

# **JOINT SELECT COMMITTEE ON END OF LIFE CHOICES**

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA  
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS  
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE  
TAKEN AT PERTH  
THURSDAY, 14 DECEMBER 2017**

## **SESSION TWO**

### **Members**

**Ms A. Sanderson, MLA (Chair)  
Hon Colin Holt, MLC (Deputy Chair)  
Hon Robin Chapple, MLC  
Hon Nick Goiran, MLC  
Mr J.E. McGrath, MLA  
Mr S.A. Millman, MLA  
Hon Dr Sally Talbot, MLC  
Mr R.R. Whitby, MLA**

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**Hearing commenced at 12.09 pm****Mrs GRACE BUCHANAN****Committee Member, Palliative Care Nurses Australia, examined:**

**The CHAIR:** On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life-choices inquiry. My name is Amber-Jade Sanderson. I am the chair of the inquiry. We have Hon Dr Sally Talbot, MLC; Reece Whitby, MLA; Dr Jeannine Purdy, our principal research officer; Simon Millman, MLA; Hon Colin Holt, MLC; Hon Nick Goiran, MLC; and Hon Robin Chapple, who has just popped out briefly. The purpose of today's hearing is to discuss current arrangements for end-of-life choices in WA and to highlight any gaps that may exist. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything you might say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. Would you please introduce yourself for the record?

**Mrs BUCHANAN:** I am Grace Buchanan and I am the representative for Palliative Care Nurses Australia, which is, as you know, a national member organisation for nurses working with people who are living with and dying from a progressive life-limiting illness. I am actually representing Jane Phillips, who is our president, and she sends her apologies for not being able to be present. But you get me instead!

**The CHAIR:** Do you have any questions about your appearance today?

**Mrs BUCHANAN:** No.

**The CHAIR:** Before we begin with our questions, did you want to make a brief opening statement?

**Mrs BUCHANAN:** Certainly. As I said, I am representing Palliative Care Nurses Australia. I am a member of that committee and I have been nursing in palliative care settings for far too many years, but closer to 30 years now. However, I am currently not a current practitioner, but I manage palliative and supportive care education, which is through the Cancer Council WA. In that role, we facilitate and provide palliative care education to health professionals across WA and palliative care volunteers across the state. Can I make clear, though, we are conscious that CCWA has made a submission and will be speaking to you at some point, but I am not representing CCWA in my answers today; I am here as Palliative Care Nurses Australia.

**The CHAIR:** I think you have been given advance notice of some of the questions. Do you want to address us on advance care planning?

**Mrs BUCHANAN:** Certainly. I am happy to also just answer the questions as we go along. I was able to do some of them as a block, but if you are happy to do the questions as we go for some others, is that okay?

**The CHAIR:** Yes, absolutely.

**Mrs BUCHANAN:** We believe that advance care planning is an integral part of ensuring patients and families clearly determine what they do and do not want when, if with the loss of capacity or ability, they cannot articulate that for themselves. Of course, that is on the patient's behalf. Training of palliative care nurses in the area is available, but there are no minimum requirements and there is no "you must not attend; you do not have a minimum process as a nurse that you must have education in this area". They can access education through advance care planning, and a component

of this training is clear, concise and described as advance care directives. In answer to some of the questions where it asks you about EPGs and AHDs, it is really about a process of ensuring people have a conversation and understanding of what that client then wants. End-of-life discussions are an integral part of palliative care nurses' role, and they are a part of the multidisciplinary team and often the patient's advocate. So knowing about advance care planning is a vital part for nurses to play within this.

**The CHAIR:** Do you think there is a need for better community education about AHDs and EPGs?

**Mrs BUCHANAN:** Yes, we do, but we also acknowledge that there is a process within Western Australia through Palliative Care WA, which is actually addressing that issue.

**The CHAIR:** Do you think a system in WA would be improved by a central register?

**Mrs BUCHANAN:** It depends how you determine the central register process. We believe that anything where it enables it to be easier for clients to have their wishes heard and be essentially available is good. One of the things that we would suggest, though, is advance care planning is the patient's responsibility, so processes such as in the United Kingdom, where people are actively invited to ensure that their most recent documentation for, in this example, around advance care planning was placed in a space where that person was able to take them with them, because that is where often it is about having the information available. That sounds a little archaic and old stream, but it is actually a process that can be for many different areas around people's health care. Also, e-health is where we would be suggesting, as it is becoming now an opt-out process. The more available people's advance care directives were, the better that would be.

**The CHAIR:** Palliative care—do you want to just address us on this, or would you rather —

**Mrs BUCHANAN:** We can run through some of the questions.

**The CHAIR:** From your experience, is the role and availability of palliative care well understood in the community; and, if not, why not?

**Mrs BUCHANAN:** We believe it is a very variable thing, and I think often you have a better understanding of palliative care if somebody you know or love, or yourself, is in the position of being diagnosed with a life-limiting illness. The general consensus, though, would be that palliative care was often thought to be that there's was nothing more we could do and that it is a very ending process, whereas we, as the PCNA, would say that palliative care for the general public needs to be better understood.

**The CHAIR:** Do you think current palliative care services in WA are adequate, and where are any shortfalls, if any?

**Mrs BUCHANAN:** We believe that Western Australia is one of the stand-out states for excellence in palliative care availability, but we would acknowledge that it depends on what people believe, or what they feel palliative care services should be, so if we were talking about everybody having access to a hospice bed on demand, it would not be an availability process. It really depends a lot on what you are actually saying are the palliative care requirements for that person. I do not know if I am explaining myself clearly enough, but it really is; you may feel that if and when you need that bed, there should be a bed. Palliative Care Nurses Australia would say that when you look at the complete services available in Western Australia, they are very good.

**Hon ROBIN CHAPPLE:** Yesterday we heard, in relation to hospices, this whole issue that if you have got somebody who needs palliative care, but for an extended period, then the hospice is not—do you think there is enough hospice availability that maybe would enable longer stays? Would that be beneficial?

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**Mrs BUCHANAN:** The design of palliative care beds now, say within a hospice or palliative care unit, you are right, is very limited to the requirements of time. I believe that the general public would want to be able to have that time extended, and often people have the disadvantage that, if they become stabilised in their deteriorative state, so with all good intent—dying is such an individual process—people are then asked to look for aged-care facilities, which can be incredibly distressing. People with neurological disorders who are perhaps younger but will require ongoing treatment may well have had some component of the care already in a hospice bed, and then be asked to look for—that would be very difficult. Would we ideally say that is a bigger question than we could answer. That is what I guess we are suggesting to you is one of the difficulties for people about what they think palliative care actually is and what it should provide.

**Hon ROBIN CHAPPLE:** Are nursing homes really equipped to deal with people who require palliative care and cannot get into a hospice?

**Mrs BUCHANAN:** Yes. Our belief is that with good education—in this state a lot of education opportunities have been, and are still, being delivered. As I said, I have to keep my other hat on here. Yes, we believe that nurses—say from PCNA’s point of view, anybody can join PCNA who has an interest in palliative care, and we would suggest that aged-care facilities should and can deliver spectacularly good end-of-life care, if we are talking about just that component of palliative care, and realistically it is a case that we have to continue to keep on assisting people working in that area to be able to recognise that and to do it.

**The CHAIR:** Do you think the current palliative care services are sufficient to accommodate preferences of patients in WA?

**Mrs BUCHANAN:** We thought long and hard about that. I think our best response to this is that it is incredibly difficult because with all the best intent, often people may wish to die at home, for example, as we know that is the expressed wish for a lot of people, but it is very variable and dependent on whether you have carers and support and all those sorts of things. Perhaps a little more flexibility in being able to access different palliative care needs, if and when they arose, would be a better option than saying, “Do we need more, or is it a better allocation?” or look at how we can access the beds.

[12.20 pm]

**The CHAIR:** What are the obstacles to patients being cared for and dying in their place of choice, whether that be at home or wherever they choose?

**Mrs BUCHANAN:** Often, with the home setting, it is actually having a carer or other people able to support you, so if you are referred to Silver Chain hospice to die at home, it is an exceptional service. However, you still need to have somebody to care for you for 22 or 23 hours of the day, or maybe more. There are other government opportunities. We understand that people can have other carers, but it is actually enabling people. I think one of our ideas is that the block is that there is not a coordinated approach to help people to be able to put those services in place, or to even access them.

**The CHAIR:** Do you believe the current palliative care services in WA meet the needs of the following groups—I will list them for the record—CALD communities; people living in aged-care facilities and disability residential care; people living in rural and remote areas; Aboriginal and Torres Strait Islanders; children and young people; patients suffering non-malignant chronic illness; patients with intellectual and developmental disability; people with mental illness and people detained involuntarily under the Mental Health Act; and prisoners and others in detention?

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**Mrs BUCHANAN:** Not fully, because we believe across all of those areas of health the people are disadvantaged, and it is no surprise that they are difficult areas to provide optimal continuous best practice with those people—not that it should not be. We believe that in WA there is a great striving to meet those needs more, and there are a lot of programs available where people are really looking at how they can better collaborate with those groups to enable better palliative care. I think we are becoming better at identifying how better to help people, but is it optimal? I would love for it to be.

**Hon NICK GOIRAN:** We have heard consistently that a couple of issues that arise in our palliative care system in Western Australia, which is also consistently described as good or excellent, are accessibility in regional and remote areas, and, secondly, this issue of the quantity of beds in hospices. Can we look at this list that you have just provided? Is there any one of those that you would say is particularly well known as being a problematic group in the area of palliative care, more so than another group?

**Mrs BUCHANAN:** Not perhaps the people themselves, but the process, certainly, around prisoners and others in detention is a very vexed and difficult area, but there are some really great programs. I name one as MPAC—I have done it now, I hate acronyms; I do apologise—it is a service that also provides support for nursing home staff to actually be delivering palliative care in their areas. They go and actually visit people in those areas, Monday to Friday.

**Hon NICK GOIRAN:** In the prisons?

**Mrs BUCHANAN:** In the prisons. But there are a lot of other legislative issues around people dying in the prison system that actually cause great difficulty for them. Aboriginal and Torres Strait Islander people is a more difficult area, but there is a lot more occurring in that area, and we are recognising how to better meet people's needs by looking at a more personal group-centred approach, rather than saying here is what you need. I think you also identified that patients suffering non-malignant chronic illnesses are now an area that we have to be a lot better at trying to give greater access to clinicians, especially about understanding of where and how to introduce palliative care into those people's continuing care, because sometimes we actually forget to initiate some of the processes and discussions. We identify somebody having a life-limiting illness but a lot of people would not have a view that that is life limiting. Does that answer your question?

**Hon NICK GOIRAN:** Yes, very well, actually, and it is very helpful. One group that you mentioned there was Aboriginal and Torres Strait Islanders. Is that just a natural consequence of the proportion of people being in remote and regional areas, or are there additional complications, other than remoteness?

**Mrs BUCHANAN:** I think remoteness makes a difference for absolutely everybody, as you highlighted. I will answer the question in a moment, but I would like to say that I think in Western Australia we have some of the best palliative care regional and remote nursing and medical services that exist around palliative care. In answer to your question, I think it is not just about palliative care but some people would say that different groups, be they Aboriginal and Torres Strait Islander people or CALD people, do not want to talk about death and dying, so we do not provide palliative care. We suggest, as a group of nurses, that that is not the case, and that we are maturing as health professionals to actually understand that we can better engage with people. It may not look like some of our traditional palliative care support, but if we make it more accessible, people are starting to actually get better opportunities.

**The CHAIR:** I think you touched on this earlier, but do you think cancer sufferers or people diagnosed with cancer generally have better access to palliative care services compared with those who have chronic or other life-limiting diseases?

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**Mrs BUCHANAN:** I think it is a perception that that is the case. However, it is a historic process because palliative care and community hospices et cetera came out of mostly treating people who had cancer and cancer diagnoses, and it would be true to say still that large percentages of people within those places do have a cancer diagnosis. However, I think that we are maturing as a group, and palliative care per se is now seen as definitely a part of people with chronic and life-limiting illnesses. It is actually how we help health professionals and the community to start to think about where palliative care comes into that process for them.

**The CHAIR:** In what ways do you think palliative care can be better integrated across the WA health service?

**Mrs BUCHANAN:** Maybe the health service could help palliative care to be better integrated. However, that is not being disrespectful. I think it is a process of us as health professionals actually acknowledging that there is a role for palliative care in most of the clients that we care for and that it is how we actually start to learn better to have clients, patients and their families, at the centre of the care that you are delivering, so when you perceive that if you start to think that it would not be a surprise that somebody I was caring for may die in the next 12 months, it is incumbent on us to be better at ensuring we are part of that journey, and finding out where they are, and that we do not actually just treat, treat, treat and then stop. I think in answer to your question, there are a lot of things that are already occurring through the cancer and palliative care network that enables us to better start to work across all health disciplines to better get palliative care as being a normal part of their practice too.

**The CHAIR:** Do you think the WA health system is responsive to consumer demand for palliative care?

**Mrs BUCHANAN:** I think that it is an absolutely growing area and as we age—it is a very trite answer—we have become much better medically as a system caring for people that, even in the time of my nursing career, would never have even been able to survive for any length of time, now live for much longer, and, of course, we are ageing, sadly, so in terms of that, realistically, it is very difficult.

[12.30 pm]

**The CHAIR:** You touched on the challenges around rural provision. What are the challenges facing palliative care nurses in the provision of palliative care?

**Mrs BUCHANAN:** Across everywhere?

**The CHAIR:** Yes.

**Mrs BUCHANAN:** I think some of the questions allude to it a little later on where you say that people are thankful for the care that they get et cetera. I think, as for all nurses, there is a greater demand on knowledge and expertise in areas, but also for nursing, it is that idea of how we help people better help themselves in regard to caring for themselves. So, the acknowledgement from your employers that there are systems to enable people to better manage their whole being and their self-care actually, especially in this area, is no different to most other high and acute areas of care.

**The CHAIR:** Are you aware of the Palliative Care Outcomes Collaboration?

**Mrs BUCHANAN:** Yes.

**The CHAIR:** Do you have any comment on the discrepancy between the benchmarks of relieving pain and suffering around hospitals versus the home setting?

**Mrs BUCHANAN:** The figures are quite clearly documented there. From our perspective as PCNA, we would like to be able to better research it to give you a better answer but our initial response is

the differences between acute care and a community care setting can be quite different. As I outlined to you before, the access to people—and perhaps it is more of a recognition of how we better educate people who are caring for that person in their home setting or their community setting to be able to make those differences to be able to administer, for example, pain relief.

**The CHAIR:** Are there protocols for prescribing opiate or derivative or any other sedating or pain-relieving medications for the purposes of palliative care?

**Mrs BUCHANAN:** Yes.

**The CHAIR:** Many submissions express great gratitude and admiration for those who care for them during palliative care. It is obviously very demanding work. Are additional supports available for palliative care nurses?

**Mrs BUCHANAN:** I would suggest that it depends on the environment in which you are working as that palliative care nurse. You identified where people are more isolated, more remote. We believe that most employers have structures available for people, but part of PCNA's role would be to get people to become more active working together as a group of nurses in that area to give better support to each other. There is no one individualised because you work in palliative care you get X more support.

**The CHAIR:** Are you aware of a particular rate of turnover for palliative care nurses?

**Mrs BUCHANAN:** It is actually a very difficult question. It seems easy. It probably looks like the easiest question on the paper. But as we are unable to tell you how many palliative care nurses work in WA—and it depends on how you define what is a palliative care nurse. So, if we are talking about specialist palliative care, the rate of the turnover if they are working in specialty areas is not that great. But if we are talking about nurses who are being exposed to people who have life-limiting illnesses and they feel underprepared and under-supported, if we are talking about areas such as aged care, we know that the turnover is high. Can we say that that is because they are being asked to care for people at end of life? I cannot say that. Can I presume that the pressures of the work and the load and those sorts of things that are being asked of them, plus then caring for people with more acuity, I would suggest is increasing why that turnover might occur.

**The CHAIR:** Can you recommend any sites in the metro area or regions that would be appropriate and beneficial for us to visit?

**Mrs BUCHANAN:** I thought long and hard about this. It would depend what you want to see. I am not being flippant. I am really asking you what —

**Hon COLIN HOLT:** What do you want us to see?

**Mrs BUCHANAN:** That would be impertinent for me to say, but we want you to see palliative care in action. It would be fantastic if you were able to go to an aged-care facility where they could answer your questions in regard to, "Did they feel that they had knowledge and support about end-of-life or palliative care?" It would be wonderful for you to see. Yes, it would be advantageous for you to go and see palliative care in action in specialist—and I am sure you could pick all of the hospices; that is what they do and it is a spectacularly good place for you to get an understanding. It would be wonderful for you to be able to go out with Silver Chain Hospice and see someone in their home, if there was an ability to do that, to get the perspective of carers and what that meant for them. It would be really great if you could visit a prison. It might be really beneficial, we feel, for you to actually visit places where—some of the areas you identified that you have concerns for might be the places you would really like to go. Does that help?

**The CHAIR:** Yes. That is very helpful.

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**Hon NICK GOIRAN:** Did you indicate at some point that there is such a thing as a palliative care nurse specialist?

**Mrs BUCHANAN:** I did not, but there are. The answer to your question is: there is not a formalised—so I have worked in palliative care, as I outlined to you, in different guises for a long time and I do not have an actual palliative care postgraduate degree or masters. However, I gained my experience by working in those areas, and there are a lot of postgraduate opportunities now and there are a lot more opportunities for nurses, especially to be able to gain that education, which is great. Within palliative care, you can be a nurse practitioner and we have four—if I am misleading you, it is not intentional. There are probably more; it depends. Please do not quote my number. I will get back to you with the exact number that we have. However, there are nurse practitioners in the palliative care specialty and you have nurse practitioners in aged care as well.

**Hon Dr SALLY TALBOT:** Is it part of the undergraduate degree?

**Mrs BUCHANAN:** It depends how you define “is it part of it”? I am not trying to be flippant.

**Hon Dr SALLY TALBOT:** Is it an elective?

**Mrs BUCHANAN:** Some areas, some nursing schools—just speaking about nursing?

**Hon Dr SALLY TALBOT:** Yes.

**Mrs BUCHANAN:** There are elective components; you can do extra in your undergraduate as an elective. Palliative care is often scaffolded through the course and you may find a lot of it in aged care, but a lot of courses in an undergraduate process do not say—as in medicine, they say, “We’re going to have the palliative care component or a week of studies.” That does not exist in most undergraduate—I cannot quote every one. But, yes, as a whole, it is scaffolded through the whole process and often in aged care, which probably speaks a little bit to then understanding and knowledge of the areas that you had in your question before, because we do not actually always teach it as an undergraduate process as palliative care is often just equated in those contexts with aged care, and we suggest it should be greater.

**Hon Dr SALLY TALBOT:** Is it a postgrad option in the same sense that the nurse practitioner career path —

**Mrs BUCHANAN:** There is not a pathway per se. You can do a postgraduate study in clinical nursing at one of our universities in WA that has an emphasis on palliative care, but that is to be a clinical nurse. Does that make sense?

**Hon Dr SALLY TALBOT:** Yes. A clinical nurse, is that the same as a nurse practitioner?

**Mrs BUCHANAN:** No.

**Hon Dr SALLY TALBOT:** Can you explain the difference?

**Mrs BUCHANAN:** Sure. Within nursing, you will have enrolled nurses, then registered nurses. Within those registered nurses, there are tiers or years of service. After that, you can become a clinical nurse, which is often somebody who is—on the ward you will have one or two clinical nurses who have more knowledge and direction over the registered nurses.

**Hon Dr SALLY TALBOT:** Is it a postgraduate qualification?

**Mrs BUCHANAN:** Not always, no. I am so sorry; I am not trying to be difficult. I think you are opening up the box of what it is like. No, it is not like becoming a registrar where you have to sit an exam. You can become a clinical nurse without. It is changing. But it is not a prerequisite to have postgraduate certification.

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**Hon Dr SALLY TALBOT:** Again, as you have described, the palliative care component is likely to be scaffolded in with a broader qualification.

**Mrs BUCHANAN:** Within the broader qualification, you can choose your specialty. So, you can be a clinical nurse with accident and emergency as your emphasis. However, there are also other courses. There are opportunities for nurses to gain scholarships to be able to do palliative care qualifications—certificate, diploma and master's level—which is sponsored within WA. That is a very generous opportunity. That is often what people who work in specialist palliative care go, "I want to be able to do that." It is all provided out of the state as—I have forgotten the word; I am sorry.

**Hon Dr SALLY TALBOT:** Is it an online course?

**Mrs BUCHANAN:** Yes. Sorry.

**Hon Dr SALLY TALBOT:** So is that TAFE?

**Mrs BUCHANAN:** No.

**Hon Dr SALLY TALBOT:** Universities?

**Mrs BUCHANAN:** In my role as palliative care case manager, Cancer Council provides an opportunity for scholarships for nurses to be able to do their postgraduate certificate, diploma or master's degree at places across the country.

**Hon Dr SALLY TALBOT:** I see. So these are the postgraduate qualifications?

**Mrs BUCHANAN:** That is right; but you do not have to have them and they are not a prerequisite to work in the palliative care specialty, but it is often how we then encourage people.

**Hon Dr SALLY TALBOT:** Because of what you have already told us about the data collection on who is working where, I suspect I know the answer to this, but do you have a sense of how many of the nurses working in the 22 services in WA that provide palliative care services would have those postgraduate qualifications in palliative care?

[12.40 pm]

**Mrs BUCHANAN:** I am not privy to be able to say how many.

**Hon Dr SALLY TALBOT:** Would you take that on notice?

**Mrs BUCHANAN:** Could I take a punt? Is that what you are asking me? I would take it on notice, absolutely. We can do that without a problem and to the best of my ability; if everyone is able to give me some figures, we would be more than happy to provide that.

**Hon Dr SALLY TALBOT:** And what those qualifications are. I think you have just said a certificate, diploma or master's.

**Mrs BUCHANAN:** It is all about the person's ongoing lifelong learning and their desire to be better at what they do.

**Hon NICK GOIRAN:** This has been helpful. I understand, then, that there is an enrolled nurse, a registered nurse and a clinical nurse.

**Mrs BUCHANAN:** And clinical nurse specialist, clinical nurse managers and then nurse practitioners. That is the hierarchy.

**Hon NICK GOIRAN:** Right. So nurse practitioner is the top of the tree, if I can use that phrase?

**Mrs BUCHANAN:** Yes. For clinical practitioners and qualifications that want to work—so the aim of those is to work as autonomously as possible, and within palliative care there are nurses who work in collaboration with doctors in community who are nurse practitioners in a model of support to

palliative care and aged care. Then we have within Royal Perth and, I think, St John of God and others across the state who have done their postgraduate and are studying to be or are nurse practitioners.

**Hon NICK GOIRAN:** Just so I am clear on the hierarchy, nursing practitioner is the top.

**Mrs BUCHANAN:** Yes.

**Hon NICK GOIRAN:** Some of those nurse practitioners specialise in the area of palliative care.

**Mrs BUCHANAN:** Yes.

**Hon NICK GOIRAN:** Some nurse practitioners specialise in other fields.

**Mrs BUCHANAN:** Yes, absolutely. Renal units would be places where you would find a lot of people, emergency departments. It depends, though, on the state government's view on where they wish to employ them.

**Hon Dr SALLY TALBOT:** A lot of regional areas, of course, employ nurse practitioners.

**Mrs BUCHANAN:** That is right.

**Hon COLIN HOLT:** Primary health care.

**Mrs BUCHANAN:** Primary health. Thank you. Would it be useful if I again provided, with my colleagues, to you all, how the hierarchy—who we employ. Would that be useful?

**The CHAIR:** Yes. That would be very useful.

**Hon NICK GOIRAN:** Yes. I would never say no to more information. But the nurse practitioners who specialise in palliative care, we have some of them in Western Australia. Is that one of the things that you are taking on notice in terms of getting back to us as to how many nurse practitioners specialising in palliative care we have?

**Mrs BUCHANAN:** I can. Yes.

**Hon NICK GOIRAN:** Is that the one that you said earlier, but not to quote you, you thought might be around four or something like that?

**Mrs BUCHANAN:** I was underestimating and I would like that retracted and be able to give you the right number, because I am not privy to all of that knowledge and I would like to give you the right number.

**The CHAIR:** Absolutely.

**Hon NICK GOIRAN:** All right. You will get back to us with a precise figure, but in the interim, is it reasonable for us to assume that the number of nurse practitioners in palliative care is a small number?

**Mrs BUCHANAN:** Yes. I would suggest that the nurse practitioners are not a large number across the whole of the state.

**Hon NICK GOIRAN:** Are or are not?

**Mrs BUCHANAN:** Are not. But I would be very happy to provide you with that. Could I also ask you what else I am providing you, because I am actually a little bit —

**The CHAIR:** Do not worry; we will write to you with a list of all of that.

Now, members I am conscious of the time and we are due to release this witness in five minutes or so. Do you want to give me an indication of which questions you want to ask and we can put the rest in writing to the witness?

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**Hon NICK GOIRAN:** I would have thought limitations of palliative care. Some of the other areas might not be —

**The CHAIR:** All right. Generally speaking, what do you think are the limitations of palliative care, and is it 100 per cent effective for all patients?

**Mrs BUCHANAN:** I think the limitations are that you need to determine what you want in regards to palliative care. Would you like us to narrow it down to more end-of-life care discussions?

**The CHAIR:** Yes.

**Mrs BUCHANAN:** Certainly. The limitations, I would suggest, are that I do not think you can ever talk in definite 100 per cent effectiveness numbers for any treatments or care. That was a part of my concern for how we could answer this. The limitations in terms of what has been covered in some of the other questions is to determine what people want in palliative care and how we then can provide it. So, it is about a determination about numbers and available beds and all those sorts of things would impact on that. Our limitation, we believe, is that health practitioners—all health teams—often do not have a clear and good understanding of what palliative care is and, at end of life, often it can become quite confusing as people see palliative care as being a case of, “There’s no more we can do”, rather than it being an option of treatment.

**The CHAIR:** In terms of managing pain and suffering—that specific issue?

**Mrs BUCHANAN:** Yes, is it effective? We believe that palliative care is an effective means of managing people’s pain and suffering, but we could not say that you can control everybody’s pain and suffering at all times, but no treatment can. We would also say that it is a determination and a lot of suffering comes from people not wishing anybody to die. Whilst we, as a society and a community, have a death-denying attitude and we do not see death as a normal part of living, suffering is very great and the desire often for people, when you are treating somebody or caring for somebody, when they are at the end of life, there is often the emphasis of, “How long will this take?” rather than seeing it as a normal process of our living.

**The CHAIR:** Are current laws too constraining on health professionals providing palliative care?

**Mrs BUCHANAN:** No.

**The CHAIR:** The committee received a number of submissions supporting the right of medical practitioners not to treat patients in accordance with their personal views. In your opinion, do nurses have the same right not to treat patients in accordance with their conscience?

**Mrs BUCHANAN:** Yes.

**The CHAIR:** Regarding refusal of medical treatment, when is a patient or person authorised to make a treatment decision on their behalf entitled to refuse medical treatment?

**Mrs BUCHANAN:** At any time. You should all have the ability to say what you do and do not want to happen to you.

**The CHAIR:** Would you say that the arrangements relating to refusal of medical treatment are well understood and respected by palliative care nurses?

**Mrs BUCHANAN:** Yes, but we would put a caveat on that that often health professionals struggle with how to best acknowledge this. There can be times when people say that it might not be in their best interests to do something so what we would suggest is health professionals and nurses have to ensure that they are doing what is requested of them by their patient.

**Hon NICK GOIRAN:** Mrs Buchanan, a couple of times when there are questions asked about palliative care nurses, you have responded by referring to health professionals.

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**Mrs BUCHANAN:** I apologise for that.

**Hon NICK GOIRAN:** Apologise for nothing; I really appreciate your evidence this morning. Can you just explain to us the distinction?

**Mrs BUCHANAN:** There is not one, but when we are defining palliative care nurses, I am trying to broadly say to you that there are palliative care nurse specialists in the field but we would suggest that all nurses in their practice should have palliative care as a component of what they do for everybody. I guess that was my bid. Also, I think it is just my failing or my foible in suggesting that nurses do not work in isolation. We are very much part of a team. That sounds a little trite but the actual process is that to be able to deliver really great care for people, you actually have to do it in a connected form.

**The CHAIR:** In your view, does permitting the refusal of medical treatment compromise efforts to reduce suicide generally in the community?

**Mrs BUCHANAN:** No.

**The CHAIR:** Do you believe the relationship between palliative care nurses and patients is compromised by permitting the refusal of medical treatment?

**Mrs BUCHANAN:** No.

**The CHAIR:** Are you aware of any concerns that vulnerable people are being influenced or coerced into refusing medical treatment?

**Mrs BUCHANAN:** No, but we would say that people who are more vulnerable must be even more protected.

**The CHAIR:** Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to refuse medical treatment or are exploiting their position in their own interests?

**Mrs BUCHANAN:** No. However, we do believe that there are some people that exploit their own interests that we could not comment on, and also that it is very difficult being a substitute decision-maker and it should not be taken lightly. It is often not well described and people who take on that role sometimes do not get the support or the understanding and the knowledge they should before they become that.

**The CHAIR:** The refusal of medical treatment can include refusing artificial hydration and nourishment, as in the Rossiter case. In your assessment, is this issue now clearer for palliative care nurses?

[12.50 pm]

**Mrs BUCHANAN:** Via the law, if our practice is being determined by our fears, then we are not practising well. So, in real terms, you asked before if people have the opportunity to make choices. Yes, they do. Does that law or that case actually clear it for both sides, as in the institution and the person? Yes. So it does make it easier to be able to practice. We would say, however, that not eating and drinking and those choices are often a normal part of end of life because physiologically and psychologically, the intake—the desire and the need to be able to take food—can sometimes be confused with the idea that we are stopping or refusing people's desire.

**The CHAIR:** Would you say the practice is implemented consistently across WA?

**Mrs BUCHANAN:** We cannot comment on the whole process of what happens across WA, and I am not being disrespectful.

**The CHAIR:** Of course; not at all.

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**Mrs BUCHANAN:** But we believe that people in palliative care settings have a very strong and clear understanding.

**The CHAIR:** In your experience, do palliative care nurses report incidents where medical treatment is refused?

**Mrs BUCHANAN:** It is not a requirement for us to do that. We had great trouble when you were asking this because we would say, as in our previous answer, that when people make a choice not to have treatment, that is part of their treatment choice. That is rather than if you are suggesting where somebody has been given all the benefits of having a surgical intervention and they say no; of course, there is a process you must follow in regards to wherever you practice. Against medical advice, these things occur, which is very different to then making choices about, “Do I actually want for quality to not have X, Y or Z treatment?” We would support that.

**Hon NICK GOIRAN:** I know we have run out of time, so I will limit it to one question. I was just interested, before you go, to get your perspective with regard to the interaction with substitute decision-makers from a nurse’s perspective. Obviously, it is largely pretty straightforward when you are dealing with the patient themselves, all things being equal, but when there is a substitute decision-maker, there is clearly a complexity around that. Is that problematic for nurses or is that left more to the doctors to deal with?

**Mrs BUCHANAN:** A lot of nurses would say, “Let’s leave it to the doctor to deal with”, if you are talking about complex issues. However, realistically substitute decision-making is actually really clearly and well-defined in our legislation. It is really easy to follow. What it actually needs is for nurses to determine and I will say health professionals, so us as teams, to really work out who is the substitute decision-maker rather than what we often did in my older past saying, “You’re the next of kin.” That is not part of legislation. That is not the way it works. So, in real terms it is not hard if we actually ask the right questions and determine who the substitute decision-maker is, but also that we work with them, because being a substitute decision-maker does not mean that we can go, “What do you want to do?” That is not fair and that is not right practice. Right practice is about working together with people who are the substitute decision-makers and when they have to be enacted, they have felt part of the process and part of understanding what is happening, not just a proxy for having to make difficult decisions.

**Hon COLIN HOLT:** Sorry, I do not want to keep you too long, but did you just say that substitute decision-making is quite defined in the act?

**Mrs BUCHANAN:** If we are talking about advanced health directives —

**Hon COLIN HOLT:** Okay.

**Mrs BUCHANAN:** Sorry, I was not taking the —

**Hon COLIN HOLT:** I am just trying to clarify what act.

**Mrs BUCHANAN:** Substitute decision-making quite clearly states that there is a hierarchy for non-emergency consented medical interventions, and again, I would be very happy to supply that.

**Hon COLIN HOLT:** Is this in the guide —

**Mr S.A. MILLMAN:** It is in the Guardianship and Administration Act.

**Mrs BUCHANAN:** That is it.

**Hon COLIN HOLT:** The Guardianship and Administration Act; thank you.

**Mrs BUCHANAN:** But it is very clear.

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**Hon ROBIN CHAPPLE:** If somebody does not have a directive and I think you might have heard us asking this previously, what ability do you have to then go to guardians or relatives, if there is no directive from the patient, that they are their power of attorney, so to speak?

**Mrs BUCHANAN:** Power of attorney is around the idea of their money, but around —

**Hon ROBIN CHAPPLE:** No, sorry; I have used the wrong word.

**Mrs BUCHANAN:** That is okay.

**Hon ROBIN CHAPPLE:** What role do they play in the decision-making about choices pertaining to palliative care and medication if they are not prescribed in a living will or whatever?

**Mrs BUCHANAN:** It goes back to what I was saying to Mr Holt. You would follow the hierarchy of decision-makers; if you do not have an advance health directive, then it goes to the state-appointed guardians, then it goes down. That is how the law works. My answer to you in regards to practitioners is that we should be conversing with people to actually not make assumptions about whom the right person is to speak—who is the right decision-maker. When and if the patient is at a point where they could not have told us that and we have not done a better job of finding that out beforehand, we would really hope that we were sensitive enough to be able to have those conversations. That is where the difficulty comes in. That is why I said the law is really clear, it is often just very difficult for health professionals because we have actually not determined it much earlier, when we should have. We should actually have the patient thinking about that ages before. Did that answer your question?

**Hon ROBIN CHAPPLE:** Absolutely; thank you.

**The CHAIR:** Thank you for your evidence before the committee today. A transcript of this hearing will be forwarded to you for correction of minor errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. Should you wish to provide additional information or elaborate on particular points, please include a supplementary submission for the committee's consideration when you return your corrected transcript of evidence. The committee will write to you with questions taken on notice during the hearing. In addition, we will include the proposed questions that we were unable to address due to time constraints. Thank you very much.

**Hearing concluded at 12.57 pm**

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