

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

Melbourne — 14 October 2015

Members

Mr Edward O’Donohue — Chair

Ms Fiona Patten

Ms Margaret Fitzherbert

Ms Nina Springle

Staff

Secretary: Ms Lilian Topic

Witnesses

Ms Maree McCabe, Chief Executive Officer, and

Dr David Sykes, General Manager, Learning and Development, Alzheimer’s Australia Victoria.

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 welcome Ms Maree McCabe and Dr David Sykes from Alzheimer’s Australia Victoria and thank you both very much for being here today. We look forward to hearing from you shortly. Before I invite you to make some opening remarks 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, and you will be provided with a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee’s website. We have allowed 45 minutes for our session today. Thank you both again for being here. We look forward to hearing from you.

Ms McCABE — Edward, to you as chair and to the other members of Parliament, thank you very much for the opportunity to speak to this inquiry. It is certainly one that is very dear to the hearts of our clients and our members. Dementia, as you may know, is a terminal illness. It is the second leading cause of death in Australia after heart disease, and right now in Victoria alone we have 82 000 people who are living with dementia. By 2050 that figure will skyrocket to around a quarter of a million. Australia wide right now we have 342 000 people who are living with dementia, and by 2050 that will be almost 1 million, so there will not be anybody in this country not impacted in some way by this life-ending chronic condition.

One of our greatest accomplishments has been our increasing longevity, but it has brought with us one of our greatest challenges, which is a chronic condition like dementia. With dementia, unlike other chronic conditions, at the end of life the majority of people will be incapable of consent. They will also have a profound physical disability and a significant cognitive disability. This inquiry has the opportunity to really make a profound difference to the quality of death that people living with dementia have.

I would like to table that we are not here to put forward a position; we are here to advocate for choice, and that is the context in which we will be addressing the inquiry this morning. We want to be of most value to you, and we have some information, but we actually want this to go in a way that serves you and gives you the information that you need. We thought we would cover off firstly on the area of policy, and David will do that. David also has a background of working in the Office of the Public Advocate, so he is well informed to make comments on policy.

Dr SYKES — Perhaps before I go into the policy area, I think the other overlay with all of this is around the difficulty in our community talking about not only death but dementia, and that makes it incredibly difficult for us to even really start to consider this area in a very open way. I am sure you have had submissions already that have probably raised some of those challenges in our community, and obviously that is what Parliament and the lawmakers then grapple with. But I think certainly what our very strong emphasis with most of the work that we do is about encouraging the opening up of that conversation, and certainly with the resources we provide and the services we offer it is all about opening up the conversation so that people can have a dialogue around this, because it is enormously stressful, as you can imagine, for families if that has not happened, and it can be stressful as well if it has, and it is how to really open that up.

I have provided some of our resources, and I left those with Lilian. One of those is actually about a website that we set up nationally that is called Start2talk. It provides a wealth of resources about how to start opening up that conversation and start to think about the range of issues associated with end-of-life planning, from advance care plans to including the appointment of substitute decision-makers. They are certainly some of the overarching challenges I think we face when we are trying to have a really open kind of exploration of the issues around this.

The other thing I would say is that one of the papers we have there is around euthanasia. You will see that there are actually two papers. We engaged Professor Colleen Cartwright to look at the area of advance care planning for us, but we deliberately chose to separate out the whole area of euthanasia because we feel that so often when you start to talk about advance care planning in a society that is not comfortable with talking about death straightaway people can potentially go to that space. What we have done in the paper very well, thanks to Colleen’s work, is that we have not stated, as Maree said before, a position; what we have outlined in there are the issues that are surrounding this so that we can really try to get some more mature discussion around that issue, but not cloud the whole question of advance care planning with that discussion. I certainly refer you to those resources as really mapping out, probably in more detail than what we can do in the next 45 minutes, some of that.

Ms McCABE — In relation to our conversation with our clients, it is informed and led by them. They lead with what is important to them. We encourage in our initial counselling sessions with clients that planning for all sorts of areas in their lives is really important, and we encourage that and also raise the issue of advance care planning, but the options are led by them. We do not provide them. The issue of euthanasia is raised frequently by clients, and as with other areas and other resources at Alzheimer's Australia, we provide information across a range of topics requested by our clients. As a consumer-driven organisation our response to them is to provide information that informs their questions and what is important to them, so it is driven by consumers.

Dr SYKES — In lots of ways one of the key challenges in this space is timely diagnosis. We know that the average time it takes to get a diagnosis of dementia is three years. So, straightaway you have a lead time there for someone to receive a formal diagnosis. I guess the importance of that from our point of view is assisting that individual and their family to start to grapple with the challenge they are being confronted with. Associated with that there are a whole range of issues, including the issue of advance care planning, and it is a really sensitive one. I know that if Leanne, who is our general manager of client services, was here she would say there are a whole host of issues that people grapple with when they get the diagnosis of dementia. It is not necessarily at that point that you want to start saying, 'Okay, let us talk about the end of life.'

There is a whole lot of sensitivity around when you do this. I guess obviously given the trajectory of the disease and the extent to which that is going to reduce someone's cognitive functioning, that needs to happen in a timely way, recognising that everyone is different. It is that consideration of putting some of that planning in place early so that it enables some of those really important, really difficult discussions between the family and the person living with dementia. It is important that they have happened and that there has been some documentation of that, ideally, so that there is something people can point to.

But we also need to recognise that this is an evolving thing and we need to consider how you continue to capture that, whether that is through a diary or some other means. If someone is continuing to have conversations throughout the progression of the disease, their views may change. I was making the comment to Lillian before that anyone who has seen the movie *Last Cab to Darwin* is a really good example of how someone who is facing terminal illness does change their view. It is recognising that we need to be responsive to that individual's perspective on things.

I think that certainly a timely diagnosis is important, as is advance care planning. The other thing we would say along with that, and this is where we are starting to get the policy challenges, is the appointment of a substitute decision-maker. Whilst I acknowledge that there has been some valuable improvements and changes to enduring power of attorney legislation in Victoria more recently, we still have a very problematic framework there for families and carers to navigate.

If I give the example in this context around consent to medical treatment, we obviously have the person responsible provisions in the context of doctors being clear about who they can approach to receive substitute consent when someone is unable to do that. We then have the enduring power of guardianship which enables someone to give consent to medical treatment, but they are not able to refuse treatment. Whereas, under the enduring power of attorney medical, they can have that authority. So you can see just in that area the complexity. Families have to understand, 'Okay, so I am a person responsible in this context. I could be an enduring guardian. I had better potentially take out a medical power of attorney as well' — if they are aware of that. If they are not aware of that they might quite reasonably think, having an enduring power of guardian, that they have rightly got the substitute decision making around where someone lives, the sort of health care they receive and treatment. I think we have an issue at present where there are probably a number of people out there who think through having an enduring power of guardianship that they have the power to refuse treatment.

I think that is part of the challenge that confronts our community, certainly in the legal framework around this area and how that dovetails with advance care planning which does not have a legal basis but is certainly important in informing those substitute decision-makers because it gives them something in writing to actually be referring to. That can help, particularly in a context where you have treatment teams who may be nervous about taking or not taking certain action in a treatment context and the potential litigious aspects of that or even just the fear that the organisation is going to be exposed to some risk in that context.

Maree and I were just having that conversation before we came in about how that can really drive some adverse outcomes. Do you want to share that story you have?

Ms McCABE — When my mother was dying there was an order for her. She had had a massive stroke. She had been caring for my father, who had dementia, and she died unexpectedly before him, but in the process of her dying the doctor had ordered her some morphine. She had a shocking headache from the stroke, and he ordered the morphine PRN, so whenever as necessary. I was with my mother, and I was requesting morphine, because she was moaning and I could see that she was in pain. At 2 o'clock in the morning the registered nurse who was on refused to give it to her and said to me, 'There is a fine line between killing your mother and pain relief'. My response was, 'My mother is in pain and you will draw up the morphine and give her the pain relief'.

It was so confronting at a time when we were all very vulnerable, and my mother was in pain and I had promised her a pain-free death. My mother was a nurse, I was a nurse and it was a promise I made to her. To be thwarted on giving pain relief to somebody who is in pain, somebody who you love, is incredibly frustrating. Our consumers tell us all the time that they cannot get the medication for their loved one that their loved one needs, because health professionals take the stand that they have a duty of care to ensure that they give medication judiciously. They do have a duty of care, but they also have a duty of care to ensure that people have adequate pain relief. It is one of the major challenges for people living with dementia, because they cannot express when they are in severe pain, and to give medication on a PRN — whenever necessary — basis, as it is often ordered, is not helpful in many cases to people living with dementia.

There needs to be a regime that is prescribed and available for people to ensure that we minimise any suffering that they have so that they can have a good death. In 2015 the fact that we are still fighting this battle is unbelievable. If you read the paper by Colleen Cartwright — we commissioned two papers by Colleen — certainly the evidence has changed over the years. As a nurse many years ago when I was practising, it was common practice to feed people, to encourage fluids and to encourage food, well on into the dying process, but what we now know from the evidence is that that in fact makes the death worse for people and more painful because the body in its process of palliation produces natural endorphins and pain killers that we inhibit when we give food and fluid. That is not well understood. As a profession we do not understand sufficiently the impact of doing those things that we do in good faith thinking that we are being of service. There is a whole piece of work and education that really needs to occur around ensuring people have a good pain-free death, and also in pain management, particularly in the area of dementia where people are unable to express that pain.

Dr SYKES — There are other areas as well around that. The use of antibiotics is not uncommon, but again there is strong evidence to show that they are of limited benefit. With the loss of ability to swallow, again, the use of PEG feeding in that context also can be found to have some limited benefits as well. There are a whole lot of ramifications around sometimes the lack of understanding of dementia in the context of the medical area, which means that you really get some incredibly adverse outcomes that are unnecessary and are often driven by some other pressures that are not focused on what that individual needs.

The other story I can share with you is my own father's situation. He passed away last year. When the ambulance arrived — he had had a massive cardiac arrest and I think he was dead when they got there, to be honest; he certainly was not breathing — they spent 20 minutes trying to resuscitate. Probably the worst part of it was then they turned to my mother and said, 'Do you want us to stop?'.

What sits behind that for me is the reason they have gone about it in that way is not because of what they felt my father needed in that context. They were concerned from an organisational viewpoint that if they stopped what would be the potential risk to the organisation. I think we get these kinds of perverse outcomes. People were absolutely doing what they thought was the right thing in that context, but you can see how there are some things which drive that altogether in the wrong direction.

Ms McCABE — It is not an issue at the level of individual. It is an issue of the system, and the system fails people particularly at the most vulnerable time. I think that is the area one of the areas that we need to address.

Dr SYKES — The other point I think is worth talking about is where you die. Unfortunately again, often because of the lack of planning, the lack of degree of comfort or the services that are there, either in residential aged care, where they might not feel they have the skills or they might not have had these conversations about what someone's wishes are — —

Most commonly it can be driven by an acute episode or a fall that can trigger an admission to hospital. The evidence unfortunately is very strong that hospitals are the worst places for people living with dementia or dying with dementia. They have incredibly adverse outcomes in that context. In the absence of some clear

planning — and again this is sometimes driven by some of those risk concerns for organisations — the person is often moved into an environment they would not want to die in.

I think if we did a straw poll of people in the room here today, how many of us would want to die in a fairly impersonal environment of a hospital linked up to a whole lot of machines that are not necessarily the things we want at that point in our life? Certainly there has been a lot of work done with COTA and others over the years about consulting with people about how they would like to die and have a dignified death. It comes through very strongly. People want to die around the people they love in an environment they are comfortable in. That is more commonly the home, but even if it is in a residential aged-care facility and they have lived there for a while, that can equally be far more supportive than potentially going into a very strange environment at that very final stage of your life.

For us the whole key is that dying a dignified or a good death requires discussion, conversation and planning. It is not just going to happen. Because of those added pressures that we have outlined around the organisational drivers in health and other areas, there are probably extra drivers that are going to make it more likely that it will not happen, unfortunately. It is how we can shift that thinking, increase the understanding in the medical profession, but in the wider community more generally, around opening up these conversations so people can die in a way they choose.

Ms McCABE — I have just one other point about the acute sector. Unfortunately knowledge and experience in the acute sector for people living with dementia is — and David mentioned it — a difficult environment for people living with dementia. There will be residents with dementia who are admitted post fall. They might have a fractured hip or pelvis, and the nursing or medical staff will ask them, ‘Which hip did you fall on?’. They will not know. It is that kind of lack of awareness and understanding that contributes to adverse outcomes in hospitals.

They also may not know if, in the admission process, they are asked whether they have an advanced care planning. My father was asked that. I happened to be there with him at the time. Dad had dementia, and they asked him a whole range of questions, and to everything he said, ‘Yes, love’, because he did not understand. They said to him, ‘Do you want to be resuscitated’, and he said, ‘Yes, love’. When the nurse left the room, I said, ‘Do you know what the nurse meant?’. He said, ‘No, I don’t know what she said’. I said, ‘What she’s asking is if you die, if your heart stops, they will inject you, they will put tubes in you, they will give you a shock to start your life again’. He said, ‘Over my dead body’, and I said, ‘Correct, so the answer is no’. So it is a lack of understanding, where in fact people with dementia can give misinformation that is contrary to what they actually want because they do not understand.

The CHAIR — Thank you both for those insightful opening remarks. I have two questions. First, Dr Sykes, in relation to what you were saying around the diagnosis to intervention is three years — or maybe it was you, Ms McCabe; I cannot remember — but anyway, the time from diagnosis to intervention is three years?

Ms McCABE — Yes.

The CHAIR — We have heard from others that there should be a point where a mandatory discussion about an advance care plan or advance care directive is triggered, and that could be age based. Is that something you would support in the context of a diagnosis — that is, a point in time when the relevant practitioner, if giving a diagnosis, should also commence the discussion about an end-of-life plan?

Dr SYKES — I always feel difficult about mandating something when we are talking about human beings.

The CHAIR — Yes.

Dr SYKES — The law can be a terribly blunt instrument — in managing personal relationships. I think we can make sure that it is raised at some point and is certainly on the radar for people. Because the other thing we know about advance care planning is often it is the health professionals who are uncomfortable about talking about it, not the families. There can be that issue as well. So it is the importance of improving the extent to which health professionals are comfortable about opening up that conversation as well. But I do not know, Maree, I would feel — —

Ms McCABE — I would rather it be given as information. In fact we should all have an advance care plan.

Dr SYKES — Yes.

Ms McCABE — And none of us know when our time will come or what will happen. But I think that as part of the process it should be discussed and information given. I am with David; I am not sure about it being mandated. I think there are processes and times along the way where it is more appropriate to discuss it. But it definitely should be part of the information that is given, because some people will say, ‘No, I’m not doing it’. It is like a will. We all know that we should have a will, and there are some people who just will not attend to it. So I am not sure that taking away people’s choice is a good thing either.

Dr SYKES — The other thing I would add is that in flagging the importance of advance care planning, perhaps not in a mandated way, that you should also in that same breath be talking about the substitute decision-maker. Because I think now that there is probably much more awareness of advance care planning people might think, ‘If I’ve got an advance care plan, that is it’, rather than actually recognising the importance of having someone who you trust, who understands your wishes, who can act on your behalf and make those important decisions. I think one without the other is problematic.

Ms McCABE — And it does need to be revisited. So circumstances may change for people and they may say, ‘Okay, I made that decision a year ago; that’s not how I’m thinking right now’. It is more a dynamic document than one that is done, tick, and we do not need to revisit this again.

The CHAIR — My second question was in relation to what you, Ms McCabe, said about the nurse and your mother and the pain relief aspect. That is something which I do not think we have heard in the way you have described it. We have heard from medical practitioners about the double effect, but the situation you described appears to be different to that. I think you said that that is something you get feedback from — —

Ms McCABE — Frequently.

The CHAIR — Could you perhaps just talk to that a bit further?

Ms McCABE — A number of our consumers who have got parents, loved ones or partners dying with dementia say that there is insufficient pain relief, and when they ask for it, it is refused. Often people living with dementia can display behaviours of concern. They can become aggressive — physically aggressive, verbally aggressive. It is often in response to pain. There was a study done in the UK in a residential aged-care home where as part of a medication regime they prescribed for people living with dementia Panadol four hourly, and what they noticed was it had a massive positive impact on the reduction in unwanted and challenging behaviours. It is something that health professionals often do not consider. When people are living with dementia they can have lots of things. It can be toothache, it can be arthritic pain, and of course for people living with younger onset dementia it is a similar issue.

So when people cannot express that they have got it, we need to make sure that we cover it off. It is something that I think we need a lot more information about. There is nothing more distressing for our consumers than to see their loved ones with dementia suffering and not being able to get the care and the medication that they need.

Ms SPRINGLE — Thank you for your testimony this morning. I have a couple of quick questions. On that, and you talked about the lack of understanding by the medical staff and how that can lead to adverse consequences, do you think that that is due to a general lack of understanding by many medical professionals about dementia? What is the underlying cause of some of these inappropriate responses to what is happening within a medical situation?

Ms McCABE — Nina, I think it is a lack of understanding, and when we talk to GPs — and we are doing a lot of work at the moment with GPs — what they say is that many of them only see one case of dementia a week or a month. So if they do not have a practice that specialises in an elderly age group, and they may have people with younger onset dementia but it takes up to seven years to get a diagnosis then, so they may not know that that is what they are dealing with. Also with nursing staff, their understanding and awareness is very low, and they do not know that pain can be there and not expressed. So what they are relating to is people who they see look physically similar to you and I but who actually cannot express that they are in severe pain. So what they are getting is behaviours of the person: they might be hitting out, they might be moaning or they might be agitated. So they are not looking for the more subtle signs of pain that we can detect. They are viewing people

with dementia like the normal population or the normal cohort of patients that they would deal with that could express it.

That I think is the major issue, and that is certainly what our consumers tell us. They tell us that; that is a very common concern that they raise with us around pain management. The paper we have brought in, by Jenny Abbey, is really good, and Jenny developed the Abbey Pain Scale years ago. What that picks up is the more subtle features of pain, so encouraging the use of pain scales for people living with dementia in acute care and in residential care — it is in residential care — but certainly in acute care would be beneficial.

Dr SYKES — I think the other issue that is sitting in behind that is the extent to which the medical profession more generally, including nurses, are not well skilled in exploring those issues and having the conversation around treatment options and potentially non-treatment and when that crosses over into something that potentially might be seen as assisting someone's death that there can be a fine line at times with all of that.

I am aware of the work — I am not sure if he has made a submission — of Professor Joe Ibrahim from Monash University. He has actually done some work around developing a tool to assist doctors, particularly in the acute setting, to work through and explore some of the issues about when someone is presenting. What are some of the judgements they are making by that person's situation as to what treatment they should or should not be offering, and how are they promoting that conversation? Because certainly in his practice — and he is doing a lot of training of medical practitioners — he is finding there is a common lack of real consideration of how you explore some of those things. They are often poorly equipped to really open up the conversation. They might be clinically very sound, but perhaps just on some of the moral and ethical questions that sit around this they really need some more assistance in that.

We do a lot of training of medical students, so we are certainly assisting. I think there is a new breed coming through, which I think is really encouraging that as part of that training we actually expose them to talking to families and carers and talking about the importance of having that conversation with the carers as part of that whole process because they are an invaluable source of information.

Ms McCABE — And families are often valuable to health professionals in saying, 'Look, that is not how mum or dad normally look; I'm worried they're in pain'. But when patients have no-one to advocate, that is a very scary thought.

Ms SPRINGLE — You talked earlier about — you have mentioned it a couple of times — the substitute decision-makers, and an issue that has come up is around trust, particularly in terms of right towards the end of life. Does that come up as an issue in your work in terms of trusting that substitute decision-makers are doing the right thing by who they are advocating for and that issue of whether that trust can be breached?

Ms McCABE — Yes, and, Nina, the issue of abuse is a very real one. The issue of financial abuse, physical abuse, sexual abuse, it is absolutely real. David, I am going to hand over to you.

Dr SYKES — I think the trust issue really comes down to the choice right at the outset, that there has to be that clear trust in the person you are appointing to make decisions on your behalf in that context. If you have any doubt, if you are in any way unsure, that is the point at which you should be going, 'You know what? I actually don't think that's the right person'. Sometimes I know this is vexed for family because they go, 'Oh, I don't want to appoint my daughter over my son. Perhaps I should have both'. Some of those issues actually can be about doing the right thing for other people but not necessarily thinking, 'You know what? Actually I think my daughter understands me best in this context. I need to appoint her as my substitute decision-maker around medical', let us say, and potentially the son around finances. Although we know sons are actually the more abusers in financial, so maybe that is not a good idea. Let us have the daughter there. But do you know what I mean? I think some of that stuff can be playing out further down the track.

The other thing I would say is there is still not a huge uptake around the appointment of substitute decision-makers. I think that lack of trust is actually probably more prevalent in the context where there has not been someone appointed, rather than where there has.

Ms McCABE — The issue of course, too, is if somebody is appointed as a substitute decision-maker and they then become abusive, what do people do then? There is a very clear process available for family members or the medical professionals or friends to step in and actually have that be reviewed at VCAT. That again is an

awareness thing that people need to know about. It is a very real issue, Nina, that health professionals do need to be aware of.

Dr SYKES — That is an important point, Maree, because that at least gives people a clear avenue, whereas in the absence of having appointed a substitute decision-maker, there is the question of what do people do. They can of course do an application to VCAT and take that sort of process there, but it is sometimes easier if someone has already got a formally appointed decision-maker in place. But I think the whole question of choice and trust is about that continuing conversation we have been talking about. What is the relationship that is there that enables me to be confident that mum shared a view on this this week, and that was potentially a variance to what was last week? Take into account how she is. We know that the cognitive issues make that problematic, but if you know the person, you will more likely be able to see a sort of line through that where it potentially is fluctuating.

Ms FITZHERBERT — One question I wanted to ask about was the timing of diagnosis in relation to being competent to give instructions that are going to withstand scrutiny, if that makes sense. I just wondered if you could clarify that for me — obviously not an easy question! What are the critical times in terms of someone with dementia, or a diagnosis, being able to give instructions and make arrangements? I understand that nothing is ever safe from any form of challenge, but something that would be considered robust, if I could put it that way.

Ms McCABE — It is a great question, Margaret. The earlier stages is the best answer I think. However, people's capacity fluctuates during the process that the dementia takes. It is a disease of the brain, it is chronic, it is progressive and it does fluctuate. Somebody may not have capacity this morning, but this afternoon they might actually be okay. We always say that the early stages are the best times to make decisions that they want to be lasting.

But again, as people progress in their dementia, they still can have capacity in many, many areas. Whilst they may not have capacity to manage complex things like financial affairs, they may very well have the capacity to choose about their care, their treatment and their advance care plan. It is a very difficult question to ask. But that is why we always encourage people in the early stages to make the plans that they want, that are really important to them and they want to be lasting. Certainly GPs are then called in to determine if somebody has capacity to consent to treatment or otherwise. I am sorry, it is not a very clear answer.

Ms FITZHERBERT — If that is the answer, I understand.

Ms McCABE — Is there anything you can add to that, David?

Dr SYKES — Obviously there are those standard elements of capacity in terms of understanding the decision, the consequences of that decision, being able to convey that decision, if any of those perhaps is going to be problematic around feeling comfortable that that person is in a position to make that decision. Probably our overriding comment is, as Maree was arguing is the danger of presuming by the sheer fact that someone has a diagnosis of dementia that they therefore lack capacity. That would be our overriding concern, because straightaway you are taking them out of the discussion.

I think it is also recognising as the disease progresses that the people who know that person best, whether it is family or friends or carers, will have an incredible amount of information about how that person can convey their wishes. Sometimes we get caught up in, 'Oh, well, they can't convey it in a verbal way, and so therefore they lack capacity', and we kind of close that off, rather than actually being open to the possibility that there are a whole lot of ways someone can communicate their wishes. That is not always easy around legal frameworks, I guess, when you are sort of looking at it in that more specific way.

Ms PATTEN — Thanks very much. Maree, you mentioned that voluntary euthanasia is something that your clients and consumers raise regularly, and obviously enough to develop these publications. How is it raised, or what are they saying?

Ms McCABE — It is often raised in a counselling session with the person living with dementia and one of our counsellors, and often in the early stages. When people are most likely to consider suicide is actually shortly after a diagnosis of dementia. They will raise with our counsellor, 'My mother or father died with dementia. I never want to get to that stage. I want to know: is there an opportunity for me to be euthanased?'. It is not legal,

and of course what we offer people is the advance care plan, that you actually can have a say about the care that you get at the time that you are ready to die and in the dying process. There is a lot of work that our counsellors do, but it is raised frequently. It is raised by families. They will say, 'My mother, father, would never want to live like this. We want to know why there is not the option to voluntarily euthanase'. It is a very big issue for people, and particularly when they have had family members that they have seen die with dementia. It is very confronting, and for them to think that the same thing will happen to them is unbearable.

Ms PATTEN — Are there any statistics on — —

Ms McCABE — On suicide?

Ms PATTEN — Yes.

Ms McCABE — I am not aware of any, Fiona. But certainly what I do know is that suicide amongst older males is the greatest number of suicides that we have in Australia. There are often times where people with dementia are said to die by misadventure, and it is often thought that it is actually not misadventure, rather it may be at their own hand.

Dr SYKES — There is certainly research around suicidal ideation in people who have been diagnosed with dementia as being higher than the general population. There is certainly that data there that shows that directly.

The CHAIR — Ms McCabe and Dr Sykes, thank you both very much for your evidence today. It is greatly appreciated. You have given us an insight we have not heard from others, so we do appreciate that. As I said, the transcript will be provided to you in the next week or so for any minor corrections and will ultimately be made public. If you have any additional information you wish to submit following our discussion this morning, please give it to the secretariat in due course.

Ms McCABE — Thank you so much for the opportunity to present on a critical topic to our consumers.

Witnesses withdrew.