

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 23 July 2015

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**Necessary corrections to be notified to
executive officer of committee**

The CHAIR — I declare open the public hearing of the Legislative Council’s Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I welcome Professor Paul Komesaroff, director of the Centre for Ethics in Medicine and Society, Faculty of Medicine, Nursing and Health Sciences at Monash University. Thank you very much, Professor, for joining us this morning.

I caution you 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. Witnesses found to be giving false or misleading evidence may be in contempt of Parliament. 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.

Professor, we have allowed an hour for this session, and I invite you now to make your opening statement. Thereafter the committee will have questions for you.

Prof. KOMESAROFF — Thank you very much, Mr O’Donohue. My name is Paul Komesaroff. I am a practising physician and professor of medicine at Monash University, executive director of the international NGO Global Reconciliation and director of the Centre for Ethics in Medicine and Society. I have more than 25 years experience in clinical practice, both in the public hospital system and in the private sector. I have a special interest in ethics and the philosophy of medicine, having started the first clinical ethics service in Melbourne in 1998 and having published over 400 articles and 14 books on ethics, science and medicine.

I chaired the ethics committee of the Royal Australasian College of Physicians from 1994 until 2013 and have been a member of the ethics committee of the Australian Medical Association for 17 years. In 2014 I was awarded a Medal of the Order of Australia for my work in ethics. I emphasise, however, that I am speaking today in a personal capacity and not on behalf of any institution or organisation.

I commend the work of this committee, which I believe is of great public importance. I am honoured to be able to assist you in your deliberations. In my comments today I will not attempt to address all the issues for discussion you have identified but will focus only on a few and argue for a simple strategy of legal reform. My philosophical views on end-of-life matters are covered in many of my writings, especially in two recent books: *Experiments in Love and Death* and my novel, *Riding a Crocodile*. My main argument here is largely based on articles I have written together with Stephen Charles, QC, a former judge of the Court of Appeal of Victoria.

Before proceeding further, I would like to note that the first parliamentary committee before which I appeared was the Social Development Committee in 1987. This was when I was a junior doctor, and the hearings were those that led ultimately to the passing of the Medical Treatment Act 1988. I believe this was an outstanding and innovative piece of legislation with which Victoria led the way in providing protection to people undergoing medical care. It established the legal rights of patients to refuse unwanted treatment and to appoint enduring medical powers of attorney to make decisions on their behalf. Arguably, however, this act’s greatest achievement was to stimulate a healthy and productive debate about end-of-life decision-making in the community and to give clear and unambiguous expression to the prevailing social consensus at that time.

The current hearings are also responding to public debates, which have identified both common ground and major differences. I believe that there is universal agreement that individuals suffering from terminal illnesses should not be kept alive against their wishes and that people should be able to make key decisions about when and how they die. There is also universal agreement that people with serious illnesses who are in pain or otherwise suffering should receive whatever treatment is needed to alleviate their symptoms. There is widespread concern that this is not always achieved because of uncertainty about the present law.

There are, however, major differences about the extent to which the law should permit active interventions intended directly to hasten death. Some sections of the community support legalisation of active voluntary euthanasia or physician-assisted suicide in cases of terminal illness, although this has been vigorously opposed by medical professional organisations and many religious and other groups.

I believe there is minimal public support in Australia for legalisation of euthanasia in settings of non-terminal illness. Certain overseas legislative models, especially from Oregon in the United States, from the Netherlands and from Switzerland, have been widely discussed and have both vigorous supporters and opponents. Indeed I

believe it is not an exaggeration to say that the sides have become so entrenched and polarised that nowadays little productive debate and dialogue occurs between them. Often the arguments regarding the contending positions are formulated as contests between ethical values such as personal autonomy and sanctity of life. In reality, however, ethical dilemmas at the end of life are rarely decided on the basis of abstract philosophical concepts. Rather, decisions are taken after careful, respectful dialogue with all the affected parties, often mediated by caring and compassionate physicians.

In cases where a patient is unable to provide direct instructions to carers, any wishes he or she may have previously expressed must be taken into account but may not be absolutely decisive. We do not exist or function as isolated individuals but rather as persons embedded in relationships of love and care. On the other hand, elderly people and others suffering from serious illness often find themselves under extreme pressure as a result of which they may consider themselves a burden on their families or society or may respond to isolation or lack of social support. For these reasons, end-of-life decision-making should not be seen as a purely instrumental matter of determining the technical details of care but as part of a fluid and complex process in which large and important issues of physical symptoms, hope, loss and meaning are simultaneously addressed. This is part of the historical task and challenge of medicine.

There is, I believe, significant uncertainty about key aspects of the legal situation regarding end-of-life decision-making in Victoria among both medical carers and the broader community. It is commonly believed that doctors face legal limitations on their ability to maintain pain or suffering. There is a widespread belief in the community that there are many cases in which medical treatment is inadequate because of fears amongst doctors of criminal prosecution in case their actions result in death. If such confusion does exist, it is because the legal principles that apply in such settings have never been clearly articulated in legislation. Rather, they have only been stated in common law judgements, the principal one of which being that by Justice Lord Denning in 1957, which has never been formally tested in a medical setting in an Australian court.

In his judgement in the *Bodkin Adams* case, Lord Denning established the principle of double effect as a pillar of English law. Originally an ethical doctrine from the 13th century, this principle acknowledges that there are circumstances in which an act may be undertaken for a legitimate purpose even though it might also cause foreseeable effects that one would normally be obliged to avoid. For our purposes a key example of this is the acceptance that one can provide whatever treatment is needed to relieve the suffering of a patient, even in circumstances in which the unintended but foreseeable outcome is that person's death.

As Lord Denning recognised, the distinction in the principle of double effect between relieving suffering and incidentally causing death on the one hand and undertaking an act with the deliberate intention of killing someone on the other is absolutely fundamental. A doctor acting humanely and within the bounds of normal professional practice to take action to relieve suffering that may incidentally hasten death should not be subject to criminal prosecution. This is a protection that I believe is already present within the law, despite the uncertainties to which I have referred.

On the basis of these considerations, I would like to put to the committee the following propositions and then a course of action that I feel is likely to command wide acceptance in the community. First, there is a vigorous debate about end-of-life decision-making leading to entrenched and polarised positions about the need for legal changes. As I have said, the intense and sometimes acrimonious tone of the debate has made a constructive approach to key uncertainties in the law difficult.

Second, there is nonetheless widespread consensus that individuals suffering from terminal illness are entitled to adequate treatment and should be able to make key decisions about the circumstances of their death.

Third, many doctors and patients regard the current law as unclear or uncertain, and this may well be contributing to bad outcomes and unnecessary suffering.

Fourth, there is therefore a need for careful and judicious legislative change to clarify the law in relation to end-of-life medical care and to reduce the uncertainty of both doctors and the community.

Fifth, any such law should preserve the requirement that doctors should remain accountable for their actions and decisions.

In response to these conclusions, Stephen Charles, QC, and I have suggested what we have referred to as a minimalist solution to the problem of euthanasia. Specifically we have proposed that legislation be enacted to amend relevant criminal law to provide a defence to a charge of homicide or manslaughter when a doctor has prescribed or administered a drug that has hastened or caused the death of a patient with a terminal disease. This defence would be allowed if the doctor reasonably believed that it was necessary to prescribe or administer the drug to relieve the pain or suffering of the patient and prescribed or administered the drug with the intention of relieving such pain or suffering.

In other words, for such a defence we suggest that four conditions need to be satisfied: first, that a patient has a terminal illness; second, that the doctor's action is undertaken with the intention of relieving pain or suffering; third, that the action is reasonable in terms of current medical practice standards; and fourth, that it is necessary in view of the circumstances. We believe that such legislation would effectively address the main uncertainties in the existing law and satisfy most of the concerns of doctors and community members in relation to medical care in cases of terminal illness. The changes would be compassionate, modest and prudent. They would be welcomed as a clarification and codification of what most experts agree is already the law in Victoria. They would command wide community support, including amongst traditional opponents of euthanasia, such as the major medical professional organisations, the Catholic Church and other religious groups. Most importantly, they would alleviate the significant pain and suffering associated with the present uncertainty in the law.

The minimalist approach to end-of-life law reform would not solve all the problems in this area and certainly not end the debates about euthanasia and physician-assisted suicide; however — and this would be one of its main objectives — it would address one of the main causes of public concern and would open up a new space for continuing fruitful debate about these crucially important issues. I commend our proposal to you, and I welcome your questions.

The CHAIR — Thank you very much, Professor, for that most interesting proposition you have put to the committee this morning in your opening address. We will now commence with questions, and I will hand over to Mr Mulino.

Mr MULINO — Thank you, Chair and thank you, Professor Komesaroff, for your submission. My question is whether or not you are aware of any other jurisdictions that have codified Lord Denning's statement of the double effect principle.

Prof. KOMESAROFF — There are three jurisdictions in Australia where a version of double effect has been put into effect. There is South Australia, which has a freestanding act, the Consent to Medical Treatment and Palliative Care Act, and Queensland and Western Australia, which have modified their criminal codes to effect a similar kind of change. The laws are slightly different in all cases, and I think it would be advantageous to us in Australia for there to be a unified approach by all states and the commonwealth. There has clearly been a move in this direction in other areas.

Mr MULINO — Do those three codifications broadly capture the four elements that you have suggested?

Prof. KOMESAROFF — Yes. They express them slightly differently, but the general gist is that the intention has to be to relieve pain and suffering and the need of the patient has to be sufficient. It cannot be undertaken frivolously, of course. There need to be sufficiently serious circumstances to warrant the action that is undertaken, and the behaviour or actions of the medical practitioners have to be within the standards of current medical practice.

Mr MULINO — My final question on this point is: has there been any feedback from the medical community in those jurisdictions as to the impact of those legislative changes on their capacity to put into place certain treatments?

Prof. KOMESAROFF — It is my understanding that all of these approaches have been favourably received. The South Australian act is perhaps the most advanced, but it is limited deliberately and implicitly to the setting of palliative care, the significance of which is not completely clear and suggests that such actions may be restricted to people who have particular expertise in palliative care. We believe that we need to address the broader setting of end-of-life care generally.

Ms FITZHERBERT — Professor, thank you for the contribution. It may be significantly useful. I think a lot of my colleagues will have many questions, so I will keep mine quite brief. Forgive me if I sound a bit perfunctory; it is just to let others have a go. I have a query about page 4 of the submission that you have made, and you also spoke to the issue of a possible defence in the situation of a doctor participating in euthanasia under the minimalist approach that you have outlined. Point 4 is that a condition would be that the action was necessary. Could you take me through what that might mean in some detail?

Prof. KOMESAROFF — Yes, and it may require more careful formulation by people who draft legislation. It arises specifically from Lord Denning’s judgement in *Bodkin Adams* in 1957, in which he included this provision. The idea is that three on their own would not be sufficient because the circumstances have to be sufficiently serious to require whatever actions are undertaken. So necessity really means an appreciation of the seriousness of the medical circumstances. As I said before, the concept is that an action that could potentially hasten the end of the life of a patient should not be undertaken frivolously, but it should be proportionate to the need in those circumstances.

Ms FITZHERBERT — If I could follow on from that, I guess what I am trying to understand is the difference between reasonable and necessary. Reasonable suggests an element of fairness in all the circumstances; necessary, to me, suggests that it was inevitable or that it must happen rather than it was alright for it to happen.

Prof. KOMESAROFF — Reasonable, according to my intention, is that it is in accordance with the standards of current practice; necessity means there is no other alternative — there is no lesser alternative that is available under the circumstances — so it is a slightly stronger criterion.

Ms FITZHERBERT — I see. Would opponents of euthanasia argue that it is never necessary?

Prof. KOMESAROFF — What I am arguing is that there is no other alternative left but to do this, so the opponents of euthanasia would have to come up with another course of action that would adequately relieve the symptoms — the pain and suffering of the patient — under those circumstances. That is the concept.

Ms SYMES — Thank you for your presentation, Professor. I guess my question probably flows on a little bit from Ms Fitzherbert’s in being more of a devil’s advocate question. How do you defend or how would you respond to the view that this is absolutely just allowing overdoses to effect death?

Prof. KOMESAROFF — To effect, in the sense of bringing about death?

Ms SYMES — Yes. How do you argue against someone saying, ‘Really all this is doing is allowing people to provide more pain relief than is necessary so that they get an outcome of death’?

Prof. KOMESAROFF — What I am proposing is that there are certain criteria that are potentially testable in law. I made the point that I believe doctors, including me, should be prepared to stand up and take responsibility for their actions, and if there are questions that are asked about an action, that doctor should be able to give an account of the reasons for the decisions and the actions that he or she undertook. It is notoriously difficult of course to assess what someone’s intention is, and the essence of double effect is that one intends to bring about a good outcome but foresees a bad outcome as something that may eventuate. In the setting about which we are talking the intention is to relieve pain and suffering, but it is recognised that that may bring about death. It is notoriously difficult, as I am saying, to be able to determine what the actual intention was and whether the person really deliberately intended to bring about death.

Ms SYMES — Earlier.

Prof. KOMESAROFF — Yes, earlier; that is right. That is why we have concentrated on focusing on being able to identify some objective criteria that would enable us to draw the conclusion about whether or not this action was actually an appropriate one in those circumstances.

Ms SYMES — Would you envisage that the medications that are administered are those medications that are already administered now in terms of treatment and that your proposal does not propose to introduce other medications that are designed to end life?

Prof. KOMESAROFF — That is correct, and indeed that has been part of the discussion in some subsequent legal cases in which a medication has been given that could only have the effect of ending life; for example, administration of intravenous potassium chloride in one case. That could not come under this framework because it is not conceivable under those circumstances that it was intended primarily to relieve pain and suffering. I accept what you are saying — that under this proposition it would not be permissible to administer medications that only had the effect of hastening death; however, it would allow whatever medications, present or future, that were available that may assist in the management of the patient’s symptoms.

Ms PATTEN — I have enjoyed reading some of your work on this, and you have obviously been considering this for many years. When you put this proposal forward, at first I thought, ‘That’s quite an elegant, simple response’. But am I right in thinking that this just leaves it completely up to the doctor’s decision? The patient has no input into this decision. Then I wondered when a doctor does make this decision and it is against the family’s will, is the doctor willing to risk a manslaughter charge using this defence? And while this is a simple and elegant defence, do you think doctors would be willing to risk facing a charge and then using this defence?

Prof. KOMESAROFF — These are all very important questions. I would certainly hope that it would not happen that a doctor would make such a decision unilaterally. It is almost unthinkable that that would be the case, even in the present circumstances. It is just not the nature of medical practice; it is not the doctor’s job. It would not be consistent with any current, past or hopefully future ethical standards. I would be appalled by the concept that this would just simply be a unilateral decision by the doctor without adequate, appropriate and exhaustive consultation with all the parties involved, especially the patient — if the patient is able to participate — but also the patient’s close relatives, friends, loved ones and so on. I did make the point that in this setting — and maybe this is something we can come back to — decisions of this sort are very rarely made unilaterally by a patient. They usually reflect the current existential circumstances of that patient, their relationships with their loved ones and so on.

I have made a point of saying that I believe doctors should be held accountable, because one of the thrusts of many of the proposals about euthanasia is to take the risk out of actions of this sort. Doctors have been uncertain or felt that they are potentially vulnerable if they do what is accepted within medical practice. I think that should not be the case, but I feel that people who are engaged in actions as serious and momentous as this should always be in a position where they have to give an account of their actions because there are serious risks involved to the individuals concerned and to the community at large. As a doctor I have no problem with that, and I am prepared to stand up and justify any action I take, even if that means I am vulnerable in some way or another.

What we really want to do is to avoid the situation that many people have suggested may well be occurring at present, which is that people are undertaking actions in secret. They are not documenting them because they fear that there may be repercussions. We want to bring this all out into the open. We want to open to public scrutiny the actions that are undertaken. We want to make sure that they are adequately discussed amongst all the people who are affected. Does that answer your question?

Ms PATTEN — Yes. I guess I still see this as a defence. It is a reactive rather than a proactive approach, and I am concerned about particularly a litigious family or a situation where the patient is saying, ‘Please up the dose’, and the parents are saying, ‘Please don’t’. The doctor may say, ‘I deem this necessary because the patient is requesting it’, but is that enough for a defence?

Prof. KOMESAROFF — This is part of the complexity of daily medical practice of course, and these situations do arise. It is the doctor’s job — it is his or her expertise — to be able to deal with that. In the circumstances that you have just imagined — which is certainly not unrealistic by any means — what would normally be the case is that the doctor would consider what the pain is that the relatives are going through and assist them in commencing the grieving process. That is an important point that I think is not always captured in the euthanasia debate — that is, the people involved and the people suffering are not just the patient who has symptoms of pain or whatever but the network of relationships — the family — who need to be cared for as well.

We have come to a point — and I am as bad as anyone else — where we tend to emphasise the relationship between the doctor and the patient, sometimes to the exclusion of our responsibility to care for the relatives. In circumstances like this it is the relatives who will live on for many years and bear the consequences — —

Ms PATTEN — And maybe sue the doctor.

Prof. KOMESAROFF — That is right. I want to preserve those caring relationships between the doctor and the relatives, and I really want to allow those to be negotiated. That is the reason for couching the proposal in the terms that I have as opposed to simply focusing on the instrumental processes of effecting euthanasia or death.

The CHAIR — Professor, I am interested in your opening statement and in the case you referred to that was decided by Lord Denning, which has never been formally tested in Australia. That surprises me, given the potential for litigation in this area. Would you like to comment as to why that may be or perhaps give some further background on that?

Prof. KOMESAROFF — It is interesting. We have scoured the books looking for such a case, and it does not exist. There have been a number of cases. I do not know if there have been many, but there have certainly been a number of cases where carers have been charged with the mercy killing of their husband or wife or whatever. Some of them have been well discussed in the community, but there has never been a case when a doctor has been prosecuted in these circumstances in Australia. There have been a few overseas cases, in the United Kingdom. Why that has been the case I guess we can only speculate. It could be that doctors in Australia are really good at what they do and do not arouse suspicion. That would be hard to believe. But it could also be that the police or prosecutors are very reluctant to intervene in what is clearly a very complex, fraught and intimate set of relationships involving the doctor and his or her patients and their families.

It would be a very difficult setting in which to collect evidence, I think, particularly because of the questions about what the intention might be. I think it would be a hard area in which to launch a prosecution in general. But, having said that, that does not mean that there has not been uncertainty, as I have argued, and that arguably that has led to bad consequences in terms of medical care.

Mr MELHEM — Professor, my question is: what policy changes are required, for example, in relation to encouraging active involvement of both family members and health professionals in relation to end-of-life programs. What are your thoughts on that?

Prof. KOMESAROFF — When you talk about policy changes, policy can occur at a number of levels. My concern is primarily with clinical practice and the expertise of clinical practitioners, who are not all doctors of course. Policy at that level can refer to things like codes of ethics of professional organisations and curricula to train junior doctors and nurses. At another level of policy, there are the principles that are adopted by hospitals, for example, or by health organisations, which do have some influence about the ways in which the clinical practitioners actually go about their work, although they are not capable of determining their actual actions. Then there are higher levels, such as legislation.

I think that the legislation needs to be kept at the most minimal level possible here in order to establish a framework within which individuals can negotiate their own ethical decisions. That is the philosophy behind the proposal that I have put here. It is the job of the law to protect people but to establish the possibility of ethical decision-making by individuals in such a way that they can respond to the specific circumstances of individual contexts. Particularly in the settings we are talking about, the issues, the decisions, the timing and so on are exquisitely sensitive to the actual circumstances that exist at that particular moment, and it is not possible to anticipate them on any large-scale level in any policy formulation.

Ultimately I think if we get the law right, then the individual organisations must go about their job. It is the job of the professional organisations, the universities and so on to devise their curricula and codes of ethics in a way that is aligned with the views of the public and the needs of their patients. The public debate about these issues is in itself an important device to effect that, and in my opening comments I referred to the Social Development Committee. I do not know if any of you remember that discussion, but it unleashed a very vigorous — and I think very productive — debate amongst the community, and many patients would raise it at that time.

In fact the number of people who have actually availed themselves of the device of the enduring medical power of attorney has been quite small. It would be a rarity: I would see two or three a year at most. But that does not mean that the Medical Treatment Act has not had a very profound effect, in the understanding of both doctors and the community, of the nature of the relationship between them. I think that the public debate, the context of

the legislation really had a profound effect in shifting the way in which doctors and patients negotiated their relationships.

Mr MELHEM — Just a follow-up: you talked earlier about the main purpose of end-of-life services being to put an end to pain and suffering. As an example, how can we put some safeguards to prevent family members or interested parties, making a decision on someone's behalf where pain and suffering is not there, in cases of dementia, for example, where a person is physically okay but mentally not capable of making a decision? Do we have one rule, for example, to end pain and suffering, but then say for people who are tired of life or dementia-type where a person is not suffering, then end-of-life does not apply in that case? What is your thought on that?

Prof. KOMESAROFF — One of the main reasons for referring to a minimalist approach here was the idea that I have put that debate in Victoria, and Australia more broadly, has become stuck. The positions have become so entrenched that no-one is really saying anything new. We have gone around in circles talking about euthanasia, the sanctity of life, autonomy and so on for some decades now. The focus has often been on the question of euthanasia, and as we well know some Melbourne newspapers have had an ongoing campaign in support of assisted dying, and they have talked about dignity of death.

There is not just one problem of euthanasia or one problem of dying; there are many of them. I think that confusion caused by putting everything in one box has really been a great obstacle to change. What I am really trying to separate out here is the particular case of end-of-life treatment where someone is suffering, in pain or distress. What I would like to do is take that out of the equation — and I would be hopeful that you would be able to achieve that — and then we can see what is left. That will include a lot of the other discussions which are much more difficult, that refer, for example, to people with chronic diseases, people with multiple sclerosis or motor neurone disease or muscular dystrophy or whatever, who have increasing debility and wish to make decisions about the end of life. I have not addressed those at all in this. I want really to put those aside for a separate debate, because the considerations are really very different, and they are much more difficult.

The idea of someone who is in otherwise good health but has a chronic physical disability and wants to die is really a quite different question from that in which someone is in the process of dying and is experiencing severe pain and suffering. The conflation of those two I think has partly been at the root of this impasse that we have got to. The easy part in a sense is the one that I am talking about, dealing with pain and suffering at the end of life, but it is also the one that is by far the most numerous. If we deal with that, we can allow the social debate to move on, and maybe in five years time we can come back and talk about the much more complex issues of someone with multiple sclerosis, or whatever, who pleads for assistance in dying. I really would like to keep that separate at the moment.

Mr MULINO — I must say, Professor, I am sympathetic to your view that the priority should be to focus on a common-ground approach rather than things which might set us at poles. You have suggested that the solution you have put forward could be part of that. Do you also see another element that might become part of a common-ground approach as being perhaps a legislative approach, or a more robust legislative approach, towards advance care planning and that that might be an element where you could bring different parts of this debate together and that might also provide more certainty for practitioners and for patients and for families?

Prof. KOMESAROFF — I have some reservations about advance care directives being legally enforceable, I have to say. I would like to say that quite clearly. Advance care planning is a necessity, I think, these days it has really only been in the last 5 to 10 years that doctors in general practice as opposed to specialty practices have become aware of that, but I think it really is now becoming an accepted and necessary part of everyday clinical practice.

There are many aspects to advance care planning. It requires careful, sympathetic, sensitive, respectful discussions with all the people involved. It can be a long, time-consuming process, but it is what doctors are supposed to do, and to be able to do it properly you need an ongoing relationship. We have a really good medical system in Australia, and we have very highly skilled practitioners. It is our job to keep increasing their expertise in this area. The concept of an advance care directive that is legally enforceable does concern me — with the qualification that we actually do have an advance care directive in Victoria, in the form of the appointment of an enduring medical power of attorney, which I think has been a brilliant innovation which I strongly support.

But apart from that, the concept that an individual can write down a set of injunctions about the kind of care that he or she might receive is potentially troubling for the simple and obvious reason that it is impossible to anticipate what those circumstances might be, and that the directives that people make are often not sufficiently specific to allow a decision to be made in an actual or individual case. People will often say they do not want to be attached to a ventilator or they do not want heroic treatments or whatever, and if they say that, that needs to be respected, but there are different circumstances. If someone is at the end of life and such treatment is the only thing that will keep them alive but will not treat their underlying condition, but if they then have a new event and develop an illness that can be treated very quickly with this same technique, then it might be appropriate to use it nonetheless. The specificity of those directives is a real problem.

In addition to that, I have seen many patients who would have said well in advance of an illness that they would not want to live under certain circumstances, and yet the experience of illness is one that provides them with an opportunity for real growth, for the development of wisdom, knowledge and insights that they have never even anticipated. It changes family relationships and so on. I would not want to preclude the possibility of those opportunities for growth and development. I am nervous about the rigidity of advance directives for which there would be no other alternative.

Having said that, in every case an advance care directive or statement must be considered carefully by the practitioners involved. It must be given serious weight and it should be complied with unless some of these other circumstances that I have been referring to were thought to exist at that time. It would be hard legislation to formulate. I am not sure that legislative change is necessarily needed in relation to that. I think we are doing reasonably well with advance care planning and advance care directives in Victoria at the moment, and I do not think that is where the main problem lies.

Ms FITZHERBERT — I have just a couple of what I hope are simple questions. The first is: under your minimalist model that you have suggested, who should be able to consent and when? The second thing is: you referred earlier to, if this were in operation, bringing it into the open and allowing scrutiny. How would that look to you?

Prof. KOMESAROFF — Sorry; when you say who would be able to consent — —

Ms FITZHERBERT — Yes. Who would be able to consent to having a doctor take them through the end-of-life process that you have outlined in your paper and submission?

Prof. KOMESAROFF — We have not built consent explicitly into this proposal — yes, you are quite right about that — whereas some legislation, such as the Oregon legislation, is built around consent. That, I guess, reflects a philosophical difference between the approach that we take in Australia, which recognises the complexity of networks of relationships — that an individual is not just an isolated person who controls every aspect of his or her life or body, which is an American idea, but rather that we live in communities and families, and it is the doctor's job to facilitate the kinds of reflections that occur within those settings. Consent is critically important in medicine, but the processes of consent are more complex than they are often presented in the American bioethical literature, where it is thought of as simply an act that an individual who is isolated — a sort of atomised or atomic individual who is isolated from all other relationships — takes on his or her own.

I am talking, I guess, a little bit circuitously. Consent will be one of the tests of the reasonableness of a doctor's action, but I would not be proposing a formal process of consent here because I do not see this as an act that is designed to hasten death. This is part of an ongoing treatment program that we want to facilitate or enable that will allow the medical practitioners to address the needs of the patient.

Ms FITZHERBERT — It makes sense on one level, but we have spoken earlier in this hearing about, effectively, protections for doctors who are working within this sort of model, and I would have thought having some sort of clear measure or evidence of consent, be it by a patient or that person's guardian or whomever, would be critical for protecting doctors if nothing else, leaving aside the issue of what an individual may want for themselves. I was just keen to flesh out how that may work while taking your point that in the real world it is not always as simple as one person signing a piece of paper.

Prof. KOMESAROFF — Yes. I think it is a really good point, but I am just trying to think how it would work in practice.

Ms FITZHERBERT — Which is basically what I am asking.

Prof. KOMESAROFF — Yes. So I am thinking about the actual circumstances. The setting would be a person who is dying of a terminal illness, who is in pain and suffering, and the doctor negotiates widely, determines to the extent that he or she is able what that person's wishes would have been and then talks with the family and devises a plan of action. The plan of action is devoted towards alleviating the symptoms of the patient, and it may be recognised by all involved that the kinds of actions involved may hasten death, but that risk would be something that everyone would be prepared to accept in those circumstances.

The doctor, under those conditions, would be obliged to document the nature of the decision and the circumstances under which that decision was taken. In this sort of setting — and you can talk to the palliative care people who you will be talking to later today — there is not a process of formal, signed consent at every step along the way. There would be some kind of recognition that a discussion has taken place and a decision has been made. The act of consent is not a signature on a piece of paper. The act of consent is that an adequate discussion has taken place and agreement has been obtained. That could well be one of the tests that is applied to the doctor in retrospect, because that is part of everyday acceptable practice. Whether or not one would build it explicitly into the legislation, again I would think it might be too difficult, but I am happy to leave that to you.

Ms FITZHERBERT — Okay. The second part of my question was in relation to, as you put it, bringing it into the open and providing some form of scrutiny. Do you have any suggestions on how that might work in practice? Is there, for example, some kind of reporting process that you would envisage?

Prof. KOMESAROFF — No, I was not really thinking about that. What are the ways in which you could bring out into the open? You could do it like that, or you could have a Medicare item or something like that. In the United States it is being proposed that a Medicare item — Medicare is the system that deals with elderly people in the United States — is being created to encourage end-of-life discussions between clinicians and elderly people in the United States. That is a device that could be used. I guess that could be considered. I would hope that would not be necessary. I think what I would like here is to take the fear and uncertainty out of the decision-making process but retain the possibility of accountability. I do not know that every decision has to be recorded in the public setting because many of these are very painful, intimate circumstances. I am adopting here again a minimalist approach, which is to remove the obstacles to people disclosing openly what they are doing.

Mr MELHEM — Just a follow-up question from that: are these things not happening already? The question is whether now we do it in the last week, where the doctor is sort of saying, 'Look, it's a lot of pain and suffering; they are not likely to recover, so we will go and help the patient to basically leave this world'. But I think your argument is probably that we could perhaps have started that process much earlier than that. Is that what we are talking about? Can you tell us how much of that is already happening unofficially today?

Prof. KOMESAROFF — We do not know what is happening because it is presumably not being reported and because of the uncertainty in the law. That is a fundamental point. But I want to clarify one thing about what you just said, which is that the idea of double effect is that the intention of the doctor and the focus of his or her actions is to relieve the symptoms of the patient, not to cause death. I cannot imagine a situation in which I would ever be in my entire life where it would be my intention to kill someone. I would never want to do that.

On the other hand I have often been in circumstances where my intention is to relieve pain or suffering, but I recognise that the act I may undertake may increase the possibility that that person may die. I think that although from some perspectives that seems like a fine distinction, to me it is absolutely and totally fundamental, and I think it is really built right into the foundations of medicine that there is a very big difference between those two. It was in that context that I said that I believe that the approach I am putting will be acceptable to the medical associations. I think you probably have received submissions from the Australian Medical Association, which has already discussed this and supported this idea, and they have been long-term opponents of active intervention to hasten death.

I have mentioned the Catholic Church also. One of the beauties of this idea is that the principle of double effect is a mediaeval Catholic doctrine that comes from St Thomas Aquinas in the 13th century. The approach that we are talking about is in fact one that is acceptable to the main groups in society that have resisted serious change in this area. That is why I think this is a strategy that may well bring together the community and enable them to address what is seen as a serious obstacle to good care at the end of life at the present time.

Ms PATTEN — Thank you, Professor. I agree with you, and I think one of the reasons that we formed this inquiry to look at palliative care, advance directives and voluntary euthanasia was to try and bring the community along with us as far as we could go. Certainly I can see that this proposal that you are putting even has the imprimatur of a saint, so that is — —

Prof. KOMESAROFF — It is a pretty good start!

Ms PATTEN — Exactly. Wow! You do not get that often. But I was actually reading a piece that you wrote in 1995 where you were saying that death itself is philosophically complex, and that really struck me. So we go down your path and provide this defence for doctors, but the vast amount of submissions we are receiving are from the families of people, and this is not their solution. Their solution is that they want to be able to have that autonomy to say, ‘At this point I do not want any more pain and suffering. At this point I want to be able to make that decision’.

You mentioned a little while ago that maybe in five years time we could talk more about this if we go down this path. I think we have been talking about this seriously in the community since the 1980s, and it is now 2015. Do we really have to wait until 2020 before we can actually say, ‘You know what? We are living longer; we are living with terminal illnesses’. I agree with you — let us stick to terminal illnesses — but do you not think we might be at the point that we could say that a patient could have greater decision-making in that end-of-life choice and that we do not have to just leave it up to the doctor to make that decision and defend the doctor in his decision-making?

Prof. KOMESAROFF — That is a complicated question. The presupposition behind it is that there is an opposition between the interests of the doctor and the interests of the patient and that the problem to be solved is the ability of patients to make up their own minds and to exercise their autonomy. I do not believe that either of those is an accurate representation of the problem at the present time. I am well aware of the submissions that you are receiving, and I am very familiar with the kind of pain and trauma that family members experience when their loved ones die. It is our role as carers, and the responsibility of other people in the community, to respond to the needs of those people. Death is always a painful and difficult occurrence no matter what the circumstances.

Research that I and others have done, as well as my own personal observations, have emphasised that individuals who are dying most commonly do not focus on their own needs and their own autonomy or freedom but the —

Ms PATTEN — Collective.

Prof. KOMESAROFF — pain and suffering that their loved ones are going through. That is one of the reasons why I think the medical enduring power of attorney is such an important device: because when you actually go out and interview people — and I have been involved in a number of research projects that have done this — they often would say, ‘It is not what I want that is important but what is good for my son or my daughter or my wife or my husband’. The focus on personal autonomy, I think, misses that sense of the embeddedness in relationships of love and caring. It is this complexity that I really want to retain or to preserve here. The doctor’s job is not to make decisions. The doctor is not a powerful authority to make decisions. The doctor’s job is to be the servant of the people who are in need and to facilitate the appropriate conversations. If the doctor is making a decision on his or her own, then the doctor is not acting in accordance with the ethical standards of the profession or the current existing reasonable expectations of them.

It should always be the case that the professional carers facilitate this complex conversation that enables the family members to commence the process of grieving and bereavement, that the wishes of the patient are as far as possible brought into alignment with the concerns of the family members. That is often a tough ask, and we do not always get it right. It will never be the case that we can always get it right, because death will never be able to be purified of all of these intricacies and complexities and the pain and the sense of loss and mourning and so on, and I do not think as a community we would want that to happen.

Ms PATTEN — A really quick question: are we ready for physician-assisted suicide in Australia in 2015?

Prof. KOMESAROFF — I do not think so, and I do not think that is necessary at the present time. I think to propose it would be unnecessarily provocative. It would not command the support of large parts of the

community, it would increase community division and it would maybe even be unworkable at the present time. On the other hand, we can make a really major step forward that will enable us to preserve that ongoing discussion.

The CHAIR — Professor, the committee thanks you very much for your presentation this morning and your preparedness to answer our questions. As I advised you earlier, you will receive a copy of the Hansard transcript for your review in the coming days. Thank you again for being here this morning.

Prof. KOMESAROFF — It is a pleasure. Thank you for your allowing me to talk, and thanks for your probing questions.

Witness withdrew.