

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Subcommittee

Inquiry into end-of-life choices

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Professor David Kissane, Head, Department of Psychiatry, Monash University.

The CHAIR — I would now like to welcome Professor David Kissane, the head, discipline of psychiatry, at Monash University. Thank you very much, Professor, for being here with us this afternoon. Before I invite you to make some remarks I just caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and is further subject to the provisions of the Legislative Council's 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, and the transcript will ultimately be made public and posted on the committee's website.

We have allowed about 45 minutes or so for our time this afternoon. Again, thank you for being here, and I note with interest your experience in New York as well, so I look forward to hearing what you have to say. Thereafter the committee will have questions. Thank you very much.

Prof. KISSANE — Thank you very much, Chair, and thank you, committee members, for allowing me to make an oral presentation in addition to the written submission that I have put before your committee. First of all perhaps I should say a little bit about my background and training. I have been a medical practitioner for 40 years. I worked initially in general practice and then in psychiatry, and for over the last 25 years I have specialised in cancer psychiatry, or psycho-oncology, and palliative care.

In 1996 I became the foundation chair of palliative medicine at the University of Melbourne, founded the Centre for Palliative Care and initiated the Victorian educational courses to train clinicians and medical students in palliative medicine. In 2003 I was invited to chair the department of psychiatry at Memorial Sloan Kettering Cancer Center in New York, which is America's largest comprehensive cancer centre. In 2012 I returned to Melbourne as head of the department of psychiatry at Monash University. I have published over 250 papers and 5 books. I serve, for your interest, on the committee of management of Eastern Palliative Care. I work clinically in McCulloch House at Monash Medical Centre, and I run a psycho-oncology outpatient clinic for Monash Health. That gives you a flavour of my clinical experience.

I want to make this afternoon 10 succinct points about legislation that your committee has been asked to consider, and I have numbered these for you.

No. 1: firstly, many patients who seek to hasten their death have undiagnosed psychiatric disorders, such as clinical depression or adjustment disorders with demoralisation, which can underpin their suicidal thinking. These disorders often go unrecognised, so psychiatry has a major role to play in diagnosing and treating these patients.

Point no. 2: a psychiatric gatekeeping role within legislation for euthanasia, I want to suggest here, does not work effectively. Basically, in my experience of studying the rights of the terminally ill legislation in Darwin — and I believe that that failed in that regard — I studied Philip Nitschke's medical records with his permission. I had a week to visit him in Darwin, tape-record him, review his files and go into the Coroners Court and review the files held by the Coroners Court, which was the body of oversight. Together we published these case reports in the *Lancet* in 1998. A copy of that paper has been made available to you. Pain control and symptom management was very evidently poor in those cases. Clinical depression was ignored by the psychiatrist reviewing these patients. One patient on low doses of antidepressants, for example, did not have that dose increased or the medication changed. These clinicians, in my view, did not have the subspecialty skills within psychiatry to recognise and intervene with these patients and families.

The third point I want to make is the gatekeeping role of the Northern Territory Coroners Court, which was the legally constituted body of oversight as specified in the ROTI legislation. It failed, in my view, in its role. The office of the coroner did not appear to review these specific cases. I am saying that this is really a most difficult job to make informed judgements about the quality of care and that legislators, in my view, would be asking too much of our coroners to expect them to do this. In Darwin it was not done amid all the controversy of the ROTI legislation.

Point 4: in care of depressed patients — those losing hope about their future, those struggling because of their medical illness to retain a sense of meaning and the point of their lives, those contemplating the premature ending of their lives, those existentially distressed and struggling to cope — the psychosocial clinician seeking to assess and treat such patients needs to be a source of hope to them, needs to inspire confidence that more can be done, that their suffering can be ameliorated, that their distress assuaged. Such a clinician cannot be an agent

of physician-assisted suicide whose stance is that the patient's life is no longer worthwhile. These roles, I suggest, are fundamentally incompatible. The psychosocial care provider cannot be the legislative gatekeeper at the same time.

Point 5: you need to recognise that the scientific study of prognostication has always shown over 20 years of studies a fivefold error rate. It is a most inexact science predicting when someone will die or when an illness has become terminal. It seems to me that legislators assume that this is easily done, but this expectation, in my view, is flawed — and with many new life-prolonging treatments emerging in cancer care and medical care it will only get harder. To legislate that two clinicians must agree about the prognosis of an illness is foolhardy.

Point 6: Professor Brian Kelly led a very interesting study in Brisbane — a study of GPs who referred some 256 patients to palliative care. They found that 14 per cent of these patients held a wish to hasten their death, which was associated with clinical depression, poor family support, a fear of being a burden and high anxiety about what was to happen to them in the future. Most interestingly, he showed in this study that those doctors who felt untrained or least experienced in being able to help these patients who had begun to despair about the value of their lives were the very GPs who began to think that the patient's life may in fact be no longer worthwhile. Hopelessness is contagious between patients, doctors and care-providing teams. It takes quite experienced clinicians to be able to identify this and not be drawn inappropriately into this hopelessness. The quick 5 to 10-minute consultation that might provide a prescription for barbiturates is a cheap form of medicine but one that is totally lacking in quality of care. A grave concern is that the most inept doctors would be the ones to function in this way, providing the barbiturate prescriptions.

Point 7: I believe that the slippery slope does exist, and I would not dismiss it, as Julian Savulescu did before you in his recent presentation. The steadily increasing number of young people dying from barbiturate overdoses, as they copy exit information about how to die, is an example of a slippery slope — one referred to by Dr Dwyer from the coroner's special prevention unit. Over the past two decades euthanasia of thousands of non-consenting adults in the Netherlands is another example of the slippery slope. Dr Savulescu went on to tell you that in his opinion intractable depression develops into a life not worth living, which he argued becomes suitable then for euthanasia. In my view that is a slippery slope. A number of patients in the Netherlands now receive euthanasia for mental illness. That is a slippery slope.

The disabled and vulnerable in our society need to be protected from such legislation. The state of Oregon in the US does not release case details, to avoid scrutiny about such issues. But there ought to be no doubt in your mind as legislators that once you open the door, the mentally ill with suicidal ideas will find their way to use this legislation. For every 100 subjects that you permit to autonomously control their dying with physician-assisted suicide, another few hundred will be vulnerable individuals pressured by their families or non-voluntary patients whose families request that their life be terminated. The Netherlands has acknowledged over many years that as many patients die from non-voluntary euthanasia as die from voluntary euthanasia. That is a slippery slope.

As a quick aside, legislation about aiding and abetting suicide could be tightened by your government by preventing the publication of information about how to obtain barbiturates from veterinarian surgeons or overseas mail order — that is little different to how we prevent news broadcasts about suicide when they occur to stop copycat events from following on.

Point 8: we can comprehend the argument of the intellectual person, the philosopher or the advocate for autonomous choice about when to die, but legislation for a few people within society is bad legislation if it harms more than it helps. The ethical principle of justice for the disabled and vulnerable must trump granting freedom to a small few, many of whom advocate for euthanasia, but I can tell you from many years of seeing such patients that when their own time comes to die, the vast majority accept a peaceful natural death. I have had that experience dozens of times.

Point 9: it is my contention that if euthanasia legislation is brought in, the resulting outcome for the standard of medical practice in our community would be a decline in the quality of care. The ROTI legislation in Darwin taught me that. In my opinion, our Parliament and our health department carry a grave responsibility to uphold the quality of medical care for our society, our children and the future good of our community.

Point 10: let me comment on case examples, as Judge Olle did before you recently. Mrs X was a lonely and depressed 70-year-old widow who asked me for help to die. With active treatment of her depression, the engagement of her extended family and use of community volunteers, her plan to jump from a high building

was aborted. She might have looked like a case Judge Olle would have included in his list, but resources were provided for her and a good outcome was achieved.

Mr Y was an isolated and you might say a crusty old bachelor, alienated from his family. He sought physician-assisted suicide, as his life in his view now appeared to be pointless. He talked about hanging himself or getting a gun. He was introduced to a biography service, where a volunteer visited him over eight weeks and recorded his life story. That brought back into focus for him the strengths of his earlier years, affirmed the value and contribution of his life and brought a smile back to his face. Early resourcing helped him to accept a natural death, supported by his palliative care service.

Judge Olle's cases included two he described as depressed, in his words, two who were lonely and isolated and three who told their families that they had had enough, but their families did not seek out help. Desperation is a serious warning sign of a pending suicide, and it necessitates hospitalisation. At that time Mr Mulino asked Judge Olle if greater resources could have been made available to the patients in the coroner's series. Judge Olle did not think so, but in my opinion they most certainly could have been. These are exactly the patients I see in my psycho-oncology practice, and there are many ways that treatment and support can be rallied to help them, particularly if a referral is made early on in the care pathway.

To conclude, the main issue — that I have not really spoken to thus far — that I made in my written submission was about adequate resourcing of our services. While palliative care has developed substantially in Victoria over the past two decades, considerable deficits still exist, especially in psychosocial care provision. Early intervention is central to improving our quality of care. There is so much we can do to reduce suffering, treat depression, relieve existential distress, help family conflict, assist where there is communication breakdown and support people who have a fear of dying. If psychosocial services are properly funded and made available to our community, we could accomplish much of this. I encourage you as a committee to advocate for this — to recommend that an expert task force be formed to guide our Department of Health and Human Services to equitably distribute competent psychosocial service providers across our state of Victoria. They are lacking within palliative care, and they are also lacking within cancer care — that earlier phase before people get to palliative care — and they are needed across the broad care of the medically ill; they are greatly needed.

Much of my written submission provided you with prevalences of disorders, evidence of lack of need and scientific papers supporting that. In this oral submission I just wanted to further emphasise that and put this emphasis on the importance of psychosocial care and of the need to develop psycho-oncology and psychosocial supportive care services across the whole spectrum of cancer services.

Thank you for giving me this chance to speak with you today.

The CHAIR — Thank you very much, Professor, for that considered oral submission reflecting on our terms of reference. I would like to take you to point 9 of your oral submission, where you said:

It is my contention that if euthanasia legislation is brought in, the resulting outcome for the standard of medical practice in our community would be a decline in quality of care.

You cited the ROTI legislation in Darwin as having made that point to you. Given your experience in the US, I would be interested in your thoughts on the Oregon legislation, because we have heard conflicting evidence, both in oral evidence and in written submission, about the regime that exists in Oregon, but basically to the point that palliative care and care more broadly is not compromised by the regime they have. I would ask you to perhaps respond to that proposition.

Prof. KISSANE — Well, I can tell you that I was staggered when I arrived to work in New York at the poor standard of palliative care practised in the US and how long a way behind our standard of care it is. To give you an example, I ran a department of psychiatry where we had 36 faculty, and Sloan Kettering, as a specialised cancer centre, had six palliative care physicians. We were six times as big. It is much easier for Americans to refer someone to a psychiatrist to talk about their dying than it is to get a palliative care physician to consult. Across the road from Sloan Kettering was the New York-Presbyterian Hospital, the home of Cornell University, 1000 beds. They had a 0.5 full-time equivalent palliative care physician on their staff.

America is a long way behind the rest of the world in developing palliative care because it is a death-denying society. They have Halloween. They celebrate the conquest of death. The emphasis within the American psyche is on life and living and living at all costs, and they refuse to give up on their living. In my decade in working at

Sloan Kettering I served on the hospital clinical ethics committee, where we would take about 50 referrals each year of people who were ethical problems for the physicians looking after them. These were typically people who were dying, dying in the intensive care unit, but would not let go of life, could not accept their dying, were hanging onto life at every shred. Their families would not allow a CPR order, a 'Do not resuscitate' order, to be written. So these became ethical cases. They were invariably a breakdown of communication. People did not realise they were so close to death. Their doctors would avoid talking about death and dying. It just reflected how far behind palliative care is in its development in the States. That is really I think why I was hired there, because we built a large communication skills training laboratory and trained over 1000 of their clinicians to begin to be able to talk about death, which is something that they did not do.

It is within that context that for America to begin to introduce the sort of legislation that Oregon has introduced it is coming from a completely reverse direction to the direction that is there within our society, in my view. There are many people there who fear technological medicine, fear being kept alive, fear that doctors take it too far, they do not know when to stop, and that is a big drive behind American legislation around autonomous choice. But we are a different society. We have built a well-established palliative care program. It needs to be enriched, it needs to be matured further. There is quite a way that we need to take it. In particular, we are very good at relieving pain and physical symptoms; we are poor at meeting the fear, the distress, the existential concerns that people have. It is the cancer psychiatrists, the clinical psychologists, the social workers, the allied health programs that are lacking in our programs here.

Part of that is a developmental journey that takes time to get there. Part of it is a funding issue. Victoria's task force in the 1990s — I served on that task force, as a government and health department advisory task force — was about trying to get physicians and nurses into our palliative care program, to get them equitably distributed. Very little attention was paid to the other dimensions of the palliative care program. When you look at the funding made available to family support workers, at Eastern Palliative Care we have issues because they are paid much less than a social worker would be paid in our hospitals, because the funds made available to community palliative care are proportionally smaller. To hire people, it is much easier to hire somebody who is willing to take a salary as a pastoral care worker than it is to get a dedicated clinical psychologist or family therapist, social worker trained as a family therapist, to come in with the right skill base to be able to do the good quality work that is needed across all of these programs.

We have got a couple of sites of excellence: Peter MacCallum, St Vincent's, strong psychosocial programs built in with their cancer care programs. But if you go to the east, the south, the west or the north, it is deficient everywhere. I was invited to the Austin after the Olivia Newton-John centre was built to help them to find a pathway to get one or two psychologists employed. They have got all of these esoteric allied health helpers with massage therapy and aromatherapy and treatments like that made available by special funding, but they do not have a clinical psychologist serving their cancer centre. The Alfred hospital has half a psychologist available to its whole cancer program. Monash Medical Centre has 0.1, a tenth, of a psychiatrist, myself, and 0.1, a tenth, of a clinical psychologist looking after its cancer.

There are multiple sites. We have got Moorabbin Hospital. Moorabbin Hospital actually has a 0.1 full-time equivalent psychologist in the lymphoedema service, because the lymphoedema service pays for it, but there is no-one else serving that whole cancer centre. Dandenong Hospital is short. Eastern Health is short. The west is crying out for help. How to do this, how to build this program? I believe we need the health department to be directed to pay attention to it. The way they get there is by setting up a working party, a task force, empowering it, asking it to look at the demographics, to look at the clinical need, to look at the studies and to design the kind of service profile that then needs to be injected.

But eventually it needs you folk to come up with a special funding package, to actually say, 'This is an unmet need. The health department needs to grow and mature this program, and we need a funding package to deliver this'. That tends to happen at election time, one party or the other. But if that does not happen, then I think we will struggle with this for years to come. Of course then it becomes easy for people to say, 'I'm frightened about my dying and let me have physician-assisted suicide', because there is not care that would really address those issues. We have treatments, we have therapies that can help people with these problems. There is so much that we could do, and it is lacking in our services at this point of time.

The CHAIR — Thank you for that answer, Professor, and I would like to ask one further question. If one accepts the proposition that you have just advanced, is it your contention that this debate before us today would be diminished or removed?

Prof. KISSANE — It would be diminished. I think there will always be people who want to control their dying, who feel loss of independence. I understand where the motives for a euthanasia debate come from. Of course they are comprehensible, but we have treatments to help people, and I see many patients who fear a loss of independence, and as you journey with them and support them, they come to terms with it. It is a fear of the unknown in the first place, but as they find they have a disability, as they learn to live with that, as you support them and give them strategies and techniques to cope, that tends to fade as a concern and they continue to embrace life. You help them to find what is purposeful, what is meaningful, where the joy of life can still persist, right through to a natural dying process taking over.

The CHAIR — Despite what I just said, I will ask one further question. Again accepting the proposition you are advancing — and I think you have answered this but just for clarity — and noting that there will still be a small group that will want the option of voluntary euthanasia, are satisfying those two things mutually exclusive? Is providing the resources and satisfying that small group that remains mutually exclusive?

Prof. KISSANE — I believe it is mutually exclusive because of the need of the good of the community, the quality of care that has to be delivered. There was a very interesting case report coming out of Oregon that illustrates this. One person went to request a prescription for a barbiturate for their physician-assisted suicide. At the same time they went to a palliative care program. This was subsequently published in the *American Journal of Psychiatry*, the author was Hamilton, and that person had the next year of their life receiving palliative care. They really appreciated that, they gained a lot from it and they found their life was enriched. They did not need to make use of any prescription. In the end they asked them to contrast the care. The care of the cancer doctor who gave that prescription for a barbiturate was minimalist — ‘here is your prescription, away you go’. That is the kind of quality of care that I fear, that that standard of care would become the norm. That was the approach that Philip Nitschke took in Darwin — deliver the end-of-life treatment, not really caring for the needs of the person, for their other symptoms, for how they are adapting and coping with their life.

We have to grow a medical care system that treats the whole person, treats the family, treats them with optimum quality care. They are demanding tasks, and they are hard tasks. To have those happen well we have to set our standards there. Psychosocially you had to have hope for these people. To let go of that hope, then the other pathway I suggest is a very poor quality of care. So my argument is that to sustain the quality of care we need to avoid legislation that might appease a small number but run the risk of spoiling the quality of care or reducing the quality of care for the greater majority, because it is so easy to be a prescription prescriber. You can do that script in a moment, but to really be with the person, relate to them, get to know them, build your relationship, treat them, care for them as an individual, that is a skills base that we strive constantly to develop in our medical community but it is ongoing work and it is challenging. We have to keep striving to do that well. That is why I think quality of care would be reduced if you bring in physician-assisted suicide or euthanasia legislation.

Mr MULINO — Thank you for your evidence. One of the points you raised is the difficulty of defining ‘terminal’ because general practice has been improving so much over recent decades. I would be interested in your comments on whether you think improvements in the diagnosis of and understanding of and treatment of mental illness has also improved significantly over recent decades, and whether you would expect that to improve further over coming decades, given that that is, in a sense, one of the key elements of what might help in treating people — providing support to people.

Prof. KISSANE — One always hopes that. I think I would have to say that when it comes to the gains we have made with mental illness, they have been smaller than the gains that palliative care has made over the last decade or two. There has been no new medication in the last decade that has made a significant change in the treatment of schizophrenia; there are no new antidepressant medicines that have come about. Some of the work that I think offers hope is more psychotherapeutic work, psychologically supportive work, which recognises where people lose morale, where loss of meaning and loss of purpose come about in people’s lives. I think there have been a series of new interventions, particularly developed as applied interventions in the cancer field, which have been about restoring meaning or purpose to people’s lives so that their dignity is upheld, so that their sense of a worthwhile future — whether that is a week, a month or a year, that that future is worthwhile to them. Those interventions have become stronger over this past decade.

That is why I say we are getting better and better at being able to deliver treatments to help these people. There is a long way to go in preventing suicide and in helping, for example, adolescents. We have got a hypothesis that very often these adolescents who kill themselves or suicide brutally in clusters often do not meet criteria for a clinical depression, but they seem to be demoralised — that is, they seem to have lost a sense of how their life can have meaning, where they can build a career, a future that has got value and worth. We need, I think, in that population of patients to develop better interventions that help them to build up that sense of meaning or purpose in their life so that they can truly have self-worth and have a sense that they have got a future.

So in some ways the issues around loss of morale, loss of meaning, loss of purpose and future in life are just as problematic for our teenagers who are suiciding as they are for our 40-year olds or our 60-year olds or our 80-year olds. It is the same problem, and we have got a lot of work to do in mental health to grow those interventions and understand that a lot better.

Mr MULINO — I do not want to reduce this to dollars and cents because I think these issues are far more important, but I also understand that if we are calling for more resourcing for a certain area within the health budget we have to be cognisant of the fact that the department, as a whole, has certain limitations. When we talked about certain aspects of community palliative care and helping people, for example, to die at home if that was their wish, where they may not be able to currently, there was some discussion about the fact that there may be some offsetting savings — better resources there might save on expenses elsewhere in the system. Do you think there is an argument that the same might be true to some degree, with early intervention in your area potentially saving on costs down the track?

Prof. KISSANE — Undoubtedly in my view. Early intervention is worth buckets of money in preventing unnecessary hospitalisation and preventing expensive treatments. Jennifer Temel's study coming out of Boston a couple of years ago showed early palliative care for patients with lung cancer not only saved money but in fact extended their life. Why? Firstly, because there were more cases of depression identified and successfully treated, which otherwise would have been missed, and secondly, there was less use of expensive chemotherapy in the final weeks of life, with that chemotherapy invariably bringing complications of infection, causing hospitalisation and increasing expenses.

There is no doubt in my mind that early involvement of palliative care helps people to work out when for them is the right time to cease intrusive chemotherapy treatments that are a burden to them, are causing side-effects, are spoiling their quality of life and increasing their rates of hospitalisation. In America 25 per cent of cancer patients die in intensive care. We do not want to be a society like that. To overcome that you need really strong palliative care programs that are integrated, that are seeing people across the whole of the last year of their life — very early involvement. That is a model that is still being built and needs to be developed, but it is not here in our society yet. We have got to get better and better at doing that.

Doctors sometimes are a bit possessive of their patients. They use that word 'my' patient and they do not think of the patient and the patient's illness as being able to be shared by a team and helped by a number of clinicians all making a worthwhile contribution. I think the answer to your question is yes, there would be cost savings; there would be a redistribution of funding that would be appropriate and very worthwhile. Governments should get behind it and encourage the health department to find the means to put the work profiles in place to grow these programs.

Mr MULINO — My final question is probably one to be taken on notice. There are a couple of references in here about, for example, over the past two decades the euthanasia of thousands of non-consenting adults in the Netherlands, and I think there was another reference to non-voluntary being about the same number as for voluntary and also a couple of references to Oregon. My apologies if I have missed this in the documents you have already provided, but it would be very useful to get some references.

Prof. KISSANE — I can supply those. There are about 10 publications coming out of the Netherlands showing the same data year after year — non-voluntary equalling — but we can easily supply those. I am happy to.

Ms PATTEN — That was a very interesting case that you mentioned about the Oregon man whose oncologist or cancer doctor had provided him with a prescription for barbiturates and he also then took on palliative care. What we have heard from other evidence is that they improve by knowing that they have that power and that control.

Prof. KISSANE — That is a hypothesis.

Ms PATTEN — Yes, indeed. Certainly there are a lot of anecdotes. We have heard a lot of anecdotal stories of this and people telling this story that having that knowledge enabled them to live life more fully. It enabled them to enter into palliation with greater trust, knowing that if there was a time that they felt they wanted to say goodbye they could say goodbye at that time. You are suggesting they would not —

Prof. KISSANE — The problem there you see is that it is anecdotal, it is after the event and it is often a view put forward by people who are advocates of physician-assisted suicide legislation. Nobody has done a study that carefully tests the difference in the gold standard way.

Ms PATTEN — Yes, sure.

Prof. KISSANE — That is why it can only ever stand as a hypothesis. Sadly I think there will be people who will be given a prescription and who will go and use it. They are not accessing the alternative approach where they get support and where they get psychological guidance to restore meaning, to help them to reconnect with people they are estranged from, to help them to build back some sense of worth and dignity in their life. It is a very one-sided comment, and I think that is its weakness. Therefore it does not convince me that that is a good reason to go ahead and legislate that way.

Ms PATTEN — With some of the psycho-oncology work, when you have patients who are refusing treatment in palliation, refusing all future treatments — whether it is chemo or any other form of treatment — asking not to be resuscitated and not to take antibiotics, do you think that is the depression or is that —

Prof. KISSANE — Acceptance of dying is very normal. We all reach a point, hopefully, where we come to accept our dying because we appreciate the frailty of our body and we recognise that our time is nigh. Acceptance of dying is not to be pathologised. It is healthy, it is normal and it is fully recognisable and quite discernible from a person who is suicidal, from a person who is despairing and hopeless. It is quite common to meet particularly senior citizens who will say, ‘I’ve had a good life, I know this cancer is progressing, I know I’m going to die, I’m accepting of that, I’m open to that and when my time comes that will be fine’.

Ms PATTEN — But you would suggest that they must wait for their time to come, that they should not have the power to hasten that or to make a decision?

Prof. KISSANE — I recognise that you may have a small number of people who will say, ‘I am ready to do it today’ and want to choose to do that. I do not think you base your legislation on the fact that they ask for that, because that legislation, if it is bad for our society, if it is going to harm others, is going to mean that the same sort of care will be poor care to vulnerable and disabled people. You have that principle of justice for the greater good of the community and the needs of a few who may want to make an autonomous choice because they like to have control or they fear loss of independence. To legislate on the basis of those few you would have to be absolutely confident that there was no way you were going to harm the greater majority who will not use that pathway. I am suggesting to you that there is strong evidence that harm will be delivered to the greater majority. That is why it will be a bad law.

A bad law is, say, gun laws in the US. It is hard for us to comprehend how they can defend their love of the gun and their right to carry a gun when it harms so many in society. But there you have the autonomous right of the individual saying, ‘I want to have my gun so that if I want to defend myself I can defend myself immediately’. Then you have lots of people arguing that that is a bad law because the rights and the justice needs of the total society have to be better considered than is the case. That is what I mean by ‘bad law’ and I think a euthanasia law would be like a bad gun law.

Ms PATTEN — I appreciate your position. We heard evidence earlier this morning from a gentleman who was recounting the death of his wife. That last week was very painful for him, very painful for his family and very painful for her too. What he was requesting of us is that we enable legislation to allow some sort of medical euthanasia or some sort of physician assistance at that point. He felt that the physicians at that time would not take it that way and that his wife suffered unnecessarily in those last days and weeks of her life. Would you support any changes at that point, or do you think doctors are sufficiently protected to hasten death at that time?

Prof. KISSANE — I am sympathetic to people who may sometimes have a tough experience of dying. It is particularly hard for the onlooker and sometimes a medical onlooker has a hard task because they have a view of ‘I could do this’ or ‘I could do that’. Watching is hard. The experience of the onlooker is sometimes much tougher than the experience of the patient going through it. In my experience very often people will come and want to talk to you about euthanasia because they have watched a loved one, in years gone by — 10 or 20 years before — have what to them was an awkward experience, a difficult experience, where it hurt them and it caused them emotional distress to watch that.

It is very comprehensible to my mind that when you are an onlooker, you see something as being much, much worse than it really is. You as a group of onlookers have listened to coroners give you stories of what sounded like terrible deaths. They selected certain suicides and said, ‘These were terrible’. Every suicide is terrible. All that goes before their court are horrible to watch, to look on, to go and read accounts of people who become depressed, who struggle with mental health, who lose the joy of their life and who then end up suiciding. They are terrible accounts.

So, as an onlooker, it is always exceptionally hard. Maybe what we do not have is enough care, or support of the caregiver, enough resourcing to in fact help that person to debrief and talk through some of their distress, for them to feel better supported, so that as they watch the dying person, they are not so anguished by it. The person who is dying is often semiconscious or going into a coma. They are peaceful. They are not actually experiencing terrible things. But if you sit beside a relative who is watching that process, they find it very hard, and we need to have very good resources to support people going through that experience.

Ms PATTEN — I have one final question, off topic now. You mentioned the young people accessing drugs or getting information over the internet. Obviously that information is already illegal in Australia, *The Peaceful Pill Handbook* is a prohibited import; it is a refused classification publication. How else could we censor this material or legislate to prohibit that material from people accessing it or finding it online?

Prof. KISSANE — My suggestion to you was to take a tougher stance in your legislation about people who aid and abet suicide. This has been going on for a long time and nobody has done a thing about it. In my series of the seven deaths that occurred in Darwin the first death was one that occurred from a barbiturate overdose because she had arrived in Darwin and the regulations of the ROTI legislation had not been finally written, so she took a barbiturate overdose. Philip Nitschke was on the record at the time indicating that he had provided the mechanism for how she could go and procure her barbiturates. What does our society do about that? Nothing. What do our legislators do about that? Sadly nothing has been happening.

The police gave evidence to you that it is very hard for them to prosecute somebody because unless they can get evidence that the person has been present at the time, their rules at present cut that out. I believe you folk could change those rules. I believe you could look at that legislation and tighten it so that it is in fact truly a problem if people are aiding and abetting suicide. We are very soft in our society about that, but much more could be done. I think that is the pathway that you should reflect seriously about looking at and gaining advice about how to do a better job around such legislation. Currently it is ineffective legislation. That is the problem you are putting to me and I am reflecting it back I guess. I do not have all the answers, but I think there are experts that you could get advice from on how to do a better job on that legislation. It needs to happen.

The CHAIR — Professor, perhaps I will just conclude with the final question, if I may. I will invite you to give further comment on the article that you wrote with Philip Nitschke and Annette Street. I note in the final paragraph it is explicitly stated that:

... we have deliberately avoided being drawn into the debate about euthanasia and physician-assisted suicide.

But I am intrigued about — —

Prof. KISSANE — I had to frame that final paragraph that way because Philip Nitschke was a co-author, and he was a co-author to say that all of the medical evidence put into that publication was factual and correct. It then takes a medical eye to look at that evidence and say, ‘Here is an example of someone who had back pain with prostate cancer and they got no radiation therapy. They could have had that back pain easily treated, but radiation therapy was not thought about’, and so the list goes on.

There is a second article that I supplied through Lilian, which was a chapter that I had written in a book. I think you will find that that, as a commentary on that *Lancet* paper, it really gives more of a medical commentary on the strengths and weaknesses of the quality of care. It is called ‘Deadly Days in Darwin’, and it was also made available to you.

The CHAIR — Thank you.

Prof. KISSANE — I think it is easily readable, and it gives you a behind-the-scenes commentary on what you could not put into an article that Philip Nitschke himself was going to be a co-author of, because he would not necessarily agree, understandably, to all of those judgements. But I think the medical community at large has long looked at that *Lancet* publication and accepted the fact that it is evidence of poor quality care when euthanasia is permitted. So much so that Oregon, very cleverly, denies people to go in and study their cases. That is now becoming the norm, so that there is a cover-up of what really has happened with many of these cases. The real story is not necessarily told. That is a concern to me as a researcher, as an academic, because you are getting such censored material.

Ms PATTEN — That is interesting. While Oregon does this, do the other states like Montana, Vermont, New Mexico — —

Prof. KISSANE — They have been following.

Ms PATTEN — They all deny access to case studies?

Prof. KISSANE — They put out their annual data, their bald statistics, which mean nothing — just numbers and gender and such — but they do not allow people to get in and study that anymore. The Netherlands have been much more open as a society over many years, and they have published much more, and that is why you can see all of these papers talking about their non-voluntary euthanasia deaths alongside their voluntary. They are very accepting of that. Our society ought not to be, I think. It goes against the whole grain of doing something for the autonomous right of an individual.

Ms PATTEN — Yes, I appreciate that.

Prof. KISSANE — It does.

The CHAIR — Thank you very much, Professor. Much appreciated.

Prof. KISSANE — Thank you for listening to me.

Witness withdrew.