



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



Transforming Care in the last 1000 days – Partnering to realise choice

Clinical Senate of Western Australia

November 2020

Acknowledgement of Country and People

WA Health acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. It acknowledges the wisdom of Aboriginal Elders both past and present and pays respect to Aboriginal communities of today.

Using the term – Aboriginal

Aboriginal and Torres Strait Islander may be referred to in the national context and 'Indigenous' may be referred to in the international context. Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. No disrespect is intended to our Torres Strait Islander colleagues and community.

Contents

Joint statement	4
Recommendations	6
Vision	10
Approach	10
Presenter highlights	11
Welcome to Country	11
Chair's opening address	11
Intensive Care in the last 1000 days	11
Personalising Experiences	11
Primary Health Care in the last 1000 days	12
Senate Meeting	12
Acknowledgement of Country	13
Session One: Senate Business	13
Chair's welcome address	13
Report on the Recommendations from the recent debate on Health and Wellbeing of our Workforce	13
Setting the scene – End of Life Care	13
Session Two – Advance Care Planning	14
Session Three – Goals of Care	15
Session Four – Palliative Care	15
Session Five – Voluntary Assisted Dying	16
Appendix 1: Presenters, expert witnesses and invited guests	17
Appendix 2: Graphic representation	19

Joint statement

The Clinical Senate of Western Australia held their 53rd meeting in November this year, giving Senators an opportunity to reflect on person centred care and how we can transform that care in the last 1000 days of life. Recent legislative changes have made this topic an important one for the Clinical Senate to debate. These include but are not limited to:

- The passing of the Voluntary Assisted Dying Act 2019
- Release of the WA End of Life and Palliative Care Strategy 2018-2028
- Sustainable Health Review Strategy 3 “Great Beginnings and a Dignified End of Life.”
- Increasing use by the public of Advance Care Directives;
- The use of Goals of Care driven by both the clinician and the consumer

This was a vast topic to address in one meeting and required both significant preparation from all Senators prior the meeting and a fresh approach to the meeting structure and process. The achievements of the Senate during this meeting are a reflection on the hard work and dedication of the Senators. The discipline shown by Senators during the meeting, to be able to remain focused and purposeful throughout each session, is a credit to all who were present and allowed the Senate to achieve its purpose in forming recommendations and providing a strong clinician voice in the discussion of End of Life Care.

The journey started over dinner with discussions facilitated by Ms Di Darmody focused on ‘Partnering to Realise Choice’. Senators learned about care in the last 1000 days in the intensive care ward, with Dr Simon Towler and Dr Jacqueline Donnelly presenting their unique experiences. Ms Shannon Calvert described her personal experience and Ms Nola Naylor presented on what should be considered when caring for our Aboriginal clients. The evening concluded with Dr Scott Blackwell discussing primary health care in the last 1000 days. The importance of consumer stories and shared experiences was highlighted throughout the evening. This allowed Senators to be challenged, reflect on their own personal experiences and to feel connected with the topic.

The following day was divided into sessions on Advance Care Planning (ACP), Goals of Care (GOC), Palliative Care, and Voluntary Assisted Dying (VAD).

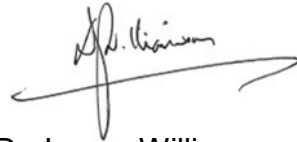
Feedback received from Senators highlighted changes in process that could further be refined. Having a subject matter expert to close the debate allowed for key points to be summarised, for topics to be linked together succinctly and accurately and to highlight upcoming workforce education opportunities hosted by the Department of Health. However, this may have been a missed opportunity to feed back to Senators on the process of formation of recommendations from the day and to indicate where the Senate recommendations may be usefully implemented.

This closing session may have allowed for a prioritisation session which a few Senators indicated they would find beneficial. Other feedback did note the meeting already contained a significant amount of work, and to shorten it further to allow for a prioritisation session may not be beneficial for all.

As Chair and Executive Sponsor for this debate, our take away highlight has been not only the dedication of senators to tackle this considerable topic respectfully, but the strong sense in the room of interaction between Senators across disciplines, experiences, backgrounds and opinions giving rise to interesting and valuable discussions. As clinicians, we always strive for the best for our patients, the recommendations in this report seek to provide the System Manager, Health Service Providers and Clinicians with tools and enhancements to make improvements in the patient journey in the last 1000 days.



Ms Tanya Basile
Chair
Clinical Senate of WA



Dr James Williamson
Assistant Director General
Clinical Excellence Division, Department of Health

Recommendations

The WA Clinical Senate members acknowledges the WA Health “The-End-of-Life Framework” and “WA End-of-Life and Palliative Care Strategy 2018-2028” and the way in which these articulate with the “WA Health Clinical Services Framework 2014-2024” levels for Palliative Care.

Recommendation One – Systemic enablers for high quality End of Life Care

End of Life Care includes Advance Care Planning, setting Goals of Care, Palliative Care and Voluntary Assisted Dying. Successful End of Life Care will be enabled by:

- Improved systems that can easily upload documentation of conversations on Advance Care Planning, Advance Health Directive and Goals of Care plans to readily accessible portals across all areas of health including primary care, ambulance services, the public and private hospital sectors.
- My Health Record is a potential common pathway to house these patient-centric documents and to facilitate interjurisdictional mobility of documented plans. Whilst My Health Record has the capacity, it is limited by the selected uploading of documents by patients and access is limited, excluding ambulance officers and paramedics. Other strategies could include
 - Accessibility through a barcode or QR code in mobile phones
 - Using existing alerts in WebPas to inform clinicians of these plans being available
- Standardising a documentation process across WA Health for Goals of Care conversations. Commitment from clinicians to attend subsequent education and training on how to use these systems.
- A measure of success to show the uptake of documented conversations at site level.
- Improved engagement of the community through expansion of education programs and awareness campaigns.
- Additional support put in place for minority groups to ensure clear language and cultural appropriateness.

Recommendation Two – End of Life Care upskilling for clinicians and our community

Improving communication, training and education around End of Life Care for clinicians and the community.

Clinicians will

- Actively seek opportunities, within the constraints of episodic care, to incorporate aspects of End of Life Care discussions into otherwise routine care conversations.

At a Site level this can be driven by:

- Committing to increasing Advance Care Planning and Goals of Care training for all staff.
 - Expand on Royal Perth Hospitals ‘Simulation Goals of Care communication training’ program
 - Utilise a ‘train the trainer’ model to be followed up by an e-learning package.

- This training could be included in mandatory training key performance indicators (KPIs).
- Increasing capacity for specialist palliative care teams to build capability in local clinical teams to support appropriate palliative care management of patients.

At a System level take opportunities to:

- Create a “What is palliative care?” awareness and myth busting campaign to improve community health literacy.
- Emphasise and mainstream End of Life training within undergraduate programs via partnering with Universities.

Recommendation Three – Create an End of Life Care Charter

The absence of an End of Life Charter for WA provides an opportunity for the Clinical Senate to sponsor a working group to develop such a Charter that would succinctly encapsulate the responsibilities that patients, clinicians and the broader system has in relation to End Life Care.

The creation of this Charter will address how:

Clinicians

- Normalise routine Advance Care Planning sessions with an appropriately skilled nurse or allied health practitioner at 6-8 weeks following a new life-threatening diagnosis or after a significant clinical event.
- Commit to having earlier opportunistic discussions with patients about realistic expectations for their health and health outcomes without diminishing hope.

Sites

- Extend the remit of community based Palliative Care teams to integrate more effectively with GPs, to commence the process of Advance Care Planning in aged care and close the loop with patients such that these conversations could then be finalised with the GP.
- Embed shared decision making and shared goal setting as a routine part of all health care encounters, starting in the community and available to hospital.
- Systematically identify people in hospital who need an Advance Care Plan. Alert the patient’s GP, offer resources to assist with this and start the process in hospital (or not) as appropriate.

The System

- Ensures there is an appropriate funding model
 - For suitable time to enable quality conversations to occur and to be appropriately documented.
 - Supporting patient access to community-based organisations that can assist consumers to develop an Advance Health Directive, Advance Care Plan, Enduring Power of Guardianship, Enduring Power of Attorney and to engage their preferred End of Life Care provider.

Recommendation Four – Strengthening governance for End of Life Care

At a Site level this might look like

- Reviewing the governance (and supporting resources) to expanding Goals of Care conversations in accordance with the NSQHS standards. In particular, the areas of
 - Advance Care Planning documentation
 - Communication, and
 - Partners in Care.
- Acknowledge that consumers and carers have different levels of health literacy and require time to process what is happening. Create safe spaces away from the bedside for families to be together in private.

At a System level this might look like

- Developing a system wide policy, supported by a standard, establishing patient reported outcome and experience measures of high-quality Goals of Care conversation.
- The System Manager advocating for the inclusion of Goals of Care conversations as a measure of complexity within the activity-based funding model.

Recommendation Five - Linking the patient journey for the last 1000 days

Clinicians

- Work to understand patient preferences, goals and truly partner with the patient to ask honest questions, be realistic in their dialogue and understand their options.
- Change the thinking of clinicians to be more opportunistic where appropriate, to broach End of Life discussions, including for example at the time of routine health checks, ED visits or during pre-operative work up.
- Ask, actively listen and record patient expectations. Sense check between clinicians and the family. Then review patient experience and allow patients to revise their expectations if required.

At a Site level

- Commit to a multidisciplinary team approach to Palliative care and the inclusion of Palliative care input to other specialty multidisciplinary teams where appropriate
- Review public hospital infrastructure ensuring appropriate palliative care rooms and spaces for family and carers are available and investing where this is insufficient to need.
- Encouraging early referral to Palliative Care from diagnosis.

At a System level

- Develop Palliative Care Packages similar to the aged care level 4 packages.
- Build upon existing tools and electronic dashboards to automatically recognise multiple re-admissions to help recognise patients in their last 1000 days and address this with referral into existing programs.
- Resource services such as Silver Chain Hospice to align better with community expectations and patient needs.
- Continue to capitalise on videoconference use and technology and continue to develop administrative systems to support this for palliative care delivery.

An awareness campaign slogan for Palliative Care- 'Life and Living, Not Death and Dying',
Palliative Care - 'Living your Best Life Right to the End'.

Vision

Recent changes which inform End of Life Care processes include:

- The release of the *My Life My Choice Report* by the Joint Select Committee on End of Life Choices
- Reports by Ministerial Panel for Voluntary Assisted Dying and Advance Health Directives
- Passing of the *Voluntary Assisted Dying Act 2019*
- The release of the WA End of Life and Palliative Care Strategy 2018 – 2028
- The *Sustainable Health Review 2019*
 - Strategy 3 – A dignified end of life. Recommendations 8, 9 and 10.
- The work of the Clinical Senate in the March 2015 debate: Great Expectations – Planning for Expected Deaths in Acute Health Settings.

The Clinical Senate aimed to consider the impact on clinical care and how clinicians can optimise the currency (time) of health consumers in the last 1000 days. The senate contemplated the following questions:

- How do we support integration of different forms of Advance Care Planning for best patient outcomes?
- How can the system support clinicians to have quality conversations? And
- How do we better recognise and realise people's expectations for care in the last 1000 days?

Approach

The Executive Sponsor for the debate was Dr James Williamson, Assistant Director General, Clinical Excellence Division.

This debate was scheduled to be held in March 2020, however due to the disruptions of COVID-19 it was delayed until November 2020. The delay allowed Senators to provide a richer and more critical voice in the discussion as legislation and implementation around End of Life Care moved forward.

The day was segmented into four key sessions. Advance Care Planning (ACP), Goals of Care (GOC), Palliative Care and Voluntary Assisted Dying (VAD). Recommendations have been developed based on the discussions during the first three sessions. These recommendations were sent to Senators following the debate.

The fourth session on Voluntary Assisted Dying consisted of an overview presentation and a question and answer panel for the senators to pose questions to three experts.

Presentations from the day can be found on the Clinical Senate website: <http://ww2.health.wa.gov.au/Improving-WA-Health/Clinical-Senate-of-Western-Australia>

Presenter highlights

Dinner

Welcome to Country

Ms Vivienne Hansen along with her husband Mr Morton Hansen performed a Welcome to Country for the Clinical Senate.

Chair's opening address

Ms Tanya Basile, Chair – Clinical Senate of Western Australia

Ms Basile opened the evening, welcoming members of the Clinical Senate of Western Australia reminded Senators to make their voices count, to make their feedback honest, valid, constructive and actionable and encouraged Senators to be representative of their front-line colleagues. Ms Basile reminded the Senators of the formulation of recommendations, asking them to think about:

- What could they do as Clinicians?
- What their teams needed from their service providers?
- What could the system provide to complete this challenging work?
- How will providing clarity and reality improve the last 1000 days for patients and their families?

Ms Basile concluded by:

Reflecting on her time as Chair as both challenging and rewarding. She reminded Senators to use their skills to be heard and strategies to ensure those who need to be listening. She encouraged Senators and the executive committee to find common ground and together to choose the pathway that will make the biggest difference to patients and the workforce.

Intensive Care in the last 1000 days

Dr Jacqueline Donnelly and Dr Simon Towler

Dr Jacqueline Donnelly and Dr Simon Towler presented their own unique experiences from the Intensive Care unit from caring for patients in the last 1000 days. A hypothetical patient was proposed who had not completed any Advance Care Planning or had discussions with her family about her wishes and choices. The presenters discussed what challenges they would be faced with: how decisions would be altered if she had an Advance Care Plan, what the long-term impact would be on the patient, her family and the health professionals who cared for her.

Dr Donnelly and Dr Towler concluded by:

Discussing how clinicians can help start the discussion around Advance Care Planning and encouraged all clinicians present to have conversations often and early.

Personalising Experiences

Ms Shannon Calvert and Ms Nola Naylor

During an interview style presentation with facilitator Di Darmody, Ms Calvert discussed her personal lived experience caring for her mother in the last months of her life following her diagnosis with a life limiting disease. She discussed how her mother was given few choices in

treatment protocols and was not given a choice of or access to Palliative care. Ms Calvert became an advocate for her mother and requested a conversation including Palliative Care. She discussed the difficulties she faced around this, which ultimately led to her mother being given options, and the experience of the 'best death possible' which aligned with her mother's wishes.

Ms Naylor discussed her experience as an Aboriginal woman and how there were cultural differences that clinicians should be aware of and become familiar with for Aboriginal patients related to End of Life Care. Ms Naylor talked about how death is discussed as a part of life, how young people were not excluded from the End of Life experiences of their friends and relatives, how there were key people who needed to be present at the End of Life Care decision making process and that this was not always the next of kin. She advised that clinicians need to have respect, listen and to ask family if everyone who needed to be present was present, or if other people needed to be contacted. There are rituals that need to happen after death for people to pay their final respects and to allow this to happen where possible.

Primary Health Care in the last 1000 days

Dr Scott Blackwell, General Practitioner, Chair Voluntary Assisted Dying Implementation Leadership Team.

Dr Blackwell discussed his experiences as a Primary Care doctor in treating patients in the last 1000 days of their lives. He reflected on the journey of Palliative Care over the past 35 years and on key learnings he has had over that time. He shared his personal experience in treating a young girl through the end of her life, how she was the key that held the Palliative Care team together and how Senators could learn from this experience. Dr Blackwell reflected on the themes of Humility, Patience, Delight, Kindness, Honesty and Right Speech and how these are key attributes of Palliative Care. He discussed the importance of emotional connection on person centred care and how he felt confident that Senators would be able to identify with this.

Dr Scott Blackwell concluded:

Reminding Senators that Palliative Care was about teamwork, to allow themselves the space to feel and to let their feelings flow.

Conclusion of evening Session:

The evening was concluded by Ms Tanya Basile, who provided a summary of the evening and challenged Senators to think and feel forward to the following morning and carry with them what they had learnt that evening.

Senate Meeting

The day was structured into five sessions. During the first session, Senate business was conducted. During sessions two to five a different topic of End of Life Care was focused on. In each of these sessions, presentations were made then whole senate mini-plenary discussions were held. Questions were posed to the Senators then group table discussions held. Recommendations were then put into Mentimeter by Senators before a short reflection back to the group by the facilitator. A graphic recording of this was created and is included in Appendix 2.

By using the domains of influence at “System, Site and Individual level” to form recommendations it made it very apparent each has a role to play in progressing End of Life Care. The final set of recommendations is reflective of the collective responsibilities held by all.

Acknowledgement of Country

Ms Janinne Gliddon, a Badimia, Yamatji and Ballardong, Noongar senior woman and clinical senator performed an Acknowledgment of Country.

Session One: Senate Business

Chair’s welcome address

Ms Tanya Basile, Chair Clinical Senate of WA

Ms Basile welcomed the clinical senators back to the debate acknowledging that this meeting was being held during NAIDOC week. She acknowledged and thanked the A/Director General for the Clinical Senate dinner the previous evening. She welcomed Clinical Associate Professor Anthony Bell as the incoming Chair of the Clinical Senate of WA. Ms Basile outlined the format of the meeting of the Clinical Senate, introducing to the Senators the changes that had been implemented based on their feedback from previous debates. These include removing titles from name badges, introducing an idea’s board and clarifying the role of expert witnesses. Ms Basile reminded Senators of the formation of recommendations for the Health Executive Committee.

Ms Basile concluded by:

Reflecting on the previous evening and encouraged Senators to work hard and be fearless for the rest of the day.

Report on the Recommendations from the recent debate on Health and Wellbeing of our Workforce

Dr James Williamson, A/Director General, Department of Health

Dr Williamson acknowledged and welcomed the incoming Senate Chair, Clinical Associate Professor Anthony Bell and thanked outgoing Chair Ms Tanya Basile for her outstanding contribution over her tenure as Chair. Dr Williamson discussed the day’s debate, identifying this as an extremely important topic for the Senate to debate with the recent legislation putting a renewed focus on all end of life care.

Dr Williamson presented the Director General’s response to the August debate on “The Health and Wellbeing of our workforce: Becoming a Fearless Organisation”, acknowledging that “fearless individuals give us the opportunity to improve”.

Dr Williamson concluded by:

Acknowledging that the recommendations provide the system with scope to enhance the cultural landscape of WA Health to lift workforce wellbeing and engagement.

Setting the scene – End of Life Care

Dr Simon Towler, Clinical Lead, End of Life Care

Dr Towler discussed the increase in the number of people dying over the last decade, identifying more people are living with chronic disease than ever before. He discussed how 55% of people

are dying in hospital, 32% of people are dying in residential aged care while 75% of healthy people would prefer to die at home. Dr Towler recognised that care needs to be accessible to everyone everywhere: it needs to be coordinated, involving primary care is critical and that families, carers, and health professional all need to be supported and prepared.

Dr Simon Towler concluded by:

Encouraging the Clinical Senate to be vigorous in their participation and take advantage of the opportunity to make real change.

Session Two – Advance Care Planning

Advance Care Planning is everyone's responsibility

Associate Professor Kirsten Auret, Dr Scott Blackwell, Ms Lana Glogowski and Ms Irene Montefiore

Advance Care Planning opened with a 30minute panel presentation from four front line experts:

- A/Prof Kirsten Auret, Clinical Director of Palliative Care, WACHS discussed her research in the Great Southern and the advances that have occurred with Advance Care Plans (ACP). Her key messages included:
 - Personal responses to dying badly
 - Completing ACPs and other planning was often left until a person had a change in prognosis or admission to hospital
 - ACP should be completed when people were not sick
 - Everyone involved in care needs help to complete the forms (medical team, families and carers)
- Dr Scott Blackwell discussed a collaborative approach to aged care, working with GPs and nurse practitioners. His key messages included:
 - Nurse practitioners provide an advantage as they have more time to talk at length with families and patients
 - Important to address difficult topics with families and give families the opportunity to decide what treatments were important – this often results in avoiding unnecessary trips to the hospital and emergency departments, reducing stress on older patients and those with dementia.
- Ms Lana Glogowski, CEO Palliative Care WA discussed 'Are you good to go?' ACP workshops Palliative Care WA run for 'grey nomads' – a colloquial term for older persons travelling around the state or country). Her key messages included:
 - Workshops were popular, and attendees felt empowered
 - Participants left with a change in attitude, knowing what the forms were for, how to have conversations with family and how to make these important decisions
 - 'You only die once' campaign run in 2020 on TV, radio, social media and print media as a success in educating the population on the importance of ACP
- Ms Montefiore outlined a consumer perspective as co-founder of a 'death café' in Albany. Her key messages included:
 - Her journey towards being comfortable talking about death and dying herself.
 - This enabled her to facilitate conversations in a relaxed, informal environment with consumers around death.
 - Consumers she spoke to were comfortable having ACP and palliative care conversations with health professionals and understand what tools and resources are available.

Following the panel presentation, the Senate held a question and answer session with the panel generating group debate. The Senate membership were then asked, “How do we support integration of different forms of Advance Care Planning for best patient outcomes?” Table debates were held, and recommendations submitted electronically to the Senate secretariat.

Session Three – Goals of Care

Goals of Care – Quality discussions and processes

Dr Derek Eng, Palliative Care Consultant, Royal Perth Hospital

Dr Eng presented research and a recent pilot program run at Royal Perth Hospital in collaboration with the Cancer Council of WA on simulation training for Goals of Care (GOC) communication. His key messages included:

- Most doctors do not receive training on GOC communication skills and they felt this was a barrier in the GOC discussion.
- Pilot review showed that doctors valued the training and recommended it to their colleagues.
- The REMAP framework for a GOC discussion was helpful to facilitate the GOC discussion.

A mini-plenary session was held followed by table discussions on the question “How can the system support clinicians to have quality conversations?” Recommendations from these table debates were submitted to the Senate secretariat.

Session Four – Palliative Care

Associate Professor Alison Parr and Ms Shannon Calvert

A/Professor Parr presented on the changing needs and choices of patient’s, carers and families. Her key messages included:

- Barriers to good Palliative Care
- Changing landscape of Palliative Care including data improvements
- Multidisciplinary nature - Palliative Care does not need to involve a specialised team
- It is not only for oncology patients
- Palliative Care can save the system money, meet patients’ needs, and improve patient choice

Ms Calvert addressed a consumer perspective in her presentation, sharing her personal journey. Her key messages included:

- Importance of consideration of people with no security, with mental health issues and those with no capacity
- Grief and bereavement need to be acknowledged, that grief is hard, and it is sad.
- Consumers have the right to these conversations, the conversations can be difficult, for health professionals, patients and families, and people need support and preparation for the conversations to go well. Ms Calvert challenged the senators to give each other the human right to have the conversations with clinicians, families, and patients.

Following A/Professor Parr and Ms Calvert’s presentation a mini-plenary session was held followed by table discussions on the question “How do we better recognise and realise people’s

expectations for care in the last 1000 days?” Recommendations from these table debates were submitted to the Senate secretariat.

Session Five – Voluntary Assisted Dying

Dr Scott Blackwell and Ms Lisa Furness

Dr Blackwell and Ms Furness presented on the journey of Voluntary Assisted Dying (VAD) in Western Australia to its current position and status today. They provided a summary of the work that has occurred since legislation passed in 2019. They discussed the 8 workstreams the VAD Implementation Leadership Team is focused on, and implementation work that occurring in the lead up to enactment of the legislation on 1 July 2021. Highlighting that VAD is not a choice made in isolation, it is an option and part of the choices available in a person’s End of Life Care, one of many in the End of Life.

This presentation was followed by a question and answer session by Dr Blackwell, Ms Amanda Bolleter and Dr Elissa Campbell. The questions asked by the senators will inform the education programs being prepared by the Department of Health for clinicians, consumers and families.

A graphic representation containing key messages emerging from the day is provided as Appendix 2. The discussions and table debates highlighted the complexity and vastness of the topic. The importance of quality End of Life Care was evident during all presentations and conversations.

Appendix 1: Presenters, expert witnesses and invited guests

Presenters

- Ms Vivienne Hansen, Balladong Wadjuk Yorga woman from the Noongar people
- Ms Tanya Basile, Chair, Clinical Senate of WA
- Dr Jacqueline Donnelly, Intensivist Rockingham General Hospital
- Dr Simon Towler, Clinical Lead End of Life Care, Department of Health (Senator)
- Ms Shannon Calvert, Lived Experience Advisor, Educator and Advocate
- Ms Nola Naylor, Director Aboriginal Health Strategy, South Metropolitan Health Service
- Dr Scott Blackwell, Chair Voluntary Assisted Dying Implementation Leadership Team
- Ms Janinne Gliddon, Badimia, Yamatji and Ballardong, Nyoongar senior woman (Senator)
- Dr James Williamson, Assistant Director General, Clinical Excellence Division, Department of Health WA
- Associate Professor Kirsten Auret, Clinical Director Palliative Care WACHS
- Ms Lana Glogowski, Chief Executive Officer Palliative Care WA
- Ms Irene Montefiore, Consumer Advocate, Death Café facilitator
- Dr Derek Eng, Consultant Palliative Care, Royal Perth Hospital
- Associate Professor Alison Parr, Clinical Lead Palliative Care, Department of Health
- Ms Lisa Furness, Project Manager Voluntary Assisted Dying Implementation project, Department of Health
- Dr Elissa Campbell, Head of Department of Rehabilitation and Aged Care at Sir Charles Gairdner Hospital
- Ms Amanda Bolleter, Director End of Life Care, Department of Health
- Ms Di Darmody, MC and Facilitator

Expert Witnesses and Invited Guests

- Clinical Associate Professor Anthony Bell, Incoming Chair Clinical Senate of WA
- Mr Brett Hayes, WA Wheatbelt Regional Specialist Palliative Care Manager
- Ms Louise Appleton, Nurse Practitioner, Hall and Prior Health and Aged Care
- Ms Rene Deleuil, Clinical Nurse Consultant Palliative Care, Paediatrics Dr Margherita Nicoletti, Palliative Care Consultant, Head of Department Haematology Rockingham General Hospital
- Dr Alicia Massarotto, Geriatrician Fremantle Hospital
- Dr Anton Leonard, Royal Perth Hospital Clinical Champion
- Ms Tish Morrison, Director Palliative and End of Life Care Silver Chain Perth
- Dr Daryl Kroschel, Medical Director of Home Hospital Silver Chain
- Dr Audrey Koay, Executive Director of the Patient Safety and Clinical Quality Directorate, Department of Health
- Dr Peter Spirvulis, Chief Clinical Information Officer, Department of Health
- Ms Brenda Shum, A/Head of Department Pharmacy, Sir Charles Gardner Hospital
- Dr Jacquie Garton-Smith, Clinical Lead for Primary Care Integration, Department of Health
- Ms Valerie Colgan, Nurse Educator – Palliative Care with WA Cancer and Palliative Care Network
- Ms Debra Letica, Consumer Advocate
- Ps Sheldrin D’Rozario Chaplain / Coordinator of Pastoral Care South Metropolitan Health Service
- Mr Paul Forden, Chief Executive, South Metropolitan Health Service
- Ms Liz MacLeod, Chief Executive, East Metropolitan Health Service
- Mr Jeff Moffett. Chief Executive, WA Country Health Service
- Mr Joseph Boyle, Chief Executive, PathWest
- Mr Will Bessen, Facilitator and Graphic Recorder, Tuna Blue Facilitation

Appendix 2: Graphic representation



SIMON TOWLER

INTENSIVE CARE IN THE LAST 1000 DAYS



JACQUELINE DONNELLY

FAMILY

A HYPOTHETICAL

JANE

- 48 YRS
- MUM
- FIT

• C4 SPINAL INJURY & HEART ATTACK

• CHANGING FAMILY VIEWS & TREATMENT

• NEVER DISCUSSED END OF LIFE

• SURFING

• A PROTRACTED PROCESS WITH THE FAMILY TO REACH CONSENSUS

• OFTEN ASK THE FAMILY "DID SHE EVER MENTION DYING SUPPORTED?"

• IF I'M EVER A VEGETABLE

• OFTEN THIS IS NOT IN CLINICAL LANGUAGE

• WHAT IS MEANINGFUL?

EXTENDED FAMILY DECISIONS CULTURALLY

REASSURE THE NOMINAL DECISION MAKER

YOU ARE NOT ALONE

A CLEAR VIEW OF WANTS IS CLEAR IN A SPECIFIC CIRCUMSTANCE

WISHES

WE NEED TO BE HAVING THESE DISCUSSIONS

BUT I LOVE MY CUPS OF TEA

BUT NOT ALL DOCTORS HAVE THE SKILLSET

WHAT TO ASK?

PLANNING

THE CONVERSATIONS

WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020

DECISIONS

HAVE THE CYCLICAL FAMILY CONVERSATIONS

KEEP COMING BACK

THEN YOU CAN START TO UNDERSTAND THE VALUES

PLANNING

OFTEN NOT SPECIFIC ENOUGH TO THE CLINICAL SITUATION

BUT GIVES SOME IDEA


IF THE PERSON HAS LOST DECISION MAKING, IT IS SO HARD FOR FAMILY

DIFFERENT REALITIES DIFFERENT EXPERIENCES

TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE


SCRIBED WITH THE DEEPEST RESPECT ON WHADJUK NOONGAR BOODJA

SCRIBED BY TUNA BLUE



SHANNON CALVERT & NOLA NAYLOR

Personalising Experiences



OCTOBER 2014 MUM IS DIAGNOSED WITH CANCER & GIVEN WEEKS TO LIVE

ANTOPILOT

YOU START GRIEVING INSTANTLY

NO OPPORTUNITY TO TALK ABOUT MUM'S WANTS

WHEN RAISED PALLIATIVE CARE IMMEDIATELY SHOT DOWN

FINALLY A REFERRAL VIA THE GP

LEARNED ABOUT PALLIATIVE CARE FROM BROCHURES

SHE DOESN'T NEED IT

THE BEST DEATH POSSIBLE FOR MUM

Dignity AND Grace

CAME FROM THE DIFFICULT CONVERSATIONS

IM TIRED

IM SCARED

IM DYING

THIS TAKES TIME 1000 DAYS

DEATH & LIFE

A CONVERSATION & SHARING OF EXPERIENCE IN ABORIGINAL FAMILIES

THE RIGHT TO KNOW THAT YOU'RE DYING

HEAL ~ TIME TO MAKE MEANING

KART (HEAD)

KOORT (HEART)

MOORT (FAMILY)

Listening

INTERGENERATIONAL CAREGIVING IS AN IMPORTANT PRACTICE

KEY PEOPLE IN SUPPORTING LOVED ONES

GRANDSON?

DAUGHTER?

PARTNER?

IDENTIFY THROUGH DIALOGUE

CULTURAL PROTOCOLS

FAMILY VISITATION

SPIRITUAL PRESENCE

DYING ON COUNTRY

WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020

TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON WHADJUK NOONGAR BOODJA

SCRIBED BY TUNA BLUE



SCOTT BLACKWELL

PRIMARY HEALTH CARE IN THE LAST 1,000 DAYS

SANDING & THINKING

"PETER WHAT ARE YOU DOING?"

"PEOPLE WILL NEVER FORGET HOW YOU MADE THEM *feel*"

MAYA ANGELOU

TEAMWORK

END OF LIFE CARE WILL NOT ALWAYS REQUIRE "YOU"

A TEAM OF EQUALS BUILT ON RESPECT

KINDNESS

THE CORNERSTONE OF OUR WORK

RIGHT SPEECH

THE RIGHT WORDS ARE NOT THE SAME FOR EVERYONE

DYING PASSING MOVING ON

HONESTY

DISHONESTY PROVIDES FALSE HOPE, PAIN & SUFFERING

PALLIATIVE CARE HAD A MARGINALISED START IN WA

HOLLYWOOD HOSPICE



IN THE END WE ARE

- BODY
- MIND
- SPIRIT

PATIENCE

GIVES THE POWER OF MIND REQUIRED

DELIGHT

KOBY'S FRIENDS AFTER SCHOOL



WHEN I WAS IN MY MUM'S TUMMY, I DIDN'T KNOW WHERE I WAS GOING... AND IT WAS GOOD

SO WHERE I'M GOING... MUST BE GOOD TOO

Humility

THE ABILITY TO SEE SOMETHING BEYOND OUR OWN POV

THE QUALITY WE CAN HAVE IN THE TIME WE HAVE



WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020

TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON MHADJUK NOONGAR BOODJA



SCRIBED BY TUNA BLUE



SIMON TOWLER

SETTING THE SCENE

CONTEXT

THE END OF LIFE CARE ENVIRONMENT HAS CHANGED



2008 LEGISLATION

CHARLIE CORKE

TOO OFTEN WE LEAVE END OF LIFE DISCUSSIONS TO TOO LATE - THE

CRISIS POINT

THE NUMBER OF PEOPLE DYING IN AUSTRALIA INCREASES

WE'RE LIVING LONGER

but... DIFFERENT AGES HAVE DIFFERENT NEEDS

80% OF DEATHS FROM 5 CONDITIONS

62% OF DEATHS ARE PREDICTABLE

54% OF PEOPLE DIE IN HOSPITAL

IMPLEMENTATION

ACCESSIBLE CARE

COORDINATED

STAFF PREPARED



PERSON CENTRED



FAMILY & CARERS



COMMUNITY AWARE

TODAY

1. ADVANCE CARE PLAN
2. GOALS OF CARE
3. PALLIATIVE CARE
4. VOLUNTARY ASSISTED DYING

LET'S MAKE *meaningful* CHANGE

Dignity & CHOICE

IN THE LAST 1000 DAYS

ADVANCE CARE PLAN GOALS OF CARE

RECOMMENDATIONS



TANYA BASILE



HAPPY NAIDOC WEEK

KEEP IN MIND THE THEME "ALWAYS WAS, ALWAYS WILL BE"



INTRODUCE OUR NEW CHAIR ANTHONY BELL



OUR 53RD SENATE



SPEAK FREELY

ALL EQUAL MEMBERS

SENATE CHANGES

ONLY YOUR NAME ON YOUR NAME TAG



IDEAS BOARD

ROLE OF EXPERT WITNESS



SCRIBED BY TUNA BLUE



WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020

TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON MHADJUK NOONGAR BOODJA

ADVANCE CARE PLANNING

KIRSTEN AURET

GREAT SOUTHERN EMBEDDING ADVANCE HEALTH DIRECTIVES

EMPOWERMENT TO PLAN DEATH

SUSCEPTIBILITY TO A POOR DEATH

THE BALANCING POINT

ADVANCE CARE PLANNING IS EVERYONE'S BUSINESS AND EVERYONE NEEDS SUPPORT

TALKING WITH A TRUSTED INDIVIDUAL IS CRITICAL

\$30k → \$350 FACILITATOR MODEL

CAN WE FORM A PARTNERSHIP WITH WILL-MAKING?

START HERE THEN DISCUSS HEALTH WHAT ARE YOUR EOL WISHES

THERE IS NO LEGISLATIVE IMPEDIMENT BUT THE PRACTICALITIES VARY STATE TO STATE

SCOTT BLACKWELL

GP'S & NURSE PRACTITIONERS IN RESIDENTIAL AGED CARE

AT THE 6-8 WEEK MARK WE HAVE A FAMILY MEETING

24/7 SERVICE TO AVOID HOSPITAL

2% CHANCE OF RESUSCITATION

UNCOMFORTABLE HOSPITAL TRIPS

"HOSPITAL ONLY IF HOSPITAL CAN FIX IT"

LANA GLOGOWSKI

CARAVAN PARKS, GREY NOMADS & ADVANCE CARE PLANNING

PEOPLE WANT TO KNOW ABOUT THIS?

2 HR WORKSHOP

DO THE DOCUMENTATION WHEN READY

ENGAGE WHILST WELL

2018 CAMPAIGN

CEO ROUNDTABLE

60% INCREASE IN ADVANCE CARE PLANS

"YOU ONLY DIE ONCE"

DEATH CAFES

CAN THESE LINK CLOSER?

HEALTH SERVICE

MORE ABOUT DEATH LITERACY

WHO ADVOCATES FOR THE AHD?

IRENE MONTEFIORE

THROUGH EXPERIENCE OF DEATH I REALISED

BEING TOTALLY UNPREPARED IS UNACCEPTABLE

FOR A NATURAL PROCESS

2014 ALBANY DEATH CAFE

SO MANY PEOPLE DON'T KNOW? OR ARE DETERRED BY GP'S?

UNTIL COMMUNITY IS AWARE

AHD

IT NEEDS TO BE CLINICIAN INITIATED

LACKS ADEQUATE GP INCENTIVES

FINAL KPI? HOW WELL THE FAMILY GRIEVES

SOCIAL WORK INVOLVEMENT IS CRITICAL

NO REGISTER TO STORE/ACCESS AHD'S



WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020 TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON WHADJUK WOONGAR BOODJA



DEREK ENG

GOALS OF CARE

"TRUTH", RIGHT WORDS & UNDERSTANDING

VARIES FROM FAMILY TO FAMILY

DEFICIENCIES IN COMMUNICATION SKILLS IN THIS AREA

TEACHING SKILLS THROUGH SIMULATION TO BUILD CLINICIAN CONFIDENCE

WORKSHOPS

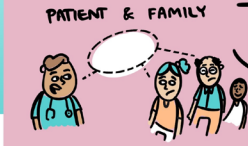
VIDEOS

TEAMS CHANNEL

HEADLINE IMPORTANT!

GOALS OF PATIENT CARE

IS A DISCUSSION WITH THE PATIENT & FAMILY



SHOULDN'T BE AT THE CRISIS POINT

LISTEN TO CUES

THE CEILING OF CARE

THE FAMILY SHOULD NEVER FEEL ALONE IN A DECISION

"CAN THEY JUST SAY THAT?"

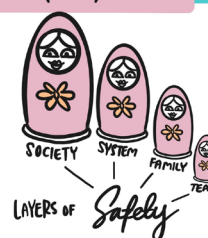
WHAT IS THE CONSUMER EXPERIENCE?

PSYCHOLOGICAL SAFETY

FOR CLINICIANS TO HAVE THESE CONVERSATIONS

IN A SYSTEM OF ABF NON INCENTIVES

LIKELY UNDER HUGE WORKLOAD & BURNOUT



HIGH FIDELITY SIMULATION

EXPERIENCED FACILITATORS ARE CRITICAL

YOU CAN'T LEARN TENNIS FROM A LECTURE



IDEAS CONCERNS EXPECTATIONS

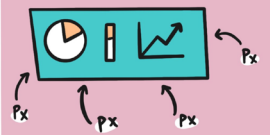
PACKAGE READY TO ROLL OUT

THE RESULTS?

SIGNIFICANTLY IMPROVED CONFIDENCE

A SAFE ENVIRONMENT FOR DOCTORS

CAN WE UTILISE PROMS & PREMS?



SPECIFIC NEEDS OF PAEDIATRIC GOALS OF CARE

TRANSFER OF CARE

WE OFTEN TRANSFER CLINICALLY BUT DON'T PASS ON PSYCHOLOGICALLY



WESTERN AUSTRALIAN CLINICAL SENATE NOVEMBER 2020 TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON WHADJUK WOONGAR BOODJA



ALISON PARR

PALLIATIVE CARE

SHANNON CALVERT

"RELIEVING SUFFERING" IS NOTHING NEW TO HEALTH

but...

PALLIATIVE CARE WAS ONLY ESTABLISHED AS AN AUSTRALIAN SPECIALITY IN 1987

PALLIATIVE CARE IS

- EVERYONE'S BUSINESS
- DOESN'T SHORTEN LIFE
- HOME vs HOSPITAL SYMPTOM CONTROL
- NOT JUST FOR THE DYING
- PAIN ISN'T #1 CONCERN
- NOT EXPENSIVE

PEOPLE AFRAID OF DYING ARE OFTEN AFRAID OF WHAT WILL HAPPEN TO THOSE THEY LOVE



THESE CONVERSATIONS ARE A HUMAN RIGHT

GRIEF IS SAD GRIEF IS HARD

A FOCUS ON Attitudes

- PEOPLE'S NEEDS
- CO-MORBIDITIES
- EXPECTATIONS

ARE ALL CHANGING



Family INVOLVEMENT IS INCREASING

EMERGENCE OF COMPASSIONATE & CULTURALLY APPROPRIATE PALLIATIVE CARE



PALLIATIVE CARE GOOD OR BAD LIVES ON IN MEMORIES OF THOSE LEFT BEHIND



Quality of Life IS SOMETIMES TALKING ABOUT Death

SUPPORTING PEOPLE WITH



WITH



TRANSFORMING CARE IN THE LAST 1000 DAYS - PARTNERING TO REALISE CHOICE

SCRIBED WITH THE DEEPEST RESPECT ON MHADJUK NOONGAR BOODJA



"Thank You"

"THE FIGUREHEAD"

THE WA HEALTH SYSTEM

SENATORS



FOR A WONDERFUL TENURE AS THE WA CLINICAL SENATE CHAIR

Happy Dragon Days Ahead

TANYA BASILE

**This document can be made available in alternative formats
on request for a person with disability.**

© Department of Health 2020

Copyright to this material is vested in the State of Western Australia unless otherwise indicated. Apart from any fair dealing for the purposes of private study, research, criticism or review, as permitted under the provisions of the *Copyright Act 1968*, no part may be reproduced or re-used for any purposes whatsoever without written permission of the State of Western Australia.