

JOINT SELECT COMMITTEE ON PALLIATIVE CARE IN WESTERN AUSTRALIA

Final Report — “Palliative Care in Western Australia — Progress Report” — Tabling

MR C.J. TALLENTIRE (Thornlie — Parliamentary Secretary) [11.11 am]: I rise as Chair of the Joint Select Committee on Palliative Care in Western Australia to table our final report titled “Palliative Care in Western Australia — Progress Report”.

[See paper [4015](#).]

Mr C.J. TALLENTIRE: It has been a privilege to chair this committee into the progress of palliative care in Western Australia. Indeed, a compassionate caring society must ensure that it allows citizens to die with dignity and with minimal pain. In a great many cases, good quality palliative care can provide this. Western Australians should be confident that even in the latter stages of our lives, we can access the highest quality service and care.

The committee spent useful time understanding what palliative care is and its scope. We heard evidence of a misconception amongst the general public and health professionals that palliative care is solely for the elderly and imminently dying. Associate Professor Alison Parr, clinical lead and member of Palliative Care WA and the WA Cancer and Palliative Care Network of the Department of Health, advised the committee —

Palliative care is about supporting people with progressive incurable illness. It is about a multidisciplinary approach. It focuses on quality of life. The prognosis for some of these people that receive palliative care may actually be years—and that is a common misconception; it is not all about end of life. They may still be receiving disease-modifying treatments alongside palliative care interventions; for example, chemotherapy, or radiotherapy, for those with cancer. It is about keeping people as well as possible for as long as possible, despite incurable illness, and it is about keeping them functioning and also supporting psychological wellbeing and practical support for those people as their illness progresses.

That explanation of palliative care by Associate Professor Parr is extremely valuable and needs to be properly understood by the whole of our Western Australian community. Only a year ago we were in this place debating the voluntary assisted dying legislation. A feature of the passage of that legislation through this place was the broader community discussion around end of life. At times it was apparent that many mistakenly felt some form of voluntary assisted dying would be their only end-of-life option. It is important to note that a guiding principle of the Voluntary Assisted Dying Act 2019 is —

a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person’s suffering and maximise the person’s quality of life.

Through this inquiry I hope we have contributed to advancing community appreciation that palliative care is about maximising a person’s quality of life when they have a life-limiting or terminal condition. The professionalism and commitment of those who work in palliative care in a paid, and sometimes unpaid, capacity does our society great credit. For many of the witnesses to the inquiry, their professional lives involve helping people going through the final stages of their lives. No doubt this can be emotionally draining work, but I was struck by the impressive blend of professionalism and compassion evident in all our witnesses.

I now turn to some of the findings and recommendations we made through the report process. One of the findings is for a system of navigators. Navigators would be a welcome and valuable addition to WA’s palliative care services. The president of Palliative Care WA, Dr Elissa Campbell, told the inquiry that within WA Health cancer streams, there is a specialist nurse who helps patients navigate between their different appointments with the different specialties and different services they can access. She went on to say —

Having that one-stop shop for palliative care would be very helpful ... I know that I, as a health professional with a high level of health literacy, find it very difficult to navigate all of these things. I can only imagine how difficult it is for someone who is very unwell or is caring for a loved one who is very unwell. I think a care navigator service would be really useful in helping to access palliative care services.

I turn to the issue of telehealth. In this year of COVID-19 this is very much to the fore. I heard members of the previous committee express some concerns about the use of various video linkages and what have you. I think we used Zoom exclusively and found it excellent. We found most of our witnesses as well were very at ease with this medium. We looked at telehealth as a means of communicating with people receiving palliative care. We found, and witnesses told us this, that it was a useful means of enhancing the service provision that the health sector is already able to provide. However, there were some words of caution, especially from Silver Chain. It said —

Overall, we see telehealth or other technologies as an adjunct, but not a replacement of face-to-face visits in the provision of community-based palliative care service.

One of the big issues we dealt with was the need to meet need, not just demand, for palliative care. In fact, we came up with the following recommendation. It states —

WA Health further refine the methodology for determining the unmet need for palliative care, and ensure the measure of unmet need includes:

- a) the number of those accessing palliative care for the first time very late in the trajectory of their illness and therefore not receiving timely referrals
- b) general practitioner and primary care data
- c) patients who received palliative care in the community and did not have any hospital admissions in the year prior to death.

It is very important to ensure that we understand how big the need is and not just satisfy ourselves with meeting demand.

I turn to regional communities and how their needs are being met. We came up with the following recommendation. It states —

The Department of Health undertake a detailed assessment of demand and/or need for palliative care services in regional and remote areas of Western Australia.

I turn to palliative care for Aboriginal people. We determined that palliative care units need to be designed in consultation with local Aboriginal community members and elders. When we visited the palliative care unit at Busselton Health Campus, it was very interesting to hear that for an Aboriginal person to die in a building raised above the ground is not a natural circumstance at all. That could have perhaps been considered and avoided had the proper design process been gone through. As satisfactory and pleasant a setting as it can be, the health campus is not suitable for all members of our community.

Another very important issue was about advance care planning. Palliative Care WA encouraged the committee to consider the critical importance of advance care planning as an integral part of palliative care. The Department of Health advised us —

Advance Care Planning is a voluntary **person-led** process that outlines a future plan for health and personal care. The process enables the person to describe to family, carers and health professionals the treatment and care that they would want for themselves in the event they are unable to make or communicate decisions. Advance Care Planning occurs on a continuum from an Advance Care Plan recognised in common law to an Advance Health Directive/or appointment of an Enduring Power of Guardian which is supported by West Australian legislation. These only come into effect if the person lacks capacity to contribute to decision-making at the time a decision is required. Few West Australians have any form of Advance Care Planning.

Another important area is the contribution of volunteers. Palliative care, like so many spheres of our society, benefits from volunteer effort. It was a privilege to meet volunteers, and I mentioned our visit to Busselton Hospice Care and the conversation we had with the volunteers. Finding 7 states —

Volunteers play a valuable but unquantified role in the provision of palliative care services in Western Australia.

We received evidence that volunteers provide essential community connection and a very personalised service to clients, who stated that if there were no volunteers, paid staff levels would have to be increased. Finding 19 states —

The funding of volunteer services to support, train and guarantee the sustainable involvement of volunteers in the delivery of palliative care in Western Australia remains under-prioritised.

I move on to the paid workforce. A major issue for any sector is the size of its workforce relative to the task before it. The WA Primary Health Alliance noted —

Knowledge about end-of-life care and specialist palliative care across the GP workforce is variable and there is significant scope to improve capability.

It was noted that some general practitioners have concerns about the medico-legal implications of palliative care, which the WA Primary Health Alliance noted “may potentially be limiting their engagement with education and training.” The Royal Australian College of General Practitioners noted —

... that a key issue in increasing GP knowledge and capacity in palliative care was the creation of GP registrar positions in palliative care. GP registrar positions do currently exist, but in the RACGP’s view there are not enough.

Recommendation 10 states —

The Minister for Health prepare a plan to:

- a) increase the palliative care workforce
- b) increase the availability of further education in palliative care and general practitioner registrar positions in palliative care.

A strong focus of our report was on the implementation of the recommendations of the Joint Select Committee on End of Life Choices. Progress was noted to varying degrees on the implementation of the recommendations of the end-of-life choices committee, noting that its report was tabled in August 2018. In our inquiry, we members of the Joint Select Committee on Palliative Care in Western Australia found that implementation of the following recommendations had significantly progressed. Recommendation 7 of the Joint Select Committee on End of Life Choices states —

The Minister for Health should facilitate the establishment of an inpatient specialist palliative care hospice ... in the northern suburbs of Perth.

Recommendation 9 of that same committee states —

WA Health should conduct an independent review, from a patient's perspective, of the three models of palliative care in Western Australia ...

Recommendation 11 states that WA Health undertake specified measures to improve understanding of palliative care. Recommendation 12 states —

The Minister for Health should prioritise policy development and improved governance structures for the delivery of palliative care by WA Country Health Services.

Recommendation 18 states —

WA Health should provide specific guidelines on the use of terminal sedation by health professionals for patients at the end of life.

We found that some progress had been made on recommendation 10, which states —

WA Health should implement a process to determine the unmet demand for palliative care and establish an ongoing process to measure the delivery of palliative care services ...

Progress had also been made on recommendations 15 to 17 regarding ongoing professional development for health professionals about end-of-life treatment and decision-making. We found that limited progress had been made in relation to recommendation 8, which states —

The Minister for Health should ensure that community palliative care providers ... are adequately funded to provide for growing demand.

The progress and implementation of recommendation 13 of the Joint Select Committee on End of Life Choices states —

The Minister for Health should ensure regional palliative care be adequately funded to meet demand.

This recommendation cannot be evaluated until a more detailed assessment of demand and/or need for palliative care services in regional or remote areas has been undertaken.

The committee received evidence that the end-of-life choices committee recommendation 14, that the Minister for Health appoint an independent reviewer to audit palliative care activity and spending by WA Health, will not be progressed. That is in relation to one of our findings on the need for us to ensure that the processes be about meeting unmet need rather than unmet demand. That is the explanation for that recommendation not advancing further. We made recommendation 14, which states —

The WA Country Health Service and the Department of Health report on the progress of implementation of recommendation 13 of the Joint Select Committee on End of Life Choices —

This relates to funding for palliative care in regional areas —

in their next Annual Reports.

As I said, much of the committee's work was done via Zoom meetings, which enabled us to take evidence from across the state. We heard evidence in person or by videoconference from witnesses based in the following regional locations: Albany, Newman, Busselton, Chittering, Northam, Kununurra, Derby, Broome, Geraldton and Kalgoorlie. I believe people adapted well to this process and, indeed, seemed quite familiar with it. To my recollection, there were virtually no technical hitches with the process. Very rare were the occasions that we were waiting for a connection to be established. I only recall once when there was an unfortunate cut-off midway through a conversation, and we had to terminate our hearing a little quicker than we would have liked. Overall, it seems the capacity for our community to work with various videoconferencing options worked well.

I move on to some very important thank-yous, especially to all the witnesses who generously gave their time to improve palliative care in WA. As I said earlier, their professionalism and compassion shone through at all times. Their desire to invest time with us and to help us provide recommendations and make findings so that we can continue to improve palliative care in Western Australia absolutely stood out. A big thank-you to my deputy chair, Hon Nick Goiran; Hon Alison Xamon; Hon Kyle McGinn; and to my fellow Legislative Assembly colleagues, Shane Love, the member for Moore; and Zak Kirkup, the member for Dawesville. My sincere thanks for their efforts in putting this inquiry together in a fairly compacted time frame. That was something that we had to deal with throughout the inquiry. My thanks especially go to the wonderful advisory officer, Kimberley Ould, who did an outstanding job. She was assisted by advisory officer Andrew Hawkes and our ever IT savvy committee clerk, David Graham.

I want to give a note of caution to readers of the report, especially about the findings and recommendations, that it is rather early to be assessing the delivery of commitments that were made through the voluntary assisted dying legislative process. It needs to be kept in mind that the proposal to establish a joint select committee into palliative care arose during debate on the Voluntary Assisted Dying Bill 2019 in December 2019. Here we are, less than 12 months later, tabling a report after a fairly extensive inquiry. It is early and it must be appreciated that the primary delivery agent, the WA government's Department of Health, has been rightly focused on keeping our state safe through the COVID-19 pandemic. Much work remains to be done to further improve palliative care in WA. I hope the work contained in this report will assist in making those improvements.

MR R.S. LOVE (Moore — Deputy Leader of the Nationals WA) [11.29 am]: I would like to make a brief contribution as a member of the Joint Select Committee on Palliative Care in Western Australia. I start by thanking the chair, Chris Tallentire, member for Thornlie; Zak Kirkup, member for Dawesville; the upper house members, Hon Kyle McGinn and Hon Alison Xamon; and the deputy chair, Hon Nick Goiran. It was the first time I have been involved in a joint select committee of any sort and the first time I have been involved in a committee operating under the Legislative Council's standing orders. It was quite a learning experience to find that process can take up so much time, but the upper house members are very diligent and do their work very well. I think that seeing the upper house members in action and the forensic ability that they have developed over the years at that house of review shows us just how important the functions of the Legislative Council are to this place in working through the nitty-gritty of detail and making sure that parliamentary processes are kept to.

I would also like to thank all the witnesses and participants. We had some hosts in Busselton when we did a brief visit there. I would like to thank the members of Busselton Hospice Care Inc for their hospitality at the centre and their explanation of the important work that they do as volunteers in an environment where they are working largely on a WA Country Health Service campus—that is, Busselton Health Campus. Many people do not appreciate that the Busselton hospice workers are actually volunteers. Their work has relied on donations from the community over the years. Now the community in Busselton thinks that the hospice is funded by the government and so the community does not have to contribute. In fact, the hospice is not government funded. The workers are still volunteers and there is still a need for some help there. One of the committee's findings was that the work of volunteers needs to be recognised.

We also found that there is a tremendous difference between country areas. In areas where there are established services, mainly in the south in places like Busselton, Bunbury and Albany, there are mature organisations and a mature level of services to provide that very important palliative care to the community. As we go further away from those areas, it becomes more difficult. I think it was quite noticeable and it was noted in the report that there are very few palliative care services available in the Pilbara, and we could not really get to the bottom of why that was, other than that there appears to be a general lack of services in that area. Then we looked at the Kimberley, where there is a high degree of Aboriginality. There is great diversity in the level of service available in different communities between Broome and the more remote places. We found that some of those places actually source a lot of advice and services from Darwin and the Northern Territory. I think that in our isolated existence in Perth, we forget that there are border communities in this state that visit other places to get some of their services, and the Kimberley is one such border community. That community has been particularly hard-hit by the current pandemic, for instance, whereby it has been difficult for some of those patients to get access to the tertiary hospitals in Darwin. Instead, they have had to come to Perth, and the extra time and distance has meant a lot of disruption.

Another matter is that many Aboriginal communities have different cultural beliefs and practices. There is not one standard Aboriginal point of view. Whether a person wants to spend their last days on country or in a facility away from country will depend on the community they come from and obviously the patient's own wishes. There is a tremendous degree of complexity in delivering high quality palliative care to some of those areas.

In the report we have tabled today, I think the relevant sections that really piqued my interest from a regional point of view were terms of reference (c), the delivery of palliative care into regional and remote areas, and (d), the progress of ensuring greater equity of access to palliative care services between metropolitan and regional areas. I have spoken a little about some of the difficulties of delivery into regional and remote areas.

Another matter I would like to highlight that has been raised as an issue in the past in my own electorate is the difficulty when someone is in a palliative state but wants to stay in their home and therefore has a need for palliative care and help in the home. There used to be HACC services throughout the state; a Home and Community Care service was located in a hospital or a nearby community where care could be sought for people in that situation quite seamlessly. The development of the National Disability Insurance Scheme and the change to consumer-directed care in the aged-care sector has led to an assessment process and criteria that people with palliative conditions sometimes fall through, meaning they are unable to get the home care that they desperately need. One of the most important portions of expenditure that we examined was the allocation of money to the Western Australian Country Health Service to provide that domiciliary home care. That is very, very important. It has been very well received. Members can read the relevant areas of this report and get a very good understanding of just how important that is to people, and how people at their most vulnerable moments have been let down in the past by that service not being available. It is now available. It is an allocation of only \$2 million and I am sure it will go very quickly. We need to ensure that that money keeps being reallocated in future budgets, because that need will not diminish. We might be able to say, “We’ve built a centre, we’ve expended capital, tick, we don’t have to do that again”, but this is a vitally needed service and it needs to continue.

It is quite clear that one does not have to be that remote from Perth to be remote from the provision of a palliative care service. I think that was highlighted in evidence by the Chattering Health Advisory Group from my electorate and also the WA Country Health Service Wheatbelt Palliative Care Service, which highlighted the time taken to travel to coastal locations. For instance, from Northam, it is a three-hour trip to get to those locations and then three hours to return, so six hours of the day are spent travelling. That does not leave a lot of time to actually deliver the service. In the past, a lot of people in my electorate who are just on the outskirts of Perth have not been receiving high quality palliative care. Those people and their families have come to tell me their stories, some of which have been quite harrowing. It is good to see that there is now a focus on providing services wherever people are situated.

As I say, a home care service is very important. Also important is the flexible delivery of a lot of health services through telehealth, and incorporating palliative care into that telehealth service is very important. That important work needs to continue.

This is only a progress report. It is the final report of this committee, but it is a progress report. The monitoring of this progress needs to continue. We need to ensure that allocations made as a result of the end-of-life choices discussion are not a one-off. We need to ensure that palliative care continues to be appropriately funded into the future because the need for that service will not diminish.

I would like to quickly round off by thanking the committee staff. The chair has already done that, but I learnt quite a bit being on this committee, and I greatly appreciate the efforts of all the staff. Thank you very much.

MR Z.R.F. KIRKUP (Dawesville) [11.39 am]: I, too, rise to speak on the Joint Select Committee on Palliative Care in Western Australia’s final report, “Palliative Care in Western Australia — Progress Report”, and reflect on some of the remarks made by both the chair and the member for Moore. The report before us is absolutely a progress report and understandably so because the requirement for this joint select committee to be established was largely formed as a result of debate during the passage of the voluntary assisted dying legislation. It is a good report and it reflects that the state of Western Australia is largely in the early stages when it comes to the provision of palliative care. The obvious need to make sure that we pay more attention to the issue of palliative care came about as a result of some of the conversations and debates we had during the passage of the voluntary assisted dying legislation. We made it very clear that we wanted a well-resourced palliative care option for people to pursue at the end of their life.

The committee’s 56 findings and 25 recommendations have made sure that, as part of the Department of Health’s ongoing progress of implementing and investing in a more enhanced palliative care service, there is more structure around how that investment is pursued and where these services are better rolled out. Some areas of Western Australia are still very far off the mark when it comes to the adequacy of palliative care services. In some of our public hearings, one thing that stood out was the inconsistency in palliative care services in nearly all of south metropolitan Perth compared with north metropolitan Perth. In the Peel and Rockingham districts in particular, there is a massive shortfall in appropriate palliative care services, particularly in an inpatient environment in hospitals. As the member for Moore rightly pointed out, in most circumstances, the further we get away from Perth, the more desperate the palliative care situation becomes. Pockets of investment have already been rolled out by this government. Again, that largely came about during commitments made ahead of the voluntary assisted dying debate. Those commitments are welcome, but we need to ensure that more adequate and equitable funding is available no matter where people live. I do not think it is appropriate that some people who live in a particular electoral district in Western Australia, for example, have better access to palliative care because of commitments made by the government during the VAD debate, and people in other electoral districts have a massive shortfall in those services. We find ourselves in that situation in Western Australia, which means that more work needs to be done to ensure better investment.

Members have spoken about the areas of the report that they are particularly interested in. The area of most interest for me was the findings and recommendations on palliative care services in an aged-care setting. They are increasingly important, particularly as we expect people to age in place for longer and become more attached to where they live. We want to make sure that those end-of-life services in an aged-care setting are better delivered to those residents who choose that option. We know that in those aged-care settings, investment in those services is not as much as would otherwise be required now and for future demand.

Another area of interest is regional and remote palliative care services. Members have already spoken about that. Of particular interest to me and a passion of mine is the services for the Aboriginal communities and Aboriginal people. I am very proud of the committee's attention to that area in particular. A number of findings and recommendations are attached to this area to ensure better investment in palliative care services for Aboriginal people. I raised this issue during my contribution on the voluntary assisted dying debate. It is an area of particular interest for me to ensure greater levels of investment in a more culturally appropriate sense.

I am reminded of a visit that we made to Busselton Hospice Care. One of the volunteers there spoke to us about an Aboriginal elder who decided that he wanted to spend his remaining days under a peppermint tree that was situated on the Busselton hospice grounds and near the beach. That was a really nice and endearing option that was available as part of the old palliative care services that were offered in Busselton. In contrast, Busselton Health Campus has now invested in and delivered a really good hospice service, but it is on the second floor and in a confined space with a bit of a balcony that overlooks a car park. Although it is a relatively relaxing environment, it certainly did not have the same natural aspect to it that Aboriginal people and elders from that area would opt to pursue at their end of life. We need to keep that in mind. I felt a sense of almost honour to have been imparted with that knowledge about that situation, and we should try to pursue that as much as possible, particularly for those from the Aboriginal community who have spent much of their time on the land, so that people do not have to find themselves in a clinical setting at the end of their life. They should be able to avoid a clinical setting, but still be in a safe and supported surrounding in the lead-up to their passing if they choose that. As the chair and the member for Moore said, the Busselton hospice was delivering a service that was largely run by volunteers in a really beautiful setting. I would like to see more of that, if possible, for our Aboriginal communities, particularly those people who do not live in the metropolitan area. The report speaks to the importance of ensuring that we provide culturally appropriate palliative care. If I have the privilege to serve in the forty-first Parliament, I will continue to pay attention to that area, as I am sure all members will. We all know the importance of continuing to deliver as much as we can in what are already very difficult scenarios for the health and wellbeing of the Aboriginal community in Western Australia.

This was the first joint select committee that I participated in under the standing orders of the Legislative Council. I thought there might be more investment in better food or something like that as a committee under the standing orders of the Legislative Council, but in my experience, the Legislative Council is similarly as frugal as the Legislative Assembly.

Ms R. Saffioti: I am not sure about that. Maybe it was because you are a Legislative Assembly member.

Mr Z.R.F. KIRKUP: Perhaps they do not want us to see behind the curtain.

Ms R. Saffioti: You don't get to go to the special room.

Mr Z.R.F. KIRKUP: That is right. That is why all the Legislative Council members were filing in and out—no. As part of that, I would like to recognise Hon Kyle McGinn, Hon Alison Xamon and Hon Nick Goiran as the deputy chair. I greatly appreciated their ongoing interest and the diversity of their views that helped inform what I think is a really good report. Ultimately, there is a sense of richness in information provided in this report because we have many different perspectives, including a regional perspective from a number of members, perspectives from old and young members and perspectives from those who had varying positions when it came to the voluntary assisted dying debate. It makes for a more enriched report that we have been able to offer to the Legislative Assembly.

Ultimately, as members have touched on, we must keep in mind that this is a progress report that outlines the very early stages of what we hope will become an increased level of investment in and attention paid to palliative care. I appreciate that now there is much more awareness of this issue in a parliamentary and a government sense, and perhaps awareness across our community of the quality of life at the end of someone's life. This is a very good report that can help guide our journey to give all Western Australians richer options at the end of their time on earth.