



Australian Medical Association (WA)

**AMA (WA) Submission to  
the Joint Select Committee  
on Palliative Care in Western  
Australia**



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## PREAMBLE

The Australian Medical Association (WA) (**AMA (WA)**) is pleased to provide a submission to the Joint Select Committee on Palliative Care in Western Australia. The AMA (WA) is the State's peak medical representative body, and the only independent organisation acting on behalf of Western Australian doctors. We represent the medical profession to the government and to the community and advocate for the best interests of patients.

The Australian Medical Association defines palliative care as:

*Care provided for people of all ages who are living with, and dying from an eventually fatal condition, and for whom the primary treatment goal is quality of life.<sup>1</sup> Care focusses on reducing suffering through early identification, assessment, and treatment of pain, physical, psychological, social, cultural and spiritual needs.<sup>2</sup>*

The primary role of the doctor (medical practitioner) in end of life care is to facilitate the provision of good quality patient-centred care that emphasises continuous, open, informed communication and collaboration between the patient, the health care team, and, where appropriate, the patient's carers, family members and/or substitute decision-maker.

Concerns have been expressed to AMA (WA) that the Western Australian Government has conflated Voluntary Assisted Dying (VAD) and palliative care. The two are not inextricably linked and should not be bound together. The AMA (WA) believes that **palliative care is about living, not dying**. It is a fundamental component of the care all people living with a life limiting illness receive. VAD however, is primarily about dying<sup>3</sup>. For palliative care strategies, funding and support to be effective, it is important that we do not focus solely on the very end of life.

The AMA (WA) believes that improvements in palliative care in Western Australia are essential. Demand for palliative care services in Australia is increasing due to the ageing of the population and the increases in the prevalence of cancer and other chronic diseases that accompany ageing<sup>4</sup>. *The Report of the Joint Select Committee on End of Life Choices (My Life, My Choice Report)*, outlined some important areas of reform. The AMA (WA) recognises that funding has been allocated and work has begun on implementing many of the recommendations made in *The Report of the Joint Select Committee on End of Life Choices (My Life, My Choice Report)*, but the sector has observed very few improvements to palliative care on the ground.

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<sup>1</sup> Palliative Care Australia. Standards for Providing Quality Palliative Care for All Australians. 2005.

<sup>2</sup> World Health Organization. WHO Definition of Palliative Care.

<sup>3</sup> For AMA (WA)'s position statement on VAD, please see the [AMA \(WA\) Statement on End-of-Life Choices and Palliative Care](#).

<sup>4</sup> The Australian Institute of Health and Welfare (AIHW) 2020, 'Palliative Care Services in Australia', *The Australian Government*. Available at: <https://www.aihw.gov.au/reports/palliative-care-services-in-australia/palliative-care-services-in-australia/contents/overview>.

Implementing reform and ensuring improvements are seen within the sector is paramount. There is a strong perception that palliative care funding has been consumed by bureaucratic processes and report writing. Reports and inquiries must be justified by tangible outcomes in service delivery. Without tangible outcomes on the ground and improved service delivery, reports and inquiries remain futile.

### AMA (WA) Recommendations

To facilitate quality reform in palliative care, it is paramount that findings and recommendations from all relevant reports and inquiries be considered in context and coordinated so that any new recommendations align and build on work already underway, rather than detracting from work in progress, duplicating services and wasting resources.

The AMA (WA) also notes that the Joint Select Committee on Palliative Care in Western Australia conducting this Inquiry was to be established in February 2020 but was not established until June 2020, with the final reporting date remaining in November 2020 (reducing the overall duration of this inquiry from nine to five months). AMA (WA) is concerned that the compressed timeframe makes the inquiry feel rushed. It does not reflect the commitment of the Committee nor the work that will be undertaken. The compressed timeframe has also compounded the perception within the sector that the Western Australian Government's commitment to palliative care is insufficient and half-hearted.

As outlined in this submission, the AMA (WA)'s key concerns are listed below:

1. Although funding has been allocated and work has begun on implementing many of the recommendations made in the My Life, My Choice Report, the sector has observed very few improvements to palliative care on the ground.
2. The public and professional views of palliative care need to shift to improve referral culture.
3. There is a chronic shortage of in home and community palliative care.
4. Publicly funded, privately operated community palliative care providers are not fully integrated, accountable or transparent.
5. There is a large unmet need for palliative care for people who are living with a life limiting illness but are not imminently dying (patients between the diagnosis and the dying phase).
6. There is a chronic shortage of palliative care specialists in WA (less than one FTE per 100,000 population<sup>5</sup>).
7. There is an issue with the availability of palliative care Registrar positions in Western Australia.
8. General Practitioners (GPs) are not fully integrated into the three palliative care delivery models in Western Australia.
9. Telehealth is not yet available and accessible to all people who want to receive palliative care at home for as long as possible.
10. There is concern that VAD and palliative care have been conflated.

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<sup>5</sup> The Australian Institute of Health and Welfare (AIHW) 2020, 'Palliative Care Services in Australia', *The Australian Government*. Available at: <https://www.aihw.gov.au/reports/palliative-care-services-in-australia/palliative-care-services-in-australia/contents/overview>.

11. Residential Aged Care Facilities (RACFs) are wrongly considered to be palliative care services.
12. There are not enough allied health staff (psychologists, physiotherapists, occupational therapists, bereavement support and more) that are trained in and recognised for providing palliative care.
13. Palliative care funding has not been needs-based and transparent.
14. GPs and Rural Generalists are not fully recognised for their role in providing palliative care in regional and remote areas.
15. The My Life, My Choice Report omitted recommendations for improvements in key areas of palliative care including:
  - Publicly funded palliative care beds in the southern suburbs of Perth;
  - Publicly funded palliative care beds in outer metropolitan areas of Perth;
  - Neonatal and paediatric palliative care; and,
  - Palliative care for disadvantaged groups including people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal people, people with dementia, people with disabilities, LGBTQI+ people, prisoners, refugees, people experiencing homelessness, and more.

#### AMA POSITION ON PALLIATIVE CARE

The AMA believes good quality end of life care should:

- i. ensure the patient is always treated as an individual, with respect, dignity and compassion in a culturally sensitive manner;
- ii. endeavour to meet the patient's care needs and uphold their care preferences which should guide decision-making and planning;
- iii. strive to ensure that the patient is free from suffering;
- iv. endeavour to facilitate care in the patient's environment of choice, where practical, recognising that a patient's health care needs may change in the course of their condition;
- v. ensure that the patient's goals and values for end of life care are respected;
- vi. respect the patient's privacy and confidentiality, even after death;
- vii. support not only the physical needs of the patient but also the psychological, emotional, religious and spiritual needs of the patient and their family members and carers;
- viii. empower patients and, where appropriate, their family members and carers to participate in managing their treatment;
- ix. provide counselling and other support to patients, their family members and carers throughout the patient's condition, including support for family members and carers beyond the patient's death;
- x. ensure patients and their family members and carers have access to good quality palliative care resources such as educational materials as well as physical aids in a timely, easily accessible and coordinated manner;
- xi. recognise the role of doctors, allied health care professionals, carers and the wider community in working together to meet the needs of patients;

- xii. facilitate continuity and coordination of care within and between medical, health and community services including when the patient transitions from medical care that is primarily focussed on curative treatments to care that is focussed on palliative treatments.

Death, dying and bereavement are all an integral part of life; however, reflecting on and discussing death can be profoundly confronting and difficult. Open and frank discussion of death and dying including end of life care options, approach to futile treatment, caring and bereavement should be encouraged within the profession and in the wider community.

In AMA (WA)'s submission to the Ministerial Expert Panel on Voluntary Assisted Dying, the AMA (WA) recommended the following:

1. There must be greater education in palliative care for all medical practitioners and healthcare workers.
2. Palliative care needs to be cemented in models of care, not confined to the end of life.
3. The AMA (WA) advocates for a more holistic, integrated funding model that values end of life care, including Advance Health Directives, and consultative liaison services.
4. Communication and integration between hospital, community and GP sectors is required to improve patient outcomes and achieve more effective care.
5. The role of Advance Care Planning needs to be better understood by the medical profession and wider community.
6. There should be training for doctors to improve their understanding of medico-legal issues.
7. Any legislation to introduce assisted dying needs to be coupled with improved resources and training in palliative care.

#### PALLIATIVE CARE IN WESTERN AUSTRALIA & THE IMPLEMENTATION OF RECOMMENDATIONS OF THE JOINT SELECT COMMITTEE INTO END OF LIFE CHOICES

The AMA (WA) understands that the Western Australian Government fully accepted the recommendations from the My Life, My Choice Report, that funding has been allocated in the 2019-2020 Budget and work has begun on implementing many of the recommendations. The Government also committed to the Sustainable Health Review (2019), which supported the recommendations from the My Life, My Choice Report<sup>6</sup>. However, at the point of this submission, the palliative care sector and the public have seen very few improvements to palliative care services in Western Australia.

The AMA (WA) believes that the My Life, My Choice Report outlined some important areas of reform, however, unless progress is seen within the sector, additional reports, plans and further inquiries may be counterproductive to facilitating progress.

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<sup>6</sup> Sustainable Health Review 2019. Sustainable Health Review: Final Report to the Western Australian Government. *Department of Health, Western Australia* (Recommendation 9).

### View of Palliative Care in Western Australia

A key objective of palliative care reform in Western Australia should be to shift the public and professional views of palliative care. There is a pervading erroneous belief that palliative care is solely for the elderly and imminently dying. It is paramount that this misperception is corrected to facilitate better access. Palliative care is not just care of the imminently dying, it is critical from the point of diagnosis of a progressive, incurable condition. Palliative care embraces the whole journey for those with incurable illness (planning ahead, avoiding crises and keeping people out of hospital) rather than merely the final few days of a person's life.

A shift in the professional and public understanding is needed to:

- Improve the referral culture;
- Improve in home and community palliative care; and,
- Provide palliative care for people who are living with a life limiting illness but are not imminently dying (patients between the diagnosis and the dying phase).

### Palliative care referral culture

Palliative care specialists in Western Australia are concerned about the referral culture in palliative care. Specialists have expressed that non-palliative care medical professionals do not refer patients to palliative care services early enough. They also report that non-palliative care medical professionals do not refer their patients to palliative care if they are asymptomatic. Palliative care specialists understand the issue as a direct result of the misperceptions surrounding palliative care. This is a key concern of the AMA (WA) and dedicated resources should be committed to ensure that all medical professionals receive adequate and ongoing education and training in palliative care referral (in line with Recommendation 15, Page 113)<sup>7</sup>.

The AMA (WA) understands that an educational framework is in development that will link health care workers with the education and training to help them address gaps in knowledge and skills. This will hopefully help address the wariness that still exists about referring people to palliative care services.

### In home and community palliative care

In home and community palliative care in Western Australia is delivered by Silver Chain Hospice Care (Silver Chain) and Metropolitan Palliative Care Consultancy Service (MPaCCS).

Silver Chain is a hospital-level accredited service funded by the State Government to provide community-based specialist palliative care at no out-of-pocket cost to the patient. Access to the service requires a referral from a medical practitioner. MPaCCS is a mobile specialist palliative care team, funded by WA Health and administered by Bethesda Health Care, which aims to build the capacity of residential, mental health, disability care and correctional facilities to care for residents at the end of life.

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<sup>7</sup> My Life, My Choice 2018. *Western Australian Government*. The Report of the Joint Select Committee on End of Life Choices.

Demand for in home and community palliative care in Western Australia is high. Consequently, Silver Chain has been providing community palliative care to more patients than for which it is funded (Finding 11, Page 68)<sup>8</sup>. This is a key concern of the AMA (WA) and should be rectified. If we truly want to be able to offer choice and give people the opportunity to receive palliative care and die at home (if they want to), then organisations providing in home palliative care need to be funded and resourced appropriately.

The AMA (WA) believes that the solution for this problem is not as simple as granting more funding to the existing in home and community palliative care services. The AMA (WA) acknowledges that Silver Chain provides a vital service but has concerns about the transparency, accountability and delivery model of publicly funded, privately operated providers. The AMA (WA) recommends that private providers of publicly funded palliative care services should be integrated, collaborative, accountable and transparent. Any such providers should undergo regular review to ensure quality and safety of palliative care in Western Australia.

#### Palliative care for people who are not imminently dying

There is a large unmet need for palliative care for people who are living with a life limiting illness but are not imminently dying (patients between the diagnosis and the dying phase). Early and proactive intervention at home keeps people out of hospital, improves quality of life, leads to better outcomes in bereavement and, in some cases, leads to an improved prognosis<sup>9</sup>.

A shift in the professional and public understanding, additional funding and dedicated resources are needed to ensure this cohort of people receive individualised and tailored palliative care. Providing palliative care for a longer duration is not necessarily more expensive. It is, however, a way to ensure that resources and service are provided on a needs basis, at the intensity that patients require them.

#### Palliative care specialists in WA

Palliative care funding and workforce in Western Australia remain below optimal or comparative rates. Western Australia has less than one FTE of specialist palliative medical physicians per 100,000 population<sup>10</sup>. This is below average in Australia and significantly below the Australian recommended medical specialist staffing levels for palliative care<sup>11</sup>.

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<sup>8</sup> Ibid.

<sup>9</sup> Department of Health. National Palliative Care Strategy 2018. *Canberra: DoH, 2018.*

<sup>10</sup> The Australian Institute of Health and Welfare (AIHW) 2020, 'Palliative Care Services in Australia', *The Australian Government*. Available at: <https://www.aihw.gov.au/reports/palliative-care-services-in-australia/palliative-care-services-in-australia/contents/overview>.

<sup>11</sup> Palliative Care Service Provision in Australia: A Planning Guide 2003, *Palliative Care Australia*, Deakin West ACT. Available at: <https://palliativecare.org.au/wp-content/uploads/2015/07/Palliative-Care-Service-Provision-in-Australia-a-planning-guide.pdf>.

Recommendation 13 of the My Life, My Choice Report was to ensure regional palliative care be adequately funded to meet demand. While WA Country Health Services (WACHS) requires investment and reform, it is important that metropolitan and outer metropolitan services continue to evolve, receive funding and workforce support too.

#### Availability of palliative care Registrar positions

In addition to palliative care specialists, additional advanced training positions must be made available to ensure the ongoing development of the specialty area and to enable future clinical service requirements to be met. There is significant concern that there are not enough palliative care Registrar positions in Western Australia. At present, there are only 10 Registrar positions available in Western Australia. Five of these positions are Specialist Training Program (STP) funded, which means that only doctors in training to become palliative care specialists can occupy them (doctors that want to upskill within a separate specialty cannot). There is also a shortage in hospital placement and community placement positions, a limited capacity within the field to train the next generation of specialists and no source of funding for a formal training director role.

This causes substantial 'brain drain' - motivated doctors who want to train in palliative care (to become a palliative care specialist or to upskill in their specialty area) move to other states to do so and often, they don't come back to Western Australia because of the lack of jobs. The AMA (WA) believes that access to palliative care Registrar positions should be examined and addressed. Centralised funding for training places would be welcomed to secure a workforce into the future.

#### The role of General Practitioners in palliative care

Further to Recommendation 5 (*"The Minister for Health recommends to the Council of Australian Governments an amendment to the Medicare rebate schedule to include preparation of advance health directives with general practitioners"*), the AMA (WA) believes that GPs should be integrated into the three palliative care delivery models in Western Australia.

The rationale is compelling for GPs to extend management of progressive chronic diseases to meet patients' needs for community-based end-of-life care and a 'good' death<sup>12</sup>. GPs are able to provide holistic, continuity of care and are often easily accessible to patients. The AMA (WA) believes that further to Recommendation 5, the role of GPs in palliative care should be identified as an essential component of palliative care.

#### Telehealth

The safe approach to *End of Life Choices: License to Care not Licence to Kill* Report (August 2018) included a Recommendation to increase the availability and flexibility of Telehealth (Recommendation 3f, Page 13).

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<sup>12</sup> RACGP Aged Care Clinical Guide (Silver Book – Part A) 2019, *Royal Australian College of General Practitioners*, Victoria Australia.

The AMA (WA) believes that palliative care telehealth can improve access and quality of palliative care. Clinically appropriate telehealth services in Western Australia should be maximised to support patients who find it difficult to attend face to face appointments due to their illness in rural, regional, metropolitan and outer metropolitan areas.

The out of hours Palliative Care Advice Line in Perth provides a welcome service but needs to be expanded to ensure equity of care. As WACHS enhances its telehealth structures and starts to provide palliative care via telehealth to rural and regional Western Australians, it's possible that patients in metropolitan Perth will not have the same level of support. It is important to try and avoid unnecessary duplication of services but there needs to be consistent access to support throughout WA, regardless of geographic location. Services should ideally be available 24/7 to all Western Australians and details of how to access this service must be clear to patients and health professionals.

### Palliative care and VAD

Palliative care specialists in Western Australia are also concerned that the Western Australian Government has placed greater emphasis on VAD than on palliative care. The two are not inextricably linked and should not be conflated. The approach to palliative care reform in Western Australia has been interpreted by some medical professionals as half-hearted and tokenistic. The compressed overall duration of this Inquiry has made it feel rushed and has compounded the aforementioned view.

Ensuring people who wish to explore/access VAD receive appropriate palliative care along the way is important, but the emphasis on palliative care reform in Western Australian should remain exclusively on palliative care issues.

### Residential Aged Care Facilities

Residential Aged Care Facilities (RACFs) have been referred to as “the new palliative care service” because a lot of people die in RACFs<sup>13</sup>. However, RACF staff generally have limited palliative care training. Medical cover for RACFs is often not adequate, and very often is not 24/7. There is a need to develop better models for medical cover in RACFs to provide palliative care and / or solutions so staff can have palliative care support, for example, via telehealth after hours.

### The role of Allied Health in palliative care

Interdisciplinary palliative care teams comprising allied health personnel in addition to medical and nursing staff are an essential component of comprehensive quality palliative care for all. In Western Australia, there is a shortage of allied health care staff providing palliative care (psychologists, physiotherapists, occupational therapists, bereavement support and more).

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<sup>13</sup> Eighty per cent of elderly people in Australia use an aged care program before their death (AIHW, 2018).

Bethesda Health Care has no funding for allied health for palliative care. An amendment should be made to their contract with North Metro Health Service (NMHS) to ensure patients can access a multidisciplinary team for palliative health care.

Additional allied health staff should be trained in providing palliative care to improve palliative care services in Western Australia.

#### DELIVERY OF THE SERVICES ASSOCIATED WITH THE PALLIATIVE CARE FUNDING ANNOUNCEMENTS IN 2019-2020

The AMA (WA) cannot report on the delivery of services associated with the palliative care funding announcement in 2019-20 further than what has been reported in Hansard<sup>14</sup>. The AMA (WA) believes palliative care funding should be needs-based and transparent. While the additional funding for palliative care services is welcomed by the AMA (WA), we continue to reiterate that the additional \$41 million announced in the 2019-20 State Budget is just a drop in the ocean. Critically, money invested in end-of-life choices, should not be conflated as investment in palliative care services.

#### DELIVERY OF PALLIATIVE CARE IN REGIONAL AND REMOTE AREAS

In regional and remote areas of Western Australia, palliative care, much like other health care, is less accessible. Palliative care patients should not be required to choose between staying close to home and receiving limited treatment or travelling to major hospitals in cities to receive face-to-face palliative care, unless it is absolutely necessary. Travel is often time consuming, expensive, daunting and stressful – especially if it has to be done regularly.

The AMA (WA) understands that significant progress has been made on the recommendations relating to palliative care services for regional and remote areas of Western Australia. However, as mentioned above, the translation to on the ground service delivery has not yet been felt by some medical professionals in rural Western Australia.

The increase in rural and regional palliative care specialist staffing (from 31 FTE to 61 FTE) is a welcome and necessary improvement, but delivery of palliative care in regional and remote Western Australia requires further attention.

GPs and Rural Generalists should be central in providing palliative care at home in regional and remote areas, with the support of palliative care specialists via telehealth. Rural and regional palliative care specialist are unlikely to be able to treat all rural palliative care patients across Western Australia, because of the sheer size of our State. Rural GPs deliver palliative care across a number of primary

<sup>14</sup> Hansard 2020. Fortieth Parliament, First Session. *Legislative Council*. Page 3595. Available at: [https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/15A7647F8C3477ED4825858C001A68B9/\\$file/C40%20S1%2020200616%20All.pdf](https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/15A7647F8C3477ED4825858C001A68B9/$file/C40%20S1%2020200616%20All.pdf)

and secondary care settings in rural Western Australia and facilitate the broad range of services required to meet diverse patient need in rural areas. More emphasis on those generalist skills and essential service links, which can see the patient through their end-of-life experience and at home in their community, is required.

Rural hub hospitals provide vital back-up capacity when patients have problems that cannot be managed at home. This is appropriate, but as rural hospitals are generally staffed by GPs, telehealth back up from palliative care specialists is also vital. The level of nursing and allied health palliative care that is available in rural areas also needs to be addressed.

#### PROGRESS ON ENSURING GREATER EQUITY OF ACCESS TO PALLIATIVE CARE

Palliative care should be made available to everyone, regardless of age, culture, beliefs, background or geographic location. Equity in palliative care in Western Australia has not yet been achieved. The My Life, My Choice Report failed to make specific recommendations for improvements in key areas of palliative care including:

- **Publicly funded palliative care beds in the southern suburbs of Perth.**

The My Life, My Choice Report found that “Access to inpatient specialist palliative care in Perth is limited” (Finding 9, Page 67) and therefore recommended the establishment of an “inpatient specialist palliative care hospice providing publicly funded beds in the northern suburbs of Perth” (Recommendation 7, Page 67)<sup>15</sup>. This leaves a huge and inexplicable gap in inpatient palliative care services in the southern suburbs of Perth. St John of God Hospital in Murdoch only have 20 palliative care beds, which does not meet the needs of the population in the area. Publicly funded beds in the southern suburbs of Perth cannot be omitted and should be included as a recommendation going forward.

- **Publicly funded palliative care beds in outer metropolitan areas of Perth.**

If the focus remains solely on the northern suburbs of Perth and regional and remote areas of Western Australia, palliative care in outer metropolitan areas will fall behind. For people who live in outer metropolitan areas of Perth, travelling into the city for palliative care is often daunting, inconvenient and expensive. It is also inappropriate to keep palliative care patients in their local acute hospital (especially when acute hospitals in outer metropolitan Perth are under resourced). Outer metropolitan areas of Perth desperately need more inpatient palliative care beds and access to the telehealth services implemented in WACHS.

- **Neonatal and paediatric palliative care.**

Tragically, children and neonates are not immune from life limiting illnesses. There are a variety of illnesses that cause suffering and limit the lives of people under the age of 18 years.

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<sup>15</sup> My Life, My Choice 2018. *Western Australian Government*. The Report of the Joint Select Committee on End of Life Choices.



Children who are dying (and their families) have particular needs often different to those of adults. The per capita number of paediatric palliative care specialists in Western Australia is much lower than in other Australian jurisdictions. There is also a lack of funding for paediatric palliative care specialist positions in WA Health and no funding for training. This causes substantial ‘brain drain’ - motivated doctors who want to train in paediatric palliative care move to other states to do so and they don’t come back to Western Australia because of the lack of jobs. Achieving equity for neonatal and paediatric palliative care will be unattainable unless these workforce issues are addresses.

- **Palliative care for disadvantaged groups including people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal people, people with dementia, people with disabilities, LGBTQI+, prisoners, refugees, people experiencing homelessness, and more.**

The Joint Select Committee received much evidence that Western Australians living in rural and remote areas, Aboriginal and Torres Strait Islanders and persons from culturally and linguistically diverse (CALD) backgrounds experience inequitable provision of specialist palliative care services (Page 5)<sup>16</sup>. However, the Committee did not make any recommendations to improve access to palliative care for disadvantaged groups.

WA Health should continue to endeavour to make progress on ensuring equity of access to palliative care.

## CONCLUSION

| AMA (WA) Concerns and Recommendations |  |
|---------------------------------------|--|
| 1.                                    | <b>Although funding has been allocated and work has begun on implementing many of the recommendations made in the My Life, My Choice Report, the sector has observed very few improvements to palliative care on the ground.</b> |
|                                       | Reports and inquiries must be justified by tangible outcomes in service delivery.  |
| 2.                                    | <b>The public and professional views of palliative care need to shift to improve referral culture.</b>   |
|                                       | An educational framework needs to address the wariness that still exists about referring people to palliative care services.   |
| 3.                                    | <b>There is a chronic shortage of in home and community palliative care.</b>   |
|                                       | Organisations providing in home and community palliative care need to be funded and resourced appropriately.   |
| 4.                                    | <b>Publicly funded, privately operated community palliative care providers are not fully integrated, accountable or transparent.</b>   |

<sup>16</sup> My Life, My Choice 2018. *Western Australian Government*. The Report of the Joint Select Committee on End of Life Choices.



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|            | Private providers of publicly funded palliative care services should be integrated, collaborative, accountable and transparent. Any such providers should undergo regular review to ensure quality and safety of palliative care in Western Australia. |
| <b>5.</b>  | <b>There is a large unmet need for palliative care for people who are living with a life limiting illness but are not imminently dying (patients between the diagnosis and the dying phase).</b>   |
|            | A shift in the professional and public understanding, additional funding and dedicated resources are needed to ensure this cohort of people receive individualised and tailored palliative care.   |
| <b>6.</b>  | <b>There is a chronic shortage of palliative care specialists in WA (less than one FTE per 100,000 population<sup>17</sup>).</b>   |
|            | To ensure metropolitan, rural and regional palliative care services continue to evolve, funding for workforce support is required.   |
| <b>7.</b>  | <b>There is an issue with the availability of palliative care Registrar positions in Western Australia.</b>  |
|            | Access to palliative care Registrar positions should be examined and addressed. Centralised funding for training places would be welcomed to secure a workforce into the future.   |
| <b>8.</b>  | <b>General Practitioners (GPs) are not fully integrated into the three palliative care delivery models in Western Australia.</b>   |
|            | GPs should be identified as an essential component of palliative care and integrated into the three palliative care delivery models in Western Australia.  |
| <b>9.</b>  | <b>Telehealth is not yet available and accessible to all people who want to receive palliative care at home for as long as possible.</b>   |
|            | Clinically appropriate telehealth services in Western Australia should be maximised to support patients who find it difficult to attend face to face appointments due to their illness in rural, regional, metropolitan and outer metropolitan areas.  |
| <b>10.</b> | <b>There is concern that VAD and palliative care have been conflated.</b>  |
|            | Emphasis on palliative care reform in Western Australian should remain exclusively on palliative care issues.  |
| <b>11.</b> | <b>Residential Aged Care Facilities (RACFs) are wrongly considered to be palliative care services.</b>   |
|            | Better models for medical cover in RACFs to provide palliative care and / or solutions so staff can have palliative care support, for example, via telehealth after hours is required.   |
| <b>12.</b> | <b>There are not enough allied health staff (psychologists, physiotherapists, occupational therapists, bereavement support and more) that are trained in and recognised for providing palliative care.</b>   |

<sup>17</sup> The Australian Institute of Health and Welfare (AIHW) 2020, 'Palliative Care Services in Australia', *The Australian Government*. Available at: <https://www.aihw.gov.au/reports/palliative-care-services-in-australia/palliative-care-services-in-australia/contents/overview>.

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|------------|--|
|            | Additional allied health staff should be trained in providing palliative care to improve palliative care services in Western Australia.  |
| <b>13.</b> | <b>Palliative care funding has not been needs-based and transparent.</b>   |
|            | Palliative care funding should be needs-based, transparent and separate from investment in VAD.  |
| <b>14.</b> | <b>GPs and Rural Generalists are not fully recognised for their role in providing palliative care in regional and remote areas.</b>  |
|            | GPs and Rural Generalists should be central in providing palliative care in regional and remote areas (with the support of palliative care specialists via telehealth).  |
| <b>15.</b> | <b>The My Life, My Choice Report omitted recommendations for improvements in key areas of palliative care including:</b> <ul style="list-style-type: none"> <li>○ Publicly funded palliative care beds in the southern suburbs of Perth;</li> <li>○ Publicly funded palliative care beds in outer metropolitan areas of Perth;</li> <li>○ Neonatal and paediatric palliative care; and,</li> <li>○ Palliative care for disadvantaged groups including people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal people, people with dementia, people with disabilities, LGBTQI+ people, prisoners, refugees, people experiencing homelessness, and more.</li> </ul> |
|            | The recommendation listed above should be included going forward to ensure equity of access to palliative care in Western Australia.   |