



PalliativeCare
WESTERN AUSTRALIA

Sector Consultation Report

Consultation 3 December 2019

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1.0 Introduction

The past decade has seen some significant changes for palliative care in Western Australia, particularly in the past few years. As 2019 drew to a close, Palliative Care WA felt it more important than ever to consult our members, the palliative care sector and the WA community regarding our priorities as we headed into a new year and were planning to renew our strategic priorities for 2020 and beyond.

Palliative Care WA recognised that the sector had been involved in a number of critically important processes over the past couple of years, some of which resulted in reports and sets of recommendations including:

- WA Parliament Joint Select Committee on End of Life Choices;
- Ministerial Expert Panel on Voluntary Assisted Dying;
- Ministerial Expert Panel on Advance Health Directives;
- WA End-of-Life and Palliative Care Strategy 2018-2028;
- WA Government Sustainable Health Review;
- National Palliative Care Strategy – 2018; and
- Royal Commission into Aged Care Quality and Safety (ongoing).

Given the resources available to Palliative Care WA it was not feasible to respond to all the issues identified in these processes, so the sector consultation process was aimed at guiding our priorities.

I thank all those who attended for their high level of engagement and contribution. Your enthusiasm and commitment were very inspiring, and your contributions will help inform our strategic priorities for the years to come.

Elissa Campbell

President

2.0 Purpose, process and outcomes

2.1 Purpose

The purpose of the event was to consult with members of Palliative Care WA, the broader palliative care sector and particularly members of the general community to assist in identifying strategic priorities for the organisation moving forward.

2.2 Process

Facilitated by the CEO, Lana Glogowski, the consultation was only ninety minutes long and used a highly engaging and conversational process as follows:

1. **Small table activity** – considering the recent panels, reports and recommendations to identify key strategic priorities for Palliative Care WA;
2. **Presentation** – summary of the recent projects, events and activities delivered by Palliative Care WA;
3. **Small table activity** – Identification of the top ten priority strategies for moving forward.

2.3 Outcome

Twelve key issues were identified for consideration by Palliative Care WA and are summarised in Section 3.0.

To maintain the integrity of the consultation process, it was resolved to create a document that was close to a verbatim report as possible. In-keeping with that commitment, all table workings are recorded as appendices in Section 4.

Approximately fifty people attended the consultation and their names are also recorded in Section 4.0.

2.3 Where to from here?

The outcomes of the consultation process will be considered by the Board of Palliative Care WA at their strategic planning process in January 2020. The finalised strategic plan will be shared via the Palliative Care WA website, newsletters and social media.

Given the success of this event it is proposed to undertake a consultation event annually alongside the AGM. It is anticipated that other engagement and consultation events will be scheduled during the year.

3.0 Agreed priority areas for consideration by PCWA

Agreed sector priorities (NOT in order of importance)	Rationale (from table reports and discussions)	Strategies (from table reports and discussions)
Community education and awareness	Dying is normal and inevitable-we need to encourage community to talk and plan more	<ul style="list-style-type: none"> Media campaign ACP workshops
Sector engagement and consultation	PCWA members and the sector have the opportunity to debate, strategise, synthesise and evaluate	<ul style="list-style-type: none"> Increased number of sector forums Regular newsletter
Recognition of diversity	Actively consider the needs of groups including: Aboriginal, CaLD, rural, disability, LGBTQIA, homeless and Mental Health	<ul style="list-style-type: none"> Engagement and consultation with various sectors Customised approaches
Visibility of carers	Recognise the critical role of carers and their need for information, regular respite and support	<ul style="list-style-type: none"> Engagement and consultation Customised approaches
Compassionate Communities	Critical importance of activating community to provide support for the person with illness, their carer, and their family	<ul style="list-style-type: none"> Weavers program Dignity Therapy
Service integration	Models of care and service providers should prioritise both person centred and integrated approaches	<ul style="list-style-type: none"> Service mapping Promoting innovation and best practice
Paediatric palliative care	Increased awareness that children and young people access palliative care	<ul style="list-style-type: none"> PPC referenced in all forums and planning documents
Early access to specialist assessment	Promote the value of early assessment in achieving best outcomes	<ul style="list-style-type: none"> Develop and promote key messages Media Campaign
Workforce issues	Recognise increasing demand for services and limited capacity for growth	<ul style="list-style-type: none"> Palliative Caring training package Emerging Leaders network
Death literacy & consistent language	Recognise lack of death literacy and lack of consistent language	<ul style="list-style-type: none"> Consult and develop glossary
Dementia	Need to change community attitudes and understanding	<ul style="list-style-type: none"> Supported decision making Customised ACP training
Home care for all age groups	Recognise common desire to die at home and limited, but growing capacity to do so	<ul style="list-style-type: none"> Information campaigns Include in ACP workshops

4.0 Appendices

4.1 Agenda



Palliative Care WA SECTOR CONSULTATION 2019	
DATE	Tuesday 3rd December 2019
TIME	5 – 6.30pm
PLACE	Cancer Council WA Seminar Room, 15 Bedbrook Place, Shenton Park
AGENDA	
Facilitator: Lana Glogowski, CEO, Palliative Care WA	
5pm	Welcome and apologies
	Acknowledgement of Country
	Purpose and process
5.05pm	Introductions
5.15pm	<i>Activity 1 – Consideration of key reports and recommendations</i>
5.35pm	<i>Presentation – Palliative Care WA's recent strategic priorities</i>
5.50pm	<i>Activity 2 – Top 10 strategies in priority order</i>
6.25pm	Where to from here?
6.30pm	Meeting close and refreshments in foyer

4.2 Table conversations on sector reports

Table 1

My Life My Choice

- Development of dedicated position to support discussions for GOC/AHD – inform CEO round table
- Public Awareness to normalise death – campaign to public
- Stories – identify patients

Table 2

My Life My Choice

- Needs and wants
- Support to sector – financial
- Advertising campaign
- Advanced Care Planning
- Resources from PCWA to educate choice
- Access to palliative care and we have a role to build standards and capacity

Sustainable Health Review

- More presence to promote PCWA and to engage community/ awareness
- Project money
- Project advocacy
- Not enough reference to palliative care
- PCWA-more presence to engage Compassionate Communities

WACPCN

- Access for all – more inclusive
- Acknowledgement of diversity
- Regional plans to reflect local needs (Health Service Board)

Ministerial Expert Panel on AHDs

- Access to Advanced Care Planning/ Health directive/ V.A.D.
- Access to health records
- Trained and dedicated staff / value statements

Royal Commission into Aged Care Quality and Safety

- National replication – MPACCS
- Capacity of palliative care
- Best practice of new models of care i.e. education
- Access to end of life institutions – advocacy
- Be bold
- Home care packages

Other

- Public awareness that dying is NORMAL

Table 3

My Life My Choice

- Involvement in palliative care gaps – advocacy
- Rural and community increase in funding/ resources
- Advocacy and education for palliative care, specialty as well as agencies/ services
- Community understanding of palliative care and role in EOLC
- Education – what does palliative care mean? Change the conversation, culture and stigma

Sustainable Health Review

- Guide use/ movement of funds towards providing gold star palliative care
- Strategy – great beginning/ dignified end of life

WACPCN

- Advocacy – 2 in 3 people who need palliative care do not receive it
- Exploring barriers – what are they and how do we break them?
- Education – consumers and service providers, so they understand what they should be receiving
- Diversity – CALD/ disability/ LGBTIQ/ mental health

Ministerial Expert Panel on AHDs

- Advocacy for EOLC – clinical specialists involved in expert panels rather than just legal
- ACP education – community and health care professionals
- Involvement in the development of storage of AHDs

Royal Commission into Aged Care Quality and Safety

- Identification and dissemination of best practice models of care
- Ongoing education
- Leadership role – partnering with peak aged care bodies/ providers
- Advocacy for palliative care and acknowledgement that EOLC in aged care is not easy both in residential and at home

Table 4

- Exploring models of palliative care from consumer perspective
- Review of 3 models
- Integration of care, different pathways
- Consumer education – “palliative” what does it mean?
- Partnerships beyond traditional e.g. paramedics (education/ resources)
- Silos in palliative care – not speaking (e.g. SJA & Health)
- Community education regarding ACP including RACF and GP
- Systems to access AHDs/ ACPs when needed – not locked in a drawer
- Sustainable Health Review “dignified end of life”
- Communities of practice – operational/ HSP level group

Table 5

- Care is coordinated
- Awareness raising – PCWA to find out where care is not coordinated
- PCWA to find out what consumers think of their care (gaps) including those without capacity
- Increasing public awareness that “dying is a normal part of living”
- Children – adult – elderly
- Advocate for amount and type of hospice/ facilities across the North
- Advocate for where funding is needed
- Future/ horizon scanning on what is coming up in 10-20 years and what to be planning for NOW
- Industry readiness
- Enabling people to know what they need and where to get resources

Table 6

- Access for all
- Communication, awareness and education
- ACP plus conversations
- Diversity acknowledgement
- Regional/rural
- Carers/support
- Pediatric sector – increased involvement
- Compassionate communities
- Normality of death and dying
- Increased resources
- Partnerships with other organisations
- Greater consultation with our membership in formulating submissions
- Services – membership based and peak body with access to government
- Collaborative partnerships – reflect membership needs and engage the membership

4.3 Whole room conversations on sector reports

My Life My Choice

- Public awareness and education
- Stories
- Stigma
- Challenging the notion of “dying badly”
- Recognise gaps and barriers
- Input into training and diversity
- Compassionate Communities

- Consumers perspective on 3 models
- Empowering health professionals

Sustainable Health Review

- Dignified end of life
- Paediatric palliative care
- Communities of practice
- More palliative care focus
- What are the carer's needs?
- Compassionate communities
- Realistic medicine programme

Ministerial Expert Panel on AHDs

- Community education including aged care
- Access to Advanced Care Planning
- Input of value statements
- My Health Record
- Trained and dedicated staff
- Needs to be clinically useful

WACPCN

- Paediatric addendum
- Regional/ rural
- Independence
- Person-centered
- Consumer's voice
- Diversity
- Access for all
- Regional differences
- HCC
- Carers

Royal Commission into Aged Care Quality and Safety

- Community education including aged care
- Access to Advanced Care Planning
- Input of value statements
- My Health Record
- Trained and dedicated staff
- Needs to be clinically useful

Other

- Public awareness that “dying is normal”!

4.4 Table considerations of top ten priority areas

Table 1

- Consumer and Carer group
- Communities of practice to drive service improvements (public, private, NGOs, aged, palliative care, ambulance, GP etc)
- Access to palliative care for anyone with a life limiting illness from time of diagnosis
- Training carers/ framework for education/ support of carers
- Bereavement care
- Facilitation of integration of services and models
- Public awareness – dying is normal
- Advance care planning public education
- Realistic medicine

Table 2

- Address need for public education that dying is normal and inevitable
- Knowing what death looks like (public education)
- Including death in curriculum in schools/ relevant post school course
- Advocacy for specialist paediatric palliative care in hospice
- Accessibility to specialist palliative care when needed or as a minimum for assessment
- Advocacy and support for indigenous Australians to the best palliative care – including connecting with local groups
- Access to level 5 & 6 home care packages to allow full EOLC at home

Table 3

- Campaigning and awareness raising – changing attitudes and empowering public and caregiver
- Supporting decision making for minority groups e.g. dementia
- Dedicated roles for GOC/AHD discussions
- Compassionate Communities project
- Training and developing – advocacy for workplace capability and support
- Advocacy for 24/7 access statewide to specialist palliative care

Table 4

- Facilitating access and education to a more diverse audience – CALD, youth, LGBTQIA, Aboriginal
- Broadening reach: mass media, penetration of message e.g. more “You Only Die Once” campaigns – well strategised and interesting
- Advocacy and education
- Partnering
- Best practice
- Workforce developments and network

Table 5

- Community awareness, education and training
- Improved visibility of the carer
- Stories – learning from the positive and negative and giving inclusive voice to all
- Appropriate language around dying and considering child/youth/young people

Table 6

- Community education
- Public awareness – people’s rights/ palliative care, what? When? How? ACP, AHD
- Advocacy on what palliative care and EOL care are and the differences
- Awareness raising of choices and what is good palliative and EOL care
- Advocates conversations of values – “what is important to me?”
- Representing the sector at the table of important conversations
- Synthesizing what is happening in the EOL and palliative care space and putting that out to the sector in an easily digestible way
- Advocacy of everyone’s role in palliative and EOL care (not just community advocacy)
- Advocating for palliative and EOL care for vulnerable populations

4.5 Whole of room consideration of top ten priority areas

Top ten priority areas

- Dying is normal and inevitable – need for public education
- Regular consultations with members; broad representation & opportunity to synthesize information
- Diversity (Aboriginal & other cultural diversity – particularly in country; models of care and education)
- Improve visibility of carers
- Compassionate Communities
- Integration of models of care and services
- Consumer and carer group
- Co-design
- Partnerships and collaboration
- Specialist paediatric palliative care and hospice
- Early access to specialist assessment
- Early referral
- Supported decision making
- Care at home for all age groups
- Consistency and clarity re: language
- Dementia – campaign to change attitudes and empower people with a diagnosis

4.6 Attendees and apologies

Attendee Name	Title	Agency
Alison Barnard	Chairperson	Chittering Health Advisory Group
Alison Parr	Consultant palliative medicine	SJOG
Alison White	Director of hospice + pall care	SJOG
Angelita Martini	Director	Brightwater Group
Anna Petterson	Consultant	Self employed
Carmel Markham	Funeral director	Purslowe Chipper/ PCWA Board
David Easton	Social Worker	DOHWA
Derek Eng	Doctor	Health professional
Desmond Williams	Orthopaedic Surgeon	PCWA Board
Douglas Bridge	Emeritus consultant	RPH
Elissa Campbell	President	PCWA
Gabriella Jerrat	Program Mgr, PCS Program	DOHWA
Gary Wilson	Paramedic	Ambulance Wish WA
Glynis Hourquebie	Registered nurse	TPG Aged Care
Grace Buchanan	Manager Palliative Care	Cancer Council WA
Hiren Mehta	Gen Manager Group Finance	Silverchain/ PCWA Board
Jonathan Smith	CEO	Echo Community care providers
Karen Bradley	Exec director L/ship and Reform	DOHWA
Karyn Salter	Client Services Manager	Home Instead
Lauren Breen	Assoc Professor of Psychology	Curtin University
Liz Behjat	State Manager, WA	Leading Age Services Aus (LASA)
Lou Angus	Nurse practitioner pall/care	
Luke Austin	Clinical Practice Support Officer	Aboriginal Health Care WA

Margherita Nicoletti	Palliative medicine specialist	DOHWA/ PCWA Board
Megan Burley	Acting Director Health Networks	DOHWA
Melanie Chatfield	Health Policy Manager	WAPHA
Melanie Marsh	Information/ Support services	Cancer Council WA
Micaela Salvato		
Moira O'Connor	Academic	Curtin University/ PCWA Board
Neale Fong	CEO	Bethesda Healthcare
Nicholas Way	Senior Media/Comms advisor	LASA
Paul Rogers	Business Development & Disability Services Manager	Carers WA
Phuntsho Om	Senior Lecturer	Edith Cowan University
Pip Brennan	Executive Director	Health Consumer's Council WA
Rachel Saw	Support Worker	Hendercare
Renee Deleuil	Paediatric Pall Care Nurse	Perth Children's Hospital
Roseanne Adamson	Aged Care Project Lead	WAPHA
Sarah Keenan	Senior Policy Officer	DO Justice WA
Sharon Gronow	Educator	Dementia WA
Susan King	Clinical Services Manager	Hannah's House
Susan Lee	Deputy Chairperson	Pureland Project
Susie Wilson	Establishment group member	Ambulance Wish WA
Tish Morrison	Director of Operations EOL	Silverchain/ PCWA Board
Valerie Colgan	Nurse Educator	WACPCN
Will Hallahan	Project Officer Palliative Care	Bethesda Healthcare
Yasmin Naglazas	Consultant/ NFP Director	PCWA Board
Zoe Clarke	Senior Social Worker	DOHWA / PCWA Board

Apology Name	Title	Agency
Sharon Rodger	A/ Manager	WACPCN
Nicky Howe	CEO	South Care
Daniel Norgard	GM WA Healthcare	Silverchain
Paula Moffat	Palliative Care Physician	Bethesda
Michelle Fyfe	CEO	St John Ambulance
Andrew Allsop	Support Manager	Silverchain
Stephen Pratt	Senior Policy Advisor	Dept Premier and Cabinet
Michelle Jenkins	CEO	Community Vision



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