T R A N S C R I P T

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Melbourne — 7 October 2015

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Ms Caitlin English, Coroner,
Mr John Olle, Coroner, and
Dr Jeremy Dwyer, Manager, Coroners Prevention Unit, Coroners Court of Victoria.

The CHAIR — I declare open the public hearing of the Legislative Council's Legal and Social Issues Legislation Committee in relation to the inquiry into end-of-life choices. I welcome Her Honour Coroner English, His Honour Coroner Olle and Dr Jeremy Dwyer from the Coroners Court.

Before I invite you to make some opening remarks, I remind 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.

Today's evidence is being recorded. You will be provided with a proof version of the transcript in the next week. Transcripts will ultimately be made public and posted on the committee's websites. We have allowed an hour for your time tonight, and we sincerely appreciate not just your attendance this evening but all the assistance that the Coroners Court has provided to the committee and the submission that you made to us. It is greatly appreciated. I invite you to make some opening remarks, and the committee will have questions thereafter.

Ms ENGLISH — Thanks very much, Chair, and thanks for the opportunity to speak to the committee today. My name is Caitlin English, and I have been a Magistrate for 15 years. I am currently assigned to the Coroners Court as a Coroner. I am going to commence by giving a very brief description of the coronial role and some of the suicide figures that we are facing at the court. My colleague Coroner Olle is then going to speak about a specific cohort of cases that we think are of particular relevance and interest to this inquiry and some research that has been done by the coronial prevention unit at Coroner Olle's behest in respect of a number of cases he was concerned about. Then Dr Jeremy Dwyer, who is the acting manager of the coroners prevention unit, will speak to some of the detail of the research that has been done.

I will start off by saying that there are 10 coroners in Victoria, and we have the jurisdiction to investigate what are called reportable deaths. Reportable deaths are those deaths that have a jurisdictional nexus to Victoria. They are unexpected, violent, pursuant to an accident or an injury, or unnatural. Those reportable deaths are also deaths that arise during the course of a medical procedure or are causally related to a medical procedure where death was not expected. There is also a category of people who come under the definition of reportable deaths — those people in care and custody, so they would be involuntary patients and prisoners.

The Coroners Court is a specialist inquisitorial court, and our legislative requirements when we investigate death are to ascertain the identity of the deceased and to look at the medical cause of death and also the circumstances of that death. The coroner also has a preventive role, which really is the intersection of law and policy at work. In respect of that role we are able to make comments, and we are able to make recommendations with a view to contributing to the reduction of preventable deaths. As part of a finding we can make a recommendation or a comment to either a minister, a statutory authority or another entity on issues relating to public health and safety and the administration of justice. We are greatly assisted in that role through the coroners prevention unit.

I will talk a little bit about the work of the court in suicides. In 2013–14 there were some 6260 deaths reported to the Coroners Court that were investigated. A confronting part of our work is the number of deaths that are as a result of suicide. It is the largest category of unnatural death. It is higher than the road toll, and it is higher than the homicide rate. There are approximately seven per week in Victoria, and it is the highest cause of death of young people between the ages of 15 and 19. The most common method of suicide is hanging or suffocation, and some professions have a higher rate; for example, those in the medical field, such as ambulance officers, who have access to means.

Although it affects the spectrum of the members of the community, those who are at highest risk are middle-aged men. Some who suicide suffer from mental illness, other suicides are highly planned and seem to be as a result of rational choice. Often, though, many suicides are seemingly spontaneous. They have been the cause of many coronial recommendations covering this area, such as preventative measures, such as the installation of barriers on the West Gate Bridge. Other coronial recommendations have related to same-time drug prescribing and also important public health initiatives such as education about suicide prevention in schools.

Within the reportable deaths that we investigate there is a cohort of deaths that we have to determine whether they are preventable or not. There seems to be a cohort within the suicide group that it has been very difficult to

come up with recommendations or comments that could contribute to their prevention. This is really what we want to talk to you about today. These are people who are suffering from irreversible physical terminal decline or disease, and they are taking their lives in desperate, determined and violent ways. They are the category of suicides we want to talk to you today about.

Coroner Olle and myself are obviously well aware that as judicial officers we are not advocating a policy position; that is for you as legislators. But we are a specialist court, and we do have information of a specialist factual nature. We also have research that we believe is important for the committee to consider as part of your consideration of end-of-life choices. At this point I will hand over to my colleague Coroner Olle to talk about the specific cohort of cases that we are concerned about in suicide.

Mr OLLE — Thanks, Caitlin. Edward, I want to repeat our thanks for the invitation tonight. I commend this inquiry. I suppose my motivation initially some time ago to refer several cases that I was investigating to our coroners prevention unit was really would I want a member of my family to die in the circumstances of loneliness, fear and the horror of some of these cases we are privy to — would I want that? The answer was a resounding no. People who have invariably lived a long, loving life surrounded by family die in circumstances of fear and isolation.

That was the motivation. The coroners prevention unit on which we rely so heavily — there is such a wide range of circumstances of death — to identify areas of prevention really defines the cohort as 'irreversible decline', so terminal disease; death was foreseeable; incurable, chronic disease but death not imminent; permanent physical incapacity and pain. But the cohort did not include mental ill health or feared imminent decline.

I referred only a sample of some five cases I was investigating to Jeremy's team of researchers. He has identified approximately 50 cases per year between 2009 and 2012. It is a small cohort, but a significant number. We are looking at 8.6 per cent of suicides that meet this criteria set out in our definition of our cohort. So a total of 197 deaths not in palliation at the time of death. It is important to point that out. We are not talking about this wonderful palliation. We do not in any way, shape or form undermine that. That role is so important, but we are not talking about that. We are talking about the people who unlikely would qualify, would meet the criteria of palliation.

It looks like there is equal division between gender. The highest frequency age group is over 65. What I would like to do, if you do not mind, just briefly before I hand over to Jeremy, is to identify some of the more pertinent details of the five cases I referred to highlight the absolute determination of these individuals — their desperation, their plight. I have provided de-identified information to Lilian for your benefit. It is very important of course to acknowledge the importance of de-identification.

The first individual is a 59-year-old man. He had a wife of 38 years, survived by his children and his wife, with whom he shared close and loving relationships. He had no mental health documented, a medical history of metastatic colorectal carcinoma, multiple confirmed colorectal and liver metastases. About two years before his death he underwent a liver resection for confirmed liver metastases and was subsequently treated with chemotherapy. He underwent 22 cycles of treatment, and unfortunately a CT scan performed not long before his death showed evidence of progressive disease with a new liver lesion, which resulted in the cessation of his trial treatment. His GP informed the court that the cancer had now spread to his liver and his prognosis was not good.

He was admitted to hospital with a fever, dry cough, ultimately he wished to go home. He would inform his son and family members he would rather take his life than live a life dying in a bed. He was well aware of his suffering and what was ahead of him. So he would rather die than stay in a ward. Ultimately he was observed by a motorist on a major freeway in Victoria hanging from a bridge. A note indicated his intention to take his own life.

Another case I have seen was an 82-year-old lady. She lived on her own and was survived by her children, again with whom she shared a loving lifelong relationship. Her documented medical history: hypertension, insomnia, arthritis, gastro-oesophageal reflux disease, gout and on and on and on it goes. She was feeling very poorly about it and depressed about her lot. Her vision was nearly gone. Her love of reading books, her quality of life was greatly diminished. She was described by her doctor as lonely, isolated, frustrated, impatient. Her

daughter was informed by a neighbour who had told her she could not read anymore. It was the most important part of her life. She also informed her on a number of occasions she wanted to die.

She was found on the couch in her lounge room. This 82-year-old lady had a stained towel wrapped around her left hand. There was a knife on the floor in front of her, an open wound on her left wrist. There was a white-handled knife that measured 14 centimetres on the floor beside her. In the bathroom was found two pairs of scissors, and another white-handled serrated knife, about 30 to 40 centimetres in length, was located on a table. There were traces of dried blood on all of these items. She died of exsanguination — she bled to death.

Another, 89-year-old. Again, a man. He lived with his wife of 61 years and enjoyed a long and loving relationship with his family. He had a very lengthy medical history — no hint of mental illness. His son stated his dad's lucidity, memory and eyesight were failing. He could not listen to music, watch TV or read, which he was known to enjoy. He ended up alone, grinding various tablets with either a mortar and pestle or food processor and died of drug toxicity.

Another, 75-year-old — the second last. He lived with his wife, with whom he maintained a good relationship despite their divorce. He is survived by his daughters, with whom he shared close, loving relationships. He had no documented mental health history, and again a very long, complex mental history. Not long before his death, some years, he was diagnosed with prostate cancer, treated — radical treatments — sadly without improvement and increasing pain with poor prognosis. He expressed to others his belief that his life would be so much easier if someone could help him die. He could not face his lot. He ultimately obtained a firearm which he discharged by holding the tip of the barrel against his chest and reaching for the trigger. He was found by family.

Finally, a 90-year-old man, survived by his family, again with whom he shared close, loving relationships. He was described as a delightful gentleman. He was extremely fit for his age and a proficient iPad user. He had no documented mental health history. A very lengthy history included back pain, chronic obstructive pulmonary disease, asbestos exposure and the like. Not long before his death he was diagnosed with a solitary brain metastasis in a setting of metastatic melanoma. He expressed his wishes very clearly to his treating clinicians; he did not wish to have any invasive procedure done. His main priority was quality of life.

In the final four weeks of his life, his doctor explained, he remained frail. He had lost approximately 6 kilograms in the previous four weeks. He had a poor appetite. He looked malnourished and had nausea. His family stated that from about mid-December 2014 his wellbeing deteriorated. He felt generally unwell. He was dehydrated and had diarrhoea. He was vomiting uncontrollably. He had fevers. He was wobbly on his feet, even with the assistance of walking aids. He was diagnosed with likely viral gastroenteritis and was commenced on IV fluids for rehydration therapy. He improved as a result of the rehydration therapy markedly and was discharged home to the care of his grandson in January this year.

The family explained that when he learnt of his cancer he went downhill emotionally. He was depressed and angry that there was no cure. He often told his family he would rather do something to end it straightaway and that if he could no longer drive, he might as well be dead. He mentioned a nail gun. He was subsequently found dying with nail gun wounds to his head and to his chest. He died ultimately from the injuries sustained from the nail gun.

I have other cases still before us. The tally is not ending: a lovely lady who had the ability to step off the platform in front of a train; a man with the ability to tie a hessian bag full of sand around his waist and step off a pier. It goes on and on. These are the cases I have sent to Jeremy. This is the information we are privy to. I make no comment upon it other than that it is information we alone are privy to that we feel may be of some assistance in the important task that lies ahead for you. I will hand over to Jeremy Dwyer. Thanks Jeremy.

Dr DWYER — Thanks very much, Coroner Olle. What I wanted to do was just to give a very brief — I guess more of a thematic — overview of what is going on with these deaths, drawing from the Victorian suicide register and to try to give, if you like, a bit of a typology to help you understand the different types of issues that might be underpinning them. These deaths are drawn from an analysis of data held in the Victorian suicide register between 2009 and 2012. This is a register that was developed within the Coroners Court to assist coroners with their investigations. We applied very conservative criteria for inclusion of the deaths, because I did not want to over-report and depict the issue as larger than it is.

I will say that there were at least 197 suicide deaths in those four years where the deceased was suffering an irreversible deterioration in their physical health. When you break them down, about 80 per cent involved physical illness and in about 20 per cent, if you like, the aetiology of the deterioration is physical injury.

I will talk about the physical illness ones first. I guess if you are doing an anatomy of them, about 50 per cent are associated with cancer diagnoses, particularly the return of cancer after successful first treatment, the metastasising of cancer, and particular types of cancer such as pancreatic cancer. The themes are that the deceased has been engaged in treatment and has usually been through multiple periods of treatment and has reached a point in most cases where they feel that the treatment is, I guess, detracting from their quality of life to the point where they make the decision that they do.

The second group — around 30 per cent of these deceased — are people who do not actually have a terminal illness but who usually suffer a range of different physical illnesses from which they are no longer able to recover. I have a list by deceased of the ranges. I will just give you an idea — for example, someone suffering heart disease, prostate issues and lumbar spinal osteoarthritis. A very common combination is diabetes, stroke, hypertension and heart disease. One suffered breast cancer, hypertension, spondylosis, pancreatic cyst and shingles. There are things like that. So they have multiple medical issues, and a lot of them are interrelated. They have been engaged in treatment for a long time, they are not getting any better and the drugs are not doing them any good, and they have come to a realisation that their physical health is not going to improve.

The third group here — about 15 per cent of the deceased — are those who have what I guess, for want of a better term, we would classify as incurable conditions, usually very well advanced: cerebral palsy, Parkinson's, multiple sclerosis, muscular dystrophy and so on — degenerative brain and nerve disorders.

The last group, a small group — about 5 per cent — have illness-related pain disorders. Usually they have been in treatment for a very long time. They are not getting relief from opioids. They are not getting relief from the more exotic forms of pain treatment such as direct spinal stimulation and so on. They end up in a situation where every day is distressing for them.

That group leads nicely to the second group — on physical injury — because this is the general scenario we see in these as well, where they have sustained a physical injury; it is usually either from a motor vehicle collision or a workplace injury rather than an injury around the home, and they will have been in treatment for anywhere up to 15 or 20 years, and the treatment has been just unable to slow the decline in their, if you like, quality of life. In about 80 per cent of these cases the suicide ultimately is related to a medication overdose, which some people have framed as being an access to means issue. But there are other ways of looking at it. If you think about what medication means to an ordinary, healthy person, and medication means you get sick, you take something and you get better. But these are people who have been taking medications for 10, 15, 20 years, and who are getting worse all the time, suffering the ill effects, the side effects, of the medications and ultimately making decisions to end their lives.

I hope that gives you a bit of a sort of a thematic overview of the deaths that Coroner Ollie was talking about in specificity.

The CHAIR — Your Honours and Dr Dwyer, thank you very much for that opening presentation. I noted, Coroner Olle, in one of the reports you have given us, one of the paragraphs summarises by saying that the tragic circumstances of death graphically illustrates a common theme encountered by Victorian coroners, namely having lived full, productive and loving lives, the irreversible deterioration generates a determination to end their lives in circumstances of violence, desperation, loneliness and fear.

I suppose noting the limitations or the roles that you have identified as members of the judicial branch, and the fact that you are not advocating for a policy position, but from where you sit and the cases you see within the current legislative framework that does exist, can you identify any changes or make any other observations in addition to those made by Dr Dwyer that would assist the committee in its deliberations — from a general sense, which encapsulates the case studies that you have identified?

Mr OLLE — I think it is just so important that there is certainly no prevention aspect here for people who are determined to end their life, so we are not talking about prevention. Your role, your term of reference, is just so succinct. I think this sort of information hopefully — —

I remember when I first referred this cluster of cases, they are obviously — and for anyone would be — so distressing. There was no panel; there was no inquiry afoot, or even mooted, and that was my great concern — that there has not been information that we have that the community do not have and should have to be aware and to address this important issue. The need for laws in Victoria to allow citizens to make informed decisions regarding their own end-of-life choices — your very term of reference. I think not.

I think we perceived our role, and hopefully can be of assistance to you in carrying out your function, is to offer information which is privy to us and that you should have as part of your deliberations. So I think not. I think really we saw our role to do what we have done, to give you this information. These are the figures, as I have said. It is under 9 per cent, so we are not talking a huge cohort, but the numbers are nonetheless significant, and the pain and distress to some people is so significant. And least of all, these beautiful individuals who have lived full lives and die alone.

Ms SPRINGLE — Thank you for your testimony, it was very powerful. I am not quite sure whether this is a question you are going to answer, but I guess I would like to bring it up anyway.

Mr OLLE — I might give it to Caitlin!

Ms SPRINGLE — Only from the perspective that it may well be a question for palliative care specialists. You mentioned in the beginning that most of the people you are talking about were not palliated, were not in palliation, but some of particularly part of the 80 per cent physical illness category do appear to have similar kinds of conditions to people who we have heard are receiving palliative care. So there seems to be a disconnect there somehow, in that these people perhaps are not accessing services that others are, or have not found it successful. There is something there that does not sit right in my head, so I guess I am looking for some comments — perhaps a response from you — about what you think might be that disconnect.

Ms ENGLISH — As in, why they are not in palliative care?

Ms SPRINGLE — Correct. Whereas others who suffer from the same complaints or multiple complaints are. Does that make sense?

Ms ENGLISH — Yes, I see your point. Often there is an intervening medical event that might mean that a person ends up in hospital and then goes down a palliative care track. And a classic example of that is an elderly person who has been living in a nursing home, has a range of comorbidities and has a fall. Then the fall is the event that leads them to hospital. They are not a candidate for surgery or other types of intervention. They are conservatively managed, palliated, and they often pass away in that context. That is a common scenario that we see.

But these are people who have a range of significantly difficult and complex medical issues who are really not going to get any better. They still seem to be having a level of independence, but they are just not at that point — they have not had that incident or that intervening medical event that has put them into a palliative care setting. I do not know whether Jeremy can shed any more light on that?

Dr DWYER — Well, for some of them I do not think that they would qualify for palliative care, in my understanding of how palliative care is delivered. I mean, someone who has, for example, diabetes/hypertension/heart disease would not ordinarily be a palliative care candidate. Sometimes you get also, if you like, the trigger. The thing is that the conditions are of significance to different people in different ways. Sort of looking at the stories, and the significance of what happens, you can have someone who has lived with diabetes and hypertension and so on for years, and then their eyesight starts to fail. Then their licence gets taken off from, and then that is the trigger for their realisation that things are never going to get any better. It is not criteria for going into palliative care. It is their trigger for the realisation that their physical ill-health is never going to be relieved or returned to what it was.

Ms SPRINGLE — So in a case like that, would it be fair to say that it is also their mental health that is impacted upon by this situation, as opposed to only their physical health?

Dr DWYER — Absolutely. What we did not discuss, because we did not want to confuse the two different cohorts, which have some overlap, is that you often have the emergence of mental ill-health following upon the physical health. I do not know the number off the top of my head, but it is somewhere around 60 per cent, and

that is a very common thing. People who have long term chronic illnesses that are not being relieved by treatment can develop depression or develop anxiety. There are well-established side effects of taking morphine long term and so on, so they will end up also getting adjunctive therapy for depression — for anxiety and so on.

Ms PATTEN — Thank you very much. I must say, in reading some of these reports, they were somewhat harrowing in, as you said, the violence and the isolation of these people. I am interested in the families of these people, and obviously in a number of the cases you mentioned, the deceased had indicated a desire to die. So does that change the effect that it has on the family compared to a suicide that may be more — without pre-empting, these families knew that their loved ones had an ongoing issue, that they were reaching depression, is there a difference in the way the family reacts to a suicide like this compared to, I guess, a more unexpected suicide?

Ms ENGLISH — As part of our investigation we obtain a coronial brief in these matters which will include detailed statements from family members, and so time after time we are reading their expressions of horror and concern that their loved one was, as they see it, put in a position where they were forced to use a nail gun or jump off a bridge, and as John indicated, this is really just the tip of our investigations. I have one at the moment where a 93-year-old woman with crippling arthritis and back pain had gone into an aged-care facility and smuggled a razor blade into her wallet which she then used, and she died of exsanguination with her arm dangling over the toilet bowl. The statement from her daughter is very compelling. The essence of it is that, from the family's point of view, if only there was a better way, that their loved ones did not have to die in such violent circumstances and alone. I think that you are right to say that it is very different to other types of suicides.

Mr OLLE — In no way, shape or form, by answering that question, do I in any way undermine the horror of having suicide in your family, but in these instances what seems to be a common thread through the family is this absolute sense of someone they love and respect, and always have, and the sense of helplessness. There is a cry for help that they cannot answer. So it is almost like a double blow, if you like. They have loved and respected this individual. There is a cry for help. It may be muted, it may be veiled, but it is there nonetheless, and they all know it — including doctors. They know that this person is screaming for help, but no-one is going to answer this call; not in this society. So they have got to die alone.

Dr DWYER — If I can add something, there is a cohort of suicides that are relevant to what you are talking about where the deceased has discussed it with the family and the family have come to a collective decision and so on. Most of those suicides have not made it into this dataset. They actually happen, I guess, further back up the track, if you like, prior to decline, where they have had a long and fulfilling life, have discussed it with the family and the family will assist them, sometimes even with the means of suicide. And there is a certain amount of closure, and the family are happy that the life has come to an end in that way. But these are not those suicides. There is very little overlap between that group and this group.

Ms FITZHERBERT — Two things: if I could just follow on from the evidence you were just giving about a set of people who commit suicide in different circumstances to that which is outlined in your written submission, how many people each year would fall into that category, do you think — people where there is a suicide with closure, as you put it, and I guess a degree of, maybe, tacit cooperation by family?

Dr DWYER — Here I could not put a number on it. I can tell you it is not a large number, though, and it is mostly elderly people who are living with their families and so on. To be honest I would not want to put a number on it here.

Ms FITZHERBERT — Sure. If I may ask another question as well, in your written submission there is a reference to cases that you need to deal with when someone has died in hospital and the family sees this as an unexpected event, but the treating medical people do not. There is clearly a disconnect there, and that is an issue that has come up in other submissions that we have received. I am just interested in any suggestions or views you may have on how that situation might be rectified in a practical way.

Ms ENGLISH — We see it a lot because often the cases are not actually referred to the court by the medical staff from the hospital; it is the family who are taken by surprise at the death of their loved one, which, when the medical file is obtained, seems that it was not an unexpected event. I think we have referenced the work of Professor Corke in our submission. His recommendations make a lot of sense, and we see time and again, from the medical records that it does not look like the difficult conversations have been had between the medical staff

and the family, often, or it has been left to junior medical staff. — just those hard conversations to have about prognosis, the viability of treatment and what is ultimately medically expected. It seems to be the trigger for why they are referred suddenly to the Coroners Court as opposed to perhaps the family and the patient sometimes being better prepared.

Ms FITZHERBERT — Is there a recommendation we could make that might address that issue?

Ms ENGLISH — Yes, for sure, in respect of improving that communication. I have had a look at the transcripts of other medical people who have addressed the committee and have made similar comments in respect of that it should be the role of the more experienced and senior practitioners. There should be better training for hospital staff. We have a judicial college that helps judicial officers with education, and sometimes we engage in role play to improve skills. That seems to me a classic example where doctors could be having that similar sort of training to just practice having those difficult conversations, learning the language they need to use that is clear, that is concise and understandable by lay people.

Mr MELHEM — Could you talk to me about the differences between the various suicides? I think you touched on that earlier: terminal illness, physical illness, injury, people suffering from pain — so the different approaches to these. If we were to make a recommendation, for example — and I heard about the 8 per cent of people who are suffering terminal illness or injury or are in a lot of pain — how do we distinguish between them, have a solution for that and then look at people with mental illness?

The third one is the West Gate Bridge example you talked about earlier. I have forgotten the name of the father who went through a bad divorce and jumped with his daughter, I think. If we allow euthanasia, for example, say it is illegal and you can do it, how do we distinguish between all these various cases? Do we do it as a blanket approach across the board that you can just euthanase or that in certain circumstances you might be able to, not to die alone as in the example you talked about?

Mr OLLE — I have heard through a family member in one of these cases of their belief that it had to happen before the illness got to such a stage that they could no longer act. I think that would cover across the board; I do not know. I do not know that you could, from my view, distinguish. I just feel there is this determination.

Dr DWYER — The thing is we are approaching it from after the fact of the death, and what is clear from the circumstances of the death, looking across hundreds of suicides, is that you have thousands of people every year who are diagnosed with diabetes and heart conditions and so on and thousands of people who are diagnosed with cancer and so on who do not go on to end their own lives. It seems to be that different things have different significance for different people and affect people in different ways as well, and I would have no idea how to make predictions on that for the living. We are seeing the end point. We are coming in after the death and applying our retrospective analysis to it.

Mr MELHEM — That has sort of confirmed my thinking, and I appreciate that you are investigating after the event. Following on from that, my understanding is that in Switzerland, for example, there is the right to die. They assist people, but then they go and notify the police and the coroner to carry out an investigation to ascertain whether or not there was anything untoward in the suicide. Have you got any thoughts about whether a system like that might or might not work in Australia?

Ms ENGLISH — No. That is the challenge that you are facing, is it not, as a legislature. I do not envy you.

Mr MULINO — I just have one question to follow up on a question that Ms Fitzherbert asked. You seem to be broadly supportive of Professor Corke's suggestions in relation to the Coroners Court having a closer look at the extent to which there are appropriate discussions and interventions in relation to end of life and whether there is appropriate documentation on medical files. I just wanted to clarify whether you think the Coroners Court's role in that would require legislative change to implement his recommendations.

Ms ENGLISH — I think probably not, that it is probably an educative recommendation and training that is required.

Mr MULINO — You have obviously focused on quite a narrow subset, looking at irreversible decline and situations where somebody feels hopelessness and obviously in many of these cases are driven to do things that

are, as Ms Patten said, very harrowing to read about. Obviously the potential to help people in different circumstances changes over time, and our capacity to treat certain conditions but also potentially to provide support to people who are feeling distressed about certain things changes. I am just not talking about medical treatment but also potentially to provide support for people to help cope with things. Usually it improves, and to some degree the capacity to provide increased support is about resourcing the system.

I am just wondering whether, firstly, even within that subset that you have looked at you feel that there are instances where there is the potential to help people feel less alone and more supported and, secondly, whether in the data that you have looked at there is any change over time as palliative care perhaps improves. Have you noticed that that cohort is changing the composition of the overall rate of suicides over time?

Mr OLLE — I do not think it is an issue in this small cohort we are referring to, where very tight criteria are applied. The numbers might be far greater than the numbers we have found — very tight, very conservative. No, to my knowledge the people we are talking about in this small cohort have made an absolute clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life.

Dr DWYER — On that point, at the time when they have made the decision to suicide, I completely agree that the potential for intervention in a number of these cases would be a long time before that. There are some well-documented issues that coroners have been discussing repeatedly, particularly around the management of pain and the need to get more pain specialists involved earlier rather than it being like the mental health system, which devolved to where you could not get into the mental health system unless you were in crisis. It appears to be that way at the moment with pain treatment, and this has been pointed out by all kinds of organisations involved in pain treatment and so on.

What I am thinking about particularly is the people who have suicided after 15 or 20 years of unsuccessful treatment for their pain conditions. You just wonder what would have happened if 15 years ago, instead of escalating them from 20 milligrams of morphine daily to 900 milligrams daily equivalent with amitriptyline and diazepam to enhance the effects of the opioids, a pain specialist had got involved at that early stage to try to head that off instead of getting involved at the stage 5 or 10 years down the track when they are hopelessly addicted and nothing is going to make a difference to their lives. That is a theme that comes out of a number of coroners investigations. Did that answer your question?

Mr MULINO — So in some cases, by the sound of it, intervention earlier might have been possible.

Dr DWYER — I think so. In a lot of these suicides there is a trajectory over time. It is not like something suddenly happens and they make a decision. There is this trajectory, and there are attempts to engage in treatment. It would be interesting to get some kind of review of whether earlier and different treatment might have made a difference, but by the time they are at the point where they are suiciding, as Coroner Olle has indicated, these are not people where you can say 'Oh, if we just switch medications, everything will be okay'. It is a long way past that.

Ms ENGLISH — I also think that it is not a case of people taking or not taking the time to try to adjust to their deterioration. I think that it is a slow and long evolving process of deterioration that leads people to the point they think there is no other option.

Mrs PEULICH — Are the figures you quoted just for one year?

Dr DWYER — That is a four-year study.

Mrs PEULICH — Four years, so you have had 50 deaths per year over the four years. Are figures for the last 10 years available?

Dr DWYER — No. It is quite difficult to identify these deaths, and so we needed to use a specialist data base, the Victorian Suicide Register, which is only populated from 2009 to 2013 at the moment.

Mrs PEULICH — It seems to me that there would probably be some benefit to actually having a periodic academic study to unpack those figures, so that you can actually customise and understand where the interventions may be necessary in terms of profiling, in terms of the age, gender, metro, rural, the role of mental health issues and whether there are drugs, alcohol, gambling. I think there has been evidence to suggest that when mental health issues are treated and the pain is treated more effectively, that there is often a higher

willingness to live. The figures that you have cited, are they available in a table that unpacks information, and who could undertake such an appropriate academic study to shine a greater depth of understanding on the figures?

Ms ENGLISH — Is this in respect to suicide generally or just this cohort?

Mrs PEULICH — Yes.

Dr DWYER — There is a range of different people who could who are actually engaged in a project at the moment with St Vincent's to understand the suicides in a context of diagnosed cancer better, and the approach used there could be applied more broadly to this cohort.

Mrs PEULICH — So they were just terminal.

Dr DWYER — No, they were people with a confirmed diagnosis of cancer.

Mrs PEULICH — They were the only views that you were quoting.

Dr DWYER — The figures that are quoted here are suicides that occurred in a context of irreversible deterioration and physical health, and so they include: there is a cancer group; there is a group with multiple, non-terminal health issues that combined mean that they have reached a point where the treatment is not having any further effect on them; there are smaller groups with pain disorders and a smaller group with incurable conditions such as motor neuron disease.

Mrs PEULICH — There have been calls by others to open up the options of euthanasia to people who suffer even experiential pain, so that means that cohort would need to be broadened if we are to understand the dynamics and link that person's willingness to live or wish to die. How would you broaden that cohort? Can those figures be extracted? Is there a cohort where suicides are being committed because of mental health issues?

The CHAIR — Dr Dwyer, if I could assist, just to clarify for Mrs Peulich: the small cohort that you have been discussing tonight is research the Coroners Court has done to assist this committee.

Dr DWYER — That is right, yes.

The CHAIR — Against this very small, identifiable cohort, so I think perhaps some of the additional groups that Mrs Peulich is discussing may be for discussion with others, but this cohort of approximately 200 are those who have been identified against that very strict criteria that the Coroners Court has very helpfully prepared for us in the committee.

Dr DWYER — The brief answer, in any event, is yes, there is an enormous amount of data collected under suicides, and they can be examined in a number of different ways. There are about 200 variables coded per suicide death. We have about 3000 suicides coded now into the Victorian Suicide Register.

Mrs PEULICH — Is there anyone doing that work?

Dr DWYER — Yes, we have got collaborations with Melbourne University, Monash University, there is a collaboration with Deakin on some of the research as well and with St Vincent's hospital.

Mrs PEULICH — Some of this work is ongoing?

Dr DWYER — Yes. To be honest, it is all dependent on funding. We have got a bit of funding for a couple of projects. We have got projects that we are doing to assist the coroners where we do not have any funding. Everyone has probably told you it is all about funding.

Ms SYMES — Thank you very much for your presentation and your submission. I know there is a very strict criteria and you have narrowed it down so I am not going to ask you to dissect it again. Your Honour, you talked about people's determination to end their life at a particular point, and we have talked about hopelessness, aloneness and fear. I understand that probably taking out those who have had 20 years of ongoing treatment and that sort of thing, but of the cases and just drawing on the model that they used in Oregon in terms of being able to go to your doctor and access something that will hasten death by virtue of not having to be a

violent death, would it be your view that in some of the cases that you have had to examine, if an alternative option were available, that for some of those deaths we would have seen people living longer and we would have seen some people not taking their lives? I guess the question is: are people taking their life prematurely because they are worried they will not be able to enact that violent death or end their own life if they waited?

Mr OLLE — I imagine that is part of it. I think that was what was particular mentioned in a case, that he thought that was a fear of his mother, that she may get to a stage where she could no longer end her life, that was her decision in a very miserable and distressing set of circumstances. I just think that anything to support the decision-making — it is not about prolonging — it is about supporting the decision-making of the individual; that is a good mandate. These are cases I cannot really speak to. I get a sense that yes, they would have loved to have died the way they lived, surrounded with love and support of their family, rather than die in circumstances of isolation — the antithesis of the way they lived — is my sense. If they could die the way they lived, I do not know in anything that I have dealt with that they would not have taken that opportunity, in my assessment, but we will never know. That is my assessment.

Ms PATTEN — I just want to move on to [redacted]'s report. Are we able to speak about that?

Dr DWYER — The [redacted] — —

Ms PATTEN — We will redact that name; pardon me. It is less about his death but more about the comments about rational suicide, which I thought was interesting, and also about the pentobarbitone availability. I note your comments that we can ban it, we can prohibit its import and we can do whatever we can, but obviously people are still using it. In the report you note that there were probably 52 deaths that could be related back to pentobarbitone. Of those, is there any way of telling us the number that were rational suicides, I think you said, or to look at the cohort that we have just looked at where their physical health had deteriorated and the provisions that you would use to address that small cohort. How many of those deaths to — —

Ms ENGLISH — Pentobarbitone.

Ms PATTEN — Yes.

Dr DWYER — There is a bit of overlap. I should just emphasise from the outset, sorry, the term 'rational suicide' is not a term of the Coroners Court.

Ms PATTEN — Okay. Thank you. I can see you trying to describe it in a footnote.

Dr DWYER — The purpose of this was to describe something else. This describes a bit of a different phenomenon to what we have been talking about. If I could have 30 seconds just to talk about why this was provided to the inquiry.

There is this idea that if you provide information about suicide methods and you make it targeted to your audience — so this is specifically around Exit International and *The Peaceful Pill Handbook*, and I am sure everyone is sick of hearing about it by now, but just for a bit longer. In *The Peaceful Pill Handbook* the stated audience is people who are in terminal decline, terminal illness, and there are a number of, I guess, glosses around it that talk about the concept of rational suicide. It is a highly controversial term because some people say suicide cannot be rational; other people say that the term itself is ideologically loaded and so on. But it was being used in this report and in the finding specifically with respect to looking at whether the deaths, the suicides, occurred in circumstances that were consistent with the stated audience of *The Peaceful Pill Handbook* or were not, so consistent with rational suicide — in other words consistent with the stated audience of *The Peaceful Pill Handbook* or not consistent with the stated audience of *The Peaceful Pill Handbook*.

The underlying point of the research was to show that over time there has been a big shift in pentobarbitone suicide, from people who were using it consistent with rational suicide, consistent with the scenario of an orderly end to life when you are facing a terminal illness, terminal decline and so on. There has been a big shift in Victoria from suicide in those circumstances to suicides of invariably young, physically healthy, mentally ill people. And so what has happened is that the availability of this information about pentobarbitone and how to get it off the internet — originally it was from Mexico, now China and India — is disseminated more widely. There have been claims from the authors of *The Peaceful Pill Handbook* that their messages are only intended for one group, but the unintended consequence of it is that people in other groups, people who are not the stated

audience, are picking up on it, they are obtaining their pentobarbitone in the way recommended in *The Peaceful Pill Handbook* and in the Exit International material and they are suiciding. That group used to be the minority, but now it is the majority of pentobarbitone suicides in Victoria.

The purpose of that was to illustrate a different point to what Coroner Ollie and Coroner English have been speaking about, which is the suicides in a context of unbelievable or unrelieved physical illness. I was just illustrating a different angle to the issue of end-of-life choices and how you provide people with information about those choices and what the unintended consequences are.

Ms PATTEN — Thank you. I guess unintended consequences of the internet could be put there. Just following on, from some of the anecdotal information that I have been hearing or reading there are a number of people who fit the cohort that we are talking about who have terminal illnesses and have unrelievable pain or who are declining that are using it. I just want to clarify: are you saying that people in that cohort are no longer using pentobarbitone.

Dr DWYER — That cohort has remained relatively steady, but what has happened is that this other cohort has just come up, so in terms of absolute frequency the other cohort has taken over. Just one other point of clarification, there is some overlap between this pentobarbitone group and the group we have been talking about — the 197 — —

Ms PATTEN — Yes, I would expect so.

Dr DWYER — But the pentobarbitone dataset is a 15-year dataset, where is this is just four years, so that is the reason why.

The CHAIR — Dr Dwyer, can I just ask a question about the 197 — the cohort you have identified. Coroner Ollie referred to the fact that there is not a big difference between male and female. Is there anything you can highlight in relation to the communities from which those people are drawn — whether they are from CALD communities or from any particular cultural backgrounds?

Dr DWYER — I do not know if we take questions on notice — —

The CHAIR — Absolutely.

Dr DWYER — But I could. If there are further things you are interested in, we have all the data; all the data is there, and with the permission of the coroners it would not be an issue to answer those further questions. So if you have further questions, absolutely. Intersection with diagnosed mental health and things like that — yes, I could absolutely prepare something if that assists.

The CHAIR — Thank you.

Ms FITZHERBERT — My question relates to that. You mentioned the suicide registry and that it has been in existence for four years or so. I am interested in what it contains, its purpose and who can access that information?

Dr DWYER — The Victorian Suicide Register was developed within the Coroners Court by the coroners prevention unit over about a four-year period, and the reason was because we got to a point where we felt that we just were not providing or were not able to provide the type of advice that coroners needed on suicides in order to break through just that basic number counting — this many people of this sex in this age group and so on — to get behind the numbers to, if you like, the underlying phenomena that might be underpinning these suicides and therefore identify opportunities for intervention.

We developed the Victorian Suicide Register to include a whole lot of different stuff. There are a whole lot of variables on physical ill health, on mental ill health, diagnosed and suspected, on other stressors, so life stressors that people are experiencing, interpersonal stressors that they are experiencing with family and friends and others. There is information specific to the method of suicide. There is information about health service contacts in both mental health and in general health. There is information about contacts with government and non-government organisations and so on.

The underlying idea of it all is to gather information so that we can identify points of contact with the service system where there are potential opportunities for intervention to reduce suicides. It is used by coroners very frequently. It is also available for access to people who have a valid prevention interest in it. We at the moment, as I have indicated earlier, have got a range of projects underway across a number of universities and also St Vincent's, and there is sort of a range of different research coming out across the intersection of suicide with family violence, with substance misuse, suicide and cancer.

We are looking at specific cohorts of suicides. Middle-aged men suicide at six times the rate of what you would see on average, particularly in rural areas, so trying to understand what underpins that. The suicide register is sort of a general tool. The idea is that if we code this huge amount of information, draw not just from the coroner's finding but from all of the material that was generated in the coroner's investigation — the witness statements and everything else — then maybe we will be able to start looking at some of these questions in more detail to be able to come up with ideas for intervention rather than just counting numbers.

Mrs PEULICH — That is exactly what I was thinking, that there needs to be a matrix and we need to be able to undertake some work to see where that intervention could be most beneficial. Is it possible to break it down by age and by geography and gender?

Dr DWYER — Yes, absolutely. It is coded from street address all the way up to local government area, by age, sex, everything pretty much. It is under evaluation at the moment by the University of Melbourne — Jane Pirkis in the Global School of Population Health. It is a solid research tool that has been validated by the suicide research community around Australia.

Mrs PEULICH — Are we able to obtain a briefing on the data? We are not just talking about terminal illness, because obviously we have heard the parameters.

Ms PATTEN — Yes, we are talking about end of life, not general suicide.

The CHAIR — Perhaps, Dr Dwyer, we would appreciate any further information you can provide.

Dr DWYER — Yes.

The CHAIR — The secretariat will be in touch to liaise with you.

Dr DWYER — Yes, absolutely. I would be very happy to do that.

The CHAIR — Before we close, if there is anything further you would like to say, I would invite you to make any closing remarks, having heard the questions. Or if you are happy to leave it where we are, we will leave it there.

Coroner English, Coroner Olle and Dr Dwyer, thank you very much for your evidence this evening. Again, thank you for your submission and the research that has gone into identifying that cohort in particular that you have discussed this evening.

Witnesses withdrew.