

# **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  
TUESDAY, 1 MAY 2018**

**SESSION NINE**

## **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 4.12 pm****Mr BRUCE BUCHANAN****Private citizen, 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 joint select committee. We have Mr Simon Millman; joining us shortly will be Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Mr Reece Whitby and Hon Robin Chapple.

The purpose of this hearing is to examine the adequacy of the existing laws and resources for end-of-life choices from your perspective as an individual member of the community who is willing to share your personal experience. It is important that 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 does not apply to anything that you might say outside of today's hearing. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet. The audiovisual recording will be available on the committee website following the hearing. Could you please introduce yourself for the record.

**Mr BUCHANAN:** My name is Bruce Buchanan. I think that is it.

**The CHAIR:** That is adequate. Thank you.

**Mr BUCHANAN:** I cannot say any more than that.

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

**Mr BUCHANAN:** No, I do not think I do.

**The CHAIR:** Did you want to make an opening statement?

**Mr BUCHANAN:** Obviously, you all will have read my submission. Naturally, I am willing to respond to any questions any of you may have. Thank you for allowing me to be here. I would also, with your permission, like to add a little bit to what I wrote earlier, but that is up to the committee.

**The CHAIR:** Yes, we would be very happy to hear that.

**Mr BUCHANAN:** One thing I realised was omitted from my original submission was, if you like, the locus of responsibility. What I was suggesting was that rather than go to the High Court, which appears to be the situation at the moment when something goes wrong with an advance health care directive, there should be a simple and inexpensive means of bringing that to attention with appropriate penalty. I did not say who ought to be responsible, which I realised subsequently is an error. In my opinion, the responsibility should lie with the care provider. The only alternative, of course, is the medical practitioner. A little consideration reveals that that is simply impractical, because medical practitioners might be called out one evening, as happened in the case of my wife, to two or three people. Where is the advance health care directive for them? The care provider must know, or ought to know—obviously, a defence would be that they did not know, but clearly in the case where my wife was in an aged-care facility, that had all been covered. That is one aspect that I would like to bring to your attention.

The other thing, which in part arises from listening to the lady on the internet, or wherever it came from, is about the need for more palliative care than is available at the moment. I am probably a little unusual in that I myself spent nearly five months in palliative care while they waited for me to

die. I did not die, obviously, otherwise I would not be here before you, but it took quite a while, and I had the opportunity, therefore, not only to experience palliative care but to see people on the other wards being taken away on an almost daily basis, because that is what you are in palliative care for—to die. When I recovered—because I had been misdiagnosed, I might say, and the reason for that is medical incompetence, I fear—I then spent every day with my wife, who was suffering from PSP, which is progressive sub-cranial palsy. It is one of these rare, one in 100 000 type illnesses, which is particularly unpleasant towards the end in every sense of the word. When I became ill, I just collapsed and was taken off to hospital. My wife had to, in effect, go to an emergency aged-care facility. She was taken away because I had been her carer for several years. When I emerged from palliative care, with everyone saying “You’re one of the lucky few” as I was escorted out by the staff, I saw my wife every day. It was immediately apparent to me that the aged-care facility was splendid as far as everything went while she was reasonably fit and active, as you might say. It was a positive experience. There were participatory activities she could be in. The food was good, and a pleasant atmosphere. It seemed all pretty good, until her illness progressed to the point where she was unable to move, because the illness affects balance, eyesight, swallowing and a whole range of things—continence—the lot. At that point, of course, the demand upon the aged-care facility was greater than they had the staff or the competence to deal with. Two things I noticed, apart from the fact that they lacked facilities, was I spoke to the head nursing person in charge and said, “Look, this ought to be done—surely.” The lady sighed and said, “Yes, I know that”—they are an economic activity, after all—“but the government tells us the maximum we can charge”, which is a fact. The second was that I as a payer might have a limit on what I can pay. So there is an economic squeeze. That is not within the ambit of your committee’s deliberations, I do not suppose, but it is undoubtedly a significant fact in the care granted. I was paying a little over \$4 000 a month to maintain my wife. I was going backwards, as it were, financially, but you have to do what you have to do.

The other thing I noticed was that in aged-care facilities, essentially people go there and die—not immediately, of course, and it varies upon the illnesses and so on. Some were serious and some were neurological in a more mental sense and they were not quite in their right minds and they needed to be looked after, but they were not going to die. But on the whole, I suppose, there would be deaths all the time.

[4.20 pm]

The impact that had, from my perspective at least, was that the longer-term staff become desensitised. I tried on more than one occasion to say, “Look, this or that ought to be done”, and I would be greeted with statements like, “I’ve been a nursing sister for 20 years. What experience have you got?” I also felt constrained by the fact that the healthcare facility had charge of my wife, as it were, to look after her, and if I had started to bang the table and be unpleasant, who knows what impact that might have on my wife? I was careful about that; one has to be.

I found the professional staff—that is to say, the occupational therapists, the physiotherapists and the like—all to be very good, positive and as helpful as possible. But the people who are doing the everyday work in these facilities—carers, if you like—are notoriously underpaid and notoriously underqualified. In comparison, in palliative care, where I had been, there are trained nursing staff who are not long-term, because they rotate them. If a staff member starts to feel the pinch of having people dying all the time—and they were—they can be rotated to another ward. They are selected carefully to start with, anyway.

In comparison, the aged-care facility is taking on people who are willing to take on a pretty low-paid, junior role, and they were not good at it, particularly when you are dealing with a person—in

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this case, my wife—who was by that stage barely able to move. As a result they were not washing her properly. The last shower she had was at my insistence because I was there. I said to my wife, “Have you had a shower?” She shook her head; she could not speak at this point, because that was part of her illness. She said no. So when the carers came along, I said, “This lady wants a shower”, and they said, “Oh, wait on a minute. We’ll have to get a hoist.” I said, “There’s lots of hoists up the corridor. Just get one and make sure she has a shower.” They were upset about that, but they did it. They gave her a very brief shower, and it was the last time I think I saw my wife smile. She had had a shower, which she had not had for days. The ladies among you will know what that means. Thereafter, she was washed in bed, generally very inadequately.

Way back, I nursed in a mental hospital, so I am aware of what nurses do, my wife being one as well, of course. But she was not cared for appropriately. That is the only way to describe it. She was not washed properly. She got bedsores because she slept on her back. Please do not sleep on your back, if any of you feel like it; it is bad news when you get sick. She had bedsores, and they would not tell me. The aged-care facility denied that she had bedsores. They pulled the curtains prior to me seeing her. I was her husband, and I did not mind waiting while they washed, and I remember hearing one staff member say, “Oh, my God!” and the other one said, “Shh!” I knew what was happening; they had turned her on her side to wash her and they saw her back.

In aged-care facilities, they have to ring the husband, I suppose, in this case, or the relevant people, to say, “We’re going to administer morphia.” It is part of the regulations; I did not know that, but apparently it was the case. They rang me at about eight o’clock at night and said that this was going to happen, and I said, “Why?” They said, “Oh, well, your wife is in pain.” I said, “But what for? Where’s the pain?” They said, “Ah, well, um, she’s in pain.” I said, “I know, but where?” “Well, um.” So I thought, to hell with it. Excuse me for saying that. What could you do? If that is what they felt she needed, I presumed she was in pain. Of course, I asked when I got there the following morning, I went around saying, “Why did you give my wife morphine?” “Oh, well.” I never found out; no-one ever told me as to why that was the case. I can only assume from subsequent events that she had bedsores and they were severe, as they are terrible things, and that they needed to relieve her pain from that.

Insofar as it comes within your terms of reference—I am not quite sure about that—I would advocate more palliative care. A great deal of money runs into other things, but palliative care is not a sort of choice thing. For breast cancer, it is wonderful. We all know about that and we must give lots of money for it, and good. Let us try to help them cure it. I am not against anything like that. But if you ask for money for palliative care, “Oh, well, that’s the government’s responsibility, isn’t it?” It is very much needed. Not only was I witnessing my wife’s situation, I was also witnessing that of other people in a similar way who were not being visited, as I was visiting every day, and who were laying half out of bed and going unattended and all the rest of it.

**Hon ROBIN CHAPPLE:** Which nursing home was it?

**Mr BUCHANAN:** With respect, I am reluctant to say. It was in Bunbury, but I am reluctant, as it is a public matter, to point the finger, if you see what I mean.

**The CHAIR:** Mr Buchanan, that is fine.

**Mr BUCHANAN:** I am happy to tell you afterwards, if you see what I mean.

**Hon Dr SALLY TALBOT:** We could go into private session.

**The CHAIR:** We could do, but I would like to finish the public hearing.

**Mr BUCHANAN:** I think essentially that is really all I needed to say. I would also say that when my wife was first diagnosed with her illness, which commenced about 10 years before she died—it was

one of these long, slow-developing neurological things that accelerates towards the end—the specialist said, “You will reach a point where you will not be able to swallow.” It is progressive in that the muscles fade out. One of the reasons why there was mention in my initial submission of pneumonia was because the chest muscles do not operate and you cannot breathe properly and so on. He said, “When you come to the point where you are not able to swallow, you can have a stomach tube.” My wife and I knew that and she knew straightaway that she did not want that. He said, “If you don’t have a stomach tube you’ll starve and you’ll be dead in about two to three weeks. Alternatively, you can stop drinking and you’ll be dead in three to four days. There is no hard and fast rule about these things.”

[4.30 pm]

My wife and I talked about that on and off. She decided that she would not drink. She stopped drinking, or would not drink, one evening. I was not there because I had gone home. The following day, when I arrived, all the staff of the aged-care facility were standing around saying, “Come on, open your mouth and we’ll swab your mouth out” and all that. And she just clamped her mouth shut and she would not do anything. She was conscious for 36 hours or so. She was unable to speak. I was sitting by her bed holding her hand and every now and then I would squeeze her hand and she would squeeze back. That is how we communicated at that point. That was all of that day, and at about midday the following day there was no response when I squeezed her hand. She died about 24 hours after that, as far as I know quite painlessly. To some extent, I mean I know there are all kinds of medical things about this, but we were told by two specialists that if you want to die, this is the way you can do it. Around the aged-care facility, it was commonly said that they knew quite a few people who had starved themselves to death, that simply, “Mrs Smith on the other corridor, you know, she died three months ago” et cetera. That seemed to be quite common; not drinking seemed to be less common. To that extent, I have doubts about euthanasia—although that is not really where I came from, but listening to the lady today—because it is easy to do. It certainly was for my wife; she had no trouble about it. She knew what she was doing and I knew what she was doing, and that was it. I am open to questions for any member of the committee who would like to question.

**The CHAIR:** Mr Buchanan, you have provided some really interesting evidence for the committee today, and I thank you very much for that, particularly I think around the issues you have raised with the advance health directives. Palliative care and aged-care facilities is a theme that I think has emerged over the course of this inquiry, so it is really useful to have that direct experience. Members will have a few questions; I just want you to talk through the issues with the advance health directive with your wife and that experience where she was obviously very cognisant of what she wanted and did not want and went to the trouble of writing it down in a legal document.

**Mr BUCHANAN:** That is right, yes.

**The CHAIR:** From that point on, just walk us through what happened.

**Mr BUCHANAN:** We both actually completed it at the time, as you are meant to do with your GP, all properly signed, sealed and all the rest of it. Of course, I was my wife’s carer at that point until I sort of collapsed and was carted off to hospital with a view to my dying, which as I say did not turn out that way. My wife went to the aged-care facility. When I was able to visit, the sharp decline had not commenced, though she was clearly in decline. The ward sister—I suppose you would have to call her that; I would, it is probably an old fashioned term—and I sat down and we went through the advance health care directive together. I had handed it over earlier on to make sure they had it when my wife went into the aged-care facility. She had been in three or four previously, one was respite, I am sure you are aware of that, and had had mixed experiences of that—some are good

and some are not so good. But I went right through it with the place where she was to finally reside, as it were, and it was quite clear that what ought to be done in the case of pneumonia—well, it said she would be allowed not to be given antibiotics and be allowed to die. It was quite clear.

Unfortunately, when it happened, they gave antibiotics. The aged-care facility was poor at calling doctors; I do not know why. Twice, once when I was in palliative care myself, I had to ring the doctor's surgery and say, "Send a doctor to see my wife. Don't worry about the cost; you just do whatever you can do", because she was obviously on the telephone—we are talking about mobile phones—and she could barely speak for coughing and one thing and another. She had an infection of the upper lung or whatever. I am not a medical person, but it was not pneumonia in the fullest sense of the word; she was cured from that. It happened a second time when I was released from hospital and I said that my wife needs a doctor, and they said, "Oh, well, all right", and I said, "All right, I will take her" and I took her myself. On the final occasion, they refused to call the doctor, and when I said, "My wife needs a doctor, she is obviously very ill", they said, "No, no, we can't do it." So I said, "Why not?", and they said "No, no, we just can't do that." I said, "Well, she's obviously got a very severe chest infection and something else", and I said I think she might have had a slight stroke, because she had had slight strokes before, not affecting her speech, but affecting her gait of her right foot—left hemiplegia, I suppose. I am not a medical person; some of you may be. That seemed to worry them. Heavens knows why!

So after I had gone home thinking that the help has been refused, the doctor had been refused, they actually called the doctor in. It was a Saturday. He was not a doctor with which I or my wife was familiar. He said, "This person's got pneumonia; I will prescribe antibiotics." In my judgement, having gone through the ADF with the care facility, they should have said, "No, no, we wouldn't do that", but it was administered. When I arrived the following morning, there was my wife still unconscious and looking very peaceful. She was in a shared room and I said to the other lady, who was partially paralysed with a stroke but able to speak, "She's very peaceful", and she said, "You should have been here last night." I said, "Why is that?", and she said, "She was calling out for you all night", and I said, "Oh." She said, "She's got pneumonia." I thought to myself then, "Oh, good, that is what she wants. She's looking peaceful; she's dying; isn't that wonderful?" It is a terrible thing to think, I can tell you. And then in walks the nurse, the sister, and says, "Hello! She'll be all right in a while." I said, "Why's that?" She said, "We've given her antibiotics." I think it was one of the more complex moments in my life—the one moment, I am thinking "Thank god my wife of many years is dying", and that is what she wanted, and then they are saying, "Oh, no; we've saved her for you!" I still find it very difficult.

Perhaps something else I might add, which does not seem to have come up, to my knowledge—certainly the lady from wherever it was, speaking—the survivors suffer as well, whether through euthanasia or whatever it is. My wife's death was not difficult, but it was the fact that she could have died peacefully and decently and then had to go on suffering for another 10 to 14 days and make a decision to die herself, when we had talked about it. I have since found that very difficult, mainly because I tried as best I could to see that her sufferings were alleviated by the aged-care facility, and I would say, "You must do this, you must do that", and no matter what I would say, they would say, "What do you know about it? I have been a nursing sister all this time." And I said, "She has obviously got bedsores". "No, no, she hasn't!" I could not roll her over in bed and pop her nightie and say, "Look at that", and so on. I am still tormented by that. There is not the ability to, if you like, to—in my wife's case, she wanted to die in the way she wanted to die, and that was denied to her. She had—she did—kill herself, which is, as far as I was concerned, what she wanted and I wanted, and that was good.

[4.40 pm]

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**Hon ROBIN CHAPPLE:** Thank you for providing the evidence you have. When it came to your wife's decision not to continue drinking, what level of sedation or —

**Mr BUCHANAN:** She had no sedation at all.

**Hon ROBIN CHAPPLE:** None?

**Mr BUCHANAN:** None. The nature of her illness was that there was no pain.

**Hon ROBIN CHAPPLE:** We have been provided evidence that if somebody is withdrawing from drinking, whether it be voluntary or whether it be the condition that causes that, you usually actually then provide sedation to alleviate the trauma of not drinking.

**Mr BUCHANAN:** I see. Certainly on and off at the aged-care facility, it was giving my wife morphia. As I said, they would not tell me why. I am aware of the fact that, from other people who have worked in those facilities, it is not uncommon to give morphia to people towards the ends of their lives so they think "That is all right" and pass away. I do not think it was being done, I believe, and I, of course, have no evidence directly that it was being done to relieve the pain my wife was suffering from her bedsores.

**Hon ROBIN CHAPPLE:** I just want to go back and clarify that one point, if I may. Your wife has refused fluids. She is conscious, because you were saying you were holding hands, and she was lucid.

**Mr BUCHANAN:** Yes.

**Hon ROBIN CHAPPLE:** And yet, as far as you were aware, there was no intervention to alleviate the suffering that she would have been going through because of the lack of fluid?

**Mr BUCHANAN:** No, there was not. I am not aware of the fact that she was suffering. Once she decided not to drink, she was getting towards the end of her life, I suppose. There was no indication that she suffered. And facially, as far as I could tell—I mean, you can only tell by visual cues, because she could not speak at that point—it was not as though she was writhing in agony or doing anything. She did not do that at any time. The morphia, as I said, in my judgement was given because of the bedsores, which are very painful and unpleasant. There was no indication to me by the two specialists who spoke to both my wife and I about cessation of drinking that this would cause agony or anything of that sort. They said you just stop and you feel thirsty, obviously enough, and if you are towards the end of your life you will pass, as my wife did, in a state of semi-consciousness and then unconsciousness.

**Hon NICK GOIRAN:** Mr Buchanan, I think this is our seventy-seventh public hearing.

**Mr BUCHANAN:** Is it?

**Hon NICK GOIRAN:** You would think that after all this time we will have learnt or heard nothing new, but one of the various things that is new in the evidence you have given this afternoon is you talked about an experience where for five months you were in palliative care.

**Mr BUCHANAN:** Indeed.

**Hon NICK GOIRAN:** With a misdiagnosis. When you say that you were in palliative care, was that in a hospice?

**Mr BUCHANAN:** Yes, there is a palliative care ward in the St John of God Bunbury Hospital, and that is where I was.

**Hon NICK GOIRAN:** And you were residing there for five months?

**Mr BUCHANAN:** Yes.

**Hon NICK GOIRAN:** If you are willing to disclose, what was the diagnosis that you were given?

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**Mr BUCHANAN:** I was diagnosed with cancer of the pancreas and I was given five weeks to live. At the point where this came up, I collapsed. The initial signs of cancer of the pancreas are jaundice, blockage of the bile duct and pain. I had jaundice and a blockage of the bile duct, but I did not have any pain. It is common, as it were. I am not a medical person, but from what I know of it, if you have got those symptoms, you have got either kidney stones, cancer of the pancreas or, in one in umpteen many chances, something else, and that is what I had—the something else. In fact, in hospital they said, “Sorry, chum; you’ll be dead in about five weeks. We’re going to send you up to Fiona Stanley to see what we can do for you, but this is it.” I had the slightly unpleasant task of ringing my wife, who was in an aged-care facility because I could not look after her, to say, “Sorry; I won’t see you again. I’ll be dead before anything happens.” Fortunately, when I got to Fiona Stanley, what they firstly do is they unblock your bile duct and you start to get better, and then the cancer of the pancreas should knock you off. The doctor was simply incompetent, and I say that advisedly. We all make mistakes—maybe parliamentarians do not make mistakes! But everybody else does in the world. It was more than that; it was simply incompetence, because he could have easily discovered whether or not I had cancer by a simple needle biopsy of my pancreas, which took about an hour or less, because I had one much later on when I had not died and they said, “We think you’ve got something else.” They said, “We’d better check up to see that your pancreas is all right” and an hour later someone trots in and says, “There’s no cancer at all.” I had spent all this time expecting to die and telling everyone else that I had cancer and I had not. It was an interesting experience, I can tell you.

**Hon COLIN HOLT:** My question was along similar lines. While your wife was in aged care, did she see, to your knowledge, a palliative care specialist who came to the facility or somebody who said they were a palliative care specialist?

**Mr BUCHANAN:** No. There is no cure of her illness. The PSP is incurable, progressive, as the name implies, and you can do nothing about it. The GP—as it turned out, our GP and had been for 20-odd years—was a physician who visited that aged-care facility and he would drop in from time to time, but there was nothing that effectively could be done. Essentially, other than the physical symptoms—bedsores and the like—it is an illness that progresses without pain.

**Hon COLIN HOLT:** So who prescribed the morphia?

**Mr BUCHANAN:** The aged-care facility—well, I do not know, now you come to ask that question. Presumably, as far as I am aware, it would have been the aged-care facility, because I was rung at eight o’clock at night and told, “We’re going to do this.” A doctor may have come in; I do not know.

**Hon COLIN HOLT:** They must have consulted somebody.

**Mr BUCHANAN:** Yes. I honestly do not know. I did not think to ask, because I could not understand why it was being given anyway. As I said earlier, they did not tell me on request, I might say. It was not as though I did not ask, “Why is this being done?” They fuzzled around that and would never tell me and implied that in fact I was bringing the good name of the aged-care facility into disrepute by asking these awful questions.

**Hon COLIN HOLT:** You may not be able to answer this, but do you think they considered your wife to need palliative care—end-of-life care—or do you think they were just caring for her in the state she was in and never really defined it as palliative care?

**Mr BUCHANAN:** I do not think they did that, no. I would have to say that aged-care facilities, as I stated earlier, are economic. It is an economic society we live in. Every bed that is occupied is money and that is what they are concerned with. After my wife died, they rang me up to say, “Your wife has died.” I said, “Fine; I’ll come in tomorrow morning to collect her goods.” I got there at nine

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o'clock, or thereabouts, and I was immediately assailed by the fact: "You're late! What's going on? You should have been here ages ago", while they were putting all my wife's stuff into plastic bags and so on saying, "Come on, come on, come on." There was someone else in the bed that same day. The impression left on me is a little different from the one you are implying. As I say, it is an economic world we are in and I can understand their problems.

[4.50 pm]

**Hon COLIN HOLT:** As opposed to you when you were diagnosed with a terminal illness, they would have probably booked you in in palliative care need?

**Mr BUCHANAN:** They did, yes. The diagnosis was done at Fiona Stanley, albeit incorrectly. I was sent back by ambulance and they said, "Right; you go into palliative care", and there I stayed for quite a while. I used to go out for a little while. They would say, "You're better now." The nature of the illness I do have is cyclical, so you get better and you get worse and you get better and you get worse. Of course, when I got better, they would say, "Good; you can pop out now." I would be out for perhaps a week and then I would say, "I'm not good", and I would be back in again, until finally I was properly diagnosed. I must say it was a gerontologist who diagnosed me properly—and I thought I was younger than that! He walked in and he said, "I've read your notes." He had been asked to visit the hospital for a short time. I was in hospital and he walked in and said, "I've read your notes. I think I know what's wrong. I'll come and see you tomorrow." This was in October. It was four months. I was out and then back in; there were a lot of ins and outs, I can assure you. He had his registrar in training with him, as you know how they do. He sat the registrar down and said, "Tell me what's wrong with him." The registrar said, "He's got cancer of the pancreas." He said, "Right; what else has he got?" I have forgotten what the second one was. He eventually prompted the registrar—poor lad, learning—a bit and he said, "Yes, that's it. It could be this", and that is what I have got—this IgG4 disease.

**Hon NICK GOIRAN:** Mr Buchanan, how long ago was this when you started in palliative care and you were told?

**Mr BUCHANAN:** I was admitted to hospital in March 2016. I collapsed in March 2016. I had been looking after my wife for about two years full time because she was by that stage not able to walk without assistance, doubly incontinent and all the rest of it. I was looking after her and then she had to go into the aged-care facility when I collapsed, and after a while I eventually emerged.

**Mr S.A. MILLMAN:** Mr Buchanan, thank you for your evidence this afternoon. I have a couple of questions. I wonder if you can just help me very quickly with the chronology. You just answered a question from my friend Hon Nick Goiran. When was your wife diagnosed? When was her original diagnosis? It would have been about 2014.

**Mr BUCHANAN:** I am not sure. About that, yes. One of the early symptoms, because it is a progressive disease and causes muscle wasting, was she could not walk as far. We used to walk in the morning. She could not walk as well. With everything going on, she seemed otherwise normal. She would fall over, which is another symptom. If you look up, you just fall backwards. Then she became urinary incontinent. The specialist says, "Ah, you've got a urinary problem." I suppose she must have seen three or four urinary specialists, all of whom said, "Try this, try this, try this", "I can't do any good; I'll pass you on to my colleague" and so on. It was quite a long time before the diagnosis came up. It was in fact—I do not know—two or three years. I finally said to my wife, "This is hopeless; we're not getting anywhere. Let's go back to our GP and start all over again."

**Mr S.A. MILLMAN:** When you went back to your GP at that stage, that is when you and your wife completed your AHDs?

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**Mr BUCHANAN:** No. We did that a bit afterwards. When she had a proper diagnosis—she saw a neurologist in Perth—and when we knew fully what her disease was, we both thought, “Right; let’s have an advance health directive.” We both completed one at that time.

**Mr S.A. MILLMAN:** And then for a period of time you were your wife’s carer at home —

**Mr BUCHANAN:** Yes; that is right.

**Mr S.A. MILLMAN:** — until your fall and then your admission to the palliative care unit for five months?

**Mr BUCHANAN:** That is right; yes. Correct, yes.

**Mr S.A. MILLMAN:** As per your submission, “I became unwell.” When you talk about that new submission, that is when you were admitted into the palliative care unit and perforce she was placed in the aged-care facility?

**Mr BUCHANAN:** Yes. Someone had to look after her at the time.

**Mr S.A. MILLMAN:** I understand. In the next paragraph, you talk about the legal pedantry and those sorts of things. Then it was later on that your wife became unwell. It was at that point obvious that the aged-care facility was aware of the existence and the terms of the AHD?

**Mr BUCHANAN:** Yes, very much.

**Mr S.A. MILLMAN:** My questions go to a complaints process essentially. Given the way that you were treated by the aged-care facility, did you give consideration to a complaint to consumer protection about their conduct?

**Mr BUCHANAN:** No. If I may say, I think the reason for that is I was too preoccupied in a sense with the situation for both of us really, because my situation was very unclear and I knew my wife was dying—we both knew that. The idea of going off and getting some agency involved just does not come up. There is the other fact I mentioned earlier: you have the feeling that your wife is in the care of another group of people and if you start niggling them, they—you know. They did react badly when I said, “Look, how about this?” So going to another outside agency would have been worse.

**Mr S.A. MILLMAN:** Presumably, similar considerations were operating on your mind in respect of complaining about the medical practitioners at the aged-care facility in respect of the failure to adhere to the AHD?

**Mr BUCHANAN:** That is more tricky, because it was a locum and it was a weekend; hence my initial comment that the responsibility should rest with the carer. Clearly, if you are a doctor, you are called out, you have got three or four people to visit over a Saturday evening or something because of whatever it is, so I do not think we can ask the medico to check up whether there is an advance health care directive for each person.

**Mr S.A. MILLMAN:** At the time that the locum attended on your wife that weekend, was there any question about her capacity—about her ability to participate in decision-making processes?

**Mr BUCHANAN:** Insofar as she could not really speak, mentally she knew what was going on. She could not verbalise it. She was in the throes of pneumonia, so she probably was, I would imagine—I was not there, of course—not able to communicate her wishes verbally, firstly, because she could not, and, secondly, because of the nature of her illness. If you are suffering from pneumonia, you do not suddenly say, “Hang on.” She could not do that.

**Mr S.A. MILLMAN:** My last question—forgive me if it is too impertinent—is: how does it make you feel that your wife’s AHD was not complied with in terms of the treatment?

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**Mr BUCHANAN:** Damned annoyed. We completed it because, as I said earlier, I felt—it sounds terrible for me to say it—I was gratified to think that she was about to die painlessly in a way that we had both agreed to and wanted. Then within minutes almost of what had occurred, in comes the nursing sister all full of herself saying, “Don’t worry; we’ve saved her.”

[5.00 pm]

As I said, I did say earlier one of the things that is possibly missing from some of these considerations—I have not been present of course—is that there is an impact upon the survivors which I think tends to be overlooked and the way in which people die or do not die or whatever. My wife and I talked about the fact that there is an awful lot said about you must die at home; it is good. Neither of us would want that. I think it is the most awful thing you could possibly do. My wife thought that, having been a nurse who attended many dying people and always said, “Never do I want to die at home.” There are individual thoughts about these things.

**Hon Dr SALLY TALBOT:** One final question. My mother died of PSP, so you have my deepest sympathy. PSP, of course, is extremely rare as you said. It also involves a type of dementia. It is a very different condition to Alzheimer’s so it is often seriously misunderstood by carers, facilities, nurses and doctors because they do not see cases of PSP. Following up on Mr Millman’s questions, I wondered whether the people at the aged-care facility ever raised with you your wife’s apparent lack of capacity.

**Mr BUCHANAN:** No. They were aware of her diagnosis because I told them, obviously, what she had got. The nursing sister in charge of that area, who went through the advance health care directive with me and we, naturally, talked about it, understood, as far as I was concerned, all that was in the health care directive and the situation my wife was in. She did say that the facility had had other persons with the same illness a year or so before, or a person with the same illness, so they were, I think, aware. I do not think my wife suffered any diminution of her mental capacity because in the way that husbands and wives can communicate without speaking, we understood each other pretty well right until the end.

**Hon Dr SALLY TALBOT:** It was an element of misinterpretation by carers that I found.

**Mr BUCHANAN:** I do not think so. In my mind, there is a difference between carers, the people doing the washing of the body—almost what it amounted to the way they did it—and the more senior staff who had all the notes and knew everything. I think they knew perfectly well what was going on. I do not think the people doing the body washing, as you might say, and the toileting so far as that was possible, gave a damn either way. It was just a job to them. You started at one end of the corridor on Monday and worked your way down this end. My wife was right at this end. The following day you started at that end and worked your way back. On Sundays, I could go in. I remember one day I was in late and at 10 o’clock my wife was still there. I said, “Haven’t you been washed? No, no she had not been washed. I said, “What, at 10 o’clock?” There she was doubly incontinent, poor lady, sitting there at 10 o’clock and nothing had happened. I said, “What’s gone on? Oh, it’s because this is the day they start at the other end of the corridor.” In those terms, you are not dealing with understanding.

**The CHAIR:** Mr Buchanan, we have reached the end of our time unfortunately.

**Mr BUCHANAN:** Of course, that is all right.

**Hon ROBIN CHAPPLE:** Chair, we did ask if Mr Buchanan could write down —

**The CHAIR:** The name of the aged-care facility?

**Hon ROBIN CHAPPLE:** Yes.

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**The CHAIR:** Would you be prepared to do that, Mr Buchanan? We will not publish it.

**Mr BUCHANAN:** Yes. As I say, I have no idea about the laws that evolve these things but I am quite prepared to do that.

**The CHAIR:** We will not make it public. That would be great, thank you.

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 by these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or to elaborate on your evidence, please provide it in an email for consideration by the committee. As you can tell, I have said that 77 times.

**Mr BUCHANAN:** Indeed, I understand that.

**The CHAIR:** Thank you very much.

**Mr BUCHANAN:** I am sorry for you having to go through all that for me again.

**The CHAIR:** No; you have been a fantastic witness. Thank you.

**Hearing concluded at 5.04 pm**

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