

Hon James Chown; Hon Alanna Clohesy; Hon Martin Aldridge; Hon Rick Mazza; Hon Alison Xamon; Hon Dr Sally Talbot; Hon Dr Sally Talbot; Hon Nick Goiran; Hon Charles Smith; Hon Robin Scott

PALLIATIVE CARE

Motion

HON JIM CHOWN (Agricultural) [1.08 pm]: I move —

That this house —

- (a) notes that access to inpatient specialist palliative care is limited and that this state has the lowest number of publicly funded inpatient palliative care beds per head of population;
- (b) acknowledges that access to hands-on inpatient and community-based specialist palliative care is limited for metropolitan and non-metropolitan patients;
- (c) considers that access to specialist palliative care in the early stages of a diagnosis might improve remaining quality of life, mood, resilience and symptom management, and allow for death in the patient's preferred location;
- (d) observes that more can be done to promote understanding of palliative care in the community to ensure that all patients who could benefit from palliative care are receiving it, and that community palliative care is easily accessible for all patients at end of life who wish to die at home; and
- (e) calls on the government to ensure palliative care is funded to meet demand.

Palliative care is the specialised, coordinated care and support of people with a progressive, life-limiting illness. There is a misconception amongst the general public that palliative care is only for people in the final stage of illness, whose expected death is imminent. Historically, this has been the case, and palliative care was limited to cancer patients or patients with similar trajectories. However, palliative care has come a very long way since then. Palliative care is not provided exclusively in end-of-life scenarios. In fact, it plays an integral part of a patient's journey through the life of their illness. That illness does not need to be classed as terminal in order for a person to receive palliative care.

The aim of palliative care is to improve the quality of life of patients and their families who are facing the problems associated with life-limiting illnesses. The perception of palliative care remains skewed by a large number of people, and many are scared by the word “palliative” because of the misconception that it is for the treatment of only the terminal phase of illness when active treatment has ceased. Education is needed to change this public perception. Of course, we need specialised palliative care beds. As the motion states, there is a limited number of beds in this state. In fact, as far as I can ascertain, within the realms of the metropolitan area, there is a total of 64 specialist palliative care beds, a number of which are privately funded, so they are not all publicly funded. In regional Western Australia, it is even worse; for example, Northam Heath Service has four specialist palliative care beds and Kalgoorlie Health Campus has three specialist palliative care beds. That does not mean that general wards cannot be used for palliative care, and that takes place today throughout both the metropolitan area and regional Western Australia.

Regardless of the number of palliative care beds, specialist palliative care doctors and people trained in palliative care are needed to attend to those patients who are under the umbrella of palliative care, as I mentioned in my opening statement. On 26 November 2018, I asked a question of the Minister for Health and the answer highlighted the fact that there are only 11.35 full-time equivalent public palliative care specialists in this state. It is an interesting figure, especially when the number of palliative care specialist doctors who are also in private practice are included, because that brings the number up to 15 full-time equivalents in this state. By comparison, there are approximately 150 psychiatrists in Western Australia, most of whom would have some form of public funding for their practice. Not everybody develops a mental health condition, but dying is part of the cycle of life. We all die. There is a disproportion between palliative care requirements and psychiatric health requirements in this state.

The population of Western Australia is approximately 2.6 million, which, according to the figures I have just stated, equates to 0.57 full-time equivalent palliative care specialists per 100 000 people. That is the current figure, as per the answer provided by the Minister for Health. That means that this state has the lowest ratio in the country. Victoria has 0.7 full-time equivalent specialist palliative care doctors per 100 000 people, Queensland has 0.9, New South Wales has one, South Australia has 1.1 and Tasmania has the highest with 1.8. Western Australia is the lowest possible denominator in this very critical service in the public health system in our state. The question that needs to be asked, and I do ask, is: is it a coincidence that the two states with the fewest palliative care specialists are the two states in which voluntary assisted dying either has been legalised or is being seriously considered—that is, Western Australia and Victoria? Using Palliative Care Australia's recommended national benchmark of two palliative care specialists per 100 000 head of population, WA should have 52 full-time equivalent specialist palliative care doctors. Of those 52, proportional to population, at least 10 should reside in the regions in Western Australia to attend to people who require palliative care.

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Lorna Rosenwax is a prominent researcher from Curtin University and previously the University of Western Australia. In 2005, she wrote an important paper on how to answer this question. Her methodology has been widely accepted in other countries that are looking at what they need to do to improve access to palliative care. She determined that three estimates need to be constructed. In a minimal estimate of access to palliative care based on the assumption that palliative care should be available to anybody dying from 10 specified conditions, such as cancer, health failure, kidney failure, chronic lung disease, Alzheimer's disease, liver failure et cetera, 63 per cent of all dying patients should receive palliative care. That is the minimal estimate that is accepted elsewhere in the world—63 per cent of people who die from a known disease or life-limiting illness should receive palliative care under the parameters I outlined in my opening statement for how palliative care should be conducted. In a mid-range estimate of access to palliative care based on people admitted to hospital and then dying from some other condition, along with the diseases I have already mentioned, 69 per cent of dying patients should receive palliative care. In a maximal estimate of access to palliative care based on all deaths, excluding sudden events such as death during pregnancy or childbirth or death from a car accident or poisoning et cetera, 82 per cent of dying patients should receive palliative care. I doubt if anybody in this place or in the general community would agree that the maximum number—at least 82 per cent or more—of people who are in this unfortunate position, including every one of us at some stage in the future, should not be given, or be able to make the choice to access, palliative care.

Based on the number of specialist palliative care staff in this state, we are below the minimal estimate of access to palliative care as stated in Lorna Rosenwax's paper. I remind members that her minimal estimate is 63 per cent and her maximal estimate is 82 per cent. Based on data from the Australian Institute of Health and Welfare, only 50 per cent of people who died in hospital in Australia received palliative care. I am reliably informed that Sir Charles Gairdner Hospital, which is just down the road from Parliament and is one of the largest hospitals in the metropolitan area with a highly dedicated and professional palliative care team operating within its precincts, is funded for and can service only 50 per cent of the number of patients who pass away at the hospital, regardless of its efforts.

I go back to Ms Rosenwax's statement. Fifty per cent is well below the minimal requirement stated in her paper, which is accepted internationally to be 63 per cent. I believe this is an abysmal state of affairs. No, I am not blaming the current government. Successive governments have ignored the fact that palliative care, as a medical science and a medical requirement in today's community, is essential. Eighteen months ago, I gave a speech about the lack of palliative care services in regional Western Australia. However, what has focused my attention on this particular issue is the fact that the McGowan government is pursuing, and we have been reliably informed that this year we will scrutinise, euthanasia legislation. Any responsible government that is serious about end-of-life choices would spend what is required on palliative care requirements as expected in the modern day to ensure that, at the very least, people really do have a choice when that time comes in their life. As I have stated, and I stand by the figure—I will expand on it a bit further in this address—currently only 50 per cent of residents in this state who find themselves in that position have access to palliative care under the parameters I outlined in my opening address. I am not talking about providing palliative care in the last five days of someone's life; I am talking about providing palliative care when it really matters—when someone is first diagnosed with something that may take their life but it does not always come under the palliative care provisions.

Currently only \$41 million is spent on palliative care in this state. That figure was given in response to a question without notice asked about this matter of the Minister for Health. To bring it up to the mid-range estimate of Rosenwax's statement, we need to spend at least another \$31 million on palliative care. To get to the maximum level, we need at least another \$100 million to be spent on palliative care. These are conservative estimates. I am just talking about staffing, resourcing and education in the Western Australian public health system. It does not include the commitment needed for infrastructure such as palliative care wards and beds.

I do not have time to elaborate in this address—I will probably have time later—but the reality is that education and staffing are the key to good palliative care, along with pathways for those in the medical profession who wish to become more aware and use palliative care appropriately. I am sure we will hear from the government shortly, saying that Silver Chain carries out palliative care externally to the hospital system. There are certainly external providers to the hospital system in regional Western Australia. If members talk to them, as I have, they will learn that a lot of this work is done pro bono out of the humanity of their hearts because they are not funded appropriately. In fact, nursing sisters in regional Western Australia see palliative care patients in their homes during their own time. Their nursing managers tell them to stop doing this because they have no insurance cover outside the parameters of their employment requirements in the hospital. It is not good enough.

Associate Professor Richard Chye, director of palliative care at St Vincent's Hospital Sydney, was integral to the formation of the Australian chapter of palliative care. He was awarded the Royal Australasian College of Physicians' highest award, the John Sands College Medal. His efforts led to the recognition of palliative care

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medicine by the Australian government. This man's credentials are beyond reproach. He was a groundbreaker on what palliative care should be in this country. I intend to quote a short piece from *The Sydney Morning Herald*. He commented —

... my views are based on my longstanding clinical experience and medical evidence, not on dogma.

...

... we all agree that too many Australians experience painful and undignified deaths.

However, my view, after a lifetime's work in palliative care—having stood at the bedside of literally thousands of dying people—is that none of the issues that bring us to this point will be solved by introducing assisted suicide.

...

We don't train them ...

I am paraphrasing now because my time is running out. He said that no patients need to be anxious and we need to educate our doctors to the point at which, for example, we tell the patient that further treatment and chemotherapy will not save their life; it will just extend it briefly. He said that some patients need a palliative care doctor to help them through the process, and it is not happening.

Last year, the Department of Health released a paper entitled “WA End-of-Life and Palliative Care Strategy 2018–2028”. It was a good paper. I have read it more than once. It was written by palliative care professionals in the health system. It encapsulates what palliative care should be. Its time span is from 2018 to 2088. Not one section of that paper has a time line, funding or a process of how the government will introduce or implement the very good points made in that document. I repeat: at the very least, this government must start spending on palliative care in the Western Australian health budget. We have just had a windfall of \$400 million from the GST, if members want to know where the money comes from. The government has an opportunity to take \$100 million out of that windfall and put it into programs that will benefit every Western Australian.

In this day and age, if the government is really entertaining the possibility of allowing euthanasia under law to give real-life choices or end-of-life choices, it has no option but to be absolutely responsible, put its money where its mouth is and ensure prior to that event taking place that palliative care provisions in Western Australia are not the worst in the nation but the best. The Western Australian community deserves it. I hope that this house supports that intention. I state in this place today that I am not against euthanasia; I am against lack of choice. At this stage if that legislation came forward and was carried through this house, without funding palliative care appropriately, as per my opening statement, it would be a fob off. The government is stepping away from its responsibilities for providing adequate health care for end-of-life choices in Western Australia. For example, the report of the Joint Select Committee on End of Life Choices stated that about 14 500 Western Australians die from a known disease in hospital every year. Seventy per cent of them would have benefited in some way from palliative care. That amounts to about 10 000 people every year. As I said earlier, half of them do not receive it. Every year, 5 000 Western Australians do not receive adequate palliative care but die in a ward somewhere under the administration of hardworking nursing staff and GPs doing their absolute best for them. Under the parameters of the report I mentioned, from 2018 to 2028, 50 000 Western Australians will die due to a lack of funding, resourcing, staffing and education on what palliative care can deliver to not only the patient, but also their families.

Unfortunately, I am running out of time. I look forward to members' contributions on this subject. It is one of the most important subjects that we can discuss in the form of a motion in Western Australia, especially when considering euthanasia, as I said before, at some stage in the future. It is worth repeating that if the government believes in end-of-life choices, it should give us a real choice—that is, properly funded palliative care provisions, as I stated in my opening address.

HON ALANNA CLOHESY (East Metropolitan — Parliamentary Secretary) [1.28 pm]: I thank Hon Jim Chown for bringing the motion to this place. It is an important matter and one that is worthwhile debating in this place. I am the lead speaker on behalf of the government. At the outset, I should acknowledge that the government is generally supportive of the motion. For the benefit of members, I foreshadow that I propose to move an amendment to paragraph (a). I will talk about why later. I wanted to state that up-front.

Let me reiterate that the government is generally supportive of this motion. After conducting a 12-month inquiry, the Joint Select Committee on End of Life Choices identified, as the member rightly pointed out, that palliative care is the single largest issue. It highlighted that much more work needs to be done to make sure that palliative care services keep pace with not only growing demand but also community expectations because community expectations and understanding have changed over time—I will talk more about that—partly because of the changing patterns of disease and the increasing number of people with complex health needs. In our medical world,

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technological advances increase at a pace that supports people by keeping them alive longer, which may not have happened in the past. Medical advances, not the least being antibiotics, have supported people's life expectancy. People are living longer and surviving illnesses and diseases that in the past they may not have survived. That is one of the reasons. There is also a need for the education and support of all medical professionals and healthcare workers, including GPs, as the honourable member pointed out, and providers of residential aged care. People need to be educated about exactly what palliative care is. As the honourable member pointed out, people need to understand what palliative care is and how it can assist them and their family in their journey through illness. Healthcare workers must also understand what palliative care is and how to practise it. Palliative care workers, particularly those in aged-care residential settings, and other people must understand what palliative care is so that they know where to look for palliative care services. Without a doubt, there is a need for more frontline workers, particularly in rural and remote regions. Certainly, the end-of-life choices committee identified that very strongly and it was also pointed out by the honourable member. Encapsulating all this—the committee report highlighted this—is the need for community awareness and understanding of death and dying, loss, palliative care actual services and the limits of medical interventions. It is an incredibly difficult topic—is it not?—death and dying. But that is the direction we must head towards to make sure that we have a good understanding of palliative care and how it should be delivered.

Let us get to the motion in detail. Paragraph (a) states that access to inpatient specialist palliative care is limited and that this state has the lowest number of publicly funded inpatient palliative care beds per head of population. Paragraph (a) reflects findings 16 and 17 of the end-of-life choices committee report. I will deal with the different parts of paragraph (a) separately because each component requires attention.

Let us first look at specialist palliative care being limited. There is no argument about that—absolutely no argument. As of November 2018, there were 11.35 full-time equivalent specialist palliative care physicians practising in the public sector and 15 full-time equivalents practising in the public-private sector. Although workforce issues in the sector need to be addressed, they did not emerge overnight. As the honourable member pointed out, there has been limited planning and foresight over a number of years. In fact, the questions that the honourable member has put on notice over time clearly point that out, particularly in relation to funding. Palliative care funding has increased marginally over the last 10 years—only just marginally. At one stage, funding for palliative care went backwards. Looking at one of the honourable member's questions, between 2011 and 2012–13, palliative care funding went backwards by \$500 000—there was no increase. There has been a systemic failure in funding over time. We need to look at not only funding the sector, but also expanding specialist palliative care services across the metropolitan area—I will get to rural and remote areas in a minute—and increasing the number of medical specialists through outreach and other mechanisms, such as telehealth. There is no question that we must also look specifically at regional and rural locations.

The second part of paragraph (a), which notes that we have the lowest number of publicly funded inpatient palliative care beds per head of population, has been taken directly from finding 17 of the joint select committee's report, which is based on evidence to the committee in a submission from Silver Chain, that fantastic organisation that provides palliative care support in WA. Although that may be accurate, for technical reasons it cannot be established conclusively. Publicly funded beds in private facilities are funded by contracted services; they are not funded by the number of beds. It is activity-based funding as distinct from funding based on bed numbers. I can go into the detail of that background but I do not want to dwell on the mechanics of it. I will try to get through this quite quickly. Compared with other states, WA is unique because it has Silver Chain services and palliative care consultancy services in Fiona Stanley Hospital, Sir Charles Gairdner Hospital and Royal Perth Hospital. Not all the other states have similar services. In WA, people attend hospital under specialties other than palliative care, but palliative care consultancy services attend to those people and provide them with palliative care in addition to the primary specialty for which they are in hospital. Therefore, they do not receive palliative care as inpatients even though they are receiving palliative care services. They are not identified as being in dedicated palliative care beds. In addition, I have talked about the mobile specialist palliative care team focusing on capacity building of the palliative care sector workforce through training, education assistance and mentoring. That service provides advice and support to residential aged-care services in disability care and mental health services and also in correctional facilities, which again is quite different. Firstly, many witnesses to the joint select committee indicated that 70 per cent of people wish to die at home. Secondly, as I have pointed out, WA is unique amongst the states in that Silver Chain's local hospice care service—an incredible service—is recognised nationally and internationally for its excellence and outcomes. We can certainly accept that. Thirdly, consecutive governments have maintained a policy position regarding primary investment in the community for palliative care. Basically, those are three matters we need to consider when we are looking at this issue.

Our government has accepted the recommendation of the joint select committee that WA Health appoint an independent auditor to look at palliative care activity and actual expenditure across all aspects of care, including inpatient care. I think that is really important. Rather than argue the toss about what is there and what is not, our

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government has accepted that we clearly need to audit actual expenditure across the whole sector. We have also accepted recommendation 9 for an independent patient survey to examine the risks and benefits of inpatient versus community and consultative care. Together, these audits will look at the extent of inpatient care and, importantly, patient preferences for end-of-life care. They are important. As leading palliative care researchers have noted, according to my notes —

For some patients (care at home) might not be achievable on a sustainable basis. Not all community care can offer a rapid response service on a 24 hours 7 days basis and access to medical resources is often limited relative to availability in hospitals.

While it might be true that 70 per cent of healthy people or even people in the early stages of an illness would like to die at home, there is evidence that as their health deteriorates, some people—indeed, many people—change their minds. It also may not be practicable for them to die at home. That is why we will focus on the implementation of models of care that best support the needs of all patients. Paragraph (b) of the motion states that the house —

acknowledges that access to hands-on inpatient and community-based specialist palliative care is limited for metropolitan and non-metropolitan patients;

That is taken from finding 16 of the joint select committee report. Again, the government has accepted all of the recommendations and certainly does not argue with that part of the motion whatsoever. Access to specialist palliative care is limited across the state—we have already established that. It is not only specialist medical care; frontline palliative care nurses and ancillary staff are also needed, particularly—I emphasise this—in regional and remote areas. In 2018, we recognised the need to improve and strengthen palliative care. The honourable member has already mentioned the release of the “WA End-of-Life and Palliative Care Strategy 2018–2028”. This is the first of its kind; it is the first time that what needs to happen across palliative care has been laid out. It is applicable to all services in WA that support and care for people with life-limiting illnesses and, importantly, their families. It goes from paediatric services to aged-care services. That full range of services is important, and includes both public and private services, community aged-care services by non-government organisations, primary healthcare teams, and public and private administrators, as well as training, research and educational institutions. I recommend that members look at this strategy in detail.

WA Health is leading the implementation of the strategy, and I note the member’s criticisms of that. I will get to the issue about resourcing later. However, our government accepts that there is a need for better access to specialist palliative care services, with improved education for generalist palliative care providers. The Minister for Health said in response to the report of the joint select committee —

Care at end-of-life is everyone’s business, whether it is provided by specialist palliative care or non-specialist healthcare and community providers.

We need the continuum of providers.

Paragraph 3.86 of the joint select committee report talks about access to specialist palliative care in the early stages of a diagnosis, which may improve remaining quality of life, resilience and symptom management. That is an important finding—finding 12—of the report. Members of this place who were on the joint select committee will be able to attest that they received evidence from witnesses about the benefits of specialist palliative care. One such witness, Ms Cait Calcutt, told a very moving story about the need for specialist palliative care. The report states —

Ms Cait Calcutt told the committee of her late partner who died in 2014. Prior to 2014 Ms Calcutt admits little understanding of palliative care, although she had been caring for her partner ‘who was diagnosed with three chronic life-limiting diseases in his early 40s [...] He had survived two cancer diagnoses in eight years and he was living with the disabling consequences of surgeries, treatments, opioids, medications and dealing with chronic pain’.

Her partner’s GP was experienced in caring for patients with chronic disease but the complexity of his many illnesses also meant having to coordinate fragmented care, which included ‘surgeons, endocrinologists, gastroenterologists, neurologists, pain specialists, psychiatrists, psychologists and pharmacists’. At the beginning of 2014, her partner’s health deteriorated rapidly and, while in hospital, he was told his carcinoma had returned and that he had 12, but probably six, months to live. He was not referred to the hospital palliative care team or to a palliative care service and was discharged from the hospital.

Shortly after his discharge, he suffered another health crisis that resulted in an emergency hospital admission. It was only at this point that the palliative care team became involved, ‘not at the request of the doctor but at the urging advocacy of a family member, who was a health professional and knew the hospital and its systems’.

Ms Calcutt’s experience typifies the problems with palliative care. To that end, I would like to suggest that while we have —

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The PRESIDENT: Member, you have run out of time. You are going to have to get somebody else to move that amendment.

HON MARTIN ALDRIDGE (Agricultural) [1.48 pm]: I rise to support the motion before the house today and acknowledge that this is the second motion on palliative care that Hon Jim Chown has brought to the house—we had a debate late last year during non-government business. It is clear that there is a linkage between the joint select committee’s report on end-of-life choices and the focus now on palliative care, and for good reason. I acknowledge the work that has been done by that committee to identify many of the issues that exist in palliative care, particularly as they relate to regional and remote service delivery. I must admit that some of the most challenging constituent issues that I have had to deal with in the short time I have been in this place have been in relation to end-of-life care in our regions. In saying that, I do not think people need to be in a remote regional location or community, or to be distant from Perth, for that to be an issue. In fact, in some of the communities on the fringes of Perth we see a crossover between the metropolitan health services and the WA Country Health Service and, in my experience, that service has often been somewhat lacking. The services required by the people who have contacted me have largely been focused on providing 24/7 support for their loved ones in their home as they approach end of life, and on providing some respite care to family members who are caring for loved ones as they approach end of life. It has been my experience that once these issues have been reported to my office and then elevated to the appropriate minister, there is generally very quick rectification of the issue. That suggests to me that the problem is one of resourcing rather than the quality of care or the service that is being provided. Constituents are usually very grateful for the intervention that has occurred. Certainly, in the case of one family I assisted, that assistance was received very late in the piece; the husband died just one week later. They lived only about 30 to 40 kilometres from Joondalup Health Campus in my electorate, which is hardly a remote part of Western Australia.

I want to recognise the significant value and importance of the people who work in our regional health systems, particularly in the palliative care space. That stretches beyond specialist doctors to nurses, social workers, occupational therapists, physiotherapists, counsellors, psychiatrists and GPs—the list goes on and on. I would also like to recognise that the wheatbelt is home to the 2018 WA nurse of the year, Brett Hayes, who is the regional palliative care nurse manager for the wheatbelt. Although I have not yet had time to look at some of the innovative work that has been happening in the wheatbelt around telehealth palliative care services, I understand that Brett and his team are leading some innovative changes in how we deliver services like palliative care in the wheatbelt. We have to do that not just in palliative care but also across the medical care spectrum, because the reality is that specialists, primary care workers, physicians and nurses cannot be available at the end of the street, all the time, in every community. That is just a reality of living regionally, and I think most people who live regionally understand and appreciate that reality.

The specialists who visit the regions are typically fly in, fly out, with some exceptions; I think the great southern region has a resident specialist. There appears to be limited funding for regional visits; in some locations they may see a palliative care specialist only once, twice or three times a year. Places like Geraldton in my electorate get a monthly service from a regional palliative care specialist, whereas places like Carnarvon will see a specialist only three times a year. I have heard from specialists that a lot of their work in the regions is focused on educating other healthcare professionals. As Hon Jim Chown mentioned in his initial remarks, it is a relatively new medical discipline and there are some acceptance and understanding issues amongst patients and the medical profession itself about what palliative care actually is and means.

As I have said, I do not want the focus of palliative care to rest solely on specialist consultants, although they are important, because in the regions we rely on a multidisciplinary approach in our workforce, whether it is for palliative care or other types of specialist care. That, coupled with innovation in the medical space, is really what we need to look at when we consider how we can deliver medical care differently in our regions. Obviously, the people at the forefront are the nurses and social workers in our hospitals and in our community care programs.

I want to draw members’ attention to the “WA End-of-Life and Palliative Care Strategy 2018–2028”; I think it was raised in remarks earlier today. I understand that it is the first strategy of its kind in Western Australia, and I welcome it and recognise the government’s contribution towards its creation. Interestingly, there are six priority areas outlined in the strategy. They are —

1. Care is accessible to everyone, everywhere.
2. Care is person-centred.
3. Care is coordinated.
4. Families and carers are supported.
5. All staff are prepared to care.

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6. The community is aware and able to care.

In my experience of this area, the first priority—care is accessible to everyone, everywhere—is really one of the major driving issues in regional palliative care provision. The statement following the first priority area is —

I have access to good quality end-of-life and palliative care, regardless of who and where I am, or how I live my life.

That is the first priority of the government's 10-year strategy, which I understand will be reviewed after five years. I think it is important to set the bar high for how we intend to achieve the outcomes that are expected from this strategy. It is a fairly high-level strategy; it does not talk about implementation, funding, gaps, the services that are needed or the healthcare reforms that are required, but it certainly is a good start in recognising the problems off the back of the Joint Select Committee on End of Life Choices report.

I am hearing positive things from the regions about country health officials being recalled to Perth to work on the government's palliative care plan. We are all hopeful that more detail on that will be announced in the upcoming state budget. That is going to be a key part of how the government intends to move forward on reforms to allow for voluntary assisted dying in Western Australia. I share the view of others in this place that I would hate to arrive at a point at which the only option for people living in regional and remote Western Australia will be to access voluntary assisted dying laws as opposed to options like good palliative care. I recognise from the outset that palliative care will not suit all people in all places, but if we are going to have choices at the end of life—and the government recognises this—it is important to make sure that we address the deficiencies in regional palliative care provision.

Last week I attended a public meeting in Quairading, in my electorate. There were probably only about 20 people at the meeting; some of them were involved with local seniors' groups, and their age range I expect would have been between 70 and 90 years. Obviously, voluntary assisted dying and palliative care was the issue they wanted to talk to me about. As they described it to me, they are going to be the next customers for voluntary assisted dying, so they wanted to share their views with me. The spectrum of people in that room was interesting. One gentleman in his 80s told me that he was supporting his best friend who was in hospital, approaching end of life, and how that experience has shifted his view away from voluntary assisted dying. Somebody else in this public forum then jumped up and said, "Well, 80 per cent of voters want it, and those people who don't vote for it should be named and shamed in the newspaper!" I thought: herein lies the problem we have in respect of reconciling and understanding community attitudes as we approach what is going to be a really important debate—and, ultimately, decision—later this year. The Nationals WA has written to the Minister for Health about the consultations that are occurring, not specifically about palliative care but about the Ministerial Expert Panel on Voluntary Assisted Dying. We think that visiting just Kalgoorlie, Geraldton, Broome and Bunbury —

Hon Nick Goiran: In the middle of the day.

Hon MARTIN ALDRIDGE: Yes, in the middle of the day, but it is also grossly insufficient in terms of consulting in a genuine way with those people who live outside of Perth. I do not want these comments to be political in any way, but we have nine regions in Western Australia and visiting four of them is not good enough. I hope that the government will realise and respect that and extend consultations to other regions and look at ways in which we can use our community resource centres, which are located in some of our smallest and most remote communities, and their video technology to allow people in Quairading—like the gentleman whom I spoke to—to have access to consultation with the ministerial expert panel. I am sure that there are significant time constraints on this process and this panel, but as a Parliament and a state government, it is only fair that we hear the views of those people in the community, particularly the aged, who may not have access to technology such as computers and email. That will be very valuable for how this matter of public interest progresses in the Parliament.

I will return to palliative care. One does not have to read far into the first report of the Joint Select Committee on End of Life Choices to find the Chair's foreword, which makes references to palliative care. The Chair's foreword states —

Palliative care was the single largest issue examined during the inquiry, and it became clear that much work is needed to ensure that palliative care services are able to keep pace with growing demand and growing community expectations.

Western Australia has the lowest number of publicly funded in-patient beds per capita and access to specialist palliative care is limited across the state. Access is even further limited in rural areas and almost non-existent in remote regions. In an extraordinary admission, the WA Country Health Service told us 'there is limited oversight, coordination and governance of medical palliative care services across WA Country Health Services'. This, together with the barriers to access across the state generally, must be urgently addressed by the State Government.

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That takes me to recommendation 12 of the report, which states —

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

Recommendation 13 states —

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

Obviously, I do not want us to find ourselves in the situation whereby we are merely measuring the success of regional palliative care by the number of inpatient beds. What we should be aspiring to in terms of good palliative care options and outcomes moves much beyond inpatient bed services. That is well recognised. Trying to establish the service standard that should be expected in certain communities and how we can make sure that those service standards are met by government and its agencies or service providers is an important conversation that is happening now. I am hopeful that the state government will see some positive change in the upcoming state budget by way of palliative care provision.

On 18 March, Roger Cook welcomed an election commitment by Hon Bill Shorten of \$25 million for 25 new palliative care beds in Perth's northern suburbs to be based at Osborne Park Hospital. I am sure that will be welcomed. I think that the report recommended greater inpatient bed capacity in the northern suburbs of Perth. But I call on the federal government and the federal Labor Party to also consider the types of investments that could be made with the state government to improve palliative care options in our regions, particularly regions like the one from which the family I just described came, which I think falls into the gap between a metropolitan health service and a country health service. People living in those regions are close to the metropolitan area, but they still want their family member to remain in their home and in their community as they approach the end of life, yet our current government health infrastructure and government-funded health services allow these people to continue to fall through the gaps.

I commend the motion and I look forward to this house working forward in a bipartisan way to ensure that those people in our communities will be the beneficiaries of better palliative health outcomes into the future.

HON RICK MAZZA (Agricultural) [2.04 pm]: I thank Hon Jim Chown for bringing this very important motion to the house. I note that it is in line with the “My Life, My Choice” report. Something very positive to have come out of that extensive report, which I am still making my way through, is the way it has highlighted palliative care as a major issue that we need to address within the state. It is a very important issue when we get towards the end of life. I note that part (a) of the motion states —

... that this state has the lowest number of publicly funded inpatient palliative care beds per head of population;

However, bed numbers are only one part of quite a complex process and range of services that are required when it comes to palliative care. A lot has been said about services within the country for those who are in the lead-up to end of life and the process they have to go through from receiving a diagnosis to the end. The parliamentary secretary mentioned that about 70 per cent of people receive palliative care within their home. That has certainly been my experience within our family with people who have lived in the wheatbelt and have chosen to be at home. But that creates a number of issues. Obviously, travel is a very big part of that. Today I would like to touch on the patient assisted travel scheme. My experience is that it is a very important subsidy for people who are travelling for medical attention. It is not unusual for people to travel 500 to 700 kilometres in a one-day round trip to visit specialists. That scheme has been very useful and helpful for a lot of people who have needed it. However, before I get to that, the “My Life, My Choice” report contains a definition of “palliative care” from the World Health Organization. I will not read it in full because it is quite extensive and people can pick up the report at any time and read it themselves. However, it states, in part —

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness ... Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death; ...*

The patient assisted travel scheme can provide some financial assistance to people who have to travel and accommodate themselves in the city or a regional centre to have treatment or assessment. PATS was transferred from the commonwealth to the states in 1987 to enable greater flexibility and local responsiveness. PATS is funded by the state government through the Department of Health and administered by the WA Country Health Service. Assistance is available to permanent regional residents who need to travel more than 100 kilometres one way to the nearest eligible specialist service, including telehealth services—which I will touch on a bit later—or more

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than 70 kilometres each way to access specialist treatment for cancer or dialysis when the health service is unable to provide a transport service. If eligible, a subsidy can be claimed for fuel used during private vehicle use; surface transport—that is, trains or buses; air travel in certain conditions; accommodation; and, in some circumstances, financial assistance towards the cost of having an escort or carer support them, which very often happens. Between 2009 and 2014, the number of subsidised trips increased by 72 per cent. I will run through the allocated funding in the state budget estimates for 2018–19.

Funding for the WA Country Health Service patient assisted travel scheme was \$34.706 million, with around 39 969 recipients. That is a lot of lot of recipients and a lot of claims. Funding for the Peel Health Service, which has a small PAT scheme, was \$43 000. It is concerning that the target that is set for the WA Country Health Service PAT scheme per trip is \$377, yet the actual cost of the trip is \$440. The cost is much higher than the target. It therefore behoves the government to reset that target. If this service is being used extensively by people who require it, maybe we should set a higher target so that stress is not placed on the system. People do not choose to be sick, but, when people are sick, they need to get assistance. We have spoken about Silver Chain. Silver Chain has been very helpful in providing home care for people who are in a palliative care state. It can be very difficult and distressing for family members who are assisting a palliative care patient to get on the phone and work out what medications they need to give to the person, particularly at weekends.

On 20 March, the Minister for Health, Hon Roger Cook, spoke about the funding in the forward estimates for palliative care—namely, \$41.4 million in 2018–19, \$42.3 million in 2019–20, \$43.4 million in 2020–21 and \$44.6 million in 2021–22. That is not a very large amount of money for palliative care when we look at the overall health budget. I know that funds are always tight, but with the extra GST revenue that we should pick up soon, that funding could probably be increased. Around \$45 million a year is not a lot of money for palliative care, and there does not seem to be much of an increase in the forward years.

Hon Martin Aldridge touched on telehealth. I have a flyer here from telehealth. It is called, “To the moon and back with telehealth”. Apparently, the people who have used telehealth have saved the health system about 27.3 million kilometres in travel. That is an extraordinary saving.

Hon Colin Holt: A great program.

Hon RICK MAZZA: It is a great program, yes. Obviously, as technology improves and the national broadband network becomes more stable, telehealth could be rolled out further as a better option for many people.

I now want to come back to PATS. I refer in particular to the twenty-fifth report of the Standing Committee on Public Administration back in 2015. Finding 1 was —

The Committee finds that the fuel subsidy provided by the Patient Assisted Travel Scheme is inadequate. Whilst the scheme was not designed to cover 100 per cent of out of pocket expenses, it does not reflect a realistic proportion of costs incurred by patients.

Finding 2 was —

The Committee finds that the fuel subsidy should be reviewed regularly, as announced in 2009 by the Health Minister and the then Regional Development Minister. It should be adjusted, if necessary, in line with inflation and fuel costs to ensure it continues to reflect a realistic proportion of costs incurred.

What worries me is that the target is lower than the actuals.

I refer now to a submission to the committee from the Department of Health WA Cancer and Palliative Care Network. It makes a couple of interesting points. The submission states, in part —

- Metropolitan Perth accommodation costs have increased significantly according to the 2012 Australian Bureau of Statistics but PATS funding has not increased.

...

- Patients are often required to receive their treatment across multiple health care institutions in order to receive the evidence based care they have been recommended but have to self-fund travel between sites. This can amount to a considerable amount when treatments are daily for a 6–8 week period.

Further on in the submission, it refers to both longer trips and shorter trips, and states —

- There are disparities in eligibility for patients living on or around the 100km radius; for example, patients living in Northam or York may receive assistance but those from Toodyay will not. This also relates to patients living in a 70km radius of Perth.

...

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- Patients have been refused flights from some regions and made to take a bus journey of up to 16 hours. This is inappropriate for cancer patients and can mean patients are not fit enough to receive treatment on arrival and can impact on recovery post treatment.

When I read that, I thought it seems extraordinary that patients who have received treatment, whether chemotherapy or some other form of treatment, then have to travel for 16 hours on a bus. I therefore hope we can improve those services within our state.

I refer now to the findings and recommendations in the report from the Joint Select Committee on End of Life Choices, “My Life, My Choice”. I also acknowledge the chair’s foreword, which Hon Martin Aldridge has also referred to. It is good that palliative care has been highlighted in this report. Finding 19 states —

There is limited access to palliative care medical specialists in regional Western Australia.

Finding 20 states —

There is limited medical oversight, coordination or governance of medical palliative care services across WA Country Health Services.

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.

Without doubt, there is room for improvement.

On 13 September 2018, Hon Martin Aldridge asked a question without notice about PATS. The government’s response to his question stated in part that there are currently no plans to increase the PATS subsidy—even though the government did admit that additional funding would enhance the scheme. I hope the government has changed its policy on PATS funding. There needs to be greater investment in the PAT scheme, along with the WA Country Health Service and the other health services that are provided to regional Western Australia.

As I have said, because of the tyranny of distance, the requirement to travel can be quite distressing. We have to experience it to understand what it is like to have a sick person in the car and have to travel for two, three or four hours to get to a specialist, perhaps have to wait—although a lot of places are good and try to prioritise assessment or treatment for people who have to travel long distances—and then drive the patient all the way back home. I would hate to think that the stress that may be caused to people because our palliative care services to the country are not sufficient could be one of the reasons that people might elect to end their life under legislation that we might later pass. It is very important to ensure that the palliative care system is good enough that there will not be a lack of palliative care to provide a reason for a person to make a decision to access an end-of-life choice.

HON ALISON XAMON (North Metropolitan) [2.18 pm]: I rise to indicate that the Greens will be supporting this motion, and thank Hon Jim Chown for bringing this important topic to this chamber. Members in their contributions have spoken a fair bit about the report of the Joint Select Committee on End of Life Choices, “My Life, My Choice”, for very good reasons. This motion is timely, because it is most likely that we will be debating legislation pertaining to the issue of end-of-life choices and its intersection with palliative care. I note from the report that palliative care was the single largest issue that was examined in the course of the inquiry. It is clearly an imperative that we have a robust palliative care system, irrespective of current deliberations around the issue of end-of-life choices. The report provides a thorough analysis of the current state of palliative care services within Western Australia and, sadly, found it to be wanting on many fronts.

With an ageing population and an increasing number of people dying from life-limiting conditions, as compared with accidental deaths, more and more people will need access to palliative care. The report showed us that, even now, many Western Australians do not have access to palliative care services, and this is particularly aggravated for people living in rural and remote Western Australia. It is appalling that we are bringing Aboriginal people off country to die far away from their homes. There is also a problem with providing appropriate services for people from culturally and linguistically diverse backgrounds. People with life-limiting conditions that are not cancer were also found to be at a disadvantage, compared with those with cancer, in access to palliative care. It has already been quoted by others, but of particular concern is the committee’s finding about the provision of palliative care in the regions, and the extraordinary admission from the Western Australian Country Health Service that there is limited oversight, coordination and governance of medical palliative care services across Western Australia’s country health services. The report goes on to discuss barriers to access across the state, which need to be urgently addressed by government. That is really important to emphasise. It was not unsurprising to many of us, but it is very important that it is there in black and white. This means that we do not even know how much money is really currently being spent on palliative care.

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On a more positive note, the report found that the model operated by Silver Chain, which is integrated specialist community provision of palliative care with primary healthcare infrastructure, is recognised to be best practice, but even then the committee recommended that its services should be expanded, so that more people can be reached. The model involves three specific service offerings—a metropolitan community palliative care service, a palliative nurse consultancy service and the palliative rural telephone advisory service, all guided by the principles of building capacity within families so that they are better able to care for their own. It also uses an approach around integrated and coordinated services, interdisciplinary and multidisciplinary care planning, and evidence-based, client-centred care. The report went on to provide a number of other recommendations for improving palliative care in Western Australia. The challenge is now for the government to translate this attention into adequate resourcing and effective team-based care, and sufficient support for care outside hospitals, to ensure both an efficient use of funds and also effective support for people's wishes to die well, and often to die at home or in an appropriate non-hospital setting, because that is part of what constitutes choice.

There is a need to look at palliative care also in the broadest sense—that is, looking at community education and addressing the underlying barriers to entry. Consideration of how to ensure that more Western Australians are able to access palliative care in a timely manner extends further than the simple provision of services. Generally speaking, death and dying in our culture are uncomfortable to contemplate. The result is that, realistically, often people do not come to understand the role of palliative care until they themselves are seriously unwell. This means that people may not access palliative care until the very end, and that means they are not being as well supported as they might have been if they had had the opportunity, or had been aware earlier that they needed to access palliative care. This discomfort extends beyond the patient, unfortunately, and can often exist in the treating clinician themselves. Often, a clinician's desire to cure is coupled with frustration over futility and a patient's desire to live is balanced with a desire for comfort, and these competing goals can create tension amongst the patient, the family and the clinician. We know this to be the case, and if we want to improve access to palliative measures, we will have to look at strategies such as including earlier palliative care given in conjunction with curative therapy as part of a broader guideline-directed management strategy as one way of ensuring that we are more effectively balancing these tensions. Organisations such as Palliative Care WA are playing an invaluable role in our community by increasing awareness around end-of-life considerations. Since 70 per cent of deaths are expected, one of PCWA's key areas of focus is that of advance care planning. Advance care plans give people the opportunity to be clear about what they do and do not want, and this process helps care providers enormously.

Another key consideration in the provision of palliative care is the presence of a skilled workforce to deliver these services, and this is becoming increasingly apparent as our population ages and more and more people enter aged care. In 2012, Wendy Porter, the residential care manager in WA for Aged and Community Services Australia, told a Senate committee looking into palliative care in Australia that the aged-care workforce would need to treble over the next 30 to 40 years, and a large proportion of that workforce would need generalist skills in a palliative approach to care. Given that we are failing to meet demand now, it is difficult to overstate the imperative that we act now to address increasing demand in the future. The strength of palliative care should be the multidisciplinary approach to supporting people, and this means that we need the full range of appropriately trained health providers. In this vein, I am deeply concerned about the government's recent response to a question I asked about the number of psychiatry trainees who attained certification to become consultant liaison psychiatrists. Consultant liaison psychiatrists specialise in that interface between general medicine and psychiatry, and, among other areas, they work with patients who may not have a psychiatric disorder, but are experiencing distress related to their medical condition. As would be expected, mental distress is common in people with life-limiting illness and, as such, access to a consultant liaison psychiatry service is an important aspect of minimising that the stress. Unfortunately, when I asked the minister how many psychiatry trainees had attained consultant psychiatrist certificates over the past three years, the answer was one. We are going in the wrong direction, so that needs to be addressed.

I also want to briefly touch on the palliative care needs of people with pre-existing severe and persistent mental illness. There is overwhelming evidence that people with severe and persistent mental illness are dying 15 to 20 years younger than the general population, due to a range of medical conditions. In addition to their mental illness, people with a comorbid life-limiting illness often also suffer from the compound issue of social isolation. They often have declining physical abilities and live with physical pain. Even though we know this is an issue, there is a lack of research and an evidence base on palliative care for people in the mental health system. These people are some of the most vulnerable people in our community, and they have greater barriers to accessing palliative care than the general community, and arguably need the most support. This is an area that needs greater attention.

I am aware that others wish to speak on this motion, so I may leave my comments at that point. I want to again thank the member for moving this motion. Death and dying are universal experiences, and supporting people to die well should be at the core of the priorities we have as a community. We are not doing well in this area. We need to do far, far better. Particular parts of our community are not receiving anything close to what we would

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expect to be a basic standard. I absolutely concur with concerns that to enable people to have genuine choice about what happens at the end of their lives, one of the choices that needs to and must be made available to people is the right to die without having their lives terminated early, but also to die with appropriate palliative care support.

HON DR SALLY TALBOT (South West) [2.30 pm]: As honourable members will know, I was a member of the select committee that carried out the inquiry into end-of-life choices. For me, one of the most interesting and surprising parts of the evidence we heard was around the issue of palliative care. As several members who have spoken before me have noted, a very substantial part of the report—it is probably the single largest subject—is the question of palliative care, the types of palliative care in Western Australia and where it is available, and the questions that we want to raise around its provision. The report makes several very strong and specific recommendations about access to palliative care and the way that palliative care is provided. I was very pleased that the government has agreed to support those recommendations. I look forward to playing my part in seeing those recommendations implemented over the next little while.

As the parliamentary secretary indicated, it is the government's wish to amend the motion slightly, and I understand we have the mover's consent to contemplate this amendment. I am very grateful to the parliamentary secretary for allowing time for me to move the amendment, because it is very important that we understand the practicalities behind the amendment.

Hon Peter Collier: You're moving an amendment?

Hon Dr SALLY TALBOT: I am moving an amendment that I understand has been negotiated with the other side of the house, and the mover of the motion has agreed to support the amendment.

The reason we are looking at an amendment to the first part of the motion is that the way that palliative care is provided in Western Australia is very different from the way it is provided in other states. It was heartening to see the evidence that, as a country, Australia is second in the world in terms of the provision of, and the satisfactory nature of, palliative care. Western Australia has some very innovative ways of providing that service. It is not adequate and nothing that I say should be interpreted as a defence of that inadequacy. I have put my name to all those recommendations and I will fight to see them implemented. It has been very interesting and encouraging to hear people from the crossbench, Hon Rick Mazza, and people from the Liberal and National Parties indicate that they have a deep understanding of what these inadequacies mean for their constituencies.

I thought that the best way to introduce this amendment was to talk about some of the specific work that the Joint Select Committee on End of Life Choices did. We did not have the opportunity to talk to everybody in Western Australia who will avail themselves of, or has an interest in, palliative care and end-of-life choices generally. We had a limited period in which to report, so we had a limited chance to do that over those 12 months. We did, however, take an enormous volume of evidence, and all that evidence is still available on the public record for people to consult.

It was clearly essential to look at palliative care under the heading of the choices that we want people to have access to when they come to the end of their life. For me, all these questions come under the heading of people's choice—the wish of a society such as ours to listen to what people want for themselves and for the people they care about at the end of their life. Those questions are about how to die and where to die. By the time a person looks at the provision of palliative care, they have almost certainly answered the question of why, because they have already had a diagnosis of a disease that will eventually lead to their death. The why question has already been answered, but we have to apply the full resources of our policymaking capacity to the question of how to die and where to die.

As other members have noted, there is considerable confusion about exactly what palliative care consists of. We had some absolutely first-rate submissions from both professionals and users of palliative care services that went into the question of what palliative care is. Hon Alanna Clohesy has already put on the record in this debate the comments made by Caitlin Calcutt. What the parliamentary secretary did not note was that, as well as having a personal experience of the way that well-provided palliative care can transform somebody's life, Cait is also the personal and project officer at Palliative Care WA. She gave us evidence in a personal capacity, as well as appearing with PCWA as a witness. I note that because I think it adds yet another dimension to Cait's account of the way that the lives of her and her partner were literally transformed when they finally came in contact with the providers of palliative care, and they managed the rest of her partner's life with considerably more ease and dignity than they would have been able to without that service.

There is also the question of how Western Australia provides that care, and this is where I come to the substance of what I want to say today. We have different models in WA. We have inpatient palliative care, community palliative care and what might be called consultancy services around palliative care. What we would like to see, and what all the committee's recommendations head towards, is an ideal situation in which an individual and their family would be able to have a seamless transition between those different models. That is what we so often did

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not hear in the evidence that was presented to us. At the moment, the system is very clunky. Once a person hooks into an inpatient consultancy service, it is hard to then transition into a community-based service, and vice versa.

What impressed me beyond words was the service delivered by Silver Chain. I have cared for a couple of people who have died while in the care of Silver Chain. The experience that I had as a committee member when Silver Chain offered to take us out and make house calls with the Silver Chain care providers—I am sure that the other three members of this place who took up that offer would agree with me—was an absolute revelation. It was a real inspiration to see the way that Silver Chain is delivering that service in the home. I remember some 25 or more years ago when I had my first contact as a carer with Silver Chain that there was a limit to the services that Silver Chain could provide at home. For example, when a person got to the stage of being intubated or needing an intravenous mechanism to deliver pain relief, they had to transfer to a hospital or a hospice. That is no longer the case. The Silver Chain nurse with whom I went on a couple of house calls told me that nobody in any circumstance cannot, at least in theory, die at home. If that is what they want to do and if they have family support to do that, from a medical perspective and from the point of view of the delivery of pain relief and other drugs prescribed by other practitioners, they can die at home. That is a fantastic service. The technology used by Silver Chain is just about world class in terms of the evidence that the committee heard. It runs a fantastic service, but it is not adequately funded. This is an interesting point. I was going to say that people still miss out. According to the books, people still miss out, but one of the reasons that I think every Silver Chain worker deserves to be made a saint and go to a special place when they die is that nobody misses out, because Silver Chain extends its capacity and works on the basis that nobody is turned away. But it stretches its services very thin. That certainly needs to be part of the way that services are delivered in Western Australia.

We also have some very impressive hospice services. What upsets me enormously about hospice services is that there are some people who are not deemed sick enough to access them. If a person is deemed unwell enough and at the stage of their disease for which they would get a hospice bed, clearly, according to all the evidence we have had, that person receives superb service from all the professionals that then attend to them. However, we did hear one account, which I think will never leave me—I am sure that the honourable members who were on the committee and heard that evidence would agree with me—of a woman who had motor neurone disease who was deemed not sick enough for hospice care, despite the fact that she could not look after herself. She kept being sent away from hospices into aged care, and she kept ringing 000 to get the ambulance to come and take her back, because she was in such distress in an aged-care setting. That is not a reflection on the aged-care provider or on the hospice service; it is a reflection on the need for more resources. There are specific paragraphs and recommendations in the report about the need to extend hospice provisions.

We also went on a site visit to Sir Charles Gairdner Hospital. I notice Hon Jim Chown referred specifically to this service, which might come under that category of consultancy service or might be an inpatient service. It was a surprise to me when I arrived at Charlies to find that there is not actually a palliative care ward. If a person is deemed to be a palliative care patient at Charlies, they are under the care of a specialist in their disease. We know that the person most likely to access palliative care has cancer and is fairly well resourced in terms of their socioeconomic base. Certainly, there are many other people with many other diseases who need to access palliative care, but cancer patients are the most likely to access it. In the case of Charlies, their lead consultant is likely to be an oncologist; however, a palliative care specialist will be brought in when the patient has satisfied the criteria of being a palliative care patient.

We spent an hour or so at Charlies going around with Dr Anil Tandon, who was an absolutely exemplary practitioner of his—I do not know whether to call it a craft, an art or a science. Whatever it is that a palliative care specialist delivers, it does have that intangible degree of something that we might want to call a craft. Dr Tandon took us around the hospital. Each visit to a bedside involved a dash across the hospital to another ward on another floor. Palliative care patients are not all in one place. We heard that there are palliative care specialist doctors working at Sir Charles Gairdner who are on call 24 hours a day, seven days a week. However, because they are not regarded as the primary carers for many of these patients, they are often not called on to deliver a service to those patients, particularly at weekends.

We had a conversation with one patient who had a professional background in the area of health provision, so she was well able to talk the language. She understood absolutely the systems that were all around her. She described to us a weekend when she started experiencing severe pain on a Friday night. She went through the entire weekend in excruciating agony while her attending physicians attempted to relieve her distress. Nobody called the palliative care specialist, even though she had been designated a palliative care patient. It was not until the Monday morning when the palliative team came back on—I stress that they were on call 24/7 over the weekend. They went and saw her and said, “We should have been here on Friday night. We could have made the last 48 hours or so much more bearable for you.” All those systems need to be looked at for us to satisfy ourselves that we are providing the kind of access to palliative care that the Western Australia community deserves.

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Before I formally move the amendment, I briefly want to mention the site visits we went on, particularly the one to the electorate shared by me and Hon Colin Holt, who was also a committee member; indeed, he was the deputy chair of the select committee. We went to Albany for the bulk of the visit and we made a side-trip to Denmark as well. We wanted to interrogate the evidence we had received that the further away a person is from the metropolitan area, the more problematic their access to palliative care becomes. Very quickly, what I can describe to members that we saw with our own eyes is that if a person is a Silver Chain patient in Perth, they are cared for 24 hours a day, seven days a week. If a patient is in Albany, there was a time when they could access that 24/7 care, and I believe that now, after a hiatus when the provider was unable to provide that care for 24 hours a day, patients can once again get that care. If the patient is in Denmark, they can access that level of care, but only during business hours from Monday to Friday. If the patient is out in Mt Barker, their provision of care is seven or eight hours a week. That is a graphic illustration of the problem about those concentric circles. We clearly need to do a better job at our provision of palliative care for people in places like Denmark and Mt Barker. That is not for one moment to question the fact that the standard of palliative care is excellent, but there is a big problem with the way that the system defines people as palliative care patients, and that is what we need to spend a lot of time looking at.

On the basis of the description I have just given members about the actual coalface delivery of palliative care, the amendment that I want to move is to paragraph (a), which currently includes the words “this state has the lowest number of publicly funded inpatient palliative care beds per head of population”. The parliamentary secretary has provided the explanation for why the government would like to alter that paragraph so that those words are deleted and instead insert the words, “Western Australia needs more public funding inpatient palliative care beds”.

Fundamentally, what we do not want to do is change the things in our system that are actually working well and that are actually delivering to people. We want to change our funding models to increase the pool of money, but we want Silver Chain to be able to do what Silver Chain does so brilliantly.

I understand that the mover of the motion has agreed to this amendment.

Amendment to Motion

Hon Dr SALLY TALBOT: With that, I move —

To delete —

this state has the lowest number of publicly funded inpatient palliative care beds per head of population;

and substitute —

Western Australia needs more publicly funded inpatient palliative care beds;

HON NICK GOIRAN (South Metropolitan) [2.48 pm]: Madam President, I rise on behalf of the opposition to indicate that we will be supporting the amendment moved by Hon Dr Sally Talbot, assistant to Hon Alanna Clohesy. We will be supporting this amendment because we would like to continue with the debate and continue to acknowledge the good work that has been undertaken by my friend Hon Jim Chown in moving this motion. Nevertheless, I will make some remarks. Interestingly, today we heard for the first time that the government does not agree with everything that has been put on the record in the “My Life, My Choice” report of the Joint Select Committee on End of Life Choices. I draw members’ attention to the fact that the words that Hon Dr Sally Talbot, who was a member of that committee, seeks to delete are exactly the same words found in finding 17. I congratulate Hon Jim Chown for crafting the motion in the way that he has, using the precise words found in the first report by the Joint Select Committee on End of Life Choices. I remind members that that report was tabled in August last year. For the government to now say, many months later, that it is not entirely satisfied with finding 17 and it would like to delete words from the motion crafted by Hon Jim Chown and insert alternative words is rather interesting. I simply put to members that if that is the government’s position on finding 17, members may like to find out the government’s position on all the other findings and recommendations. Are there any other words in findings similar to finding 17—the government says that, even though Silver Chain said that and it thinks Silver Chain is a good organisation—that it would like to shift to a different place? The wording sought to be deleted is that this state has the lowest number of publicly funded inpatient palliative beds per head of population. Interestingly, the government’s rationale for why it wants to delete that information is, in effect, because it cannot prove to the contrary. It says that Silver Chain has said that and Silver Chain could be right but the government is not really sure, so on that basis, it would like to delete those words.

Hon Dr Sally Talbot: I think for the parliamentary secretary, you may have been away from the house on urgent parliamentary business.

Hon NICK GOIRAN: I certainly was not; I have been here for the entirety of the debate.

Hon Dr Sally Talbot: The parliamentary secretary did address that point.

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Hon NICK GOIRAN: That is right. If the member refreshes her memory and looks at the *Hansard*, she will see that the parliamentary secretary said that this is what Silver Chain said. The parliamentary secretary was at pains to say that what Silver Chain does as a service is excellent but the government could not be sure about what Silver Chain had said and therefore it preferred to delete these words.

We will be supporting the amendment because we would like to progress this excellent motion moved by Hon Jim Chown. I simply make the point to members that it is very interesting at this late stage to see the tactics of the government with respect to this report.

HON CHARLES SMITH (East Metropolitan) [2.51 pm]: One Nation will not be supporting the amendment. Per capita or per head of population reporting is ideal reporting. It shows us what is happening at the coalface. If we do not report what is happening at the coalface, we do not get the real picture. For that reason, I believe in per capita reporting, such as GDP per capita reporting. We will not be supporting the amendment.

Amendment put and passed.

Motion, as Amended

The PRESIDENT: I will give the call to Hon Charles Smith. Five minutes before the time allocated for this motion, I will interrupt you to give the mover of the motion the opportunity to reply, if he so chooses, otherwise you can continue.

HON CHARLES SMITH (East Metropolitan) [2.52 pm]: I would like to speak briefly to the motion moved by Hon Jim Chown. When we discuss the issues of euthanasia and assisted suicide, palliative care is inevitably mentioned. The problem is that it often only gets a mention. It is usually relegated to the too-hard basket. Since the McGowan Labor government seems to be following its Victorian counterparts on this issue, I urge it strongly to at the very least strive to do better than that Victorian model. Following the Victorian inquiry into end-of-life choices, the government moved to implement assisted dying legislation. With that, \$60 million would be provided to boost palliative care in the state over a three-year period. In terms of budgetary finance, that is a drop in the ocean. The Victorian health budget alone for the last year was \$4.2 billion. That palliative care boost is about 1.4 per cent of the budget.

I encourage members of Parliament who have not spoken to those who work in palliative care to do so—for example, speak to the staff at the palliative care services at Bethesda Hospital or Royal Perth Hospital. They will tell members the same things—that the public, practitioners, parliamentarians and, indeed, many in the medical community have very little understanding of the depth and breadth of palliative care. They are chronically underfunded, understaffed and lacking in support.

This is an important issue. I thank the member for raising it. It is very timely. Its examination is well overdue, as is education at a parliamentary and public level. I therefore voice my support for the motion and recommend the government establish a palliative care advisory committee, comprising those who are within the field of palliative care, to assess what is needed to increase public education about palliative care, and to access and finance better palliative care throughout Western Australia.

HON ROBIN SCOTT (Mining and Pastoral) [2.55 pm]: I rise to support the motion moved by Hon Jim Chown. The goal of palliative care is to improve the quality of life for not only a terminally ill person, but also that person's family and friends. We normally associate palliative care with the relief of pain but it also involves relief of other symptoms of illness, including physical stress and mental stress. All doctors and nurses are able to help the terminally ill. As with other aspects of health care, specialist knowledge and specialist training are highly desirable. According to Wikipedia, palliative care is provided by a team of physicians, nurses, physiotherapists, occupational therapists, speech language pathologists and other health professionals who work together with a primary care physician, referred specialists and other hospital or hospice staff to provide additional support. In regional Western Australia, the reality is vastly different. There is no question of a team consisting of a range of health professionals. Palliative care resources are incredibly thin.

If we look at a registered nurse in a hospital compared with a palliative care nurse, we see that both of them are highly skilled professionals but a registered nurse in a hospital has the opportunity in some cases to wave goodbye to the patient as they hobble out of hospital to go home to recuperate, whereas a palliative care nurse deals with death every day. They know that their patient will only leave the establishment in one way—that is, when they die. In the goldfields medical region, with a population of 55 000 people, my understanding is that at any time up to 100 patients need palliative care. Handling palliative care for the goldfields is one trained nurse with experience in palliative care. A palliative care specialist makes visits to Kalgoorlie one day a month and sees a maximum of eight patients on the day. This amounts to a maximum of 96 patient consultations a year, just for Kalgoorlie. A palliative care specialist visits the Esperance area one day every three months and also sees a maximum of eight patients on the day. That is a maximum of 32 patient consultations a year for Esperance. In the midwest medical

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region, with a population of 63 000 people, the number of patients needing palliative care may be over 100. One full-time nurse plus another nurse are allocated to that region one and a half days a week. A palliative care specialist visits Geraldton for one day 10 times a year and sees a maximum of eight patients on the day. That is a maximum of 80 patient consultations a year for Geraldton. A palliative care specialist visits Carnarvon one day every six months and sees a maximum of eight patients on the day. That is a maximum of 16 patient consultations a year for Carnarvon. For the midwest and goldfields together, around one person in 600 is in need of palliative care at any one time. If each of those terminally ill patients were to receive the benefit of a specialist consultation each month, we would need to multiply the number of specialists by 10. The probability that the majority of palliative care patients will die before they receive specialist consultations is high.

Since the introduction of the National Disability Insurance Scheme, it has been reported that home support for palliative care patients and their families is no longer provided. In the goldfields, Kalgoorlie Health Campus has only three palliative care beds. It will extend that number to seven beds if it is really necessary. Coolgardie, which is 40 kilometres from Kalgoorlie, has zero palliative care beds. Menzies, which is 128 kilometres from Kalgoorlie, will accept only patients who are at the end of life, so people in Menzies who have a sick friend or family member have to travel 128 kilometres each week to Kalgoorlie to visit them. Leonora is 230 kilometres from Kalgoorlie and Leonora Hospital will accept only end-of-life patients. Laverton is 360 kilometres from Kalgoorlie and Laverton Hospital will accept only end-of-life patients. Meekatharra is 840 kilometres from Perth and Meekatharra Hospital has one bed, no palliative care nurse and a specialist who visits only on request. Mt Magnet, which is 530 kilometres from Perth, has no beds and the same applies to Cue.

It is grossly unfair to the mostly elderly individuals who are near the end of their lives that palliative care is so neglected. The state government needs to do more. It should not be shy about calling for commonwealth assistance. I am very pleased to support the motion moved by Hon Jim Chown, and I encourage all honourable members to vote in favour of it.

HON NICK GOIRAN (South Metropolitan) [3.00 pm]: Just briefly, I indicate my support for the motion moved by Hon Jim Chown. I thank him for crafting it in the way that he has done so. In particular, I note that he has usefully referred to findings 9, 17, 16, 12 and 13 and, indeed, recommendation 13, which arise from the report by the Joint Select Committee on End of Life Choices. That was the one part of the report, the one particular chapter, that was largely done well, in my view. Members will be aware that I tabled a significant minority report but with respect to those particular findings and recommendations, I concurred with the committee.

The Parliamentary Friends of Palliative Care is continuing to do its work in this Parliament. I thank my co-chair, Margaret Quirk, the member for Girrawheen, for the honour of co-chairing the parliamentary friendship group with her. The month before last, Dr Anil Tandon and Dr Mary McNulty appeared before the parliamentary friendship group to discuss the topic of the challenges for specialist palliative care service provision in regional and remote Western Australia. The session was very well attended and well regarded by members. To those members who did not have the opportunity to attend, please do not hesitate to contact either me or the member for Girrawheen so that we can put you in contact with those two learned doctors. I also indicate to members that tomorrow, Associate Professor Rosanna Capolingua and Dr Michael Gannon will appear before the parliamentary friendship group. Their topic is the implications for doctors and patient care delivery if euthanasia and assisted suicide are introduced in Western Australia. I look forward to members attending that session. There has been a very good RSVP rate already.

I indicate in closing that the motion has my support. I encourage members to be familiar with the various findings and recommendations on palliative care made in the “My Life, My Choice” report because a lot of them have the unanimous support of all eight members of the committee.

HON JIM CHOWN (Agricultural) [3.03 pm] — in reply: I will exercise my right as the instigator of the motion to give a reply. I thank everybody who participated in the debate on this comprehensive motion and for their support. There were definite indications by every member who spoke that they agree without compromise that palliative care in this state needs to dramatically improve. It must improve to the point at which those who are suffering from an end-of-life illness, or any other illness that challenges their wellbeing as a living creature on this planet, are embraced under the umbrella of palliative care in some part of the medical system in this state.

As I stated in my opening address, palliative care has changed a lot as it has evolved. Certainly in Australia, we have a reasonably good palliative care system. However, in Western Australia, as I have already stated, we have one of the worst palliative care systems in the nation. In the vast expanse of regional Western Australia, where one-third of the nation’s population live in isolated areas, people who get sick have limited access—or, as some members said, no access at all—to palliative care. That issue needs to be addressed if this government is serious about end-of-life choices. I do not think there is any argument there; indeed, I would be happy to hear an argument

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against that particular statement. If the government is going to give the community real end-of-life choices, it must fund, staff and resource palliative care to the best of its ability.

As I said earlier, our palliative care system should be the best in the nation, but, at this stage, it is one of the worst. I cannot understand how the McGowan government can be focused on end-of-life choices without ensuring that palliative care is appropriately funded. This state of ours is one of the best states in the nation, yet it has one of the worst palliative care systems in the nation. To start with, I believe it is completely irresponsible for any government to put forward end-of-life choices or euthanasia legislation without stepping up to the plate and putting in place programs that are funded, resourced and staffed in the forthcoming state budget. We need programs locked in to ensure that palliative care is provided under the remit of the “WA End-of-Life and Palliative Care Strategy 2018–2028”, which is the palliative care bible. All I have heard from the government—from the parliamentary secretary representing the Minister for Health—is sentiment. She was light on real financial commitment or a time line to undertake what the Department of Health’s document enshrines. If a statement such as the one that I have asked for comes forward, I will be completely encouraged. If it does not, when we start to debate end-of-life choices—euthanasia—I challenge every member in this house to not stand up and say, “What have you done about ensuring palliative care in Western Australia is the best in the nation?” If members do not do that, they will have been absolutely irresponsible to the communities they represent, irresponsible to the elderly and their families and irresponsible to the people who are suffering from known life-limiting diseases. I encourage the government to put facts, figures and programs in place. It has time to do that before it entertains the idea of bringing euthanasia legislation to this place. That is the challenge for members, because if we want real end-of-life choices, we must have real choice and, at this stage, there is limited choice and euthanasia—or, as a GP put it to me, state-sanctioned suicide—without correct palliative care provisions is no choice at all. I will leave the house with that challenge. I thank members for their support.

Question (motion, as amended) put and passed.