



**PalliativeCare**  
WESTERN AUSTRALIA

Community Education | Sector Development | Advocacy

# Submission to the Joint Select Committee on Palliative Care in Western Australia

10 July 2020

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## 1.0 Introduction

The Parliament of Western Australia appointed a Joint Select Committee on Palliative Care in Western Australia on 28 May 2020. The Committee's Chair is Mr Chris Tallentire, MLA. The Committee will report back to the WA Parliament by 19 November 2020.

The inquiry will examine:

- (a) Progress in relation to palliative care, in particular the implementation of recommendations made by the Joint Select Committee into End of Life Choices;
- (b) Delivery of services associated with palliative care funding announcements in 2019-20;
- (c) Delivery of palliative care into regional and remote areas; and
- (d) Progress of ensuring greater equity of access to palliative care services between metropolitan and regional areas.

The Committee wrote to Palliative Care WA on 12 June 2020 inviting the organisation to develop a written submission to their inquiry and requesting a submission by 10 July 2020.

## 2.0 Palliative Care WA (PCWA)

Palliative Care WA is the peak body for the palliative care sector in Western Australia. A not-for-profit and member-based organisation, PCWA is also member of Palliative Care Australia.

The vision of the organisation is **quality palliative care for all** with a mission to consult, inform, support and collaborate with community and the palliative and aged-care sectors to ensure access to quality palliative care for all Western Australians.

Current priority strategies include:

- Engaging and empowering community;
- Supporting people needing palliative care;
- Supporting carers, families and friends;
- Advocating & collaborating with the palliative and aged care sectors; and
- Maintaining a sustainable peak body.

## 3.0 Methodology

PCWA has highly valued the opportunity to consult as extensively as possible with both the broader community and palliative care and aged care service providers to inform the Joint Select Committee on Palliative Care. Unfortunately the time-line to undertake these consultations was very tight i.e. 20 business days from receipt of the letter inviting submissions to the close-off date. While PCWA was grateful for the agreed extension to Monday 13<sup>th</sup> July, it has limited our opportunity to consult as extensively as we would have liked.

However, the number of organisations and members of the general public who engaged with our consultations as well as the quality of the discussions have been very encouraging. PCWA would like to acknowledge and thank the co-facilitators from a broad range of agencies who made such a valuable contribution with minimal notice.

These consultations have not only encouraged conversations about activities carried out by the WA Parliament i.e. previous and current Joint Select Committees, but also reflections about advance care planning; the provision of quality palliative care; support for dying patients and their families; and coping with death, grief and loss. Please see below a table summarising the consultation approaches undertaken, the co-facilitators engaged and attendance numbers and/or survey responses achieved.

**Table 1: Summary of consultations facilitated by PCWA**

	<i>Date &amp; time</i>	<i>Approach</i>	<i>Focus</i>	<i>Co-facilitators</i>	<i>Numbers</i>
1.	Monday 6 July from 11-12.30pm (90 minutes)	Zoom forum	Residential aged care	<ul style="list-style-type: none"> <li>Ed Gaudoin – Metro Palliative &amp; Care Consultancy Service (MPaCCS); and</li> <li>Carol Douglas – Residential Care Line (RCL).</li> </ul>	8 participants 2 presenters 3 PCWA staff <b>13 Total</b>
2.	Tuesday 7 July from 9-10.30am (90 minutes)	Zoom forum	People with disabilities	<ul style="list-style-type: none"> <li>Michelle Frost – People with disabilities WA (PWdWA)</li> </ul>	6 participants 1 presenter 2 PCWA staff <b>9 Total</b>
3.	Tuesday 7 July from 3.30-5pm (90 minutes)	Zoom forum	LGBTIQA+ communities	<ul style="list-style-type: none"> <li>June Lowe – GLBTI Rights in Aging (GRAI)</li> </ul>	5 participants 1 presenter 2 PCWA staff <b>8 Total</b>
4.	Wednesday 8 July from 9-10.30am (90 minutes)	Zoom forum	Aboriginal communities	<ul style="list-style-type: none"> <li>Lynette Henderson-Yates (Derby Aboriginal Health Service (DAHS) &amp; Aboriginal Health Council of WA (AHDWA)</li> </ul>	8 participants 2 PCWA staff <b>10 Total</b>
5.	Wednesday 8 July from 12 - 1pm (60 minutes)	Zoom forum	Regional & rural WA	<ul style="list-style-type: none"> <li>Dr Kirsten Auret, WACHS, WA Health; and</li> <li>Stephanie Barrett – WACHS, WA Health</li> </ul>	10 participants 2 presenters 3 PCWA staff <b>15 Total</b>
6.	Wednesday 8 July from 4.30-6pm (90 minutes)	Combined face-to-face and Zoom forum	Palliative care sector	<ul style="list-style-type: none"> <li>Dr Elissa Campbell – President, Palliative Care WA (PCWA);</li> <li>Dr Alison Parr – WACPCN</li> <li>Andrew Allsop – Palliative Care Australia (PCA) &amp; Silver Chain;</li> <li>Clare Mullin – Health Consumer Council (HCC)</li> </ul>	4 panel 22 in person 17 via Zoom 2 PCWA staff <b>45 total</b>
7.	Thursday 9 July from 9.30-11am (90 minutes)	Zoom forum	Culturally and linguistically diverse communities	<ul style="list-style-type: none"> <li>Vivienne Pillay – Ethnic Communities Council WA (ECCWA)</li> </ul>	7 participants 1 presenter 2 PCWA staff <b>10 total</b>
8.	Thursday 9 July from 12-1.30pm (90 minutes)	Zoom forum	People experiencing cognitive decline	<ul style="list-style-type: none"> <li>Jason Burton – Alzheimer’s WA</li> </ul>	12 participants 1 presenter 2 PCWA staff <b>14 Total</b>
9.	Closed Friday 10 July	E-survey	Sector & community	Tool developed by Palliative Care WA and distributed via Survey Monkey	<b>45 total</b>
<b>TOTAL</b>					<b>169</b>

Demographic details were not recorded for the consultation processes but the following information was gathered from the survey.

**Table2: Demographic characteristics of survey respondents**

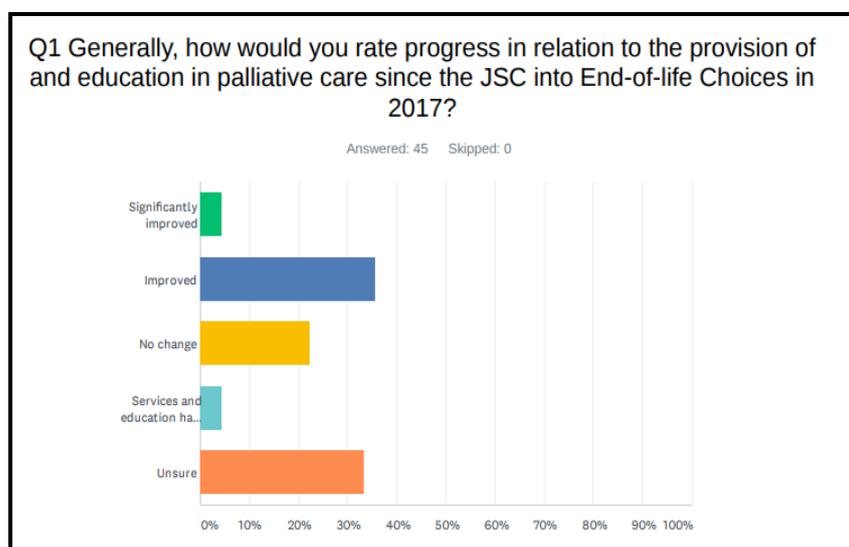
<i>Reason for interest</i>	<i>Location</i>	<i>Age</i>	<i>Gender</i>	<i>Cultural identity</i>
Work in palliative care – 42%	Metro – 78%	30 to 44 years – 16%	Female – 87%	Culturally diverse – 7%
Work in aged care – 20%	Regional – 13%	45 to 59 years – 47%	Male – 13%	Aboriginal – 5%
Community member – 22%	Rural – 9%	60 to 74 years – 35%		Other – 87%
Carers – 16%		75 years plus – 2%		

## 4.0 Progress in relation to palliative care

### 4.1 Survey

While 38% of survey respondents reported “some progress” in relation to provision of and education in palliative care, 29% indicated that “no progress” had been achieved and 27% were unsure.

**Table 3: Survey feedback on palliative care**



PCWA understands that progress has been made in implementing the recommendations of the Joint Select Committee on End-of-Life Choices and that substantial financial investment by the WA Government was undertaken in 2019. PCWA also recognises that much of the work is in very early stages and that it is likely that significant progress will occur over the next 2-3 years.

However, a feature of many of the responses to both the consultations and survey was that responders are “unsure” of the status of most initiatives. PCWA highly recommends that the Joint Select Committee on Palliative Care encourages WA Health to regularly and comprehensively communicate progress on recommendations and other initiatives to both health professionals and the broader community. This will have the benefit of increasing the profile of palliative care, increase awareness and knowledge on service delivery and educative opportunities as well as reassuring all interested parties that positive changes are being progressed.

## **4.2 Consultations**

Below is a high level summary of consultations with a range of key stakeholders and their perception of progress in relation to palliative care. PCWA acknowledges that for many specific communities this was their first discussion and that it would be a high level consultation at best. However, hopefully this would be a positive beginning and that further meetings will be scheduled in the near future.

### **4.2.1 Sector**

Representatives of the palliative and aged care sectors agreed that progress has been made. However there was also recognition that considerable work was still required to ensure that all community members have the opportunity to engage and understand the importance of advance care planning; are aware of and have ready access to palliative care services that reflect their wishes; and with grief and loss services to adequately support those who live on.

Key issues identified included:

- **Advance care planning**  
The critical need for widely available community education on advance care planning that emphasises an incremental and dynamic process that begins with an exploration of values and priorities along with ongoing conversations with family, friends and health providers and then the completion of documentation as appropriate;
- **Community palliative care**  
Community palliative care needs further funding as a matter of upmost urgency as most people with life limiting illness live at home and not in hospital or a palliative care unit. Community services remain overwhelmed and adequate funding needs to be allocated to ensure they can respond to demand.
- **Carer Support**  
It is important to recognise that carers are critical to the delivery of palliative care and in particular to community palliative care in the home setting. The provision of respite is an ongoing challenge but vital to adequately supporting the carer role.

The provision of emotional support and other social work and allied health services is also an important consideration, as is the provision of training to carers to enable them to deliver clinical supports in the home. Carers also require timely access to practical advice and support to assist them navigate the system and enable them to support their loved ones.

- **Community engagement**

We need to recognise the power and value of engaging with community (including health professionals) to facilitate better palliative care and end of life processes. This is currently being demonstrated through an enthusiastic uptake by community across WA of the Compassionate Communities approach with which PCWA is actively engaged. We also acknowledge and applaud the implementation of recommendation 9 i.e. an independent review, from a patient's perspective, of the three models of care being managed by Professor Samar Aoun. Palliative care is everyone's business and community engagement in this conversation is central to ensuring progress.

- **Recognition of diversity**

Currently there are many groups within the WA community who do not have access to quality palliative care. PCWA urges the WA Government to acknowledge and respond to their differing palliative care and end of life needs, including those for Aboriginal and culturally diverse communities; babies, children and young people; people with disabilities; the LGBTIQ community; those with degenerative neurological conditions e.g. Motor Neurone disease; people experiencing homelessness; asylum seekers; prisoners; those experiencing cognitive decline; and other groups.

- **Navigation support**

There needs to be an easier way for people with palliative care needs to access what they need. Currently eligibility criteria are complex and don't facilitate a straightforward response at all stages of the illness trajectory. A single point of contact would be very helpful i.e. a palliative care navigator model. This should operate similarly to what is being proposed as part of the VAD implementation plan in WA and cancer stream nurses employed by WA Health.

- **Telehealth**

Telehealth has potentially a great role to play. Models being rolled out in WA Country Health Service (WACHS) could be replicated in Perth particularly for people in outer metro areas and for people whose illness makes it difficult to attend face-to-face appointments.

- **Voluntary Assisted Dying (VAD)**  
 Planning needs to be undertaken to explore how palliative care will sit alongside VAD from 1 July next year to ensure people who wish to explore/access VAD receive appropriate palliative care along the way. This will be a complex issue for organisations to manage and we should not underestimate how emotionally difficult it will be for many palliative care clinicians and others to negotiate regardless of their views on VAD. No thought has been given yet to clinical supervision/support for clinicians who will be managing requests or changes to the way clinicians and organisations will need to work going forward.

#### 4.2.2 Aged care

This consultation recognised that significant progress has been made within residential aged care in relation to palliative care over the past ten years but that there was still much to be done.

Critical issues identified included:

- **Advance care planning**  
 While COVID-19 has had a significant impact, the understanding and uptake of advance care planning is still very low. The current forms are very complicated and use language not easily understood. This is resulting in many facilities developing their own forms which will likely have common law status. Residents, families and friends need to understand how advance care plans link in a practical way to the delivery of care. Unfortunately many facilities do not share their forms with health providers.
- **Goals of Patient Care**  
 The link between Advance Care Planning and Goals of Patient Care needs to be made clearer to staff, residents, families and friends. If consistent language is used across both processes they will inform each other and encourage uptake of both. The power of facilitated meetings with family and friends (noting that some people do not have connected family) needs to be recognised alongside the highly developed skill set required to manage these discussions. The Joint Select Committee should be aware of the importance of Goals of Care discussions to guide current management where an Advance Care Plan/Advance Health Directive does not exist, or where a patient retains sufficient capacity to make an informed choice.

- **Aged care is a palliative care provider**

Approximately 19,000 people live in residential age care in WA and it is important to recognise that they are critically important providers of palliative care. The Royal Commission into Aged Care Quality and Standards has increased this awareness, as has the updated aged care standards. However much work needs to be done to develop workforce capacity and deliver training to assist in the identification of clinical deterioration.

#### **4.2.3 People with a disability**

This consultation recognised that many people with disabilities were not aware of advance care planning and what palliative care could offer, and therefore much education and awareness raising work needs to be undertaken with this community.

Critical issues identified included:

- **Supported decision making**

The concept of “supported decision making” was considered essential in recognition that people with disabilities may have limited capacity in some areas but may have enhanced capacity in others. For example it is recognised that people with intellectual disability have enhanced emotional intelligence and therefore advance care planning discussions need to recognise this. This approach is consistent with the UN Convention on the Rights of Persons with disabilities to which Australia is a signatory.

- **Increased need for specialist palliative care**

Some people with disabilities have managed multiple health conditions over a long period of time. When approaching the last stage of life, specialist palliative care may be required to manage a number of co-morbidities, over a longer trajectory and with amplified care needs.

- **Advocate for Palliative Care**

Many people with disabilities feel unsupported by the health system and have sometimes disengaged. This lack of trust will potentially compromise the availability of quality palliative care. It was identified that creation of an Advocate for Palliative Care would do much to progress understanding of palliative care and progress access and equity for people with disabilities.

#### **4.2.4 Carers**

This consultation recognised the critical role that carers play in the delivery of quality palliative care but acknowledged that this view was not widely shared.

Critical issues identified included:

- **Carers role not recognised**

Unfortunately many carers do not identify that they are filling the carer role and therefore sometimes don't seek the supports they require. Furthermore some struggle in managing a balance between their role as carer as well as life partner or family member. Many health professionals do not recognise the carer role either and the carer's nuanced observations and insights are sometimes ignored.

- **Dying and death literacy**

Carers who have a culturally diverse background, have a disability or live in rural or remote localities are even more disadvantaged and report significant hurdles in accessing quality palliative care. Complicated entry criteria for palliative care services as well as complex clinical language makes exploring options difficult. Often health providers seem unaware of the power disparity and seem to make little attempt to bridge the gap.

- **Grief and loss**

Carers often have an ongoing responsibility after the person has died to manage not only their own grief and loss but also the grief and loss being experienced by family members, friends and others. This is a significant burden which could be made easier if advance care planning and palliative care processes were well managed. If carers knew the wishes of the person via an advance care planning process and were able to advocate for them and access quality palliative care, then the level of grief and loss being experienced is likely to be reduced.

- **Practical Supports**

There is a need for need for more rapid access to formal in-home care, including respite care, in order to support carers and assist people with palliative care needs to stay at home. Although we acknowledge that many care programs are funded and managed by the Commonwealth, lack of in-home care supports is a common reason for otherwise avoidable hospitalisation for people with palliative care needs. Such care could be an expanded role of community palliative care services. Palliative care teams should be able to act as assessors for in-home services in order to expedite the process – experiences with COVID have proven it can be done effectively and with less bureaucracy. Access to practical training for family carers should also be readily available, in a number of formats including Telehealth.

#### 4.2.5 LGBTIQ+ community

Members of the LGBTIQ+ community reported a significant interest in engaging with advance care planning and palliative care service providers but registered many concerns regarding cultural safety and legal issues.

Critical issues identified included:

- **Challenges with advance care planning**

Members of the LGBTIQ+ community reported that advance care planning sometimes becomes problematic if the person has not publicly declared their sexual orientation; where family members are hostile; when same sex partners are not recognised; and when health professionals have faith perspectives that interfere with their engagement.

- **LGBTIQ+ specific resources**

PCWA indicated its interest in partnering with the LGBTIQ+ community to develop specific resources and training in advance care planning and palliative care that addresses some of the issues identified above. This pilot project will inform similar processes for people with disabilities, Aboriginal and culturally diverse communities and other communities with specific needs.

- **Register of culturally safe services**

It was recognised that a number of age care service providers were promoting themselves as sensitive to the needs of the LGBTIQ+ community. While that was a positive development it was suggested that a register of culturally safe services would be very helpful and that funding would be required to establish and maintain such a register.

#### 4.2.6 Aboriginal communities

This highly engaged consultation identified some significant challenges moving forward but also some very promising opportunities.

Critical issues identified included:

- **Complexity of advance care planning**

The consultation identified additional complexities that must be considered when developing advance care planning resources for Aboriginal communities. These include the need for extended family members to be involved; the role of elders and/or key family members; and the dilemma of being transferred to Perth for treatment or remaining to die on country.

- **Symposium on Aboriginal palliative care**  
Representatives from the Derby Aboriginal Health Service shared details of how their service operated and this approach was very well received by others. However, it was identified that there was currently minimal connection between existing Aboriginal palliative care service providers and the proposal to facilitate a symposium with this focus was enthusiastically received.
- **Strength of managing grief and loss**  
The Derby Aboriginal Health Service also shared its approach to providing grief and loss support to members of community when someone had died. Again the strength of their approach was acknowledged and the importance of recognising well established cultural rituals e.g. sorry time and smoking ceremonies.

#### 4.2.7 Regional and rural

This consultation focused on current palliative care service delivery in regional and rural WA and anticipated further positive developments as the 2019 funding initiatives are rolled out.

Critical issues identified included:

- **Innovative model**  
WACHS staff shared the new model that included district palliative care teams with a multi disciplinary focus and dedicated access to palliative care medical specialists. Aboriginal health workers will be employed in every region and an additional 29.8 FTE had been appointed.
- **Aboriginal symposium**  
The proposal to organise a symposium focused on Aboriginal approaches to advance care planning and palliative care was further explored during this consultation. It was identified as a positive opportunity to showcase excellent practice examples in regional and rural communities and facilitate the establishment of a community of practice.
- **Linkage with Mental Health Services**  
While some excellent practice was shared with regard to supporting grief and bereavement particularly in Aboriginal communities, it was also acknowledged that access to chaplaincy, psychology and psychiatry was very problematic in regional and rural locations. It was suggested that linkage with the mental health sector in WA might be advantageous particularly recognising that they have very similar challenges in providing services and supports to regional and rural communities.

#### **4.2.8 Cultural diversity**

This consultation recognised the disproportionately higher numbers of older people in culturally diverse communities and the importance of engagement regarding advance planning and the delivery of quality palliative care.

Critical issues identified included:

- **Use of professional interpreters**

It was identified that the use of interpreters was very important even if the person engaging in advance care planning and palliative care spoke some English. These concepts are challenging and complex and need to be undertaken in a way that empowers the person as much as possible. Using family as interpreters possibly invites conflict of interest concerns and should be avoided if at all possible. The use of professional interpreters is the recommended approach.

- **Cultural and religious considerations**

It was identified that, similarly to the general community, much work needed to be undertaken to progress improved awareness and understanding of advance care planning and palliative care. Complicating factors within some culturally diverse communities include a religious view that believers must “endure suffering” which of course is in conflict with palliative care which aims to relieve suffering and achieving the best quality of life possible. Other issues may include a heightened sense of grief and loss particularly if people have endured trauma prior to their arrival in Australia. In some communities adult children are the decision makers for their elderly parents and again this may be in conflict with the personal empowerment philosophy underpinning advance care planning.

- **Strategy development**

It was agreed that a key outcome from the consultation was the need to develop a detailed strategy to progress advance care planning, palliative care and grief and loss with the culturally and linguistically diverse communities in WA. The Ethnic Community Council of WA (ECCWA) and Palliative Care WA agreed to prioritise developing this strategy.

#### **4.2.9 People experiencing cognitive decline**

Participants in this consultation also recognised the low level of awareness and understanding of advance care planning and palliative care and agreed that it was a priority moving forward.

Critical issues identified included:

- **Dementia as a life-limiting illness**  
Unfortunately understanding of dementia in the broader community is low and many people believe that a diagnosis will result in someone becoming “pleasantly muddled” rather than understanding that it is terminal diagnosis. It is important the carers, family and friends become aware of this fact as soon as possible after diagnosis as this then will encourage urgent consideration of advance care planning.
- **Advance care planning**  
It was considered important to promote advance care planning as guided and ongoing conversations that empower the person with dementia as much as possible throughout his or her journey with the disease. The concept of supported decision making is crucial as is the provision of as much information as possible and regular and engaged family or supporters meetings. The emphasis should not be on Advance Health Directives which, while very important, only focus on treatment decisions primarily at end of life.
- **Aged care**  
It was recognised that aged care is an important service provider and in future will likely only provide services to those with dementia and those requiring palliative care. Hospitals were generally identified as poor environments for people with dementia with home and/or aged care a better alternative. The Metropolitan Palliative and Care Consultancy Services (MPaCCS) based at Bethesda was recommended as a quality consultative service for aged care providers as was the Residential Care Line Service.

## 5.0 Progress of the Joint Select Committee into End of Life Choices recommendations

The PCWA survey tool attempted to assess respondents view on the relative *importance of* and *progress towards* the recommendations developed by the Joint Select Committee on End of Life Choices.

### 5.1 Advance care planning

Recommendations 1-6 were assessed as focused on advance care planning and were broken down into their components for the survey process. It was interesting to note that very few respondents considered any of these recommendations “neutral” or “not at all important” other than the recommendation focused on the annual report to parliament on numbers of AHDs on hospital medical records.

No matter whether the “very important” category was used in isolation or the “very important” and “important” categories were added together the results were the same.

The three most highly ranked recommendations (or components of recommendations) were:

- ❖ Greater community education on AHDs, EPGs & hierarchy of decision makers (73%)
- ❖ Implement program to educate health professionals on AHDs and EPGs (69%);
- ❖ Consider how people with dementia can have their AHDs implemented when capacity is lost (69%).

The two least favoured recommendations (or components of recommendations) were:

- ❖ Amendments to the AHD template to match leading examples in Australia (44%);
- ❖ Annual report to parliament on numbers of AHDs on hospital medical records (20%).

**Table 4 – Survey feedback on relative importance of JSC on End-of-Life Choices recommendations 1-6**

	VERY IMPORTANT	IMPORTANT	NEUTRAL	NOT AT ALL IMPORTANT	UNSURE	TOTAL
Establishment of an electronic register for AHDs	64.44% 29	26.67% 12	8.89% 4	0.00% 0	0.00% 0	45
Requirement that health professionals search the AHD register except in emergencies	55.56% 25	35.56% 16	4.44% 2	2.22% 1	2.22% 1	45
Amendments to Advance Health Directive template to match leading examples in Australia	44.44% 20	42.22% 19	6.67% 3	2.22% 1	4.44% 2	45
Consider how people with dementia can have their AHDs implemented when capacity is lost	68.89% 31	28.89% 13	0.00% 0	2.22% 1	0.00% 0	45
Implement extensive program to educate health professionals on AHDs and EPGs	68.89% 31	31.11% 14	0.00% 0	0.00% 0	0.00% 0	45
Greater community education on AHDs, EPGs & hierarchy of decision makers	73.33% 33	22.22% 10	4.44% 2	0.00% 0	0.00% 0	45
WA hospitals to ensure AHDs are stored & accessible until register established	60.00% 27	33.33% 15	6.67% 3	0.00% 0	0.00% 0	45
Recommend to Council of Australian Governments Medicare rebate for GPs to assist with AHD completion	53.33% 24	31.11% 14	11.11% 5	4.44% 2	0.00% 0	45
Annual report to Parliament on numbers of AHDs on hospital medical records	20.00% 9	46.67% 21	31.11% 14	2.22% 1	0.00% 0	45

When asked to assess the level of progress achieved on these recommendations the most striking feature was the high percentage of respondents who were “unsure”. Again this reiterates the critical need to inform the palliative and aged care sectors and community about what progress has been made and/or what is hampering progress.

Interestingly the two recommendations with the highest indication of “some progress” i.e. implement program to educate health professionals on AHDs and EPGs (29%) and greater community education on AHDs, EPGs & hierarchy of decision makers (24%) also featured as two of the three highest ranked recommendations. Unfortunately it was reported that there had been little progress in the third highest ranked recommendation i.e. considering how people with dementia can have their AHDs implemented when capacity is lost.

**Table 5 – Survey feedback on relative progress of JSC on End-of-Life Choices recommendations 1-6**

	SIGNIFICANT PROGRESS	SOME PROGRESS	NO PROGRESS	SITUATION HAS WORSENE	UNSURE	TOTAL
Establishment of an electronic register for AHDs	0.00% 0	11.11% 5	33.33% 15	0.00% 0	55.56% 25	45
Requirement that health professionals search the AHD register except in emergencies	0.00% 0	8.89% 4	31.11% 14	0.00% 0	60.00% 27	45
Amendments to Advance Health Directive template to match leading examples in Australia	0.00% 0	13.33% 6	28.89% 13	0.00% 0	57.78% 26	45
Consider how people with dementia can have their AHDs implemented when capacity is lost	0.00% 0	13.33% 6	24.44% 11	4.44% 2	57.78% 26	45
Implement extensive program to educate health professionals on AHDs and EPGs	0.00% 0	28.89% 13	24.44% 11	0.00% 0	46.67% 21	45
Greater community education on AHDs, EPGs & hierarchy of decision makers	2.22% 1	24.44% 11	35.56% 16	2.22% 1	35.56% 16	45
WA hospitals to ensure AHDs are stored & accessible until register established	0.00% 0	13.33% 6	24.44% 11	2.22% 1	60.00% 27	45
Recommend to Council of Australian Governments Medicare rebate for GPs to assist with AHD completion	0.00% 0	2.22% 1	26.67% 12	4.44% 2	66.67% 30	45
Annual report to Parliament on numbers of AHDs on hospital medical records	0.00% 0	6.67% 3	22.22% 10	4.44% 2	66.67% 30	45

## 5.2 Palliative care services

Recommendations 7-14 were assessed as focused on the delivery of palliative care services and were broken down into their components for the survey process. Again it was interesting to note that few respondents considered any of these recommendations “neutral” or “not at all important” other than the recommendation to establish a definition on palliative care.

No matter whether the “very important” category was used in isolation or the “very important” and “important” categories were added together the results were the same.

The four most highly ranked recommendations (or components of recommendations) were:

- ❖ Regional palliative care be adequately funded to meet demand (84%);
- ❖ Community providers e.g. Silver Chain be adequately funded (80%);
- ❖ Provide information and education to health professionals and community on palliative care (73%); and
- ❖ Encourage knowledge sharing between specialists and generalists (73%).

The two least favoured recommendations (or components of recommendations) were:

- ❖ WA Health to establish a definition for palliative care (51%); and
- ❖ Appoint an independent reviewer to audit the spend on palliative care and actual/recorded activity levels (50%).

**Table 6 – Survey feedback on relative importance of JSC on End-of-Life Choices recommendations 7-14**

	VERY IMPORTANT	IMPORTANT	NEUTRAL	NOT AT ALL IMPORTANT	UNSURE	TOTAL
Establish inpatient publicly-funded palliative care beds in Perth's northern suburbs	66.67% 30	24.44% 11	4.44% 2	0.00% 0	4.44% 2	45
Ensure that community providers e.g. Silver Chain are adequately funded	80.00% 36	15.56% 7	2.22% 1	0.00% 0	2.22% 1	45
Conduct a review of the 3 models of palliative care - inpatient, consultative & community	59.09% 26	29.55% 13	11.36% 5	0.00% 0	0.00% 0	44
WA Health to implement process to record delivery of palliative care & unmet need	62.22% 28	31.11% 14	6.67% 3	0.00% 0	0.00% 0	45
WA Health to establish a definition for palliative care	51.11% 23	24.44% 11	20.00% 9	2.22% 1	2.22% 1	45
Provide information & education to health professionals & community on palliative care	73.33% 33	24.44% 11	2.22% 1	0.00% 0	0.00% 0	45
Encourage knowledge sharing between palliative care specialists & generalists	73.33% 33	26.67% 12	0.00% 0	0.00% 0	0.00% 0	45
Establish palliative care information & support hotline for community	55.56% 25	31.11% 14	11.11% 5	2.22% 1	0.00% 0	45
Improved governance and policy for WA Country Health Service delivery of palliative care	66.67% 30	26.67% 12	6.67% 3	0.00% 0	0.00% 0	45
Regional palliative care to be adequately funded to meet demand	84.44% 38	15.56% 7	0.00% 0	0.00% 0	0.00% 0	45
Appoint an independent reviewer to audit the spend on palliative care & actual/recorded activity levels	50.00% 22	40.91% 18	4.55% 2	2.27% 1	2.27% 1	44

When asked to assess the level of progress achieved on these recommendations, the most striking feature was again the high percentage of respondents who were “unsure”. This further reiterates the critical need to inform the palliative and aged care sectors and community about what progress has been made and/or what is hampering progress.

Three recommendations with the highest reported indication of progress included regional palliative care be adequately funded to meet demand (43%); palliative care information and support hotline for community (42%); and provide information and education to health professionals and community on palliative care (38%).

The reported level of progress is significantly higher than those relating to advance care planning and end of life decision making. Interestingly while there has been reported progress on the establishment of the information and support hotline, this recommendation was not identified as a priority.

**Table 7 – Survey feedback on relative progress of JSC on End-of-Life Choices recommendations 7-14**

	SIGNIFICANT PROGRESS	SOME PROGRESS	NO PROGRESS	SITUATION HAS WORSENE	UNSURE	TOTAL
Establish inpatient publicly-funded palliative care beds in Perth's northern suburbs	8.89% 4	15.56% 7	20.00% 9	0.00% 0	55.56% 25	45
Ensure that community providers e.g. Silver Chain are adequately funded	2.22% 1	20.00% 9	22.22% 10	6.67% 3	48.89% 22	45
Conduct a review of the 3 models of palliative care - inpatient, consultative & community	0.00% 0	22.22% 10	26.67% 12	0.00% 0	51.11% 23	45
WA Health to implement process to record delivery of palliative care & unmet need	0.00% 0	8.89% 4	28.89% 13	6.67% 3	55.56% 25	45
WA Health to establish a definition for palliative care	2.33% 1	16.28% 7	23.26% 10	2.33% 1	55.81% 24	43
Provide information & education to health professionals & community on palliative care	0.00% 0	37.78% 17	15.56% 7	4.44% 2	42.22% 19	45
Encourage knowledge sharing between palliative care specialists & generalists	0.00% 0	26.67% 12	31.11% 14	0.00% 0	42.22% 19	45
Establish palliative care information & support hotline for community	11.11% 5	31.11% 14	11.11% 5	4.44% 2	42.22% 19	45
Improved governance and policy for WA Country Health Service delivery of palliative care	2.22% 1	26.67% 12	15.56% 7	2.22% 1	53.33% 24	45
Regional palliative care to be adequately funded to meet demand	6.67% 3	35.56% 16	13.33% 6	6.67% 3	37.78% 17	45
Appoint an independent reviewer to audit the spend on palliative care & actual/recorded activity levels	0.00% 0	6.67% 3	26.67% 12	0.00% 0	66.67% 30	45

### 5.3 End of life choices

Recommendations 15-18 were assessed as focused on end of life choices and were broken down into their components for the survey process.

It was interesting to note that compared to the other groups, all these recommendations were rated as very important.

The three most highly ranked recommendations (or components of recommendations) were:

- ❖ Professional development training for health professionals re: transition from curative to non-curative treatments (71%);
- ❖ Community education and health promotion re: end of life decision making (71%); and
- ❖ Professional development training for health professionals re: competent patients' right to refuse food and water (69%)

**Table 8 – Survey feedback on relative importance of JSC on End-of-Life Choices recommendations 15-18**

	VERY IMPORTANT	IMPORTANT	NEUTRAL	NOT AT ALL IMPORTANT	UNSURE	TOTAL
Professional development training for health professionals re: competent patients' rights to refuse medical treatment	64.44% 29	31.11% 14	4.44% 2	0.00% 0	0.00% 0	45
WA Health to amend the "Consent to Treatment" policy to include competent patients' right to refuse medical treatment	64.44% 29	26.67% 12	4.44% 2	0.00% 0	4.44% 2	45
Professional development training for health professionals re: competent patients' right to refuse food and water	68.89% 31	24.44% 11	4.44% 2	2.22% 1	0.00% 0	45
Professional development training for health professionals re: transition from curative to non-curative care & futile treatments	71.11% 32	24.44% 11	2.22% 1	0.00% 0	2.22% 1	45
Community education & health promotion re: end of life decision making	71.11% 32	28.89% 13	0.00% 0	0.00% 0	0.00% 0	45
WA Health to develop guidelines re: terminal sedation including clear informed consent	66.67% 30	22.22% 10	4.44% 2	0.00% 0	6.67% 3	45

Again we observe high numbers of respondents who are unsure as to progress of these recommendations.

Two recommendations with the highest reported indication of progress included professional development training for health professionals re: competent patient's rights to refuse medical treatments (31%) and community education and health promotion re: end of life decision making (29%).

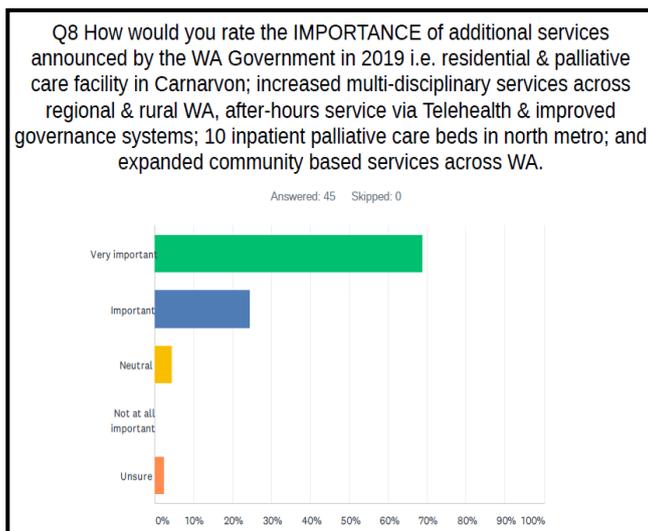
**Table 9 – Survey feedback on relative progress of JSC on End-of-Life Choices recommendations 15-18**

	SIGNIFICANT PROGRESS	SOME PROGRESS	NO PROGRESS	SITUATION HAS WORSENEDED	UNSURE	TOTAL
Professional development training for health professionals re: competent patients' right to refuse medical treatment	2.22% 1	26.67% 12	20.00% 9	2.22% 1	48.89% 22	45
WA Health to amend the "Consent to Treatment" policy to include competent patients' right to refuse medical treatment	2.22% 1	15.56% 7	22.22% 10	2.22% 1	57.78% 26	45
Professional development training for health professionals re: competent patients' right to refuse food and water	2.22% 1	13.33% 6	28.89% 13	0.00% 0	55.56% 25	45
Professional development training for health professionals re: transition from curative to non-curative care & futile treatments	2.22% 1	15.56% 7	26.67% 12	0.00% 0	55.56% 25	45
Community education & health promotion re: end of life decision making	6.67% 3	22.22% 10	28.89% 13	0.00% 0	42.22% 19	45
WA Health to develop guidelines re: terminal sedation including clear informed consent	2.22% 1	11.11% 5	24.44% 11	2.22% 1	60.00% 27	45

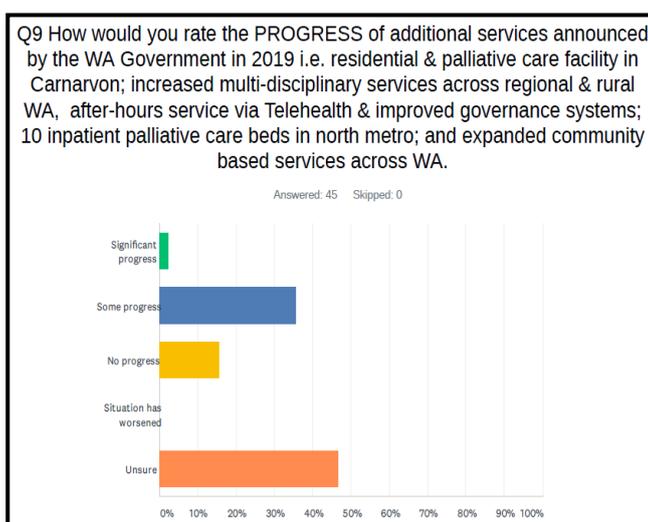
## 6.0 Delivery of services associated with palliative care funding announcements in 2019

Survey respondents indicated that the palliative care funding announcements in 2019 were very important (69%) and just over a third felt that some progress has been made in progressing these initiatives (36%).

**Table 10 – Survey feedback on relative importance WA Government palliative care funding announcements in 2019**



**Table 11 – Survey feedback on relative progress of WA Government palliative care funding announcements in 2019**



Many comments were recorded in the survey in response to these funding announcements and these are summarised below:

❖ ***Difference in hospice and acute setting models***

It was recognised that recommendation 7 in the report of the Joint Select Committee into End of Life Choices identified the need for publicly funded hospice beds and what has been developed is palliative care beds in an acute setting. This does not appear to acknowledge the significant differences between a hospice and acute care setting and is still not offering residents in the northern suburbs a choice.

❖ ***Diverse community needs***

While these funding announcements are positive, what is required moving forward is recognition that the community is not homogenous but rather is made up of a wide range of groups with quite differing requirements to meet their palliative care and end of life requirements e.g. Aboriginal people, culturally diverse and LGBTIQ+ communities, those with degenerative neurological conditions and other groups. What the WA Government and WA Health need to embrace is a nuanced approach moving forward.

❖ ***Multi-disciplinary teams using an holistic approach***

The approach by WACHS in continuing to develop multi-disciplinary teams for the delivery of palliative care in regional and rural locations was positively reinforced as critically important in delivering holistic care. However it was pointed out that there are many services in metro locations that struggle to access particularly allied health and pastoral care services and this deficit needs to be addressed with urgency.

❖ ***Community engagement and understanding***

Community involvement at all levels is critically important to progress the delivery of quality palliative care in WA. Several respondents queried how community had been overtly engaged in the development of these recommendations and funding initiatives. It was suggested that the emphasis needs to be with engaging and informing community members on advance care planning and palliative care to ensure that early engagement occurs, and outcomes are maximised.

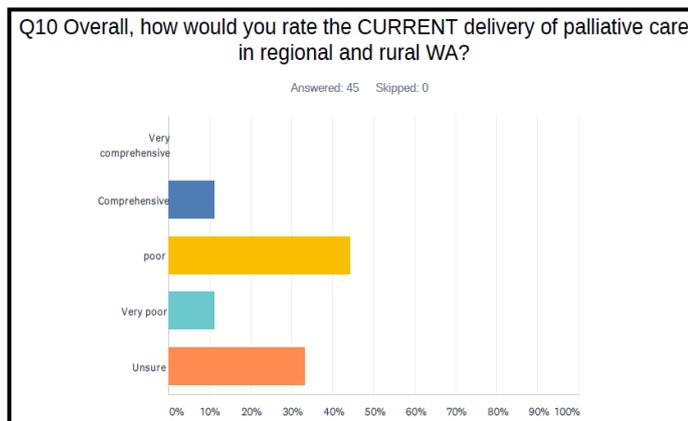
❖ ***Community palliative care***

It seems unfortunate that while the delivery of community palliative care was highlighted and prioritised via recommendation 8 of the report from the Joint Select Committee into End of Life Choices, it has not yet attracted funding to provide for growing demand.

## 7.0 Delivery of palliative care into regional and remote areas

Survey respondents indicated that palliative care service delivery in regional and rural WA is still poor (44%). However many respondents were reporting that the current initiatives will take some time to implement and that the benefits are yet to be experienced.

**Table 12 – Survey feedback on rating of palliative care delivery in regional and rural WA**



Comments from the survey on palliative care service delivery in regional and rural WA are summarised below:

❖ **Variable experience**

The palliative care experience in regional and rural WA is not consistent. There are some centres that provide a high quality service while others are minimal or not available at all. Parts of the Wheatbelt region and almost the entire Goldfields region were singled out as areas requiring additional resources.

❖ **Need to recognise strengths**

Several respondents suggested that there were strengths in regional and rural WA that were not replicated in Perth metro. These included a strong community network and an increased capacity to deliver “compassionate communities” supports e.g. emotional support of carers, meals delivered, help to maintain homes and gardens etc. It was also recognised that medical and allied health support staff will often provide services “above and beyond” what might be delivered in the metro region possibly in response to personal connections.

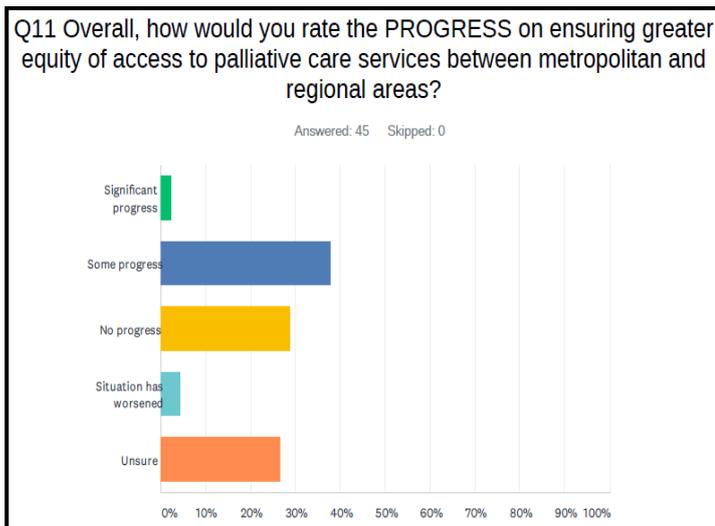
❖ **Use of Telehealth**

The increased use of Telehealth in response to the COVID-19 pandemic has demonstrated significant opportunities that could be available with the increased use of technology. Telehealth will allow regional and rural patients much improved access to specialist palliative care but will also facilitate increased training and mentoring opportunities to primary and aged care staff practicing in the regions.

## 8.0 Equity of access to palliative care services between metropolitan and regional areas

Survey respondents indicated that palliative care services between metropolitan and regional areas was still inequitable. However some progress towards addressing this inequity was reported by 38% of respondents with 27% unsure.

**Table 13 – Survey feedback on rating of palliative care equity of access between metropolitan and regional areas**



## 9.0 Conclusions

PCWA is optimistic regarding the additional opportunities that the Joint Select Committee on Palliative Care will deliver to the provision of quality palliative care across WA.

The Joint Select Committee on End of Life Choices focussed on palliative care in relation to end of life and whether or not there was a place for Voluntary Assisted Dying (VAD). It wasn't a thorough exploration of palliative care in WA so we welcome this second opportunity.

***The Joint Select Committee on End of Life Choices identified three streams of work: advance care planning; palliative care and voluntary assisted dying. It is important to recognise that these streams are not discrete, there is much overlap and they can't be seen in isolation.***

PCWA invites particular consideration to the following issues:

### 1. Advance care planning

All key stakeholders, including community, need to be made aware that engagement in advance care planning is the first critical step in the palliative care approach. Furthermore it is important that the process begins with an exploration of values and priorities along with ongoing conversations with family, friends and health providers followed by the completion of documentation as appropriate.

### 2. It's about living well...

All key stakeholders, including community, also need to be made aware that palliative care is not just about dying and the last days/weeks of life but rather it's about living well with a life-limiting illness. This may occur for years alongside life-prolonging treatments including chemotherapy or dialysis.

Unfortunately the “My Life, My Choice” report focused on the dying rather than the living aspect of life. Greater understanding about the focus on “living well” would provide greater impetus for engagement in advance care planning.

### **3. *Choice and models of care***

The models of care offered and availability of services need to reflect the above. Support at diagnosis is critically important to ensure people know what they can access when they need it and how to navigate an increasingly complex system. This also requires better access to community palliative care as most people with life limiting illnesses live at home and not in hospital or a palliative care unit. Community services remain overwhelmed and adequate funding needs to be allocated to ensure they can respond to demand. Increased inpatient palliative care beds need to be considered for the Rockingham and Mandurah areas. Consideration also needs to be given to streamlining access to care packages to ensure the provision of personal care support e.g. showering and practical supports such as transport, carer support and training etc.

### **4. *Diverse needs***

The consultations undertaken to inform the PCWA submission to the Joint Select Committee on Palliative Care clearly identified that currently there are many groups within the WA community who do not have access to quality palliative care. PCWA urges the WA Government to recognise and respond to the differing palliative care and end of life needs including those for Aboriginal and culturally diverse communities; babies, children and young people; people with disabilities; the LGBTIQ+ community; those with degenerative neurological conditions and those experiencing cognitive decline and other groups.

### **5. *Telehealth***

Telehealth has a great role to play. Models being rolled out in WACHS could be replicated in Perth particularly for people in outer metro areas and those whose illness makes it difficult to attend face-to-face appointments. This will potentially allow 24/7 access to support and advice not only for health and aged care professionals but for patients and carers as well. COVID-19 has shown that we can do it!

### **6. *Navigation Support***

There needs to be an easier way for people with palliative care needs to access what they need. Currently eligibility criteria are complex and don't facilitate a straightforward response at all stages of the illness trajectory. A single point of contact would be very helpful i.e. a palliative care navigator model. This could operate similarly to what is being proposed as part of the VAD implementation plan in WA or the Motor Neurone Disease and cancer stream nurses employed by WA Health.

## **7. *Goals of Patient Care (GOPC)***

There is a strong view from clinicians that the GOPC approach was not properly acknowledged in the report from the Joint Select Committee on End of Life Choices. While the process is directed by clinicians it does seek patient and family input in a shared decision making process. It is important to recognise it as the “here and now” decision making process particularly when advance care planning documentation does not exist but also when a patient still has capacity to decide what they want in the context of a real , rather than hypothetical situation.

## **8. *Carer support***

It is important to recognise that carers are critical to the delivery of palliative care and in particular to community palliative care in the home setting. The provision of respite is an ongoing challenge but is critically important in adequately supporting the carer role. The provision of emotional support and other social work and allied health services is also an important consideration, as is the provision of training to carers to enable them to deliver clinical supports in the home. When health deteriorates and/or care needs increase there is a need for rapid access for formal care via the Home Support Program. While we recognise that this is a Commonwealth concern, one of the benefits of the COVID-19 pandemic was the opportunity given to palliative care teams to acts as assessors and expedite these processes. Palliative care teams proved that they could manage these processes effectively with reduced bureaucracy and are hopeful that this arrangement might be continued.

## **9. *Early and proactive intervention***

Early and proactive intervention keeps people out of hospital, ensures a better quality of life, results in improved prognosis in some cases and better outcomes in bereavement. Services need to be able to respond earlier but currently there is very limited capacity to do so. Unfortunately we are still focussed on the very end of life, by which time people are distressed and carers are burnt out.

## **10. *Workforce issues***

Critical consideration needs to be given to who delivers the service and who provides the education. We need to ensure the ongoing viability of training placements and support the training of specialists/non-specialists to increase palliative care capacity.

## **11. *Voluntary Assisted Dying***

Planning needs to be undertaken to explore how palliative care will sit alongside VAD from 1 July 2021 to ensure people who wish to explore/access VAD receive appropriate palliative care along the way. This will be a big issue for organisations to grapple with and we shouldn't underestimate how emotionally difficult it will be for many palliative care clinicians and others to negotiate. No thought has been given yet to clinical supervision/support for clinicians who will be managing requests or the changes to the way clinicians and organisations will need to work going forward.

## **12. Improved communication with community and sector**

The survey undertaken as part of informing the PCWA submission to the Joint Select Committee on Palliative Care clearly identified the need for WA Health to much more regularly and effectively communicate with the palliative and aged care sectors and the broader community. This communication should focus on progress of the recommendations from the Joint Select Committee on End of Life Choices, implementation of initiatives funded in 2019 and potentially outcomes from the Joint Select Committee on Palliative Care.

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