

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Melbourne — 15 October 2015

Members

Mr Edward O'Donohue — Chair

Mrs Inga Peulich

Mr Daniel Mulino

Ms Nina Springle

Ms Fiona Patten

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Witness

Mr Graeme Lovell.

The CHAIR — I declare open the Legislative Council’s Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome Mr Graeme Lovell. Thank you, Mr Lovell, for making yourself available today.

Before I invite you to make some opening remarks, I will just caution that all evidence taken at this hearing is protected by parliamentary privilege, as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today’s evidence is being recorded. You will be provided with proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website. We have allowed half an hour for our session this morning. Mr Lovell, I invite you to make some opening remarks, and thereafter we will have questions.

Mr LOVELL — Thank you very much, Chair, and good morning to everyone. Thank you very much for inviting me here. Members of the committee, ladies and gentlemen, I would just like to say I am not an expert in this field at all; I am speaking from personal experience only. I would like you to appreciate that this situation is very emotional for me. My beautiful wife, Susan, my dearly loved wife of 40 years and mother of our three children, died a terrible death in the Alfred hospital on 24 October two years ago. She died of thirst. She had no liquids for six days until she died. I stayed with her day and night at the Alfred hospital and had to fight to get morphine for her to prevent pain and suffering. It was a very difficult period.

This committee has already heard about doctors and nurses being afraid to provide sufficient pain relief medication to dying patients, and that was my experience. In fact I think I can safely say that this experience and Susan’s death were instrumental in those comments that have already been submitted to this committee. Susan’s story has been documented extensively in a confidential submission to this inquiry. I expect some of you have probably read some of that information. The reason I am presenting today is that I do not want to see other totally vulnerable people suffer and die in pain, as Susan did. It is not appropriate.

In January 2010 Susan noticed a small growth on her lower left leg and saw her GP and a dermatologist. They each examined the growth visually, but neither biopsied it. Susan was assured that it was not malignant. Due to this misdiagnosis, she died. In July 2011 Susan had a biopsy on swollen lymph glands in her left groin and was diagnosed with advanced amelanotic melanoma, which required emergency surgery. The main growth was 50 millimetres in diameter — well advanced.

For the next two and a quarter years Susan was on an emotional roller-coaster of hope and despair, with numerous complications. It was very difficult for Susan and very difficult for the family. The cancer spread to her brain, and she had brain surgery in August 2012, November 2012, February 2013 and September 2013. She had radiotherapy and terrible chemo treatment with interferon and temozolomide, as well as a range of other medicines. I can assure you interferon is a very nasty drug. It drove her to suicidal depression. I found a knife, a boning knife, in the glove box of her car.

At 3.00 a.m. on 1 October 2013, the morning after her last brain operation, Susan attempted to get up to go to the toilet. Her bladder was full, she did not have a catheter and she was not aware of the situation at all. She was unable to think rationally to protect herself and fell and broke her right hip. Despite the acknowledged risk, the Alfred hospital failed to protect Susan from falling over. Susan had a hip operation to bolt her femur together two days later. The shock of the two operations was too much for her. Her system could not handle it. Her digestive system shut down, a condition known as ileus, and stopped food passing through and just blocked up. Over the next two weeks all attempts to get Susan’s digestive system working failed and she became progressively weaker. She went from a situation where she was able to push herself up in bed using one leg to not even having the strength to do that.

Susan was declared palliative by the Alfred medical staff on 15 October 2013. At 1 o’clock on Friday, 18 October, Susan started shaking and had a seizure. She was no longer able to move, to talk or swallow, but she was able to respond to questions by squeezing fingers placed into her hands. There was no hope for Susan, and the medical decision was made that she was to die of dehydration — that is, given no fluids until she died. I have no problem with the decision that she was to die. She was finished. I have no issue with that. It is how she died that is of great concern.

Susan's ability to respond deteriorated, and by Saturday afternoon family members could not get any response. We were sitting there, talking as a family, with Susan there, and as far as we were concerned, everything was controlled. Then a doctor came in and virtually shouted at her, 'Squeeze my fingers if you're in pain'.

We could not get a response. That doctor did, and he repeated it and Susan responded a second time. It must have been a massive effort for her to be able to do that because she could not respond to any of us. This was the last response we had from her, and we were shocked. Everyone was shocked to find that Susan was in pain and we were ignorantly sitting there, believing everything was all right and her pain relief was being controlled, and the hospital staff were not providing adequate pain relief to prevent suffering.

After that I insisted on morphine for Susan, as she cried out in pain due to the broken hip whenever she was turned in bed. In addition Susan's tongue was raw, as the skin had come off, her lips were cracking as she was breathing through her mouth and could not moisten or close it. The frequency and dosage of morphine was much less than the 5 milligrams per hour authorised by the medical staff, as Susan was typically given parsimonious 2.5 milligram doses at extended intervals, so she was effectively going in and out of pain. Instead of proactively working to prevent Susan's pain, the staff gave Susan very little morphine because she did not and could not tell them that she was in pain. I would be there with her, and she would be crying and calling out in pain every time she was moved.

At 2.00 a.m. on Sunday a nurse took exception to my request for more morphine and summoned the doctor. I explained my concern that Susan was not getting enough morphine and was crying out, and he instructed that Susan was to be given morphine 10 minutes before she was moved. She was to have a hit of morphine every time before they moved her in bed. They seemed to be more concerned that she would not get bedsores than that she would be in pain when she died. On Sunday morning I asked for a syringe driver for Susan, which I only learnt about from a nurse through the night, so she could have continuous morphine. After much delay and procrastination this was fitted, but with a token dose of 10 milligrams per 24 hours, which would basically shut me up.

On Monday, 21 October, the palliative care staff were back and they tripled the syringe driver dose to 30 milligrams per 24 hours at my request, but Susan was still crying out in pain when moved. It is not only the moving, of course; it is the pain that she was experiencing between the moves, which we had no ability to assess, but from what had happened previously we were pretty sure she was in pain through that. As Susan's body dehydrated it tried to extract every possible bit of liquid in her system. Her stomach, which had been bloated and very firm due to the blocked digestive system collapsed and became concave. As her body tissue dehydrated, her loose skin was pixelated, with numerous small flat spots, so cream was applied. Her urine flow progressively slowed, and the concentrated urine was a dark orange colour before the flow finally stopped. Susan's mouth and tongue were raw and her lips cracked, so water spray and cream were applied regularly.

On Tuesday Susan's morphine dose was reactively increased to 35 milligrams per 24 hours — this was for pain — and then to 60 milligrams for 24 hours on Wednesday, so I was finally getting it upped. On Wednesday night Susan was desperately gasping for breath, as her desiccated body tried to pump her thickened blood through her system. This gasping became progressively worse in the early morning, and she was given morphine and a sedative. My beautiful Susan died at 3.00 a.m. on Thursday, 24 October, as I was stroking her hair. Our family arrived shortly after, and everyone was terribly upset. Our daughter was wailing very, very loudly in the corridor. At 4.00 a.m. I walked out of Susan's room and was shocked to find two policemen waiting for me. They were very professional, they did their job well, and I have no issue. They had been sent by the coroner's office to take a statement and to arrange for transfer of Susan's body and records. I am still waiting on the results of the coroner's investigation.

After watching Susan die so horribly over six days, I consider that she died a barbaric death. I hate to think of how terribly Susan would have died if I was not with her for those days. In a civilised society human beings should not be forced to endure such pain and suffering when they are most vulnerable before death. As far as I am concerned, after Susan had the seizure and the medical decision was made that she had to die, the family should have had the opportunity to say goodbye and then it should have been over with no suffering. Nothing was gained by making Susan die so horribly. A less desirable alternative, if we stick with the totally moral view, is for the family to say goodbye then for heavy doses of morphine et cetera to be applied to achieve virtually a medically induced coma so there is no possibility of pain. Subject to appropriate safeguards, doctors and nurses need to have legal authority and protection so they can perform medical euthanasia or use strong doses of

morphine et cetera which may accelerate death. They should not be placed in the position of career risk for trying to help dying people to end their lives peacefully.

I look forward to positive outcomes from this inquiry so that other people do not suffer and go through the same bitter experience that my dying wife did.

The CHAIR — Mr Lovell, thank you very much for sharing your personal story and the situation with us. I am conscious that the coroner's investigation is still afoot, so I will put my questions in a general sense. We have heard evidence from a range of medical practitioners that pain relief is provided at doses that are needed to achieve comfort for patients — we have heard various evidence about that — but I think what is reasonably settled is the notion of double effect. You are looking for greater clarity in the law in regard to the provision of pain relief. Is that an accurate way to summarise your overall — —

Mr LOVELL — Yes, definitely, and I think the situation where people are afraid. It is almost like if you do nothing, you cannot get in trouble, and if you do a little bit, you are not in trouble either. But if you, as I said, can be seen at some late stage to have overstepped the mark possibly in trying to look after the patient's interest and make sure the patient does not suffer, then you place yourself personally at risk, and I think that is pervasive through the medical profession. It varies obviously. I have heard of situations in palliative care institutions basically where these things are done very well.

I would also like to make the comment that I think the old days of 'Everyone turn away while the doctor gives someone an extra shot' are gone. The morphine was very tightly controlled. It was subject to double sign-off by two nurses and the checking of every dose, and it should be. You also have situations, particularly overseas, in nursing homes where staff have gone off the rails and started injecting and killing the old patients. It must be controlled. But then there needs to be the legal protection in those circumstances, and there has to be the appropriate process, as I said, like in Switzerland maybe, where they have three doctors signing off before a euthanasia situation there are the proper safeguards and it is recognised.

I would say there is a transition point from trying to prolong life to a situation of recognising that there is now no point in doing so — and the family needs to be involved — and then saying now the objective is to make sure that this person dies comfortably. In a situation like Susan's, I see nothing at all achieved by having her die for six days from thirst and putting that person in such a vulnerable situation at the end of life through that trauma. I say nothing is gained for her, for the family. It is just devastating for everyone, and she had a terrible death.

Mrs PEULICH — Thank you very much for recounting your own personal experiences of your late wife. Again being mindful of the coroner's inquiries, from my own understanding of palliative care — and I had my own father go through palliative care — I must say that your experiences and your recounting of the experiences are shocking and I would not have thought it was typical of the manner in which these cases are handled. Have you had any indications from the Alfred in response to this? Is this treatment that you have recounted seen as commonly characterising the experiences of people who are in a similar situation or is it an unusual circumstance, to your understanding?

Mr LOVELL — I have had really no contact with the Alfred — shall we say, I might have a personal aversion — and the Alfred has made no attempt to contact me.

Mrs PEULICH — You have not expressed complaints?

Mr LOVELL — Let me say that I did send a copy of the 50-page report on what happened to Susan to the Alfred at the time, which was prepared for the coroner. Also, as I understand it, the coroner has had significant interaction with the Alfred hospital. You have had a representative from the Alfred hospital present to this committee and made comments, so that is why I say that Susan's case was instrumental in those comments.

Mr MULINO — I have just a brief comment and question. I want to thank you also for sharing your experiences. They are very valuable for our hearings and our determinations. As Mr O'Donohue said, it is difficult to comment on some of the specifics, given the fact that the coroner is examining this, but I think that some of the themes that you have raised are issues that have come up in earlier testimony, which is that we need to ensure that across the system pain relief is administered in a way that is appropriate and that respects the wishes of the family and the patients. I just wanted to flag that that is an issue that is very much front and centre.

I just make the observation that it certainly seems as though it is not appropriate if medical practitioners are resisting the wishes of family members for pain relief to be strengthened, I would not have thought, unless there is very good reasons, and there does not appear to be.

Mr LOVELL — In that situation there is, shall we say, the risk, for want of a better term, of bringing death on early, but in a situation where a person is basically going to die and that decision is already made, what does it matter? But it seems to be the case right now — that was my experience — of holding back and holding back, particularly in the situation where Susan was not able to communicate. I had to be her advocate. I had to be there to try and protect her under very difficult circumstances, and I will admit I was tempted to finish her off. It is very difficult.

Ms PATTEN — Thank you, Mr Lovell. When the nurses and medical staff were resisting your requests for pain relief for Susan, were there any specific comments they made about that? Were there any reasons that they resisted giving morphine?

Mr LOVELL — No. I suppose you are in hospital. I was the ignorant one and I was going through this for the first time. Coming from a basis of no medical knowledge, I did not know anything about morphine doses or anything like that. I was just using my logic, and I gleaned little bits of information along the way, like finding out that 5 milligrams per hour had been authorised on the medical record. Some of the nurses, I would say, were quite good. There were one or two who were particularly good, who would give the full 5 milligrams and try and get it on the hour. You would be lucky to get it every 2 — maybe a 3 hours-type situation. Invariably it would be the half shot of 2.5 milligrams, so it was very strung out, spread out. Initially, of course, she did not have any constant feed of morphine. It was only, again, when one of the nurses who was a bit sympathetic said, ‘Hey, these things exist, a syringe driver exists’ that I found out about it and started pushing for that, because I could see that getting these shots occasionally, as she was, was just not working.

Ms PATTEN — They were not saying, ‘She doesn’t appear to be in pain. She doesn’t need this’?

Mr LOVELL — Exactly.

Ms PATTEN — That is what they were saying?

Mr LOVELL — Exactly, yes. It was basically left to the nurses. The doctors had gone away and had basically said, ‘Here’s an authorisation to do it up to this’, but then it was up to the nurse’s assessment as to how much is required and when. When you have a patient who does not appear to be in pain, the patient is not in pain and basically does not need morphine. I had to fight to protect her and try to make things better for her. Even then a lot of it was not what I would call particularly successful, but I had to keep pushing.

Ms PATTEN — This inquiry is certainly hearing that there is a lot of work that can be done to improve end-of-life choices and patients’ experiences. When it was decided that Susan was in palliation, was she conscious or did they sedate her to a degree —

Mr LOVELL — She was conscious that day. That was the Tuesday before she had the seizure on the Friday. In fact her twin sister, Karen, flew back from London, and she made a special effort. She was almost her old self again for one day and then sort of deteriorated rapidly. That was on the Wednesday. Then she went downhill from there to Friday, when she had the seizure, and of course that was final. She was almost a vegetable at that stage unfortunately. She had so many treatments, so many drugs, and it had taken a massive toll on her.

Ms PATTEN — Did they offer you any other options?

Mr LOVELL — To palliation?

Ms PATTEN — Yes, when they said, ‘We’re going to give her nil by mouth, keep her comfortable’.

Mr LOVELL — Yes, once she had the seizure, of course, basically the decision was made. You could have put a line in and just kept on feeding her and giving her fluids and things, but there was no point. It was not given as an option either. I had no issue with the fact that she had to die. She was finished; she was gone. It was how she died that was the issue. That is why I personally believe families should have a chance to say goodbye

and then it should really be over, because having her suffer for all that period of time, regardless of the level of medication, does not achieve anything.

The CHAIR — Is there anything further that you would like to say to us, Mr Lovell?

Mr LOVELL — No, I think that really covers it; thank you very much. I just look forward to the results of this inquiry and possibly looking to a situation where this will be addressed so that other people should have a much better end and do not suffer in this sort of way.

The CHAIR — Thank you again for sharing your personal story. We appreciate it. As I said, you will have the transcript in the next week or so.

Mr LOVELL — Thank you.

The CHAIR — Thank you very much.

Witness withdrew.