and relations in the last stages of life and highlighted the spiritual component of life and death. She provided a touching story of the tragic loss of her foster daughter's young son and the celebration of life and experience of death in Aboriginal culture.

The Acting Director General, Professor Bryant Stokes officially opened the debate stating that more than any other time in our history, most people die when they reach an advanced age and are more likely than past generations, to know when they are going to die hence, the opportunity for planning. Despite the fact that the majority of Australians (68%) want to die at home most die in hospital (50%) or residential care (15%). He highlighted the importance of 'the conversation' and the need for health services and clinicians to properly recognise and respond to clinical deterioration.

He called on senators to embrace the opportunity stating the recommendations from the debate would be vital in helping people in acute health settings to have an end of life plan.

In her opening address Senate Chair, Adjunct Associate Professor Kim Gibson stated that in revisiting end of life care the Senate is underlining the importance of this matter to the health of all West Australians. It acknowledges that healthcare continues up to and indeed beyond end of life as we strive to help all our community members to die a good death. This debate provides an opportunity to consider the progress that has been made, particularly in the community setting.

She stated the focus of the debate was not to critique existing palliative care services across the state; instead senators were challenged to debate what needed to be done across non-palliative care services in acute health settings to support people to die at home or in the community setting if that is their wish. Where a hospital is the setting for their end of life journey, she proposed that services not engage in futile interventions, enabling patients to be supported to die with dignity and minimal suffering.

In setting the scene for debate, Professor Geoffrey Dobb, Head of Intensive Care, Royal Perth Hospital used an account from his own experience in caring for a patient in Intensive care. Through this example he challenged Senators to consider how to better respond to patients' clinical deterioration, plan for expected deaths in acute health settings and have honest conversations with patients and families.

He outlined the national health agenda and expert opinions in the form of consensus statements that are driving changes, as well as current initiatives developed in partnership between the Office of the Chief Medical Officer and the Cancer and Palliative Care Network. Prof Dobb noted the increased demand for end of life care and changing patterns of disease; gaps in the provision of quality and safety at end of life; inadequate recognition of dying; need for increased awareness that better end of life care starts before the terminal phase; a responsibility to improve end of life care for patients and their families and a clear mandate for transformative, system wide, cultural change around end of life care in acute settings in WA.

He noted that these factors, coupled with the high number of hospital admissions in the last 12 months of life and high percentage of deaths in acute health settings, also impacts on the cost of care, with \$2 billion spent per annum on older people who die in hospital. One point stressed by Professor Dobb was the strong evidence for early involvement of palliative care, including symptom control, which can lead to improved quality of life and extended survival.

Professor Dobb raised the importance of recognising disease trajectories and teaching this as a clinical skill; determining a patient's own goals of treatment as an essential part of every admission; and talking about end of life. Clinicians, he stated are trained under a culture of fighting disease however, withdrawing treatment rather than prolonging death shouldn't be considered a failure.

In closing, Professor Dobb stated, "I believe healthcare needs to be judged, not just by the lives saved, but by the quality of death for those they can't save."

Dr Barbara Hayes, Clinical Lead in Advance Care Planning, Northern Health, Victoria provided an interstate perspective on the current initiatives they use to promote shared decision making around end of life care between clinicians, their patients and family. These included: Goals of Patient Care - doctor directed, clinician to clinician communication; Advance Care Planning - patient directed, patient to clinician communication; and CPR/NFR decision making. She stated that patients should be able to trust the quality of care they receive at the end of life as much as they trust the care they receive during their life, and that they should feel safe in hospital.

Dr Hayes emphasised the importance of the clinician's role in respect to communication, in particular bringing communication back to the illness trajectory –including diagnosis, treatment options, what the patient can expect from their illness and what they might be anticipating in terms of their future death. She stated "before we know what to do, we need to know what is possible". This includes the importance of weighing up the burden of treatment and investigations against the need for symptom management and patient comfort.

In closing, Dr Hayes stressed the need for discussion to take place in respect to medicine's focus on curing or prolonging life and the need for clinicians to have the skills to diagnose end of life and impending death.

Ms Geraldine Ennis, Regional Director, WA Country Health Service, Goldfields highlighted the challenges in recognising the different needs of the multicultural and aboriginal population and access to interpreters for the variety of language groups. She identified that there were a higher rate of people wanting to die "in country" and therefore, they used hospital services more for symptom control, pain management or respite rather than palliation services. It is vital for

patients to feel like they are in control of their care planning and that communication with family members is timely.

Dr Sarah Pickstock, General Practitioner, Silver Chain, identified that talking about death is one of the toughest conversations that clinicians have with their patients, “if we don’t ask, we don’t know”. She highlighted that many clinicians often lack the skills and knowledge around Advance Care Planning. She identified the difficulties that exist regarding the interchange between acute health care and the community and urged clinicians to be realistic with patients and their families about what can and can’t be provided for someone to be treated at home.

Dr Nicholas Waldron, Geriatrician, Armadale Health Service, spoke of multi-faceted CPR decision-making and his development of a suite of video based training tools aimed at assisting clinicians in making CPR decisions in the hospital setting to prevent futile (disproportionate) care. He emphasised the need to align care with what patients want and stated that better treatment is about patient preference and consensus care.

All presentations highlighted the need for a system wide response to end of life care and the importance of early action and planning.

The plenary session ‘Planning for a good death’ was opened with a Consumers’ and Carers’ perspective. Mrs Helen Povey shared the findings from a pre-debate focus group where consumers considered communication at end of life in WA hospitals as well as what could be defined as a good death. Ms Ann Jones shared her lived experience.

Mrs Povey reported the findings were consistent with the World Health Organisation’s definition of palliative care, acknowledging that the focus is the care leading up to entering palliative care. The seven key themes emerging from the group were: Patient focus-respecting what they want; lack of general palliative care knowledge; Communication – upfront, timely and respectful; Early conversations on end of life care – at diagnosis; Involvement in the decision making process; continuity of care across health services; and Workforce capacity. She stated “we believe the most valuable resource in the health system is its workforce”.

Ms Ann Jones gave a frank and moving account from her lived experience of supporting her mother to leave hospital and be cared for at home. This included conversations that did/did not work and areas for improvement. Highlighted throughout Ann’s story were challenges in regard to the lack of communication, staff providing different advice and conflicting medical information, and importantly the lack of an understanding of her Mother’s mental state. All this made it difficult for her and her family to consider and discuss treatment options and end of life choices.

Following on from Ann’s shared learnings was a plenary debate in which participants were asked to share what resonated from Ann’s story and provide a response from their experience.

Senators and experts shared similar stories and acknowledged that there is a general lack of knowledge by all health professionals and the community around palliative care. They agreed to the need for a standard definition and knowledge of palliative care throughout WA Health and the broader community in order to provide the best quality of care that meets the needs of all palliative care patients.

There is a need through public awareness to build the knowledge around advance care planning and advance health directives particularly with people with chronic conditions who are often admitted several times. The conversation must start early and be documented and shared with both the patient and their family, including their GP.

There is a need to build better communication around end of life discussion with patients. Clinicians and experts agreed there is a culture within the broader health sector that avoids

having end of life discussions. Clinicians admitted they talk more about treatment choices and side effects that are not aligned with patient choice.

Healthcare professionals need training, education and mentoring around how to have the conversation and importantly, tools and resources to ensure there is appropriate documentation. They agreed it is their responsibility to capture the information and to share it however, there needs to be a mechanism in place for coordinated and documented goals of care. There is also the need for better communication between teams, between disciplines, hospital and community and hospital and patient.

Palliative care is everybody's business. Variation in practice and understanding of medical staff preference can and does affect the delivery of care. Timely access to information is critical in order to consider and provide appropriate end of life treatment.

There were two concurrent workshops in which participants focused either on supporting people who want to die at home or in the community or on supporting people who will die in hospital.

In conclusion, the health system does not value end of life care. Too often stories like Ann's are being shared but not heard. It is time to change our culture throughout WA Health and to provide clinicians with the tools they need to ensure every conversation and treatment is documented and shared with patients and their families, in our hospitals and in the community. People with life limiting illnesses should be given proper information and time to discuss their options and document their wishes with regard to end of life care. We must respect every patient's choice in order to provide all West Australians with a good death.

It is, as Professor Dobb stated, our responsibility to improve end of life care for patients and their families. There needs to be a clear mandate for transformative, system-wide, cultural change towards a palliative approach in acute health settings in WA.

The Clinical Senate believes the recommendations that follow are a catalyst for change. They offer important strategies for the consideration of the Director General and SHEF.

A response from the Director General of endorsed, endorsed in principle, or not endorsed is requested.

Sincerely,



Ms Kim Gibson
Adjunct Associate Professor
Chair
Clinical Senate of WA



Professor Geoffrey Dobb
Head of Intensive Care
Royal Perth Hospital
Department of Health



Ms Amanda Bolleter
A/Program Manager
Palliative Care
WA Cancer and Palliative
Care Network

Great Expectations – Planning for expected deaths in acute health settings

Recommendations

1. The Department of Health to commission a Public Awareness Campaign in partnership with key stakeholders to enhance community understanding of the limits of medical interventions, the benefits of palliative care and the importance of taking up the opportunity to develop an Advanced Health Directive and Advance Care Planning in relation to life-limiting conditions with their family, GP and other health professionals.

(E.g. Campaigns such as ACP in 3-Steps developed by Northern Health, Victoria)
2. The Department of Health to develop and implement standardised documentation to support using a 'Goals of Care Approach' system-wide.
 - copies provided to patient, GP and other relevant health professionals to complement discharge/outpatient summary and other clinical handover tools. (e.g. phone calls)
3. The Department of Health to implement an additional section in all discharge summaries across all WA Health facilities to facilitate inclusion of goals of care/treatment and outcomes of case conferences/ family meetings. A copy should also be given to patients.
4. The Department of Health to support clinical leadership in advance care planning through early identification actions including:
 - Every admission form to include a prompt to consider whether a patient requires a palliative care approach.
 - The admission form to include asking the patient/carer/family/EPG whether an Advance health Directive has been completed.
 - A goals of care pathway to be initiated for every patient with chronic disease and transferable back to the community.
5. To address the issue of inequity in state-wide palliative care service provision (specifically rural and remote), we recommend the WA Cancer and Palliative Care Network develop a gap analysis and set minimum standard targets for supporting 24 hour support.
6. The Department of Health to undertake a state-wide analysis of current practice to identify and engage carers in care planning and practical support to assist the person who wishes to die at home (to comply with Carers Recognition Act).

Recommendations continued on next page

7. The Department of Health to write to undergraduate and post graduate education providers to seek evidence that their healthcare curricula include inter-professional education for healthcare professionals in end of life discussions. They must report on the following aspects:
 - how to have difficult conversations
 - understanding of roles including patients / families / carers
 - building resilience
 - supporting team members

8. The Department of Health through the WA Cancer and Palliative Care Network to promote the use of existing educational tools for Advance Health Directives and Advance Care Planning and the use of triggers for health professionals to initiate early/appropriate discussions:
 - in primary care
 - in residential facilities
 - in hospital.

Presenters

- Ms Marie Taylor, Nyungar Elder
- Adjunct Associate Professor Kim Gibson, Chair, Clinical Senate WA
- Professor Bryant Stokes AM, Acting Director General, Department of Health
- Professor Geoffrey Dobb, Head of Intensive Care, Royal Perth Hospital and Chair, Southern Country Governing Council (WA).
- Dr Barbara Hayes, Palliative Medicine Clinician, Clinical Lead in Advance Planning, Northern Health, VIC
- Ms Geraldine Ennis, Regional Director, Goldfields, WA Country Health Service
- Dr Sarah Pickstock, General Practitioner, Silver Chain Western Australia
- Dr Nicholas Waldron, Consultant Geriatrician, Armadale Health Service
- Mrs Helen Povey, Consumer Representative, Health Consumers' Council WA
- Ms Ann Jones, Research Officer, Health Consumers' Council WA

Expert Witnesses

- Ms Pauline Bagdonavicius, Public Advocate, WA
- Professor Anne Wilkinson, Chair, Palliative and Supportive Care, School of Nursing and Midwifery, Edith Cowan University
- Dr Claire Johnson, Manager, Cancer and Palliative Care Research and Evaluation Unit, University of Western Australia
- Professor Lorna Rosenwax, Deputy Pro-Vice Chancellor, Faculty of Health Sciences, Curtin University
- Dr Derek Eng, Specialist in Palliative Medicine, Royal Perth Hospital and Clinical Director of Palliative Care, St John of God Hospital, Subiaco
- Dr David Ransom, Co-Director and Medical Advisor, WA Cancer and Palliative Care Network
- Dr Simon Towler, Intensive Care Specialist and Medical Co-Director of Service 4, Fiona Stanley Hospital
- Ms Karen Proctor, Palliative Care Clinical Nurse Consultant, Sir Charles Gairdner Hospital
- Ms Amanda Bolleter, A/Program Manager-Palliative Care, WA Cancer and Palliative Care Network
- Ms Lorna Hurst, Project Officer, WA Cancer and Palliative Care Network
- Dr David Thorne, Consultant Specialist Palliative Medicine, WA
- Dr Paul Woods, Intensive Care Specialist at Sir Charles Gairdner Hospital and Hollywood Private Hospital
- Ms Samantha Gibson, Oncology Nurse Practitioner, St John of God Hospital, Subiaco
- Ms Stephanie Dowden, Clinical Nurse Consultant in Paediatric Pain Management at Princess Margaret Hospital and President, Palliative Care WA
- Ms Lesley Oliver, Coordinator of Counselling, Carers WA
- Dr Roanna Bornshin, Silver Chain Hospice Care and WA Palliative Care Outreach Service
- Mr David Larmour, Director, Hospice Care Services, Silver Chain
- Mr Edward Gaudoin, Clinical Nurse Consultant, Palliative Ambulatory Service North (PASN)
- Ms Valerie Colgan, Staff Development Educator, Palliative Care, WA Cancer and Palliative Care Network
- Mr Kim Greeve, Project Officer, WA Cancer and Palliative Care Network



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