



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

# WA Palliative Care Summit 2019 Report



**Saturday 24 August 2019**  
**Perth Convention and Entertainment Centre**



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# Overview

Members of Western Australian palliative care sector gathered for a Summit on Saturday, 24 August 2019 at the Perth Convention and Entertainment Centre. The aim of the Summit was to discuss and reflect on the future direction of palliative care in Western Australia, in light of the End of Life Choices Joint Select Committee and Sustainable Health Review recommendations and the *WA End of Life and Palliative Care Strategy (2018–2028)*.

By the end of the Summit, the participants had:

- Built stronger networks and relationships
- Considered the Ministerial context and setting
- Developed a greater understanding of the lived experience
- Considered perspectives from interstate and international examples
- Explored the alignment across the current strategic environment for palliative care
- Considered the priorities and next steps moving forward
- Discussed key Joint Select Committee recommendations.

This Report captures the key outputs from the polling and workshop sessions.

Facilitation and reporting by Will Bessen of Tuna Blue Facilitation.



# Executive Summary

The key themes from each workshopped recommendation are captured in this Executive Summary.

## **What are the priorities for community palliative care services to meet growing demand in WA?:**

- Increased funding and resources, including more flexible funding models that enable care in both specialist and community settings
- Greater access to 24/7 palliative care and support, including clearer referral pathways, access to allied health and earlier intervention
- Increased community education, workforce capacity building and specific upskilling initiatives, especially on the process of dying (community) and the available support and referral pathways (providers)
- Improved access to appropriate services for diversity in cultural, age and socioeconomic backgrounds and experiences
- Greater partnerships, collaboration, integration and information sharing between services, particularly between formalised health services and community based services
- Greater community involvement and formal champion roles  
More consumer and family involvement in service design and delivery
- More flexible and innovative models to cope with the growing demand
- Improved support for staff wellbeing to reduce potential burnout
- Increase uptake of AHD's and end of life discussions and planning
- Greater advertisement and promotion of available services
- Tighten the definition of 'community' palliative care
- Sustainable services and staff retention in rural and remote areas
- Increased transparency and accountability of service providers.

## **What is the patient perspective of palliative care in WA and what does this mean for models moving forward?**

- Confusion and a lack of clarity on available services, expectations of palliative care and when to ask for help
- Community and staff education and awareness building on available services and what to expect
- Need for more patient and family centred models of care that listen to needs and provide holistic and flexible support
- Perception of 'giving up' or 'it's all over' once palliative care is mentioned
- Need for more integrated, multidisciplinary care networks to meet patient and family needs
- Ensure any review is evidence and data based and consider all perspectives and cohorts
- Perception of 'why did I not meet you earlier' and saviour when palliative care is provided properly
- Feelings of fear based on perceptions of what palliative care means
- Seen as the 'last resort' and death rather than a dying process and a celebration of life
- Need for culturally sensitive and appropriate care
- Concerns for how family will be involved and looked after death.

## How should WA Health measure unmet demand for palliative care in WA?

- Ask the patient/consumer, carers and families through direct conversations, surveys and patient reported outcome measures
- Conduct population level analysis of the unmet demand, including death audits
- Speak with palliative care staff and service providers, plus other services in the health sector
- Engage with a broad representation of the WA community
- Number of referrals and waitlists and shortfalls for current services
- Analysis of staffing ratios and resources for current services
- Review goals of care discussions and documentation
- Greater data collection and access by services.

## What are the education, training and information needs for community, families/carers and clinicians regarding EoL and PC in WA?

- Broader community awareness on 'what death looks like'
- Demystify what 'good palliative care is' for community and clinicians and enable better recognition and acknowledgement of palliative care as an option within clinical settings
- Better enable clinicians and patients/families to have end of life and ACP/AHD discussions in a meaningful way
- Expand education on death and palliative care to undergraduate and school settings
- Educate clinicians from the patient and family perspective
- Empower community based care, including Compassionate Communities and death doulas
- Targeted education on symptom management and medication needs
- Improve communication skills and capacity to ask difficult questions.

# Process

The event was MC'd by Andrew Jones (Department of Health)

The participants heard **opening addresses** from:

- **Marie Taylor**, Noongar Traditional Custodian – Welcome to Country
- **Hon Roger Cook**, Deputy Premier, Minister for Health and Mental Health – Ministerial Welcome
- **Elizabeth Cheong**, Wife and Carer – The Lived Experience

The participants heard a **keynote presentation** from Kathy Eagar, PCOC (graphic recording of the keynote provided below).



The participants participated in a number of online polls using their smartphones (results overpage) to explore the room's **understanding and perceptions** of palliative care.

The participants undertook the following two exercises to explore the **current context** for palliative care in Western Australia:

- Rip it Up – JSC, SHR and WACPCN Strategy
- Wave Analysis – Emerging Trends, Established Ways and Obsolete Practices.

The sessions after morning tea were spent unpacking the following **focus questions** together in small workshop groups using the smartphone technology:

- What are the priorities for community palliative care services to meet growing demand in WA?
- What is the patient perspective of palliative care in WA and what does this mean for models moving forward?
- How should WA Health measure unmet demand for palliative care in WA?
- What are the education, training and information needs for community, families/carers and clinicians regarding EoL and PC in WA?

The Summit closed with presentations and **reflections** from:

- **Pip Brennan**, Health Consumers Council
- **Lana Glogowski**, Palliative Care WA,
- **Kathy Eager**, PCOC.



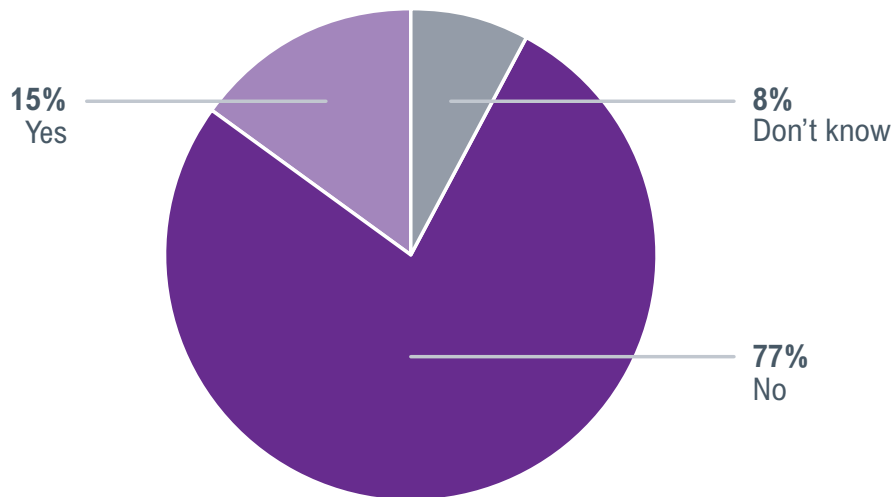
# Polls

The following images capture the polls questions the participants completed.

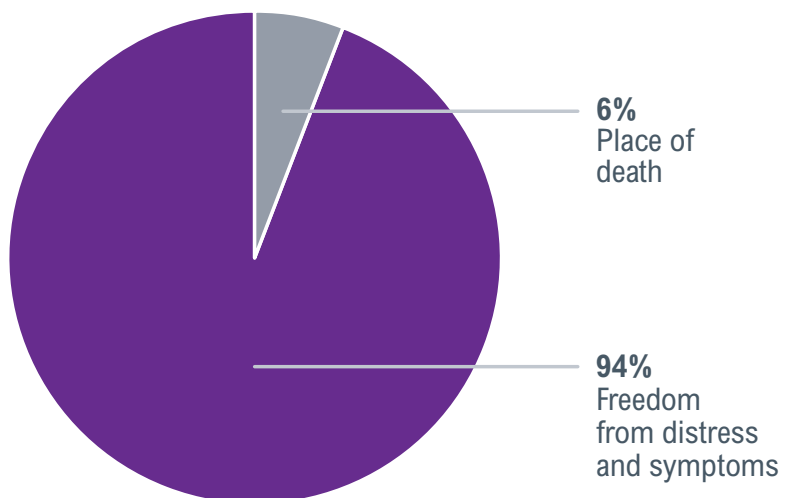
## What percentage of people prefer to die in their own home?



## Morphine makes death come sooner?



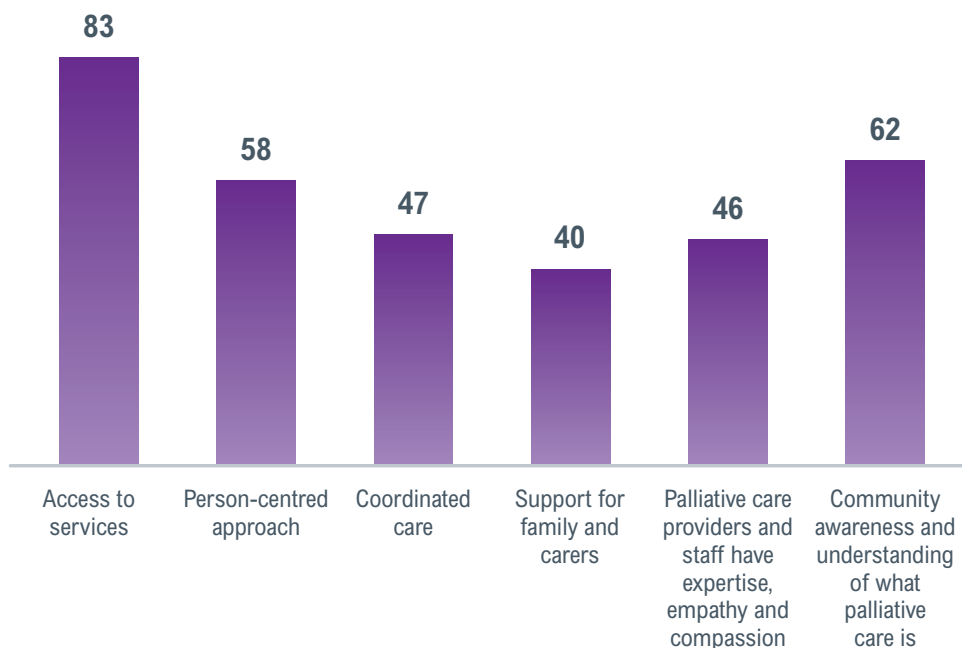
## What is more important for dying patients and their families?



## Of the people who could benefit from palliative care in Australia, what are the percentage that receive it?



## What do you think are the three biggest priorities for palliative care services in WA



## What three words come to mind when you hear or think about 'palliative care'?



# Workshop

The participants considered four focus questions informed by the recommendations from the Joint Select Committee Report My Life, My Choice:

1. What are the priorities for community palliative care services to meet growing demand in WA?
2. What is the patient perspective of palliative care in WA and what does this mean for models moving forward?
3. How should WA Health measure unmet demand for palliative care in WA?
4. What are the education, training and information needs for community, families/carers and clinicians regarding EoL and PC in WA?

The key themes and detailed responses for each question are captured in this section.

## 1. What are the priorities for community palliative care services to meet growing demand in WA?

The key themes are:

- Increased funding and resources, including more flexible funding models that enable care in both specialist and community settings
- Greater access to 24/7 palliative care and support, including clearer referral pathways, access to allied health and earlier intervention
- Increased community education, workforce capacity building and specific upskilling initiatives, especially on the process of dying (community) and the available support and referral pathways (providers)
- Improved access to appropriate services for diversity in cultural, age and socioeconomic backgrounds and experiences
- Greater partnerships, collaboration, integration and information sharing between services, particularly between formalised health services and community based services
- Greater community involvement and formal champion roles
- More consumer and family involvement in service design and delivery
- More flexible and innovative models to cope with the growing demand
- Improved support for staff wellbeing to reduce potential burnout
- Increase uptake of AHD's and end of life discussions and planning
- Greater advertisement and promotion of available services
- Tighten the definition of 'community' palliative care
- Sustainable services and staff retention in rural and remote areas
- Increased transparency and accountability of service providers

The responses in detail are:

**Increased funding and resources, including more flexible funding models that enable care in both specialist and community settings**

- Funding
- Resources
- Funding
- Funding, expertise and FTE
- Adequate funding
- Much greater investment in rural and remote areas where there are glaring inadequacies
- Funding
- More flexible funding models
- Increased funding
- Funding and resources
- Funding
- Adequate resources to service chronic diseases
- Adequate funding
- Better resources
- Funding
- Funding
- Adequate resourcing of the team to meet demand
- Funding
- Funding – make the model more flexible in terms of referral and returning patients
- Investment in community support to enable full emotional availability of workforce
- Divert funding from futile terminal care
- FTE
- Funding palliative care workers
- Funding
- Well resourced teams
- More specialist workforce
- Adequate expertise in multidisciplinary team
- Allied health roles in community palliative care teams
- Change funding model for Silver Chain
- Funding for workforce expansion
- Resources
- Funding is essential
- Funding
- More funding, more on the ground staff and more provision to build capacity; opportunity to build relationships with general practitioners; and for education of GPs; palliative care cannot be delivered by specialists alone with the anticipated growth

- More doctors recruited and trained
- More doctors with expertise
- Quality of care
- Infrastructure
- Expertise
- Adequate resources.

**Greater access to 24/7 palliative care and support, including clearer referral pathways, access to allied health and earlier intervention**

- Referral pathways
- Access
- Access
- Access to services
- Access to specialist paediatric advice
- Access to allied health
- Accessible to all
- Access
- Access to services
- Access to palliative RT medications and resources in rural and regional areas
- 24 hour access to advice or home care
- Access in real time where they need it. Reduce wait list for palliative care beds
- 24 hour care for aged care facilities. Allowing patients to make informed decisions.
- Allied health access
- Human resources
- Access to 24/7 care contact
- Paediatric patients don't have access to 24/7 advice and support
- 24 hrs, 7 days a week
- Early referrals are ok
- Shared with other providers not just silver chain
- Greater range of service providers Access to good palliative care what is good palliative care. Who decides who gets palliative care specialist
- Access to specialist palliative care for patients with longer trajectories of disease
- Access
- Accessibility.

## **Increased community education, workforce capacity building and specific upskilling initiatives, especially on the process of dying (community) and the available support and referral pathways (providers)**

- More education
- Career support and education
- Capacity building
- Workforce development and education
- Training
- Capacity building and mentoring
- Appropriate training for staff and community education
- Community education
- Education of public regarding the process of dying
- Community education
- Building workforce education support supervision
- Education to acute care providers
- Community education
- GP training
- Training and education
- Greater investment in education across multiple professional disciplines and in communities
- Better and more frequent/early education for the public
- Training and expertise of staff
- Care giver upskilling programmes/ support
- Resourcing Education and training to GP and RACF staff
- Educate health professionals to recognise death
- Increased use and education of same for patients, families and service providers
- Developing a Centre of Excellence for training and research
- Capacity building and mentoring
- Community education
- Consistent approach to workforce capability of 'palliative approach'
- Helping community understand what palliative care is
- Education for workforce and community.
- Education for migrants and refugees
- Funded education for medical, nursing and allied health staff
- Investment in training and education for staff in age care facilities to promote forward planning and symptom assessment and management
- More expert and trained staff to support patients and families and provide education
- Need education re appropriate referrals
- Education re advanced care directives
- We need a Centre of Excellence in WA for Palliative Care Training-Multidisciplinary facility.
- All disciplines need to train their students in dying conversations.

## **Improved access to appropriate services for diversity in cultural, age and socioeconomic backgrounds and experiences**

- Culturally appropriate
- Cultural awareness
- Culturally appropriate care
- Aboriginal input into service development
- Culturally sensitive care
- Age appropriate
- Age appropriate
- Paediatric hospice beds
- Cultural and age appropriate
- More expert staff allocated time to reach out to aboriginal communities to explain what palliative care is and establish trust.
- Sensitivity to CALD groups
- The important right for people to go out on country
- Culturally appropriate
- Provision for relatively disadvantaged populations (e.g. mental health, homeless, low socioeconomic groups)
- Allied health and welfare officers for the disadvantaged patient
- Access across socio economic need
- Negative impact on family when there is medical intervention rather than the choice to have access to Traditional Medicine
- Recognition that in paediatrics hospice would also provide respite services as well as support to family, siblings etc
- Aboriginal input into planning
- Access to age and diagnosis appropriate specialist advice
- Culturally responsive care
- Paediatric patients don't have access to hospice
- Monocultural
- Culturally competent, multi faith and inclusive

## **Greater partnerships, collaboration, integration and information sharing between services, particularly between formalised health services and community based services**

- Sharing of information across health care providers
- Integrated with other services (ambulance/hospital/GP/aged care, any other relevant health services)
- Coordination of specialist palliative care.
- Better communication between care providers
- Enhanced care coordination
- Stronger links between metro specialists and regional services
- Improved collaboration and partnerships

- Partnership
- Communication between private hospitals and community including regional patients
- Joint working with volunteer organisations
- More partnership be formal health services and informal community services
- Integration of service models to provide holistic care and maximise all funding options
- Embed in community
- Consideration of several other organisations who have ability to provide community palliative care
- Collaboration with all home care providers
- Service integration and care coordination across care agencies
- Communication between services
- IT system for communicating clinical information between services (inpatient and ambulatory and community providers)
- Sharing information about the patients goals of care and advance care planning across health settings
- No systems to see documents pertaining to patient values/ goals of care and preferences for care.

### **Greater community involvement and formal champion roles**

- Champions within the community
- System cannot do it alone needs greater community involvement
- Community role – more partnerships between formal services
- Embedded in community
- Community champions
- Community approach verses a medical approach
- Form community focus groups
- We need to establish conversations in wider community to talk about living well and dying well
- Establish champions to move messages forward.

### **More consumer and family involvement in service design and delivery**

- Patient-centred care
- Survey for outcomes from families
- Family support
- Partnership with stakeholders and consumers
- Family and carer support
- Consumer focused models – diversity
- Consumer aware of the rights and choices
- We need better conversations with the family and patient
- Consumers don't know what they don't know. There needs to be a much greater commitment to co-design services with consumers and families
- Ask the consumers
- Ask the staff that care on the frontline and ask the consumer experience of the services they receive



### **More flexible and innovative models to cope with the growing demand**

- Flexible models? Day hospice
- Innovative and sustainable models to cope with need
- Compassionate community model
- Natural Therapies
- Being flexible and responsive to community needs
- Integration of holistic but evidence based therapies other than medical
- Public health approach to palliative care
- Palliative care clinics for care delivery
- Home visiting medical care
- Recognising and triaging palliative patients in the ED setting
- Improved delivery and access to in-home care packages.

### **Improved support for staff wellbeing to reduce potential burnout**

- Support for staff working in palliative care
- Appropriate processes to manage staff burnout and mental health
- Future planning in the workforce
- Workforce wellbeing
- Increased stress on services
- Support for health professionals
- Care of staff.

### **Increase uptake of AHD's and end of life discussions and planning**

- AHDs
- Increased uptake of advance care planning and AHDs
- AHD – future care need
- Improving palliative care and end of life planning at the front end of hospitalisation
- Better goals of care planning at front end of admission and end of life trajectory
- Need more goals and values based discussions and documents
- Poor discussion about end of life wishes and goals when it is clear the patient is failing
- Better identification of EoL during advancing co and multi-comorbid illness
- Health professional to be comfortable about talking about death. Competence in the workforce.

### **Greater advertisement and promotion of available services**

- Advertising of services available
- WA Health need to advertise in the West Australian newspaper
- Media advertisement of services
- Greater awareness about what palliative care is and who services are for, not just cancer

## **Tighten the definition of ‘community’ palliative care**

- Definition of community palliative care needs to be tightened
- Important to define community especially in relation to hospice care.

## **Sustainable services and staff retention in rural and remote areas**

- Community – out bush for people outside of Perth (beware of metro centricity)
- Retaining of staff and attraction of staff in rural areas
- IT, telehealth and delivery of remote services.

## **Increased transparency and accountability of service providers**

- Transparency with community
- Accountability and transparency of service providers
- Accountability of aged care who deliver a palliative approach in nursing homes and packages.

## **Other comments**

- Expectations
- Earlier referrals from specialists to pall care (especially in private practice)
- Critical end stage support for families
- NOT hospice for small numbers
- Living well to end well
- Early intervention through more staffing for care and education. Staff retention especially in regional/rural areas (staff working outside of role, support, burn out). Support from larger specialist pall care services to regional services.
- Identify gaps in services
- Safe housing for palliative care
- Recommend access to silver chain hospice for 365 day prognosis, not 60 day
- Recognition of GP role and when to refer on – support for GPs
- Clinical supervision for all
- Residential services for longer palliative periods
- Family support in home
- Greater role for primary care
- Prolonging life through heroic care
- Preventing carer burnout
- Care for dementia patients
- More PC multi-disciplinary specialists
- VAD – informed consent and clarification
- Reduce financial
- Burden
- Disability VAD will work for them
- Death doulas to support palliative teams and families

- Mental health assistance with decision making
- GP to work in an MDT process
- Specialists palliative care for aged care in the rural
- Spiritual carers
- Clearer referral pathways including patient and families
- Health care cards for patient at end of life
- Choice and dignity
- Assumption it will be there when needed
- Is VAD is part of palliative care?
- Only for cancer
- I'm dying, this is the end
- Future care
- Will not be able to access treatment
- Palliative care for those with cancer
- No knowledge
- Reference to palliative care means nothing more can be done
- Death squad
- Alienating
- Why did it take so long time for us to meet you?
- The patient is not ready
- Fear and uncertainty
- Cultural needs
- Palliative care is only accessed when you are dying
- Once they understand what we do they are so grateful for our support
- Audit hospital deaths of children who could have received palliative care
- Uptake of advance health directives
- Complete random sample of death certificates to see who received palliative care
- Hospital palliative care teams could compare all deaths with palliative care deaths
- How many predicted deaths access palliative care

## 2. What is the patient perspective of palliative care in WA and what does this mean for models moving forward?

The key themes are:

- Confusion and a lack of clarity on available services, expectations of palliative care and when to ask for help
- Community and staff education and awareness building on available services and what to expect
- Need for more patient and family centred models of care that listen to needs and provide holistic and flexible support
- Perception of 'giving up' or 'it's all over' once palliative care is mentioned
- Need for more integrated, multidisciplinary care networks to meet patient and family needs
- Ensure any review is evidence and data based and consider all perspectives and cohorts
- Perception of 'why did I not meet you earlier' and saviour when palliative care is provided properly
- Feelings of fear based on perceptions of what palliative care means
- Seen as the 'last resort' and death rather than a dying process and a celebration of life
- Need for culturally sensitive and appropriate care
- Concerns for how family will be involved and looked after death

The responses in detail are:

### **Confusion and a lack of clarity on available services, expectations of palliative care and when to ask for help**

- Confusion
- Denial
- Lack of clarity
- Not know
- For cancer only?
- Confusing. Not enough knowledge or education. When they get an end of life diagnosis it's what do I do now
- Not sure when to ask for help
- Patients are unclear of what is available
- Lack of openness
- Palliative care equals VAD
- Consumers don't know what they don't know, there needs to be a much greater commitment to meaningful co-design of services with consumers and families
- Mismatch of expectations and reality
- Terminology can be confusing for patients and families
- Confusion about what palliative care is
- Clarity of referral and access
- Not enough knowledge about palliative care
- Misunderstanding of the new 'hospice' model
- Palliative care can be years months not just end of life

- Only needed for complex symptom management
- Not understanding that no one can predict time of death
- Language is clear and common understanding of terms

### **Community and staff education and awareness building on available services and what to expect**

- Community education awareness
- Community education sessions in local libraries / community centres
- Education is key
- Education for community and health professionals
- More education and knowledge required
- We've got a lot of educating the general public to do to elevate the level of discussion/debate around end of life/palliative care.
- Need for broad based education for community and all health professionals
- Great need for education and informed awareness
- Education and support from GPs, doctors, health professionals
- Community education and engagement about what palliative care is, what we can do, outcomes, expertise
- More education. Use newspaper as aged read newspaper not generally digital media.
- Education conveyed through media
- Educating patients families and practitioners about what the different stages of palliative care can be
- Starting the conversation early
- Education
- Discussion about EOL. Making own decisions
- Education and support for my family
- Education and training of providers to individualise care
- Education of health professionals from undergraduate level and throughout
- Huge public health campaign needed
- Palliative care is understood to be EOL care by public. Education needed to change this perception.

### **Need for more patient and family centred models of care that listen to needs and provide holistic and flexible support**

- Care is person centred and there are more choices
- Patient centred
- Not a patient, a person who has a life which is ending.
- Where, when, how they want it
- Individualised
- Patient informed of options
- Pt informed models: community education
- Co design models moving forward
- New model for family support
- In consultation with the patient and family

- Patients need to be empowered in process
- We need to undertake the independent review first, then we'll know more about what models are requires. The independent review must include consumers and family members
- Ownership of choices is not clearly defined
- Patients don't feel palliative care is individualised
- Prefer to be at home
- Model needs to be inclusive of all perspectives – inclusive and respectful
- More support groups for family even after death
- Consumer model of care
- Need innovation (co-design with people with life-limiting illness, families and bereaved)
- Following up with families for feedback following experience
- Listen to patients
- Speak with families
- Consult people with life-limiting illness – they may not even realise they have palliative care needs.

### **Perception of 'giving up' or 'it's all over' once palliative care is mentioned**

- Giving up
- It's all over once palliative care is mentioned
- Last few days of life only
- I am dying...
- Death, as opposed to dying.
- Giving up
- Mixed, uncertain, not ready yet
- Giving up
- Giving up
- Loss of control and decision-making for parents
- Giving up
- Death
- More end stage perception not journey.

### **Need for more integrated, multidisciplinary care networks to meet patient and family needs**

- Cohesive working
- Needs to be flexibility between settings
- Needs to be early
- Holistic care, interdisciplinary support network
- Palliative care pathways for GP's and other health workers
- Yes, a new model of understanding is required
- Models going forward – it takes time for processes to get in place
- Patients expect seamless, coordinated care. We need to do a better job of planning services with that in mind

- Communication
- Multidisciplinary
- Models of care need to be flexible, responsive
- GP time and funding to discuss AHD and goals of care with patients routinely
- Why won't my oncologist refer me for palliative care?
- Future: models which are flexible to preference and sustainable
- Navigators
- Patients expect us to have all the information that matters.

### **Ensure any review is evidence and data based and consider all perspectives and cohorts**

- Benefits and risks
- Standard around when to access and care coordination.
- Needs more balanced information during debate on palliative care. Highlighting positive outcomes as well as negative
- We need to be more open minded – the three models of care reflect the system, not patient and family choices. We have to meaningfully include the wider community in designing services, and across WA
- Funding model that accommodates long and complex discussions
- Need data (quantitative and qualitative) to inform what patients want
- Investment in funds and policies to implement change and new models that are used state wide
- Only 30 per cent of patients are impacted by cancer – think about other issues
- Demand vs supply of high quality services.
- Needs analyses
- Retrospective cohort study
- Prospective cohort study
- Audits
- Data
- Quality indicators
- Measure timeliness of referral timeline of review
- Use of national Clinical Indicators in paediatrics
- Audits
- Death audits.

### **Perception of 'why did I not meet you earlier' and saviour when palliative care is provided properly**

- Quality of life
- Life affirming, relief,
- A means to comfort in a distressing time
- Supportive
- Saviours
- Comfort

- “Thank god you are here”
- “Why did I not meet you earlier”
- What is life about?... My life!
- My life my choice.

### **Feelings of fear based on perceptions of what palliative care means**

- Scary
- Loss of hope
- Fear
- It is scary
- Fear towards palliative care
- Fear that palliative care will not hasten death
- Fear and confusion around palliative care (of death, suffering, preconceived ideas)
- Based on perception of experiences
- Fear that palliative care will hasten death (morphine).

### **Seen as the ‘last resort’ and death rather than a dying process and a celebration of life**

- End of Life care
- Last resort
- Confronting
- “There’s nothing else we can do” so let’s get palliative care
- Don’t need it until dying
- ‘Palliative’ = death and dying only, not the journey
- Normalising death
- Normalise death and the celebration of life
- Palliative care is for EOL
- Inability to move past the word palliative.

### **Need for culturally sensitive and appropriate care**

- Culturally appropriate
- “If I go get care I won’t return to country”
- Culturally sensitive
- Cross cultural sensitivity
- Indigenous need – culturally appropriate (place of death important)
- Doctors don’t understand that they want to return to country
- Younger Indigenous – chronic illness management
- Advocacy for minority groups.



## Concerns for how family will be involved and looked after death

- Family disruption
- What now. Who is going to care for my family
- What will become of my family when I'm gone
- Support family networks
- Expensive
- Time limits.

## Other comments

- Advanced health directive
- Unrealistic expectations care given funding and resources
- Morphine infusion
- End of life drug relief
- Silver Chain
- Loss of primary team and associated long-term relationships
- Future models – social disadvantaged
- Needing to go to acute care when carer not available at home
- Respect individual choices – we want different things, reflecting our different cultures and experiences.
- Positive in some areas increases confidence and uptake of service
- Lack of disease related expertise
- Accepting that death and dying is part of life's journey, and needs Love included as part of management.
- Dignity of risk
- More demand for services ensuring comfort and dignity for all
- Recognise not all patients need specialist palliative care
- Talk to the people providing services.
- Ensure patients receiving treatment in the private sector are included
- Identify what is specialist pall care and who needs it
- Resourcing.

### 3. How should WA Health measure unmet demand for palliative care in WA?

The key themes are:

- Ask the patient/consumer, carers and families through direct conversations, surveys and patient reported outcome measures
- Conduct population level analysis of the unmet demand, including death audits
- Speak with palliative care staff and service providers, plus other services in the health sector
- Engage with a broad representation of the WA community
- Number of referrals and waitlists and shortfalls for current services
- Analysis of staffing ratios and resources for current services
- Review goals of care discussions and documentation
- Greater data collection and access by services.

The responses in detail are:

#### **Ask the patient/consumer, carers and families through direct conversations, surveys and patient reported outcome measures**

- Listen to consumer
- Ask the patient
- Patient and family carer experience surveys
- Carers family
- Consult the family
- Feedback survey
- Ask the patient
- Consumer feedback
- Patient reported outcome measures
- By undertaking a thorough, independent analysis of the experiences of families of the care their loved ones have received, and making this the starting point. NOT what the funding streams are!
- Post evaluations of family
- Speak to care receivers
- Patient/family input
- Asking patients about experience alongside family/carer experience
- Ask consumers, community, families and existing range of service providers
- Talk to families
- Talk to families support organisations
- Simple survey for family
- Communication with consumers
- Specific survey that addresses patients at each level of their disease progression
- Retrospective qualitative survey of consumers and then act on it.

## **Conduct population level analysis of the unmet demand, including death audits**

- Resources versus palliative population
- Demand vs supply
- How many people with predictable death had access to high quality multidisciplinary care and for how long before death.
- Research
- Regular research audits, all data much be disaggregated by gender, ethnicity, age, regional and remote
- Do death audit within WA like other states
- Death audit of all deaths in WA
- Overlay population approach (i.e. prevalence of predictable death) with research of person preference to uptake palliative services
- Audit hospital deaths
- Compare population numbers and disease burden to provision of palliative care providers.
- Death audit on hospital.
- Population
- Focus statistical research on known high mortality populations.
- Use PCOC as a tool to measure frequency and quality of death
- Death audits with the right metrics
- Percentage of expected deaths not receiving palliative care
- Death audits.

## **Speak with palliative care staff and service providers, plus other services in the health sector**

- Talk to the people providing the services
- Speak to people who work in service
- Talking to service providers
- Discussions with workforce at the coal face
- Survey for rural and remote services to capture premature or unnecessary hospital admissions due to lack of community palliative care
- Knowledge of other health professions about palliative care.

## **Engage with a broad representation of the WA community**

- Community engagement
- Talk to the community
- Community awareness
- Ask the wider community – go deeper into the regions – do this as a place based investigation, not a statewide (aka Perth) based investigation
- Community survey looking at their understanding and receptivity of palliative care
- Survey community regarding their knowledge of service availability
- It shouldn't be the most advantaged community members who are consulted on what is needed – it becomes an echo chamber – you need to engage the right people – the most vulnerable – to get the right models.

## Number of referrals and waitlists and shortfalls for current services

- Number of referrals
- Bit controversial, but number of people pushing for voluntary assisted dying
- How many patients
- Capture referrals to palliative care and capture who wasn't (died from expected cause) and why not referred
- Reporting on waitlists and declined referrals (e.g. what services were we unable to provide) and a central reporting tool.
- Survey family who have had a family member die in WA not under the palliative umbrella
- Survey of how many patients are referred but die or do not receive palliative care before they die
- Process mapping current systems of care and referrals to pc
- Collate instances of care shortfall/staffing issues/lack of resources
- Referrals declined.

## Analysis of staffing ratios and resources for current services

- Review of current services
- Ratio of palliative care consultants to patients vs other specialities
- AMA to look at numbers of specialists ratio in palliative care
- Benchmarking against international best practice i.e. numbers of staff numbers of patients.

## Review goals of care discussions and documentation

- Goals of care discussions
- Planning and documentation of EoL wishes
- Goals of patient conversations and documents
- Goals of care is so needed.

## Greater data collection and access by services

- Accessible data for all
- 60–70 per cent of deaths are predictable and more than 50% should get specialist palliative care. This is our target
- Mechanisms to collect data need to be imbedded into service. How do we collect unmet need data?

## Other comments

- Research in vulnerable populations i.e. paediatrics or indigenous
- Both health professional and community collaborative
- Unplanned hospital admission in last month of life.
- Ongoing reviews
- Shared funding equally for country and metropolitan
- Listen to the feedback given to End of Life Inquiry
- Repeated surveys through palliative care journey

- six months after surveys so they can deal with grief first
- Communication to all
- Hospitals and health services mentoring end of life care and general health teams being mentored at point of care (e.g. how to have a goals discussion or relief of dyspnoea in cops in the ED)
- Better looking at palliative care workflows or the need for that in health services.

#### **4. What are the education, training and information needs for community, families/carers and clinicians regarding EoL and PC in WA?**

The key themes are:

- Broader community awareness on 'what death looks like'
- Demystify what 'good palliative care is' for community and clinicians and enable better recognition and acknowledgement of palliative care as an option within clinical settings
- Better enable clinicians and patients/families to have end of life and ACP/AHD discussions in a meaningful way
- Expand education on death and palliative care to undergraduate and school settings
- Educate clinicians from the patient and family perspective
- Empower community based care, including Compassionate Communities and death doulas
- Targeted education on symptom management and medication needs
- Improve communication skills and capacity to ask difficult questions.

The responses in detail are:

##### **Broader community awareness on 'what death looks like'**

- Community awareness campaign
- Education re the process of death
- Teaching about dying with dignity
- More public forums
- Community need to know what "death looks like"
- Centres around understanding
- Positive stories
- Awareness
- Normalising death
- Families and carers need to know what dying looks like and medication management
- Teach them about dying and death
- Change view in the community that death is not a failure
- What dying looks like
- Mainstream and normalise death
- Talking about death as part of life
- Topics for education – normal dying process, recognising EOL, normalising death, not fearing
- Word of mouth/talk to community groups and advocates for discussion on death

- Targeted communication sessions
- Portrayal of illness and death the media to reach the wider population
- What does dying look like and what happens next practically
- Understanding death is an integrated part of life
- Communication!
- Death is part of life
- No-one can predict time of death
- Understanding the life cycle and understanding expectations versus reality.

### **Demystify what ‘good palliative care is’ for community and clinicians and enable better recognition and acknowledgement of palliative care as an option within clinical settings**

- Symptom myths
- What good holistic palliative care is!
- Palliative care is not dying
- Clinicians being educated in the area
- Difference between symptom management and end of life care aspects of palliative care
- What palliative care looks like and what it can deliver
- Demystify what is palliative care
- Clinicians collegial acknowledgment of palliative as a speciality and essential role in all care (i.e. it is a unique set of skills with specific training)
- Define the difference between EOLC and PC (looking after dying people does not always equal PC)
- Community members do not understand palliative care – advise them of what they can expect, how palliative care differs from end of life care
- Information on what a palliative care service can provide for patients and families over their journey, not just EOL!
- Separate palliative care from dying
- Myths around palliative care
- How palliative care can add value to life for the person dying and for family members.
- Establishment of different levels or stages of PC (where at each level it’s established what may need to be addressed for the patient to live the life they want to)
- Difference between adult and paediatric Palliative Care – they are not the same
- Need for promotion of informed awareness of quality holistic palliative care among clients/ community and health professionals
- Clinicians- education about recognising dying patient, advanced health directives, what palliative care can provide, what they can provide. Continue PePA placements, extend diploma palliative care
- Where to start
- It is actually possible to be discharged from palliative care services – it means ‘alleviating symptoms without removing the cause’, not ‘dying’.

## **Better enable clinicians and patients/families to have end of life and ACP/AHD discussions in a meaningful way**

- Advanced Care Planning and what is palliative care to community
- Advance Care Planning
- How to have EoL conversations
- How to have ACP conversations that are meaningful
- Advance Health Directive
- What the EoL planning options are and when they are helpful
- Anticipatory care planning and prescribing
- Bus for ACP driving across WA
- Using goals of patient care to identify and educate
- ACP
- Doing advanced directives whilst patient still well
- AHD
- Goals of Care conversations at point of care or in anticipation of need
- Training for clinicians to overcome reluctance to explain palliative care and refer patients on for fear of inducing 'despair and trauma'.

## **Expand education on death and palliative care to undergraduate and school settings**

- Part of undergraduate education
- Does it need to start being introduced in schools?
- How early do we start talking about death?
- Early education in high school
- University training in palliative care for Allied Health
- Incorporate palliative care into undergraduate training
- Improving health literacy in schools, TV, community centres, health care providers and facilities.

## **Educate clinicians from the patient and family perspective**

- Educate clinicians on cultural beliefs and aspects of death and dying
- Real time patient specific education
- Education around social implications
- "My life in your hands" requires empathy, understanding and truth.
- Educate palliative specialist on different consumer and cultural perspectives on death and the dying process and how that impacts families and the wider community
- Communication skills for all health staff to discuss with families and patients
- CPD options which are delivered by families/carers
- That needs are fluent and fluctuating.

## **Empower community based care, including Compassionate Communities and death doulas**

- Compassionate Communities
- Holistic education programs
- Palliative care clinicians need to be consultative not empire builders
- Targeted community information sessions in the remote and regional areas by the palliative teams
- Specialists and policy makers have to hear what community have to say (the medical perspective differs from the community and there can be a large knowledge and class gap)
- Empowering people to care for each other in the community
- Death doulas to discuss early
- Compassionate Communities.

## **Targeted education on symptom management and medication needs**

- Education re medicines used
- Educational resources
- Accurate symptom assessment skills in order to effectively communicate with GP's and specialist palliative care team
- Symptoms around end of life
- Clinicians need to learn when further investigation and resource utilisation is futile
- Identifying different symptoms and establish related management.

## **Improve communication skills and capacity to ask difficult questions**

- Communication courses
- Knowledge on where to go to ask a question
- Communication skills
- Communication.

## **Other comments**

- Structured
- Consistency
- Learning needs analysis
- Access 24/7 to specialist paediatric Palliative Care
- Whatever the Information, it must be written in plain English and translated
- Specialist palliative care needs to be specialist specific disease and age related
- Continue current education initiatives (i.e. Quocca)
- Health and allied people need education re end of stage process
- Easily accessible portal and course
- Discuss clearly with carers and families how people die
- Normalise teaching the palliative approach to all health professionals to embed into normal practice
- Population health



- Using example of how media covers funeral planning, perhaps the use of such avenues to disseminate information would be useful
- Increase staff to clinicians have time to educate
- Guides of where to get help
- Coping with not knowing
- Consistency of palliative rotations in medical, nursing and allied health training programs
- Rural and remote area support
- Higher level training as opposed to repeated into courses for all allied health
- COTA providing education to community
- Palliative care providers providing education to COTA
- General physicians re looking at the model and link to PC
- Understanding the clinical indicators of dying
- 24/7 access to disease and age appropriate specialists
- Teach specialists, especially oncologists, that palliative care can be delivered alongside chemotherapy
- Education for support services as they are also involved in care (they need support too)
- Allowing the person die – it's okay to die / permission
- Culturally appropriate care education
- How to access advice, resources and education
- Practical information what needs to happen after patient has died
- 24/7 access to primary teams
- Having a key worker
- Paediatric Palliative Care at services without specialisation
- Aboriginal Health Workers trained in palliative care
- An app
- Pastoral support learning sharing
- Families /carers need practical assistance when they need it not in six months
- Employers and resources
- App for access to care services, fact sheets, webinars etc.





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

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