



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



Great Expectations- Planning for expected deaths in acute health settings

Clinical Senate Meeting
Final Report

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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 and Consumer Representative, 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

Introduction

The role of the Clinical Senate of Western Australia (WA) is to provide a forum where collective knowledge is used to discuss and debate current strategic health issues. Recommendations are made in the best interest of the health of all Western Australians and are subsequently provided to the Director General (DG), the State Health Executive Forum (SHEF) and through the DG to the Minister for Health.

The first meeting of the Clinical Senate of Western Australia for 2015 was held on 6 March at the University Club of Western Australia. 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 on the day 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.

Senators were asked to consider how patients with chronic and life-limiting illnesses can be identified, the importance of initiating discussions around end of life care and facilitating an appropriate response to clinical deterioration.

Experts invited to the debate included geriatricians, researchers, educators, lead clinicians in acute health, palliative care clinicians, and 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.

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, creating opportunities for improved 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. There is the acknowledgement 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 follow-up debate provides an opportunity to consider the progress that has been made, particularly in the community setting. She also stated the focus of the debate was not to critique existing palliative care services across the state yet to instead 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.

To set the scene for debate, Professor Geoffrey Dobb, Head of Intensive Care Unit, 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 which are driving changes in this area, as well as current initiatives developed in partnership between the Office of the Chief Medical Officer and the WA Cancer and Palliative Care Network. Professor Dobb outlined several of the key issues for consideration which included: 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 extend survival.

Professor Dobb raised the importance of recognising disease trajectories and teaching this as a clinical skill. He also reflected that determining a patient's own goals of treatment should be an essential part of every admission as well as, 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."

1. Process

The Clinical Senate in Western Australia was established in 2003 and each debate follows a standard process that has been refined over time. This process ensures that senators and others involved have a clear understanding of what is required and receive sufficient information to discuss the topic and then develop recommendations for the DG and SHEF. A copy of the program is included (Appendix A).

Prior to the debate, attendees received a series of webinars and pre-reading documents containing background information in preparation for the debate.

The full day senate debate traditionally commences with a Welcome to Country, which for this debate was offered by Nyungar Elder, Ms Marie Taylor. Following the Welcome to Country, the Chair of the Clinical Senate, Adjunct Associate Professor Kim Gibson welcomed attendees and gave an update on senate activities.

The Acting Director General, Professor Bryant Stokes AM officially opened the debate providing insight into the topic for debate and offered a response to the recommendations made at the previous meeting.

Professor Geoffrey Dobb representing Professor Gary Geelhoed set the scene for the debate with an overview of international and national policy and consensus statement that are driving change in this area as well as state-wide changes through the WA Cancer and Palliative Care Network. He provided a case study based on his role as an Intensive Care Specialist.

A series of presentations followed that provided participants with an interstate perspective, rural and primary care perspective as well as some innovative training developed in WA.

The next stage of the process was a plenary debate entitled "Planning for a good death" was opened by Consumer Representatives" Mrs Helen Povey who reported the feedback from a pre debate focus group and Ms Ann Jones shared her lived experience. This was followed by a plenary debate that completed the morning session.

The afternoon session was devoted to two concurrent workshops in which participants focused on either supporting people who want to die at home or in the community or on supporting people who will die in hospital. Clinicians developed recommendations in both workshops that were focused on solutions to the key issues emerging from the day

Recommendations from the workshop groups were presented in the final session of the day and ranked in order of importance by the full senate. A response from the A/Director General of endorsed, endorsed in principle, or not endorsed was requested by the next senate meeting.

2. Presentations

Mr Bevan Bessen, facilitator for the day, opened proceedings by welcoming participants, acknowledging the traditional owners both past and present, and introducing Nyungar Elder Ms Marie Taylor who offered the Welcome to Country.

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.

Mr Bessen thanked Ms Taylor for her welcome and introduced Clinical Senate Chair, Adjunct Associate Professor Kim Gibson, who recognised the traditional owners and thanked Ms Taylor for her welcome and for sharing her personal insight.

In her opening address, Adjunct Associate Professor Gibson acknowledged Executive Sponsor Professor Gary Geelhoed and Ms Amanda Bolleter, A/Program Manager for the WA Cancer and Palliative Care Network for working closely with the senate executive to develop the topic for debate. She also thanked Professor Geoffrey Dobb for agreeing to represent Professor Geelhoed and providing the introduction for the debate.

Adjunct Associate Professor Kim Gibson provided the impetus for the debate which was to build on progress in the palliative care sector and to debate what more needs to be done across non-palliative care services to support people to die as they wish.

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. There is the acknowledgement 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 follow-up 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 yet to instead 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.

She next reminded participants that 11 March 2015 was Change Day and that there was an opportunity for them to lead from wherever they are in the system and to make their pledge to make a difference. The Clinical Senate she stated has pledged: "To engage more clinicians and consumers in health reform through wider dissemination of the work of the Clinical Senate". I invite you to participate in a group photo to support change.

In her report to senators with regard to activity since the last meeting, Adjunct Associate Professor advised that the recommendations from the drug misuse debate had been presented to SHEF. She thanked Mr Neil Keen and Mr Neil Guard for their hard work in developing specific actions around the recommendations in order to inform the A/Director General.

She then welcomed senators and member representatives and emphasised the process of how the Clinical Senate of WA does business:

- To work collaboratively, setting aside individual and organisational agendas.
- To state your opinions freely, drawing on your clinical experience and expertise.

- To empower you to influence others in all your professional spheres with the new perspectives gained through the debate.
- To play a leadership role in health reform, developing strong, valid, priority recommendations in the best interests of the health of all Western Australians.

In welcoming the Acting Director General, Professor Bryant Stokes (AM), she acknowledged his support of the clinical senate and thanked him for offering a response to the senate's recommendations.

Professor Stokes welcomed participants, offering respect to the elders both past and present. He stated it a pleasure to open the first debate of 2015 and that this year the clinical senate would begin at the end, the inevitable end that we all face. It is important he stated, that you consider if our health system is adequately planning for expected deaths and if clinicians are having the necessary conversations to ensure that patients' wishes for end of life care are respected and adhered to.

He stated his role as the A/DG was to report back on the recommendations developed during the previous Clinical Senate debate held in November 2014: Drug Misuse – Are we up to speed. Professor Stokes stated the debate focussed on the issue of drug misuse in our community, and how we can lessen its impact on our health system particularly, in the areas of: pharmaceutical drug misuses; amphetamines and methamphetamines; and new psychoactive substances. The senate resulted in 8 recommendations, 5 of which are endorsed, 3 of which are endorsed in principle.

In his report on the first endorsed recommendation Rec 2: WA Health to develop an evidence-based State-wide illicit drug-use policy framework and implementation plan in partnership with key stakeholders. He outlined the plan to achieve this recommendation and the key issues to be addressed.

He stated WA Health will consider the most appropriate body to develop the framework, which will be prioritised in 2015/16 and that WA Health will also continue to work closely with the Mental Health Commission (MHC) and the Drug and Alcohol Office (DAO) to progress the implementation of the Mental Health Alcohol and other Drug Services Plan.

In relation to the second endorsed recommendation- Rec 4: WA Health undertake a project to identify the full cost of all drug related presentations (pilot sites 2 metro and 2 regional) to assess the savings that could be made if alternative alcohol and drug treatment services were available or expanded.

Professor Stokes reported that WA Health recognises the need for a significant expansion of a range of prevention, treatment and support services. To achieve this, he stated, businesses cases will need to be developed for each initiative and submitted for Government approval. These business cases require robust research to confirm the potential benefits on the health and hospital system if alternative community treatment services were available or expanded. Therefore, he stated, over the next 12 months WA Health will work with the Drug and Alcohol Office, Mental Health Commission and appropriate research partners to develop and consult on a suitable methodology for such a project.

Reporting on the third endorsed recommendation- Rec 5: WA Health support development of an interagency framework for family-centred alcohol and drug related care within 12 months to include: primary prevention, acute care-emergency and detox, rehabilitation/chronic care, and centralised referral pathways. Professor Stokes stated the need for the framework was to be considered using existing resources and should be complementary to the broader policy framework endorsed for development in Recommendation 2.

Endorsed Rec 7: WA Health support the development and implementation of a two-way early warning system on current and emerging illicit drugs. The system hosted by DAO will enable input from a range of key stakeholders into a dedicated central portal and output to key stakeholders on a timely basis. Professor Stokes advised that it is acknowledged that patterns of illicit use can change rapidly and present real treatment challenges for frontline clinicians. WA Health participates in the interagency Emerging Psychoactive Substances Review Group which shares intelligence on novel drugs with the intention of improving the speed and quality of the Government policy response to emerging issues. I believe an early warning system as recommended by the senate would build on this existing interagency cooperation.

Professor Stokes next confirmed endorsement of Rec 8: WA Health to form an acute drug and alcohol coordinating advisory committee in the next 12 months to improve responses within the health system. He indicated that WA Health will establish this committee with a clearly defined remit to avoid duplication with the functions of existing groups and those planned in association with the Implementation of the Mental Health Alcohol and other Drug Services Plan.

He provided a comprehensive description and detail around each of the remaining recommendations outlining key strategies, work currently underway and actions to support. In his report he stated these are endorsed in principle based on the need for a longer lead time but that all remain a priority for WA Health.

Turning his attention to the topic of the day, Professor Stokes stated that end of life care was an important topic. He challenged senators to consider whether it is the responsibility of the patient or clinician to initiate the conversation about end of life care and importantly, consider if our health services and clinicians are properly recognizing and responding to clinical deterioration in acute health care.

Professor Stokes closed “I urge you all to embrace this opportunity to discuss this important issue, knowing that the recommendations from today’s debate will be vital in helping people in acute health settings to have an end of life plan”. I look forward to your recommendations.

The Acting Director General’s response to the Drug Misuse debate can be found on the Clinical Senate website: <http://www.clinicalsenate.health.wa.gov.au/debates/nov14.cfm>

Presentations from the day can be found on the Clinical Senate website: <http://www.clinicalsenate.health.wa.gov.au/debates/mar15.cfm>

Mr Bessen thanked Professor Stokes for his address and introduced the first speaker for the day, Professor Geoffrey Dobb, Head of Intensive Care, Royal Perth Hospital to set the scene for debate.

Professor Dobb used an account from his own personal experience in caring for a patient. Through this example he challenged the 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 government policy and consensus statements that are driving change, as well as current initiatives developed in partnership between the Office of the Chief Medical Officer (OCMO) and the WA Cancer and Palliative Care Network (WACPCN). In highlighting the national health agenda Professor Dobb stated the debate directly aligns with the National Safety and Quality Health Service (NSQHS) Standard 9 – Recognising and responding to clinical deterioration in acute health care as well as the goals of the National Palliative Care Strategy 2010- Supporting Australians to live well at end of life.

Some of the current initiatives outlined in Professor Dobb's talk were: The Continuum for End of Life Framework; The Care Plan for the Dying Person; Advance Health Directive/Advance Care Planning; and Talking about end of life in Residential Aged Care Facilities.

Professor Dobb highlighted the need for change as: 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. He stated that end of life discussions often start too late, take time, and are emotionally demanding. Clinicians are trained under a culture of fighting disease therefore; recognising the possibility of death equals 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".

Mr Bessen thanked Professor Dobb for setting the scene for the debate providing personal insight drawn from his experience at the clinical coal face. He then introduced Dr Barbara Hayes, Palliative Medicine Clinician and Clinical Lead, Northern Health in Victoria.

Dr Hayes shared her perspective on Northern Health's end of life care initiatives which focus on promoting shared decision making around end of life care between clinicians, 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 noted that there are two bodies of experts who come together to gain a shared understanding about what would be in the best interests of the patient - the doctor and treating team, who are the experts in the medicine; and the patient and broader family, who are the experts on the patient.

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.

Dr Hayes outlined the intent of the Northern Health 'Goals of Patient Care Summary' which is designed to encourage communication with the patient and plan for urgent situations. It considers medical treatment goals based on assessment and decisions about treatment and what is clinically possible, together with a shared decision-making discussion between clinician and patient or substitute decision maker, ultimately leading to an agreed medical treatment plan and overall medical treatment goals, including limitations. In relation to the use of forms, Dr

Hayes noted that “the patient should not fit the boxes; the boxes should fit the patient.” In addition, Dr Hayes outlined a values based, patient-centred approach to Advance Care Planning which is used in consultation with clinicians and to plan for when the patient cannot speak for themselves. She also outlined the decision-making framework, which provides a structured approach to CPR decision-making.

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

The rural perspective on end of life care was provided by Ms Geraldine Ennis, Regional Director, Goldfields, WA Country Health Service (WACHS). She stated the region covers almost one third of WA’s total land mass and is the largest in WA. The size and breadth of the area means that a great deal of support for palliative care is required. Ms Ennis reported that within the Goldfields region they have a well-established model of shared care and identified that partnerships between regional and metropolitan areas in palliative care are well articulated.

Ms Ennis overviewed the WACHS Regional Palliative Care Services referral process and outlined the role of the service as to include: consultancy, monthly visiting specialist clinics, psychosocial and family support, liaising with GPs, liaising with metro centre for patient care, culturally appropriate palliative care, preparing family for end of life and bereavement follow up care.

Ms Ennis highlighted the challenges in recognising the different needs of the multicultural and aboriginal population and access to interpreters for the variety of language groups across regional areas. She identified that in regional areas there were higher rates 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. She stated it is vital for patients to feel like they are in control of their care planning and that communication with family members is timely.

Ms Ennis shared one patient’s journey which demonstrated the need for clinicians to listen closely to their patients and to understand their wishes for end of life care. She closed with the reflection that “It is not about medical care it is about respecting the patient’s wishes”.

Following Ms Ennis was Dr Sarah Pickstock, General Practitioner and Palliative Medicine Specialist, Silver Chain who provided a primary care perspective.

Dr Pickstock shared a community perspective of what consumers view as a ‘good death’ reporting that research has identified that 70% of Australians want to die at home when only 14% actually do. Patients she stated want to be pain free, with symptoms well controlled, surrounded by family and friends, with adequate support and culturally appropriate care.

Dr Pickstock identified that talking about death is one of the toughest conversations that clinicians can 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 emphasised the importance of accurate clinical information. Discharge summaries, she stated, must be comprehensive and include such things as limitations of treatment and discussions held outside of clinical care and between acute care and community services.

Dr Pickstock shared several case studies in which she highlighted the fact that patients dying from heart disease, chronic obstructive pulmonary disease (COPD) and dementia are less likely to receive palliative care and suggested this co-hort of patients is an important group to focus on. Dr Pickstock emphasised there is good work occurring in the palliative care sphere and

reflected that the components of care are like pieces of a jigsaw that need to be joined together. “We have a good system we just need to get it right for non-cancer patients”.

In closing, Dr Pickstock urged clinicians to plan appropriately and be realistic with patients and their families about what can and can't be provided for someone to be treated at home.

The final presenter of the morning session was Dr Nicholas Waldron, Geriatrician, Armadale Health Service and Clinical Lead, Falls Network who emphasised the need to move our hospitals from a black dot 'Not for Resuscitation (NFR)' to a gold star 'Goals of care' system with regard to CPR decision-making and end of life care.

Dr Waldron stated to manage life you also need to manage death but because, as doctors, we are taught to be heroes by doing everything we can in acute care to preserve life we don't always listen to or consider what the patient might want.

He spoke of a clinician led proactive approach to resuscitation and escalation of care planning. Dr Waldron outlined a multi-faceted intervention to improve 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 care. The tools also provide an opportunity to increase communication with patients about resuscitation.

Dr Waldron shared results from a trial implementation of the goals of care approach where patient notes were audited looking at resuscitation, decision making and communication. He reported the biggest change came through having the conversation, with the evidence showing they were talking to more people and the decision around CPR was based purely on the patient. Dr Waldron stated that goals of care changes it from doing it on a small scale to large scale and you get a much better idea about what the patient wants, with greater emphasis on what will be done rather than what won't be done.

Dr Waldron stated “we often speak about what we will give as opposed to what we won't give” and 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.

Mr Bessen thanked all the presenters for sharing their perspectives and providing senators with a comprehensive overview of the topic and foundation for debate. He then called a close to the presentation section of the program and encouraged participants to continue their discussions during the morning break.

At the end of the session participants gathered for a Change Day 2015 photo.

Following the morning break, Senators engaged in an open plenary debate.

3. Plenary Debate

3.1 Planning for a good death

Facilitator	➤ Mr Bevan Bessen
Presenters/ Expert	➤ Prof Geoff Dobb
Witnesses	➤ Dr Barbara Hayes
	➤ Ms Geraldine Ennis
	➤ Dr Sarah Pickstock
	➤ Dr Nicholas Waldron
	➤ Mrs Helen Povey
	➤ Ms Ann Jones
	➤ Ms Pauline Bagdonavicius
	➤ Prof Anne Wilkinson
	➤ Dr Claire Johnson
	➤ Dr David Ransom
	➤ Ms Amanda Bolleter
	➤ Prof Lorna Rosenwax
	➤ Ms Valerie Colgan
	➤ Ms Lorna Hurst
	➤ Dr Derek Eng
	➤ Dr David Thorne
	➤ Dr Simon Towler
	➤ Mr Kim Greeve
	➤ Ms Karen Proctor
	➤ Dr Paul Woods
	➤ Ms Samantha Gibson
	➤ Ms Stephanie Dowden
	➤ Ms Lesley Oliver
	➤ Dr Roanna Bornshin
	➤ Mr David Larmour
	➤ Mr Ed Gaudoin

Mr Bevan Bessen facilitated the plenary session “Planning for a good death”. He opened by welcoming the expert witnesses and invited guests and outlined the focus of the session.

Mr Bessen introduced two consumers who provided 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 Organisations definition of palliative care, acknowledging that the focus is the care leading up to entering palliative care. The seven key themes emerging from the consumer focus group were: Patient focus-respecting what they want; Consumers lack of general palliative care knowledge; Communication – upfront, timely and respectful; Early conversations on end of life care – at diagnosis; Consumers desire to be involved 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.” The full report from the consumer and carer focus group is available on the clinical senate website:

<http://www.clinicalsenate.health.wa.gov.au/debates/docs/ConsumerCarerFocusGroupReport.Mar2015.pdf>

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 were or were not useful and areas for improvement. Highlighted throughout Ann’s story were challenges in regard to the lack of communication with the family, staff providing different advice and conflicting medical information, and importantly the lack of understanding of her Mother’s mental state by those caring for her. 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 the 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, as well as between hospital and community and hospital and patient.

Palliative care was recognised to be 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.

At the conclusion of the debate, Mr Bessen thanked the experts for their input and contribution during the full morning session. He called on senators to consider the key messages drawn from the morning session as they moved into the afternoon workshops; the focus of which were supporting people who want to die at home or in the community and supporting people who will die in hospital.

Following the lunch break Senators participated in their choice of the following two workshops: Supporting people who want to die at home or in the community or supporting people who will die in hospital.

What follows are the workshop notes and final senate recommendations.

4. Afternoon Workshop One

4.1 Supporting people who want to die at home and in the community

Facilitator	Ms Margo O'Byrne
Executive Committee Member(s)	Prof Julie Quinlivan Dr Sharown Nowrojee Dr Dan Xu Ms Nerida Croker
Expert Witnesses	Ms Amanda Bolleter
Support	Ms Joanne Cronin/Ms Kimberly Olson

Margo O'Byrne was the facilitator for Workshop one. She informed senators of the process for the workshop and stated the focus of the session was to consider what needed to be done in the acute health setting to assist people who wanted to die at home or in the community. Senate Deputy Chair, Prof Julie Quinlivan reminded participants that approximately 68% of people want to die at home but only one third of these people actually do. Therefore, she stated, our goal is to consider how we can better aid the majority of people who wish to die at home.

Margo informed participants of the process which was to:

- generate priority issues
- group issues and develop key themes
- develop solution focused recommendations - SMART (specific, measureable, agreed, realistic, timely) recommendations to address the key themes
- vote on the 5 most important recommendations
- take these recommendations to the full senate.

Participants formed six groups, were asked to first consider their own key issues, and then within their tables share and discuss all key issues. Thirty three issues were identified with participants grouping them into nine themes. Participants selected a theme(s) of their choice and worked to develop recommendations.

At the end of the workshop, each group presented their recommendations. Eight recommendations were put forward to the group for voting with the top five taken to the final session.

The nine themes were as follows:

1. culturally appropriate care
2. ensuring care plans are culturally appropriate
3. equity and access to care in rural and remote
4. supporting carers
5. training
6. communication
7. palliation - not just cancer
8. public education
9. lack of access to expertise.

The issues related to each theme were as follows:

Care Plan – Culturally appropriate for all

- patient held care plans
- discharge planning and coordination
- how do we transition patients from hospital to home well
- incentives and drivers for embedding goal directed plans
- goal of care, goal of treatment in discharge summaries

Culturally appropriate care

- lack of an aboriginal model of care related to end of life with resources that are culturally appropriate
- lack of culturally safe care from diagnosis to end of life

Public education

- public campaign living well, dying well. Lack of focus and education on dying and current choices
- patient choice, right to refuse treatment- need to be given options
- consumer knowledge about how to make happen
- availability of information
- lack of understanding of illness trajectory and reluctance to have conversation about what is palliative care

Lack of access to expertise

- access to 24hr advise and support for patients/treating clinicians, especially in rural
- lack of access to expertise in and out of hours for patients and families and community health professionals
- easy/accessible/quick access for all carers to help/support/advise e.g. 24hour helpline

Supporting Carers

- support for carers at home
- Need to have arrangements for carers for what happens after death. Care of deceased, funeral etc...
- carers to be consulted and supported- those who want to care for loved ones at home and support/alternatives for those who don't

Equity of care in rural and remote

- unfunded rural travel to allow patients to die at home in community or remote community
- equity for rural palliative care service provision
- expansion of rural palliative care teams
- lack of resources in the community including RFDS return flights, equipment, oxygen staff/medical, medication

Communication

- poor communication process between hospital and community re: goals/plans, poor referrals
- lack of stakeholder communication between parties; patient/family/health professionals
- lack of early conversation re: end of life on initial diagnosis
- communication needs to be better between a patient's specialist and their GP is the key

- outcomes of family meetings case conference to be communicated to patients community health provider/GP
- lack of communication two way: acute to Primary, Health Professional to patient/family Also within families, country to metro and within teams /health professionals.

Palliation - not just cancer

- cultural change, to introduce a concept of palliative care to all patients with new cancer diagnosis
- non cancer care/terminal illness supports

Training

- mandatory training to all clinical/allied health staff in having end of life/palliative care conversations
- GP education/provider up skilling regarding services available in community
- rigorous training and assessment of health professionals in delivering holistic care

In each of the breakout groups participants discussed their chosen theme in great detail and developed recommendations.

Participants in workshop one discussed the opportunity to address end of life care with patients that have life-limiting illnesses. They called for a public awareness campaign around end of life planning in order to encourage the public to discuss goal-centred care particularly in relation to life-limiting conditions with their family, GP and other health professionals. They likened the campaign to that of Northern Health in Victoria and the national Organ Donations Campaigns.

It was recommended there be state-wide goals of care forms for all patients in our health services. The goals of care form should be given to the patient, be shared with their GP and other relevant healthcare professionals, and should complement all clinical handover notes such as the discharge/patient summary forms. They emphasised the need for this to include all outpatient/community patients with life-limiting illnesses and to include cultural considerations.

Participants discussed the need for the WA Cancer and Palliative Care Network to develop and implement a clinical service framework for palliative care and community services that allows equity of access for patients to die with dignity and to die where they choose. They suggested this might be achieved via a revision to the current model of care.

With regard to training senators considered minimum annual training targets for all WA Health clinical staff in Palliative Care through recognised courses such as Program of Experience in the Palliative Approach (PEPA).

They recommended that the Department of Health 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 and in the community.

Lastly, they emphasised the need to address the issue of inequity in the provision of state-wide palliative care service and proposed that the WA Cancer and Palliative Care Network develop a gap analysis in order to set minimum standard targets for 24 hours support.

Eight recommendations formed by participants in workshop one were voted on, ranked and the top five were presented to the whole Senate in the final session of the day.

5. Afternoon Workshop Two

5.1 Supporting people who will die in hospital

Facilitator	Mr Will Bessen
Executive Committee Members	Adj Assoc Prof Kim Gibson Ms Tanya Basile Ms Pip Brennan
Expert Witnesses	Prof Geoff Dobb Dr Barbara Hayes Ms Lorna Hurst
Support	Ms Frances Powell /Ms Barbara O'Neill

Mr Will Bessen facilitated workshop two. He welcomed participants and stated the focus of the workshop as to consider what is needed to support people who will die in hospital.

He explained the process as to firstly identify the key issues, next group them into themes around what needed to be done to support people who will die in hospital and finally, develop recommendations.

For the first task the Poll everywhere system was used to register the key issues. Issues were then grouped into eight themes with participants self-selecting to a theme of their choice in order to develop recommendations. Some groups chose more than one theme. Participants worked in six small groups to develop recommendations.

The eight key themes were as follows:

1. Early identification and action
2. Right setting for dying in hospital
3. Communication
4. Documentation
5. Education – health literacy
6. Lack of understanding of palliative care
7. Access to advance health directives
8. Culture

The issues related to each theme were as follows:

Early identification and action

- lack of early identification of end of life and consideration of whether a palliative care referral is required
- recognizing and responding to clinical deterioration

Communication – across the board

- communication between treating teams, between disciplines, hospital and community, and hospital and patient
- poor communication between community and hospitals, GPs and the Emergency Departments, private and public. Inadequate information sharing systems
- clinical integrity and accountability

- better communication between members caring for each patient
- lack of family involvement

Documentation of goals of care

- standardised and accessible documentation for all patients admitted to hospital regarding goals of patient care
- coordinated and documented goals of care

Lack of understanding about palliative care

- palliative care – language and distinctions between AHD, ACP
- clear definition
- misunderstanding and understanding of palliative care
- all disciplines do not necessarily understand or implement a palliative care approach
- adopt and adapt a tool to trigger timely referral to palliative care
- lack of quality of death indicators

Access to advance health directives

- lack of standardised process to both capture and determine if a patient has an AHD
- Central register of AHD – makes everyone aware

Education

- lack of education across the board
- social intelligence not just technical
- the inter-professional learning model is not instituted with regards to palliative care teaching

Culture

- culture within the health care sector
- culture with clinicians – avoidance of end of life discussions
- improved community health literacy around CPR, AHD, ACP, end of life and goals of care generally

Right setting for dying in hospital

In each of the breakout groups participants discussed their chosen theme in great detail and developed recommendations.

Participants in workshop two affirmed that palliative care is everybody's business and responsibility and should be part of multidisciplinary care. They agreed there is often a culture of avoidance across the healthcare sector around end of life discussions and advance care planning. There is also a general lack of understanding of palliative care amongst healthcare professionals and providers as well as in the community.

They called for the need for the Department of Health to support clinical leadership in advance care planning through early identification and action and proposed some actions as: prompts on admission forms to consider whether a patient requires a palliative care approach; initiation of goals of care pathways for every patient with a

chronic disease that is transferred back to the community; and for the admission form to include asking the patient/carer/family whether an AHD had been completed.

They recommended the use of existing tools and resources to promote education around AHDs and ACPs in primary care, in residential facilities and in hospitals with the use of triggers for health professionals to initiate early appropriate discussions.

With regard to the need for communication they addressed this both in terms of community understanding of the limits of medical interventions and benefits of supportive palliative care, as well as the opportunity and importance of developing an ACP and AHD. Participants identified the need for there to be better public health/community awareness around advanced care planning. They highlighted the need for better processes around identifying if a patient had an AHD and proposed development of standardised documentation to support using goals of care approach.

They suggested the WA Cancer and Palliative Care Network in partnership with key stakeholders develop consumer packages to enhance community understanding. It was agreed this information should be disseminated across the health system and healthcare providers via hospital patient packs, consumer resource packs and on televisions in patient waiting areas.

In addressing the theme of education, senators called on WA health to mandate that all undergraduate and post graduate education providers show evidence that their healthcare curricula include inter-professional education for healthcare professionals in end of life discussions. It was suggested the curricula should include: how to have the difficult conversation; understanding of roles including patients/families/carers; and supporting team members.

Lastly, they discussed the importance of the environment in terms of the right setting for patients who will die in hospital with suggestions made for dedicated rooms with appropriate lighting, linen, music and space for families. Participants called for every hospital to identify a skilled person with training in palliative care and end of life to be the point of contact for the patient and their family and to provide advice when necessary.

A total of 10 recommendations were developed by participants in workshop two. Participants agreed to merge two recommendations leaving a total of 8 which were voted on, with the top five taken to the final session. Two recommendations gained the same number of votes with workshop participants reaching consensus on which one would be brought forward to the final session.

In the final session, senators were presented with five recommendations from workshop one and five recommendations from workshop two. The group agreed to merge two similar recommendations. A total of eight recommendations were voted on and ranked forming the final prioritised recommendations from the day.

The recommendations formed in each workshop offer important strategies for the consideration of the Director General and SHEF and are a catalyst for change. They highlight the need to respect every patient's choice in order to provide all West Australians with a good death.

6. Final Session

In the final session senators reviewed each of the recommendations presented from both workshops. Consensus was reached on combining two similar recommendations and members voted to prioritise them. A total of eight recommendations were put forward from the debate.

Margo sought comments from the Executive Sponsor for the day Prof Geoff Dobb who stated today's discussions demonstrate how much our health system undervalues end of life care. The discussion was important and proved a valuable day for WA Health. Today, he stated, raised the issue that it is never too early to plan for end of life, palliative care doesn't just affect people with cancer or chronic disease and, finally, end of life needs to start at the beginning of life not end of life. Professor Dobb concluded, "It is 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".

In conclusion, the health system does not value end of life care. Too often stories like Ms Ann Jones'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.

7. Clinical Senate Recommendations

Great Expectations- Planning for expected deaths in acute health settings

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.

8. Appendix A: Program

Great Expectations - Planning for expected deaths in acute health settings

6 March 2015
Banquet Hall South
The University Club of Western Australia
Crawley, Western Australia

7.45 – 08.30	Registration	Tea & coffee
Executive sponsor: Professor Gary Geelhoed, Chief Medical Officer Facilitator: Mr Bevan Bessen		
08.30	Welcome to Country	Ms Marie Taylor
08.40	Welcome and senate update	Adj Assoc Prof Kim Gibson
08:45	A/Director General's response to recommendations	Prof Bryant Stokes AM
09.00	Setting the scene for debate	Prof Geoffrey Dobb
09.15	Initiatives to promote shared decision-making	Dr Barbara Hayes
09.35	Rural perspective	Ms Geraldine Ennis
09.45	Death – the toughest conversation	Dr Sarah Pickstock
09.55	CPR decision-making – from black dot to gold star	Dr Nicholas Waldron
10.05	Change Day photo	All participants
10.15	Morning tea	Banquet Hall Foyer
10.45 – 12.15 Plenary debate – Planning for a good death Introduction: The Consumers' and Carers' perspective Mrs Helen Povey and Ms Ann Jones		
Additional Expert Witnesses	Ms Pauline Bagdonavicius, Prof Anne Wilkinson, Dr David Ransom, Prof Lorna Rosenwax, Dr Claire Johnson, Ms Amanda Bolleter, Ms Valerie Colgan, Ms Lorna Hurst, Dr Derek Eng, Dr David Thorne, Dr Simon Towler, Mr Kim Greeve, Ms Karen Proctor, Dr Paul Woods, Ms Samantha Gibson, Ms Stephanie Dowden, Ms Lesley Oliver, Dr Roanna Bornshin, Mr David Larmour and Mr Ed Gaudoin	
12.15	Lunch	Banquet Hall Foyer
13.00 – 14.40 Workshops		
Workshop 1 – Banquet Hall South Supporting people who want to die at home and in the community		Workshop 2 – Banquet Hall North Supporting people who will die in hospital
➤ Facilitator: Margo O'Byrne ➤ Experts: Amanda Bolleter		➤ Facilitator: Will Bessen ➤ Experts: Geoff Dobb and Barbara Hayes
14.40	Afternoon tea	Banquet Hall Foyer
15.00 – 15.30 Final session		
15.00	Presentation and prioritisation of recommendations	Margo O'Byrne/Will Bessen
15.20	Closing remarks	Prof Geoff Dobb
15.30	Close	Prof Julie Quinlivan



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