

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 FIVE

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**

Hearing commenced at 12.20 pm**Ms NOREEN FYNN****Private citizen, examined:****Mrs LISA BRUMLEY****Private citizen, examined:**

The CHAIR: Good afternoon and welcome Ms Fynn and Mrs Brumley to our hearing this afternoon. I will open the hearing with a formal statement and then you may want to address the committee.

On behalf 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 and I am the Chair of the joint select committee. We have Mr Simon Millman; 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 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 proceedings. 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's website following the hearing.

Do you have any questions about your attendance today?

The WITNESSES: No.

The CHAIR: Did you want to make a statement for the committee?

Ms FYNN: Yes. I would like to thank the committee first of all for this opportunity. Clive's legacy in terms of cancer and palliative care in this state are well known. I hope that his death on election day 2017 with his statement that "Suicide is legal; euthanasia is not" will add to this legacy through seeing the introduction of legislation in Western Australia to allow for assisted dying. I do not propose to go into Clive's full medical history here; my submission contains some details of this. Suffice to say, he battled a host of medical conditions for years. This included more than one form of cancer, stroke—mini strokes—stroke-induced epilepsy and autoimmune conditions. He was complex medically with a long list of specialists and a whole regimen of medications.

He was a wonderful man, a man of strength and determination. He had fought so long to live well and he had an enormous tolerance for pain of all sorts. It is thanks to the great medical care we have and to modern medications that we had him with us for as long as we did. Unfortunately, however, the limitations of medicine and medications were also evident in that they bought him time, they helped alleviate some symptoms, but they also caused almost as many and the side effects came at a high cost, including permanent lung damage. At the end, the full force of symptoms had kicked back in. This included severe neuropathic pain, crippling headaches, insomnia and fatigue that would leave him unable to even walk to the corner of the street. His body was breaking down, his suffering was terrible to see and while he and the medical profession had tried everything, there was no prospect of a cure nor recovery and no hope. And so faced with this, he chose to end his own life on election day 2017. This was not a choice between life and death.

Professor Brian Owler, a past president of the AMA and chair of the Victorian advisory panel on voluntary assisted dying, summed it up when he addressed the press club, saying that the desire to live is the strongest of human instincts and that people endure pain and suffering when there is hope of recovery or improvement. For those who seek assisted dying, it is not a choice between life and death; it is not about giving up the fight to live. It is about the relief of suffering, choice and control. It is about quality of life over quantity, about respect for a person's choice about the manner and time of death. Clive wanted to live. He loved life and we lived life to the full. He also faced head on the prospect of death knowing it was an inevitable end to life. One of his favourite sayings was from Michel de Montaigne —

We should always, as near as we can, be booted and spurred, and ready to go ...

We his family are in no doubt about the strength and courage it took to take the action he did and we respect that choice. It was an action he would have needed to take while he had the strength to do so, and that capacity was diminishing. He is not alone in choosing to end his life in the face of irreversible and chronic illness, pain and suffering. As is evidenced by the submission from the WA Coroner, one in seven suicides in the past five years involved a person with a terminal or debilitating condition. We are also in no doubt that had Clive known that he had the choice of voluntary assisted dying, we would have had him with us for a bit longer, and that is an absolute tragedy.

Finally, given Clive's background in bringing palliative care to the state, I think it is important to note that he never stopped believing in palliative care. He remained a strong supporter of palliative care but he recognised that for a percentage of people, it had its limits. He became an open supporter of people also having the option for voluntary assisted dying. He would have agreed with Emeritus Professor Ian Maddocks, the foundation chair of Palliative Care Australia, who in February said —

Palliative care and voluntary assisted dying will find separate and complementary but not competitive roles, respecting each other in a common focus on the care of persons who experience major discomfort in progressive, advanced terminal illness.

Professor Maddocks also said that in countries where assisted dying has been introduced, palliative care has continued to grow and flourish. For us as a family, the manner of Clive's death was horrendous. This is a man who gave his all for others and for our society. But at the end, he had to die alone, a lonely and hard death. He should have been able to be at home with me, with his sons, with love and support. I think we owe it to all people living with illness and suffering at the end of their lives to do better at allowing them to make their own choices and decisions.

The CHAIR: Thank you very much, Ms Fynn, for being with us this afternoon and sharing your experience and Clive's experience. I think it is fair to say that Clive was well aware of the palliative care options available to him. Did he use those options? Was he receiving palliative care?

Ms FYNN: He was not. He had not at that stage been told that he was in a palliative state. He had not been given a definite time limit to his life. That was not at that stage an option for him. What he was aware of was that if he were to act—I was interested to hear the previous speaker say they left it too late. Something he often said was that people talk about wanting to have the control themselves, but they leave it too late. With the full onset of symptoms, he would not have had the strength to do as he did unless he acted when he did.

[12.30 pm]

Hon ROBIN CHAPPLE: As you know, Clive and I had a number of conversations. The one point you made which I would like to investigate if I can, without causing you too much grief—I understand that this is quite an emotional time for you coming here as well—you talked about how many of the

problems that he was facing were caused by medical intervention. Can you elaborate on that? I mean, they were obviously being done to try and prolong life, help —

Ms FYNN: Absolutely, and they had, but all medicines come with potential side effects. One of the ones Clive was on—I think it is one per cent of people who have the effect that he had—was to give him permanent lung damage, such that the advice at the time was that he should never fly again. He fought back from that—he fought to regain some function—and he was told that, yes, he would be able to fly, provided it was on oxygen.”

Hon ROBIN CHAPPLE: But that lung function issue, did that arise as a result of medical intervention?

Ms FYNN: It arose as a direct side effect of a medication that he was put on, as what they call a steroid-sparing. The only thing that had helped for quite some time was very high doses of steroids. Those who saw him in the last year—18 months of his life would have noticed that he put on a significant amount of weight. He was very breathless. It left him with a lot of side effects. It also bought him time, with the number of conditions he had. In fact, I remember one of his specialists saying, “Don’t even bother to read the side effects; you need the medication”, and that is pretty much what it was. I do not criticise for a second the medical profession. They were absolutely wonderful. I have only the highest praise, as did Clive, for the health sector and for health professionals.

Hon ROBIN CHAPPLE: I suppose that leads me to ask the second question. At the time of that medical intervention that enabled Clive to have a greater extension of life and fulfilment, was Clive at that stage defined as being terminally ill?¹

Ms FYNN: He was not defined then as being terminally ill. Let me go back. This was a long journey. As early as November 2014, he had been living with pain and different pain and suffering such that he was referred to a physician, because he had so many specialists involved that he had to have somebody who could bring it all together. I think his opening words when we walked in there were, “I do not know how much longer I can do this.” For those who knew Clive and knew the strength and determination of the man, you would know what it took for him to say that and to get to that point; and he went on from there for another two and a half years.

Hon Dr SALLY TALBOT: Thanks, Noreen. I want to ask you a couple of questions that I know the committee would value your opinion on, and recognising it is your opinion, rather than anything you might have collected evidence for, so just drawing on your experience. You will know, because you are very conversant with this issue, that one of the things that people who oppose voluntary assisted dying argue is that people only want access to voluntary assisted dying because either they are ignorant about palliative care or they fear they will not be able to access the services. Do you think either of those were true in Clive’s case?

Ms FYNN: Certainly not. He also believed that for most people, palliative care would be the answer. He also believed, as do I, and it was something we discussed, that often just knowing that you have the option of assisted dying is enough. You may not choose to exercise that option at the end, but knowing that you have that option is in itself a huge comfort.

Hon Dr SALLY TALBOT: The other thing about Clive’s lived experience of all this is that presumably he would have been very much au fait with the arrangements for advance health directives. I imagine he was one of the people whom governments would have talked to when they put that together. Did he have an advance health directive?

Ms FYNN: He did, as do I. He had been very much instrumental in a very long advocacy for advance health directives in this state, and his advance health directive was the first one written in

¹ Correspondence from the witness clarifying this part of the transcript can be accessed on the committee webpage.

Western Australia, together with that of the then Minister for Health, Kim Hames. His was very specific. He was very clear always that quality of life was more important to him than the years left in life. I think at the hospice—clearly he had been very involved in bringing hospice to Western Australia—they used to say that it is the life in your years that matters, not the number of years that you have. That was very much his philosophy—that it was about the life that he had in the years. He did not believe in being kept alive at all costs. He also believed, as do I, that resources that are sometimes spent to buy a few months of extra life could be better utilised elsewhere and that that was a debate that at some point we as a society need to have as to where do we put resources. He did have an advance health directive. He had discussed it with his doctors. His doctors all had copies of his advance health directive, and his was about no heroic interventions, no resuscitation, no intubation, no intensive care—he was to be allowed to go.

I need to say that it was the only way we could actually travel. He was in no way able to be covered by travel insurance. In fact, we used to laugh and say the only thing he would be covered for is if he tripped over a suitcase or fell under a bus, and even then they would probably argue that something pre-existing had caused him to do so. For us to look at what we were doing, one of our sons was married two months after Clive died and that meant us travelling to the USA, which would be the most expensive possible place to go to, and Clive was determined he was going to make that. The only way we could do that was that he had said, “My advance health directive is with my physician. Here are the details, and if anything happens to me, give the details and there is to be no heroic treatment.” He would have welcomed what has happened in Victoria, where I read that there has been a change to the legislation in terms of advance health directives and that now if you put an advance health directive in place, it is legally binding even when the person does not have capacity. He believed that that would be the way to go. Also, he used to advocate for a central registry so that it was known if a person had an advance health directive, because it is not always known.

Hon Dr SALLY TALBOT: My last question, Noreen, is about the Victorian legislation. I was interested in your answer to Hon Robin Chapple’s question about Clive’s prognosis. In Victoria, it is six months?

Ms FYNN: Yes.

Hon Dr SALLY TALBOT: If we had had that legislation here, do you think Clive would have been eligible?

Ms FYNN: Not at the time at which he died, no. That is one of the reasons I say that I think it is a tragedy that he did not know that he had that option. At the time that he died, no; he had not been told that he had only six months to go. I would also say that because I know the strength that it would have taken to do what he did, I do not think that he would have taken that action had he known that he had this option.

Hon Dr SALLY TALBOT: In your view, is the six months about right or do you think it needs to be a longer time?

Ms FYNN: Personally, clearly, I would like to see it a longer time. I also think that there is enough evidence to show that guessing—well, it is a guesstimate. It is a best educated guess as to how long a person might have. I should think any person around this table could come up with examples of people, as with the previous witness, where a time has been given that is not necessarily accurate.

[12.40 pm]

Hon Dr SALLY TALBOT: The medical people tell us it is called the surprise test—“Would you be surprised if this person died within X number of months?”

Mr J.E. McGRATH: Thanks, Noreen. As you know, Clive was a constituent of mine, as you are, and as is Mrs Brumley. I find it very interesting when we see that Clive as well as being the head of the

Cancer Council was also the chair of Palliative Care. He obviously believed in palliative care and thought it was very important. In your statement, you have quoted Clive as saying —

Even if good, modern palliative care was available for each and every terminally ill patient—we would still have the ‘nightmares’.

I guess that is what people who are coming and giving evidence are telling us. He also said —

... every day, in different settings, terminally ill patients—most with advanced malignancies and uncontrolled symptoms—are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help. And there is little or no transparency and a legal risk to the doctor and/or nurse.”

I think that sort of encapsulates what Clive was saying, but do you think that when he took the action he did, it was more to make a statement that this is not right and something needs to be done?

Ms FYNN: I do not think he took the action to make a statement. I think he took the action because he had fought very long, very hard. I think he chose the day. He realised that in a way there was no better day for him to take that action. But it was something that he had considered for a while, clearly. This was not something that he did on the spur of the moment. He had obviously had to think about—he used to say it takes the means, the opportunity and the courage. I did not think he had the means, which he did, because I had actually asked him if he had Nembutal. I knew that he had researched that, as I said in my submission. I knew that he did not have Nembutal because he told me that he did not have any. He had also told me that, and I was quite well aware, that he would not trust anything over the internet. He had even phoned Border Force. He had phoned around to say, “All right. Where can I get this tested?” This was Clive. He did not do anything that was like hidden. He was quite open about phoning and saying, “Where can I get it tested?”, and labs said, “Well, you cannot”, and Border Force said it is illegal and quoted some ridiculous fine and said, “If we find it coming through the post, we would confiscate it.”

Mr J.E. McGRATH: Further to that, how much of Clive’s thinking on this and his principle on this was based on everyone’s right to autonomy and to choice at the end of their life? Was that a big part of his thinking?

Ms FYNN: It was a big part of his thinking. He believed very much in being able to have control over your own life. He was also, as I have said, very clear about the quality of that life. That was very, very important to him. If I think back to my days when I was with Carers WA, one of the things that we had was a forum when respecting patient voices was a program being introduced in the health system here. We had Roger Clarnette, who is a geriatrician, who was introducing that at the time.

He painted a horrendous scenario of what would be the outcomes of medical treatment, the prognosis for a person, and said, “Right, now how many of you in this room”, which was a large room of people, “would want us to continue with medical interventions?” I think from memory it was about 15 per cent of people. He said at the time that that would be about right.

Mr J.E. McGRATH: One final question from me. Whether Clive maybe spoke to you about this or whether you have a personal thought about it, it has been raised with the committee that bringing in assisted dying could also run the risk of people being coerced by other family members or feeling pressured to do something that really they might not want to do but they feel maybe they should do. Do you have a view that that could be an issue, and what sort of safeguards we could put in place to make sure that that did not happen?

Ms FYNN: I think the issue of consent is very important. I know that there are—it is absolutely essential for those who are vulnerable that there should be—protections built into legislation. It comes back in my mind, and it certainly would have been in Clive’s, to the question of consent and

a person being absolutely clear. I think you can see if I take an example of someone like Clive, his thinking is very clear over a period of years. His thinking is very clear in his advance health directive; it is very clear through to his choice at the time of his death. In terms of people being pressured: how you protect against that completely? I can only say that I think it comes down to the relationship with the medical profession and actually having that strong consent and checking with a person that this is something that they want. I think the tragedy would be if the majority of people were denied any of that choice because of fear of what could potentially happen when I do not think there is evidence to say that there is clear evidence to support that.

Mr J.E. McGRATH: Thank you.

The CHAIR: Noreen, we have had evidence from people who work in the palliative care field—doctors and nurses—who have said that most people's request to die at the end of life is not from physical pain but from existential pain and unresolved issues. Do you think Clive was experiencing unresolved issues and existential pain?

Ms FYNN: I would not say he was experiencing unresolved issues, I would say that certainly it is a mistake if one focuses purely on physical pain because pain is pain across the whole spectrum. There is physical pain; there is psychological pain. I think we underestimate the suffering caused by extreme fatigue and insomnia. Somebody said to me once, "Was he depressed?" It is like, "Hello? Tell me if anybody living with that level of pain, suffering, fatigue, insomnia and is going to be skipping around in the park." Of course you are down and depressed. But is that a depression where you are saying, "I want to end my life because of that"? Absolutely not. If you looked at the measures Clive took for himself, and if I took a checklist of everything a person should try to do to help themselves, he did all of them. He tried to retain interests, he mastered social media so that when he could not leave the house he could sit at home and read newspapers. He said all he was good for at the end was to read newspapers, but he could comment on them. He went on to blogs and Facebook and Twitter and he commented. He tried to retain social networks. Our social networks had shrunk very much to the neighbourhood and the verge outside the house, but he worked to retain those social networks. I could not even begin to tell you how he fought to keep meaning and quality in his life.

[12.50 pm]

Mr R.R. WHITBY: Thank you, Noreen. I guess you have basically answered the question that Mr McGrath asked earlier, but we did have evidence earlier today that there was this competition between what may help a small group of people and the greater good. In other words, if assisted dying was introduced it was only seen as something that was a nice option for a small group of people, whereas the greater community good was protecting vulnerable people and not doing something which may, as this person alleged, promote suicide. So it was this autonomy of the individual versus the greater community good, and this was the central reason why voluntary assisted dying should be opposed. I am just wondering if you have anything further to comment on that.

Ms FYNN: I do. I think there is an undoubted need for the protection of the vulnerable community. I think for most people palliative care at the end of their days will be the answer, but there is a percentage for whom palliative care will not be the answer. There is a percentage, and it is actually a small percentage of people, who will elect for assisted dying. I think they should have that choice.

The CHAIR: Is there anything else you would like the committee to know, Ms Fynn?

Ms FYNN: No, thank you.

The CHAIR: Thank you very much for giving evidence today and answering some very difficult and personal questions. It is very valuable for the committee to have you here. A transcript of this hearing will be forwarded to you for correction of transcribing errors. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached. 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. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript. Thank you very much for your appearance today to Ms Fynn, and to Mrs Brumley for coming along.

Hearing concluded at 12.52 pm
