

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

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Mr Mark Staaf, professional officer, Australian Nursing & Midwifery Federation.

The CHAIR — I welcome Mr Mark Staaf, professional officer with the Australian Nursing & Midwifery Federation. Thank you for being with us today; we really appreciate it.

Mr STAAF — Pleased to meet you all.

The CHAIR — Before we commence I 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 a proof version of the transcript in the next week or so, and transcripts will ultimately be made public and posted on the committee's website. We have allowed 30 to 45 minutes for this session today, so I invite you to make some opening remarks and thereafter the committee will have questions. Thanks again for being with us.

Mr STAAF — Thank you very much for the offer to speak today in relation to our paper. I just want to say that nurses and midwives are an integral part of people's care at end of life and, for that reason, we felt we should provide a written submission outlining the roles of nurses and midwives in people's care at end of life. I want to make it clear that end-of-life care is embedded in many areas of nursing and midwifery practice and it is carried out in ways by nurses and midwives that culturally respect the person. That is an important element that has to come through.

We want to work with families and their nominated decision-makers at end of life, so we support processes where the quality of the life of that person is supported and there are mechanisms in place for people to be able to plan what they would like to do at end of life. It is important that there are conversations with people about their lives, whether that is with a health practitioner or their significant other. But when those conversations take place they need to be recorded somewhere so health practitioners are aware of what people's wishes are. In health care settings we try to work with people to enable them to have their wishes carried out, but if we do not know what they are, that makes it difficult. Sometimes people get treatment they do not want because we do not know what their wishes are. I guess that is the comment I would make in opening. I have prepared some slides if you would like to have a look at them.

The CHAIR — Yes, thank you.

Mr STAAF — I will pass them around. What I hope to show today is that end-of-life care is about good quality, and slide 5 outlines where I am going with that. Best practice at end of life and what it focuses on is the person, their friends and their carers. It provides physical and psychological care to address the spiritual needs of the person and their families, extending to the bereavement period. Well-planned and implemented end-of-life care requires very good communication and teamwork from the whole healthcare team. Quality end-of-life nursing care considers the physical problems of the dying person to optimise their comfort, which includes management of their pain. I heard the previous person talking to that at length. It is one of the things I would agree with. Sometimes there is delirium or agitation associated with that end-of-life phase and death, and breathing difficulties and issues around people with motor neurone disease that have lots of secretions and whether they want to go on and live their life like that. I think they should have choice about the issue of when that time comes what do they want to do. It is important that the laws reflect people's choice.

In relation to some nursing interventions that are burdensome for the patient or do not improve the person's comfort, we do not really want to continue with those and we work with people and their treating doctors to try and put plans in place. It has been my experience as a registered nurse caring for many people at end of life that you do that in conjunction with the person that you know and their families and the wishes of those people, and the treating doctors sort of plan around that. Often it involves medication and pain management at end of life, and at some point there has to be a decision about what we are doing here, whether we are treating the person or letting them die. For that reason there are some options available now, and that is advance care planning. The ANMF supports the fundamental principles of advance care directives, where they are tailored to the individuals' values, beliefs and wishes that align with their expressed end-of-life care preferences. Advance care planning usually involves conversations with a healthcare professional about what the wishes are, and then that is documented and kept as a record somewhere where people know where it is, and it is produced at the time it is needed. You might have already known that. I do not know what to tell you really. I am not sure whether you know all of this already. It must be difficult for you to have to listen to it time and time again if you already understand and know about it.

The other stuff is around enduring powers of attorney of the Medical Treatment Act. I am sure you are well aware of all of that, but what that involves is these people having to make decisions about things in advance. But it does not really provide for an advance care directive. It only allows for the health consumer to pronounce their refusal for a medical treatment, not to say what they want; it is what they do not want. That is the problem with that. If that can be amended, that would probably be useful to the Victorian community.

The act's silence means that with advance care planning processes, despite them being documented by the health consumer and clearly describing their expressed preferences, values and aims for future medical treatments, the refusal of specific treatments in the future care or the formal appointment of a substitution decision-maker often has no legal standing. That becomes problematic at end of life because even though they have got their wish documented, it has no power and people get treatment they do not want. I think that is all I wanted to say on that point really now that I think about it a little bit more.

The current Victorian law that enables the health consumer to refuse medical treatment for a current condition and the right to access continued good quality palliative care are there, but reform is needed in relation to the terminally ill consumer, having no legal right to request their treating practitioner to prescribe to the consumer or to inject voluntarily with the intent to end the life with dignity, and with all other available safeguards in place to access legal advice and the appropriate professional treatment by qualified specialist health practitioners. What I mean by that is people should have the right to end their life when that life is not really one to live for them. They should be able to document that the way they do with other care directives.

It would certainly make life easier for health professionals to know where they are going with what people's wishes are. It might also save the community a considerable amount of money for people that get treatment they do not really want. That is the point we were making there. At the same time they need to be provided with dignity. In the case of the competent adult with a terminal illness or an advanced incurable illness that creates relievable intolerable suffering, it shall not be an offence for the health practitioner to confidentially advise the sufferer or the relative guardian regarding end-of-life choices that might assist the person with their death. That has been a problem for health professionals — that if they provide advice about alternatives, it is considered illegal.

The CHAIR — You believe that should be changed?

Mr STAAF — I believe so. I think that people should be able to be given choice to be able to make decisions fully informed about what their options are. I know if I am going to buy a car or a house or something like that I seek advice about what is the best for me. Certainly with financial arrangements you look into those sorts of things and you get advice, and then you make a decision as a competent adult about what you might do that is best for you. I do not see the difference between that and end-of-life choice for people around what decisions is right for them. There has been a lot of work done. There was a program on SBS the other day which you might have seen that talked about some of these issues, featuring Professor Charlie Cork, who is somebody who has done a lot of work in this field.

The CHAIR — He has given evidence to us as well.

Mr STAAF — I support what he says. I think as a practising critical care nurse myself I have been in that situation that he would describe a lot of times, and there comes a time when sometimes treatment is futile and people should be able to say, 'This is the end for me'. What happens in reality is that treatment is often withdrawn. In a critical care environment if they are on life support, that is turned off and you just watch people fade away. Sometimes I am not sure that that person would have ever wanted to have been in that intensive care environment and might not want to have faded away in that way. They might want to die in their own home with dignity. I am sure if it was me or my loved one, that is the choice I or they might have wanted to make for ourselves. That is the point I make around that: people as autonomous adults should be able to make that decision. I think they are the only points I want to make in addition to our written submission.

The CHAIR — I just wanted to take up the point you made that sometimes people get treatment they do not want, which I suppose you were alluding to at the end there as well. We have heard a lot of evidence from various practitioners about that. Is that something that your members see often, the scenario of the —

Mr STAAF — In a lot of circumstances in the healthcare environment nurses are the people who provide that treatment. It can be quite confronting for individuals as clinicians to be able to balance what they know

about that person. If you have worked with the person for some time — for example, case managers that might look after elderly clients for quite some time and know them while they are functional, look after them through a deterioration and know what they would have wanted. It does mean that they can work with families to provide care but they also have to provide it in a respectful and dignified way, but nonetheless they also might know that that person does not want the medication regime that they are on anymore, so you can have a conversation with treating physicians about do they need to still have the multitude of medicine they are on because it is not doing anything anymore. They are the sorts of issues that we grapple with in the work that I do or my colleagues do or the members that we represent do.

The CHAIR — We have heard evidence from medical professionals that addressing that issue can be very difficult because care is often so specialised. The cardiac specialist is dealing with the cardiac issues, the oncologist is dealing with the cancer, someone else is dealing with something else and no-one actually takes a holistic view of the patient. Is that something that your members see as well?

Mr STAAF — At times I think we would see that. Let me give you an example. Say that you had made an advance care directive about what you would want if something happened to you. You are a fit, healthy sort of person — I can tell by looking at you — but if something happened to you today and you walked out on the street and you got hit by a car and you suddenly found that you were a C2 quadriplegic, ventilator dependent for the rest of your life, would be unable to do anything but blink your eyes, would have to be reliant on a ventilator for respiratory support and would have to have someone to assist you to evacuate your bowels, to clean you, to do your hygiene needs, to put you in a wheelchair, would you want to live that life into the future? It might be that you make a decision that that is not the life for you.

I have been, as I said, in my career an intensive care nurse and have worked with people with spinal cord injuries that have been in that situation and they have had to take legal action to withdraw treatment. They want to be left to die: ‘Turn that ventilator off and I’ll just suffer a nasty death’. There should be some other alternative ways to deal with what it is that you would want.

Alternatively, you might be elderly, you might have a terminal illness, a cancer or something like that and you have signed a do not resuscitate order so you will only want care for comfort but, ‘I don’t want to be ventilated or in an intensive care unit’. You present to a hospital. An emergency department physician is looking after you. They do not know you have got that order. They may know that you have got cancer but they may not know that because you have a treating doctor who has not communicated that to anybody, and you get care that you may not have expressed in your wish that you want. You might be resuscitated, defibrillated, intubated, sent to an intensive care unit, in care for quite some time at considerable expense to the public purse, to have difficulty getting off the ventilator, to need a stint in rehab, to not get out of that because you are so deconditioned with your illness before you got there and then to die anyway. Or might they have given you a quiet room in the emergency department, might they have just treated you conservatively for what is in front of them rather than the aggressive treatment and might you have had a similar outcome anyway? These are the things that we grapple with.

I think if we are going to talk about law changes around people being able to decide what it is they want, it is really timely that these debates have happened. They have been going on the whole time I have been employed at the Australian Nursing & Midwifery Federation, which is some 15 years. They get somewhere and then they seem to go backwards and then there is a change of government and we try to get bills through again, but it really is up to people to make those decisions about what they want if they want to make them, and where they do not make them they will get treatment like they do today. It would be no different.

Mr MELHEM — Just a follow-up, would you extend the same principle to someone, otherwise healthy, who suffers from mental illness; for example, a 30-year-old or 40-year-old?

Mr STAAF — No, not blanketly. No, I do not. This is my personal view. If that person could be treated with medication and if they had a likelihood of a long, healthy, productive life, then if they presented in the emergency department, for example, with something that was treatable — a heart condition — then I would support the treatment of that person and do everything you can to preserve life because that person does have a chance of a productive life. Just because they have got a mental illness does not mean that that mental illness is not treatable, and there are a lot of wonderful medications to treat people with mental illness. The problem is that people with mental illness often think that they are well and they do not acknowledge that that medication is helping them and they stop taking their medication and then they have flare-ups of their condition. There are

people out in the community every day right now — there might be people in the room — that are on medication for those sorts of things, but it does not mean you are not functional. That is a different circumstance, but they would be able to make an informed decision about what they want when they are mentally stable. The bills that I have looked at all show clauses in that legislation that sort of provide for a mechanism around people being able to be assessed properly when they are fit and competent rather than when they have an exacerbation of a mental illness.

Ms SPRINGLE — I am curious to look at what you are talking about from a slightly different angle. You talked about obviously the challenges for patients who are in a position where they are not going to have the sort of life they want and there is no room to have, I suppose, certain end-of-life choice conversations with their health professional. Does that impact on the way nurses can do their job? What are the challenges for the staff?

Mr STAAF — I do not believe there are challenges the way you have framed that question. The person who was in that scenario would get quality care from most competently practising registered nurses or midwives, so I do not think I can say that they would not get good care.

Ms SPRINGLE — I was not implying that they would not, but are there implications for staff for that?

Mr STAAF — I know personally you might juggle with your own morals and values and wonder why things happen, but in the systems that we work in you are taught to put that stuff aside and just go with the issue. But if you continually expressed to me, if I was caring for you, that you did not want the treatment that was being offered, then perhaps you and I would have a conversation. I would like to think we would have a conversation like that. You would have to know that I have heard what you have said. If you have tried to have that conversation with your treating medical team — that is, your doctor or your psychiatrist if it is a mental illness or your cardiologist — —

I have been in situations with patients I have looked after from nursing homes — for example, elderly patients — where people have said, ‘We’re going to take your leg off because you have got gangrene’ or something. And that person said to me that they do not want that treatment, but the surgeon has not heard them because they have just been on their round and, ‘This is what’s going to happen, and your surgery is tomorrow’. After they go away, the patient has called me aside and said, ‘I don’t think I have understood what he said. Are they going to take my leg off?’. I said, ‘Yes, that is what they have just said to you’. ‘I don’t want my leg off. I’m 88. That leg has served me well. I think my time is up and I will just go with the consequence here. If I die from an infection, then that is what God wanted for me’.

Then you go back to the person and be that advocate for the patient in that scenario and say, ‘I don’t think you’ve really heard what the patient is saying to you. They are saying they don’t want that surgery’. Most health services have refusal of treatment forms — it is all of that. ‘I don’t want that’, so the hospital are disclaimed, if you like, for not providing the treatment because the client has been given their options and they want to refuse that treatment. That is probably the full spectrum of the worst scenario. In terms of just general, if it is, ‘I’ve been prescribed a medication and I don’t want that’, then there would be a conversation, ‘You’ve been prescribed it because it’s going to do this for your condition’. That sort of conversation might ensue.

If the person still does not want that, then you can go back to the prescriber and have a conversation with them about what you have just heard and then they can talk to them again about it and there might be an alternative. There might be a reason they do not want it. If it is an antibiotic and they have had a reaction from it in the past, they might say, ‘This gives me a rash’. I am being really general here. I mean, I do not know. But you would talk through the whole situation with them and find out what is the cause of the problem — a bit like a root-cause analysis — and get to the bottom of it. Does that explain a little bit?

Ms SPRINGLE — Yes, I think so. Thank you.

Mr STAAF — You would not be just left there, that is for sure.

Ms SPRINGLE — We are trying to get all angles.

Mr STAAF — There are different settings too. You think about this from a healthcare context in an acute environment compared to a community environment. If you were thinking about it from a perspective of someone who was in home care under some of these new commonwealth arrangements that the state will have

to deal with, there is a lot more community care for the older, frail people in our communities that are not quite at the level of high care that need a nursing home but need full supports at home. We have tried to put structures in place where there are case managers around that person and there are some people who know what their wishes are and what their treatment is, but that is a fragmented system.

I was having a conversation yesterday with some community nurses and health and risk nurses at one of our major hospitals up the street, and they were saying to me how fragmented things are in some regards about keeping that care all together. We have got systems errors and systems issues in play here that overarch all of this stuff as well, so it is a challenge — that is for sure — to make a law that is going to meet everyone's needs. But I think the draft bills I have looked at around end-of-life decisions have been quite well written in terms of safeguarding everybody.

Ms PATTEN — I appreciate what you are saying with the advance care planning, that most of it is just a refusal of treatment — we do not have that more proactive step that a patient says, 'This is the time that I would like to say my goodbyes'. One of the concerns or criticisms we hear about about this from some of the other submissions is that is not care, and that must be quite separate from care. If you were going to offer voluntary euthanasia or some sort of physician-assisted information or prescriptions, that is not care and must be kept separate. What would you say to that?

Mr STAAF — I think they are two sort of separate arguments. An advance care directive is outlining someone's 'What if'. If I am in this situation, what do I want? Voluntary euthanasia legislation — for the want of a better terminology — really is when the person has been through all of their path I suppose to travel and they have come to the conclusion that they have lived a good life or not.

I will give you an example of perhaps someone my age, early 50s, that is diagnosed with motor neurone disease, for example, that was living a beautiful, full life and has suddenly found they have got a life-limiting illness that is going to end their life earlier than they had thought it would and that there are going to be changes in their body and body functions. Usually it results in the person having difficulty breathing, swallowing, not being able to eat. They have got an option of not being able to eat and starving into death, or having surgery and having tubes inserted in their stomach and being fed through gastrostomy feeds, and is that what they want? Then they might fix that problem of malnutrition, but they will have respiratory issues with excessive secretions and they might not be able to swallow, and then what happens? Are they going to drown in their own secretions? So it might be, 'I don't want that death for me, and I have made a decision that I would like to die before that happens, in a way that I want to die'. I think that that is a choice that people should be able to have. That is probably the collective view of most of the nurses I speak with that work in areas of advance care planning and/or palliative care. Good palliative care is great, but there are some times when palliative care is not the answer.

Ms PATTEN — But you would still see that as part of a care — —

Mr STAAF — My word I would. I think palliative care is very important at end of life, but it does not suit everybody's needs, and that scenario I just gave you is probably the exception to somebody who has maybe got a terminal cancer, is not going to drown in their own secretions but is going to die because of the disease process.

I have just been through the recent death of my sister with pancreatic cancer. She was 55, four children, a great life, was a practising nurse up until six months before her death. I talked to her about what she might want to do — have surgery, noting that the outcome would not be any different — but in that circumstance she decided to have a really good-quality six months. They went on holidays, they did lots of family things, she said goodbye, she wrote letters to her kids for their wedding days and all that sort of stuff, and then her condition did deteriorate. She was given a pain-free death in a palliative care service and she died peacefully. That was done because she was a nurse and she knew her options. She knew how death could be on A and she knew how it could be on B and she chose to do it her way, and I think that is what we would all want for ourselves and our loved ones.

Ms PATTEN — I just want to confirm that in something like that motor neurone disease example or an area where we thought voluntary euthanasia was a decision that that competent person made, would you as a medical practitioner see assisting that person down that path as part of your care, as part of the care function of that patient — —

Mr STAAF — If it was not illegal, yes.

Ms PATTEN — If it was not illegal, yes?

Mr STAAF — Yes. And certainly during my time as a nurse I have worked in areas where people have died, I worked in HIV/AIDS for a number of years back in the 1980s when young people were dying, and there were some horrendous deaths that I witnessed, and knowing what I know now, I would advocate for those people to make different decisions, but it has taken a career of nursing for me to be able to look back and reflect and think those people didn't have good deaths then, and I would like to think that the people that I care for now have a better death than they did back then because of a whole range of knowledge that you gain over a career. There are reasons why we need to change and move forward, and we have got a more educated community I think now too, just quietly.

The CHAIR — Can I ask, Mr Staaf, we have heard the assertion that sometimes euthanasia is practised in hospitals but there is a fine line between the doctor and double effect — people say it is a fine line between perhaps providing additional morphine that hastens death as opposed to palliating and providing comfort to an individual. Can I ask: do you think that euthanasia is practised at all in our medical system covertly at the moment? Even at the margins?

Mr STAAF — That is a question, isn't it? You did say there was parliamentary privilege or something, didn't you? I think it has always been the case and certainly was back in — —

All over my career I have seen people's comfort maximised, and that is what I will call it because at some point what are you prolonging when you have got your loved ones around you? I gave you the example of my own family and my sister recently. She was given a maximum dose of a drug to make her comfortable, and if we are talking about morphine, for example, it does have other functions such as it can reduce respiratory function. It is prescribed for comfort but it does have a cumulative effect to some extent, and I am sure it helps people off to a comfortable death.

Certainly as a nurse clinician holding people's hands and sitting with them when they are about to die, I always feel really comforted to say to people, 'Your time is here, I think' and that, 'You can go if you want to. You have said goodbye to everybody'. Sometimes the person you are with is just wanting — I think it is about them wanting permission to go. You know they are comfortable — mothers holding sons' hands, husbands holding wives' hands, brothers holding sisters' hands — and you watch them die. It is nice for the family and for the person. It is not as though it is the killing fields and you are out there banging seal cubs on the head. It is not like that at all. It is a peaceful, nice death. That is what I will answer to that question. I do not know any health practitioner — doctor, nurse or anybody else — who would be involved in deliberately killing people, but they certainly want people to go off comfortably.

Because they have been your treating doctor or nurse or midwife, for example, for a long time in most cases — not so much midwives but certainly nurses and doctors — they have got to know you over time. Can you imagine somebody like your dad who has known the family doctor for a long time in a country hospital? I know from doctors who have looked after me in country hospitals when I was living in the country that the doctor who delivered me looked after me for all my life, and he knows me intimately. Those people know you and they do not just make decisions without knowing the person, is what I will say to that. Does that answer your question to some extent?

The CHAIR — It does, and I really appreciate your answer.

Mr STAAF — The answer is yes to 'Have I have seen it?'. Yes, I have, but I do not think the intent is to do anything but give people a peaceful death.

Mr MELHEM — Just one last question from me. Going back to your submission and the recommendation toward the end, which is your least — —

Mr STAAF — Sorry, I did not quite hear. Could you start again?

Mr MELHEM — If you look at the submission you guys put in and the recommendation where in certain circumstances you are sort of saying people should have their wishes respected and certain criteria. But you would not go as far as, for example, the system in the Netherlands or Switzerland where it could take two

doctors to agree to someone's request to end their life. I talked about mental illness earlier and you answered that. I take it that in limited circumstances — —

Mr STAAF — I do not think I answered the question in the written submission around whether I thought that was what should happen in Victoria. Certainly when you look back on the legislation we had in the Northern Territory and look at the legislation in the Netherlands and in some parts of the USA, it is a good safeguard to have more than one person's opinion. Again, that draft bill that was produced for Parliament covered off those things quite adequately, I believe, about safeguards in place. It is not as though you could say, 'You know, I want to die tomorrow and I want you to give me a lethal injection', if that is what you are referring to. I think there is a whole process people have to work through to get to that point and it involves a lot of steps before you get there, and that is the sort of mechanism that I think holistic health care for people involves.

The CHAIR — Just one final question, if I may. You referred earlier to the draft bills you have seen in relation to the end-of-life care planning that are coming in. Have you got an expectation as to when they will be in the Parliament?

Mr STAAF — I do not know that I have personally. I do not know that the federation has either. I just think that we have mature parliamentarians that work on behalf of their constituents that will make that decision as elected officials whether they should go there or not. That is not really for me to say, but it would not be terrible if it did.

The CHAIR — Mr Staaf, we really appreciate your evidence and your insights into this very difficult and complex area, so thank you very much.

Mr STAAF — No, thank you for the time.

The CHAIR — As I said, a transcript will be with you in the next week or so.

Mr STAAF — Thanks very much.

Witness withdrew.