

JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

**INQUIRY INTO THE NEED FOR LAWS IN WESTERN AUSTRALIA
TO ALLOW CITIZENS TO MAKE INFORMED DECISIONS
REGARDING THEIR OWN END OF LIFE CHOICES**



**TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
MONDAY, 9 APRIL 2018**

SESSION ONE

Members

**Ms A. Sanderson, MLA (Chair)
Hon Colin Holt, MLC (Deputy Chair)
Hon Robin Chapple, MLC
Hon Nick Goiran, MLC
Mr J.E. McGrath, MLA
Mr S.A. Millman, MLA
Hon Dr Sally Talbot, MLC
Mr R.R. Whitby, MLA**

Hearing commenced at 12.32 pm**Mr NEIL FRANCIS****Professional Medical and Social Researcher, DyingForChoice.com, examined:**

The DEPUTY CHAIRMAN: On behalf of the committee, I would like to thank you for agreeing to appear today to provide evidence in relation to the end-of-life choices inquiry. My name is Colin Holt. I am the Deputy Chair of the committee. Our Chair, Amber-Jade Sanderson, will be joining us in a minute. As an introduction to the committee, we have Mr Simon Millman; Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research adviser; my name is Colin Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple. The purpose of today's hearing is to discuss the current arrangements for end-of-life choices in WA and to highlight any gaps that may exist. It is important you understand that any deliberate misleading of this committee may be regarded as a contempt of Parliament. Your evidence is protected by parliamentary privilege; however, this privilege does not apply to anything that you may say outside of today's proceedings. I advise that the proceedings of this hearing will be broadcast live within Parliament House and via the internet.

Would you please introduce yourself for the record.

Mr FRANCIS: My name is Neil Francis. I currently operate DyingForChoice.com, which is an information website which provides empirical evidence about the practice of assisted dying in jurisdictions where it is lawful around the world. I am a professional medical and social researcher. I am published in peer-reviewed medical literature, and I have been deeply involved with Dying with Dignity for over 15 years. I am the past president of Dying with Dignity Victoria; the past and foundation chairman and CEO of YourLastRight.com, which is the umbrella organisation of state and territory societies; and a past president of the World Federation of Right to Die Societies.

The DEPUTY CHAIRMAN: Thank you. Do you have any questions about your attendance today?

Mr FRANCIS: I do not. I guess that most of my contribution to the inquiry through appearing here would be in relation to dying with dignity legislation. I do have a suggestion with regard to advance care directives, which I believe may be part of the brief that the committee is considering, but most of the information that I would deliver will be in relation to dying with dignity law reform.

The DEPUTY CHAIRMAN: Before we start with our questions, would you like to make an opening statement?

Mr FRANCIS: Yes, a very brief one. I have a fairly enormous and what could be an intimidating amount of information. I am very happy to keep this quite short to give you ample opportunity to ask questions of your own interest. Just to sensitise you perhaps, I have quite detailed information about voter attitudes in Australia, not just about assisted dying but in relation to how voters would behave at elections in regard to politicians who support or oppose assisted dying bills before their legislature. Most importantly, I would be quite happy to correct—there is an enormous amount of misinformation about assisted dying, particularly in regard to jurisdictions where it is currently lawful. You will have heard about or read an enormous number of arguments about slippery slopes and suicide contagion—[inaudible] of Perth from the AMA, whose position against assisted dying is quite unjustifiable. I can demonstrate to you how their own research with regard to that does not support the conclusion they drew and, indeed, how very high the sources of misinformation can reach.

I will just play you a one-minute video. This is quite short but it will give you an idea of how far this misinformation comes from. I will ask the support staff to play video 5, “Some of your Dutch nursing home fears”.

The DEPUTY CHAIRMAN: We are just waiting for the sound to come from the video. I do not know if you would like to say anything else while we are waiting.

Mr FRANCIS: You will have heard an enormous number of items of misinformation; for example, the Dutch carry around little cards saying, “Please don’t euthanase me”. I have travelled to all the lawful jurisdictions, except Canada. I travelled to Oregon with the now retired Hon Ken Smith, the former Speaker of the Victorian Parliament, the Liberal member for Bass. We interviewed people about the Oregon law—the assisted dying law—which came into effect in 1997. We found that there was very wide support, including from those people who had been somewhat sceptical, a little bit concerned, before the law came in. I will show you an incredibly short video a little later on perhaps. There are three doctors in Oregon who continue to promote misinformation about practice in Oregon. When Ken Smith and I challenged them about drawing—they were making quite illogical correlations between what they thought was happening and the Death with Dignity Act, which simply did not hold. We challenged them. They acknowledged that they could not actually draw any cause and effect between the law and practices that they thought were inappropriate.

The DEPUTY CHAIRMAN: I think we are right to go now with the first video. We will play that now—potentially.

[12.40 pm]

The CHAIR: Mr Francis, I am Amber-Jade Sanderson. I am the Chair of the committee. While the staff are fixing the technical problems, my apologies for being late to start the hearing, and thank you to the Deputy Chair for kicking off. Just bear with us for a moment while we sort out the video.

Mr FRANCIS: That is fine.

The CHAIR: We have called IT to come and have a chat. Do members have questions for Mr Francis?

Hon COLIN HOLT: Have you got anything further to add?

The CHAIR: I did not realise; you are still on your opening statement.

Mr FRANCIS: I would be pleased, if the committee thought it were useful, to share some information I have about voter attitudes, particularly in regard to how voters respond to politicians who support or oppose assisted dying law reform bills. Would that be of any use?

The CHAIR: Yes, please. Politicians are always interested in that.

Mr FRANCIS: I am just going to switch screens, so you will stop seeing me and you will start to see my screen. Hopefully, you can see the first chart. Can someone confirm whether you can see the first chart?

The CHAIR: Yes, we can see that.

Mr FRANCIS: Good. I will go through this fairly quickly. This is the longitudinal support for assisted dying law reform in Australia. Back in the 1960s, it was about fifty–fifty, and over the 1970s, 80s and 90s it increased to a very significant and clear majority of support for assisted dying law reform, and opposition across corresponding levers dropped off quite strongly. We can say with certainty that current support is not an ephemeral thing; it is not a fly-by-night attitude. It is very significant and it is quite entrenched. The attitudes are quite similar between males and females—not much difference there. Across the age groups, there is very high support right across the age groups, dropping very slightly in the older age groups, and I will explain that in just a moment. Across the

states, of course you will have seen your own report data. This is from the Australian electoral study in 2016. That is run by Australian National University. You can see that support in Western Australia is very high and, indeed, opposition to assisted dying law reform in WA is the lowest of all the states.

In terms of religious affiliation, support is very high across the board, including a significant majority of Anglicans and Catholics. Opposition is highest amongst the minor Christian denominations and that actually relates to the charismatic, or pentecostal minor denominations. I will show you how that looks in terms of religiosity. This is empirical data. This is still the Australian Election Study data from 2016. You will see here this is a religiosity scale of those who reject religion; those who go to religious services but do not subscribe to any particular denomination; notionals who subscribe to a denomination but do not attend religious services at all; occasionals who attend religious services once or twice a year; regulars who attend about once a month; and the devout who attend weekly or more often. I think you can see quite clearly that the majority of the opposition to assisted dying law reform comes amongst the highly religious.

Why has it taken so long for that to translate into laws around the country? You probably will not have seen this chart before. This is quite unique. I have been through the *Hansard* records of all the state Parliaments looking for debating records by party on assisted dying bills. You will see that the green bar is the voter support and the yellow bar is how MPs voted in relation to an assisted dying bill—whether they support or oppose it. You will see that the Greens largely represent their own constituency; Labor falls a little short; others fall somewhat short; but, unfortunately, the coalition MPs have voted most significantly against the will, including of their own constituents. That can be pretty important for members of Parliament and for democracy. Certainly, amongst the coalition ranks in state Parliaments—this covers South Australia, Western Australia, New South Wales, Victoria and Tasmania; this is the sum total of the *Hansard* records where there has been a division on an assisted dying bill—the coalition is at present falling quite a bit short of the views of its own constituency.

[New slide.]

This is important because this is research from Newspoll in 2012. Just as a matter of disclosure, I commissioned this research as a professional researcher. Newspoll conducted this. It is a national Newspoll. It presents: if the voter opposes or the voter supports assisted dying, what would they do with their voting if the candidate supports or opposes—that is, they have the opposite view of the member or candidate at a general election? You can see here that the bars on the right, if the voter supports and a candidate opposes, result in considerably more consideration of voting against their usual candidate. I will say this is pretty important for legislatures to pay attention in some regards to the views of their electorate.

[New slide.]

This chart is only about Victorian data. This is about some Victorian electorates, and a similar kind of question was asked. This was sponsored by Go Gentle Australia and run by a professional market research company. It found that in an election if the position of a member—that is, the member of Parliament or the new candidate—on assisted dying was supportive, it would make 51 per cent of the electorate more likely to vote for them and only six per cent less likely. But if the candidate opposed, then five per cent would be more likely to vote, but 53 per cent would be less likely to vote, for that candidate. This has quite a significant consequence in terms of representation in the legislature.

[New slide.]

Just very quickly, I showed you the total graph previously. This is the data for swingers versus loyalists. These are swingers and those are people who are more likely to change their vote during an election period or on election day. Sixty per cent are likely to swing towards the supportive and 60 per cent are likely to swing against a negative. That is even more pronounced than those who are loyal. But still, even for loyal voters, around half of them say that they will switch their vote if their candidate does not support assisted dying law reform. Here we have the same thing broken down by parties. For Greens, 68 per cent of Greens voters will vote down their Greens candidate if that Greens candidate opposes. For Labor, it is a bit more than half. For coalition, it is 42 per cent, which in terms of those who would change their vote the other way, that is about four to one. It is a pretty important ratio. Does that make a difference in real life? This is not just theory.

[New slide.]

Here are the results from the difference between Victoria's 2006 election and its 2010 election. In 2008, Colleen Hartland, a Greens member, and Ken Smith, the Liberal member, co-sponsored an assisted dying bill in the Victorian legislature and they were hammered mercilessly by opponents of assisted dying for having done so, including at the 2010 election.

[12.50 pm]

What happened to their votes at the 2010 election? Ms Hartland's vote went up 31 per cent against an average increase of her colleagues of 12 per cent in the lower house and eight per cent in the upper house. She is actually in the upper house, so this is a massive increase in votes. For Ken Smith, a Liberal member, his increase was 22 per cent versus an average increase for Liberals—he sits in the lower house—the average increase in that house was 10 per cent, so more than double. So these things do have consequences in terms of electoral performance.

The CHAIR: Thank you very much. That is very interesting. Do members have any questions on that data before we move on to the video?

Hon COLIN HOLT: You talked about member voting against certain bills, but it does not take into account the quality of those bills, so if there were some fatal flaws. Was there anything that could have led to someone voting against it, besides the fact—you know, legislators?

Mr FRANCIS: In terms of the way that question was posed in the survey, that technically would not address that issue because folks were simply asked: the candidate for whom you would normally vote, if that candidate supported or opposed, depending on what your view was, would you change your vote for that candidate?

Hon COLIN HOLT: I am talking about a different slide. If you go back to the one of the first slides you put up about historical data of how MPs voted on end-of-life legislation. You had the coalition at 17 per cent and Labor MPs at slightly below popular support.

Mr FRANCIS: I am sorry; I am just trying to bring back the screen. Here we go. Is this the chart you are referring to?

Hon COLIN HOLT: That might be the one; that is it. It does not really take into account the potential quality of the bill and whether it comes from a government-sponsored bill or a private member's sponsored bill or even from a committee-initiated inquiry. It does not take that into account; it just takes into account the bill itself.

Mr FRANCIS: That is a good question, thank you, Mr Holt. The parties that you see on this chart—Greens, Labor, coalition and other—these are folk voting on the same bills. The coalition was not voting on bad bills and Labor was voting on good bills; these folk are all voting on the same bills. This is a differential on the basis of voting for the same bill. But you raise an interesting question

about the quality of the bill. The quality, of course, will mean different things to different folk. Let me just switch that off. In terms of quality of bills, it is a moot point as to what one thinks is a quality bill. All the bills that have been presented in Australian Parliaments have been quite conservative bills relative to other bills that are in lawful jurisdictions. They have been largely crafted around versions of the Oregon bill, which has been in effect since 1997. One might form a different view, for example, as to whether an individual who has an egregious and advancing illness that is causing intolerable suffering but is not going to result in death in the next six or 12 months—whether that sort of person should or should not qualify. These are value judgements that the legislature will need to make and so you will form your own view about that.

Mr J.E. McGRATH: Thank you very much for that input. I think it is very good for us as MPs. Have you got any evidence of members Parliament who were staunchly opposed and might have been a long-serving member of Parliament who did change their vote?

Mr FRANCIS: That is a good question. I could not tell you. When you say “staunchly”, that is a fairly strong commitment one way or the other.

Mr J.E. McGRATH: Yes.

Mr FRANCIS: Those who are staunchly opposed tend to be opposed—I showed you the religion chart—not always but often, on religious principles, and that is fine for themselves. In terms of someone who was initially opposed—somewhat with an open mind but, “I really do not think I’m going to support this”—was the Labor committee member of the Victorian committee, the Legislative Council committee there, Cesar Melhem. He was initially going to oppose the reform and he found that during the process of the investigations, including travelling to lawful jurisdictions and interviewing people—legislators and doctors and so forth in lawful jurisdictions—he found himself being quite satisfied and ended up supporting the bill.

The CHAIR: While we are talking about bills, has DyingForChoice done any work on the success or failure versus private members’ bills and government bills? This would probably have to look outside of Australia as well.

Mr FRANCIS: I think it would be fair to say that private members’ bills are consistently less successful than government-led bills. You would all be familiar with Marshall Perron’s work in the Northern Territory that brought in—it was a 1995 bill and became a 1996 act. That was government sponsored. He stepped aside from the Chief Ministership on the eve of the vote on it just to completely separate any issues of power and loyalty and so forth so members could vote according to their conscience. There have been innumerable private members’ bills that have been sponsored across the party. One of the difficulties is, if I can sensitise the committee in terms of this area—you will have had plenty experience of this in other areas—it is a catch 22 situation for a private member’s bill. As a private member’s bill, other members will simply say to the sponsors, “Bring a bill in and we’ll tell you whether we like it or not.” It is very difficult for sponsors to get input, to generate a contribution to structuring the provisions of the bill, in two very important areas: one is who may or may not qualify—that is a very broad area and needs consideration—and, secondly, the process of, procedurally, how is the thing meant to be enacted for those people who want to take the choice. Private members have a great deal of difficulty getting buy-in and stakeholder contribution to a private member’s bill. I believe the reason that the Victorian bill succeeded and is now an act—it will come into effect next year—is that it was government-sponsored and the government had resources to bring to bear, to formulate an expert committee to make recommendations to inform the writing of the bill that would then enjoy members’ support.

The CHAIR: You demonstrated that over time support for assisted dying has increased. Why do you think that is?

Mr FRANCIS: That is an excellent question. We will just go back to the video, if they can tell us as and when that is fixed. I do not want that to fall off [inaudible].

The CHAIR: The video is working.

[Video played.]

[1.00 pm]

The CHAIR: Thanks, Mr Francis.

Mr FRANCIS: Thank you. Sorry, I did not mean to interrupt you, Ms Sanderson. I will answer your question. Of course, numbers have increased in all jurisdictions where it has been made lawful, because of course the numbers are starting from zero. As a community becomes more aware that a provision is available and doctors become more convinced that they understand the processes and that they are not going to fall foul of the law, in most jurisdictions the numbers have been very, very modest indeed. In fact, just the other day I was looking at the most recent data from Canada, a fairly new jurisdiction—of course, the newest is Hawaii, which was proclaimed a couple of days ago. That is another lawful jurisdiction and that will come into effect next year. Canada has a very broad act. The act in Canada does not require the person to be terminally ill and expected to die within six months, as the US state acts do. So it has very broad provisions and yet in the second year of operation—so this is the 2016–17 report—the percentage of deaths that occurred under that act across Canada, population 36 million, was approximately, in raw figures, about 1 300 people, and in terms of a percent of all deaths, 0.51 per cent of deaths—so a half of one per cent of all deaths.

What I will do, if I may, is show you this. This chart is pretty important because most people ask this question, particularly in relation to the Netherlands, I think, because the figures are higher in the Netherlands. So let me just share my screen again. So, I have here a chart which shows—this is data from what are called the Rummelink Reports, which I am sure you have heard of. These are commissioned by the Dutch government and they are conducted roughly every five years. This is the Dutch euthanasia reporting rate. So, one of the reasons the figures appear to have been increasing is that more doctors are reporting their actual actions. You might notice that I put “euthanasia” in full quotes on the top of this chart and that is because of the definition in Dutch law, and this is also adopted by the researchers who produced this data on which this chart is based. If an intention of the doctor is to hasten death, it is classed as euthanasia, whereas in Australia, for example, many doctors would say, “Look, I’m delivering an advancing dose of analgesics to keep my patient comfortable and that is likely to bring about the patient’s death.” That would be classed as euthanasia in the Netherlands. It is not classed as euthanasia here. When we see a figure of around 80 per cent, much of the remainder—doctors are administering not barbiturates to expressly bring about death, but opioids to reduce consciousness and improve patient comfort at the end of life. That is one of the reasons certainly more Dutch people are asking for assisted death.

You will not have seen this chart before. It has been published nowhere, so, folks, here is a first for you. If you look at the data from 2001, which is when—not the blue lines. Blue lines are important. So, since 2002 here, the act came into effect in 2002 and folks say that since 2002 the percentage of all deaths, the rate has increased, those people using assisted dying. It was around 1.5 per cent. It is now around four per cent—slightly over. I just want to draw your attention to this data, because almost everybody starts at 2002 because that is when the act came into effect. But, as you all know, the Netherlands has had assisted dying in one form or another for well over 30 years. Its reforms started in the 1970s and became quite active in 1985. The Royal Dutch Medical Association published guidelines for physicians to say, “If you’re going to consider this, these are the procedures you must adhere to.”

Coupled with the reporting—so early on the reporting rate was very low. Switch from the blue bars to the orange bars; these are the reports before the act. So, the act is in 2002. This is what was happening before the act, and the rate was going up very quickly before the act. This was based on historical jurisprudence. The law did not bring anything new in. In fact, it introduced a few restrictions. For example, it put an age restriction on there that did not occur in jurisprudence. This was advancing; the rate was going up very high. The orange bars I have adjusted to the equivalent reporting rate here. In terms of actual rates, the orange bars are it, not these low reporting rates.

In late 1998, the Dutch government introduced—and you will be familiar with the euthanasia commissions. They investigate every single case that is reported, and a judge will determine that case as to whether the physician has followed procedures, has the appropriate paperwork and so forth. At the end of 1998, the government introduced those commissions. It was not introduced in 2002. It was introduced in 1998, and physicians became very nervous about whether they were fulfilling the guidelines and that they were going to—every single case was micro-inspected by a euthanasia commission comprised of three people: a lawyer, a medico and an ethicist. So, the rate dropped off quite significantly. It has only in recent years been returning to where it would have been. So, these are all explanations as to why the rates have been going up.

I just want to clarify one thing for you. In terms of misinformation, you will hear an enormous amount of critique of the Dutch—the Benelux countries' legislation is all quite similar; that is, it does not require a terminal illness. The person may simply have an advanced illness that cannot be relieved and is intolerable. You will hear a lot of misinformation about how psychiatric cases are driving this enormous growth. They describe it here as saying that this is driven by psychiatric cases. This is not true. This is the driver: cancer. By far and away, the majority of the increase in cases is driven by cancer. Here is dementia. Here is mental illness. So, they are still very, very minor and uncommon grounds for requesting assisted dying.

Why is cancer so much in the majority? Obviously, with an ageing population, you have more chance of getting cancer. Indeed, in the Netherlands, this is the rate of new cancer diagnosis in the population. It has been increasing over time. So there is more cancer around. A couple of quick follow-ups on why that is increasing. Assisted dying requests per rate of all deaths back in 1990 was 6.9 per cent. So, in 6.9 per cent of all deaths, a person requested an assisted death. That was fairly consistent before the act came in. You can see what happened after the act came in. Either patients stopped asking or perhaps doctors, indeed, stopped hearing requests because they were quite nervous about being micro-inspected by the commissions. The other piece of evidence is the proportion of requests being granted. That was increasing slightly over a period of time before the act and it dropped significantly after the act. So, in the latest data from 2015, still only half of the requests were honoured. I hope I have given some evidence to support why the numbers are increasing.

[1.10 pm]

The CHAIR: Yes. My question also went to why community support for assisted dying is increasing, so why the general community, through the polling that you demonstrated?

Mr FRANCIS: Look, I think the answer to that one is relatively straightforward, and that is approval or agreement with assisted dying in restricted circumstances is increasing because religiosity is decreasing. It is quite clear from the Australian Bureau of Statistics data that religious affiliation in Australia has decreased very significantly in the last 30 or 40 years.

Hon Dr SALLY TALBOT: Mr Francis, while we are on the subject of the statistics relating to support for euthanasia and particularly voluntary assisted dying, I wonder if I could get you to comment on some evidence that the committee heard during the course of our inquiry. You may have had a

chance to have a look at some of it, so you may be familiar with this. We heard some evidence from the AMA that there was approximately 25 per cent support for looking at some kind of voluntary assisted dying legislation. When the committee put that to one of the medical people who came to be a witness, this is what he said: Doctors would all be thinking the same way on the euthanasia issues. There are doctors in Canada who are saying, “We are very uncomfortable with this process. Initially we thought it was okay; now we’re uncomfortable and now we don’t want to have anything to do with it.”

Have you had a look at the situation in Canada, and can you comment on whether there has been such a phenomenon in Canada?

Mr FRANCIS: Look, I have not looked at the doctor opinions because I am not connected to the medical professional body there, but I can say that when I make a claim, you will see that I present the evidence to substantiate the claim. If you have any medicos presenting to the committee making this claim, then you need to ask them for the evidence for the claim.

Hon Dr SALLY TALBOT: That is a fair point.

Mr FRANCIS: I cannot furnish the evidence where there is some considerable doubt as to its veracity. I can tell you that in terms of the AMA I would be extremely surprised if both the Western Australian president of the AMA and the national president of the AMA have not already made fairly strong representations to the committee against assisted dying law reform. Their stance is well known. I have provided to your research officers a quite detailed paper of an analysis I did on the AMA’s survey. The AMA ostensibly conducted a survey in 2015–16 of its membership, and the executive of the AMA determined on that basis that it would continue to oppose assisted dying law reform. I have furnished a quite detailed report.

By the way, when that survey was in progress, I personally wrote to Michael Gannon, the AMA president, as a professional researcher to report to him that there were multiple, multiple egregious flaws in their research methodology. First of all, they were polling only AMA members. I can report to you, on the basis of the AMA’s own data, that 72 per cent of Australian doctors are not AMA members. So they only polled AMA members. They sensitised respondents by saying, “Here is the AMA policy. Do you agree with it or not?” That is a seriously biased approach, particularly when you are asking your own members. So members would be quite reluctant to say, “Well, no, I don’t agree with the policy”, but a very significant proportion of them actually did. I will just see if I can bring up the key statistics—no, that is going to be too hard. But 60 per cent of even the AMA doctors who were polled—this is what the AMA does not put in front of you and showcase their own statistics of their own members, and by polling their own members they will necessarily be finding more opposed doctors because some doctors who are supportive have actually resigned from the AMA because of its opposed stance. The sampling was biased, the questions were biased, and yet still they found 60 per cent of their own membership said that if assisted dying is made lawful, it should be delivered by doctors. So well over half said it should be delivered by doctors.

Hon Dr SALLY TALBOT: I think we have just managed to pull that up on the screen. This is from the paper that you wrote in March 2017, is it?

Mr FRANCIS: Yes.

Hon Dr SALLY TALBOT: I think the staff have found it.

The CHAIR: Sally asked the question I was going to ask next. Robin, did you have a question?

Hon ROBIN CHAPPLE: I did, but I have forgotten it.

The CHAIR: While you are trying to remember that, I had some questions about the slippery slope arguments that we have heard, and wondered if you could run through the jurisdictions of Oregon, the Netherlands and Belgium, and how those slippery slope arguments relate to those particular acts?

Mr FRANCIS: Thank you. I will bring up a document and share that from here because that will help me a bit. I am pretty sure it is this one. Professor Margaret Somerville made claims about these slippery slopes, and I published quite a detailed paper about it. I am just going to bring up a couple of charts. For example, a claim was made that there were terrible slippery slopes in Belgium, and a slippery slope particularly in terms of suicide contagion. The statement being made is that by allowing people suffering intolerably at the end of life to bring about a hastened death, it would send a suicide message to the rest of the community, and this simply is not true. For example, Professor Somerville said, “Well, the rates in Belgium and the Netherlands are terrible. They are caused by the assisted dying law”, and this is quite bizarre. This graph shows the suicide rates by European country. Belgium’s is somewhat high, and Switzerland’s is a little high—I will talk a little more about that later. This is the average. The Netherlands is lower. The Netherlands has had an assisted dying law since 1985. Belgium was only since 2002, so you would expect those two to be reversed if there was causation, so that was completely inconsistent. I will not bore you with the details, but this one is quite important. There is an awful lot of misinformation about the Netherlands. This is a longitudinal chart of the unemployment rate in blue, and the suicide rate in the Netherlands in red. You can see that there is quite a strong correlation; in fact, 80 per cent of the variance in the suicide rate is explained directly by the unemployment rate. Margaret Somerville and her cohort say that since the law was brought into effect in 2002, it has gone up enormously. Well, it actually dropped before it went up. This is related to the unemployment rate. I will not bore you with the details; you will be able to read the report at your leisure if you are interested in that amount of detail. This correlation is specifically related to unemployment, and just a few key events that occurred in the Netherlands. This 1970s case was a very light sentence for a Dr Postma who helped her mother to die. The government then issued prosecution guidelines; that is, under what circumstances would a doctor not be prosecuted. The KNMG issued guidelines—that is the national royal Dutch society.

[1.20 pm]

They issued guidelines and, at that point, that is when doctors seriously started considering offering assistance to those who requested it, so over a long period of time. This is when the practice was, first, seriously in numbers. You can see the suicide rate has decreased very significantly. It only increased after the GFC, because the Netherlands was very late and very tardy in producing protective outcomes for people. There were no employment programs. They had very poor social security programs. So, the suicide rate shot up with the unemployment rate very quickly.

In Belgium, here is Belgium before their act, with no assisted dying law at all, and the suicide rate was decreasing very slightly. Since the act has come into effect, it has dropped even further and at a faster rate, even while unemployment has stayed largely the same. There is no difference between that slope and that slope, but this is a significantly faster fall than that. So it is not the case in Belgium either. It is not true. You asked about three, but I will show you a fourth, because you did ask about Oregon, so let us speak about Oregon.

The CHAIR: I am obviously interested in the suicide slippery slope argument, but the argument that it gets expanded to include other categories of illnesses.

Mr FRANCIS: This is fundamentally untrue. Just before I answer that question, let me point you to the Swiss data, because this is quite compelling. Switzerland, as you would be aware, has an assisted

dying law. It is a single sentence in the Criminal Code, and it says that a person shall not be liable under the Criminal Code if they assist another person to die for altruistic reasons. That is it. There is no process, there are no qualifying criteria—nothing—only assisting for altruistic purposes. That law has been in effect since 1942. If that were the case, you would expect the suicide rate in Switzerland to be astronomical and to be increasing faster than anybody else's. You will see here that during the 1970s, indeed it was increasing. But when EXIT-Deutsche Schweiz, ADMD—that is the German society; this is the French society—was founded and assisted people with egregious and untreatable symptoms to die in a peaceful manner, the suicide rate dropped. When Dignitas was founded, it assists foreigners, not locals—these are people who travel to Switzerland specifically for the purpose of an assisted death—the rate has continued to drop. So I just wanted to bring that to your attention.

If I can now address your question, which was the broadening of legislation over time, there is one example. That is it—one example. While you will have enormous numbers of opponents saying to you that they are increasing the qualifiers and how it is done and so on and so forth, let me make it as clear as I can to the committee that since the Dutch law came into effect in 2002, not one word—I repeat that; not one word—of the legislation has changed. None. Whoever tells you otherwise—I would encourage you to go to the Dutch Parliament and inquire of them yourselves. It has not changed one word. There has been some further advice from the government. For example, their law allows an assisted death for cases where there is mental suffering. So the government has published further guidelines. The legislation is identical. The government has clarified that if a person has a mental condition, then these are the steps and procedures that we would deem acceptable in those sorts of cases. The law has not changed.

Belgium is the one case where there has been change, and that is they lowered the age from 18 to 12.

In Oregon, the law has not been changed. The regulations have changed very slightly, I have to say—that is, there have been minor changes in regard to, for example, it was not immediately clear in the legislation what being a “citizen” or a “resident” of Oregon meant. So the regulations were updated to say you need a driver's licence or utility bills for a period of more than a year, or whatever the provisions are, just to clarify what is in the legislation. But there have been no changes to any of those laws.

Canada is a slightly different case because, as you know, Canada has a Bill of Rights, whereas Australia does not, so the assisted dying legislation was brought about by challenging on the basis of human rights under the human rights bill. There are still conversations going on about who may qualify under those circumstances, but still, in its present form, the Canadian act, the national one—not the one from Quebec; that was a little earlier and a little separate—allows that a person does not have to be terminally ill, and they do not need to be in a position to die within six months, but the qualification criteria are quite broad, and yet here we are still with the assisted dying rate at 0.51 per cent. It is less than one per cent.

Mr J.E. McGRATH: Mr Francis, a lot of people I speak to, when I canvass this subject, say of course euthanasia should happen, provided we bring in safeguards. That is the biggest concern of people that I talk to; if it did come in, they do not want it running out of control and they want proper safeguards. What sort of safeguards do you think are the best safeguards? I think everyone agrees that patient comfort at the end of life, we all accept. We all accept that when someone is going to die in a few hours or a couple of days, a peaceful way for them to end this life or depart this life, most people would accept. But people have problems with some decisions that might be made—for instance, a mental case, or someone who does not want to keep going where with palliative

care, they might be able to keep going for a number of years. That is an area where I find with the people I talk to, some concern. What advice could you give me on this matter?

Mr FRANCIS: It is an excellent question; thank you. Can I preface it with a couple of comparative remarks, and these will become very clear as I make them. That is, as you good folks are considering the possibility of assisted dying legislation and what provisions ought be in such legislation to ensure that people really do qualify for it, and the processes are robust and clear, may I compare that to two other scenarios where a patient may actively and consciously opt for death—it is their conscious decision; they are opting for death; that is the express choice they are making—which has none of the safeguards that you may consider, and that is that a patient has a right to refuse unwanted medical treatment, even if that medical treatment is life-saving. There is no requirement for them to be shuffled off to a psychiatrist to find out whether they are loopy or not. There is no requirement to find out whether the relatives who are after the property have applied any undue pressure. These are egregious inconsistencies between identical scenarios where patients can actively opt to die. The second point is VRRF—that is, the voluntary refusal of food and fluids. A patient might decide, “Look, I’m thoroughly done. I’m out of here. I’m going to refuse food and fluids until I die.” Many Australian doctors will provide comfort care in those circumstances.

[1.30 pm]

But again, the patient’s direct thought is to die—that is the choice. There are no qualifying criteria, there are no procedural criteria, so what I would encourage you to do is to think actively about how precious we are going to be about a gazillion criteria in relation to a physician-assisted death, which is currently illegal, versus two forms of deliberately choosing death that are currently legal. Patients can legally do that now.

So, Mr McGrath, that is part of the first part of the answer to your question. In terms of what provisions you might include in legislation, I can only share a few thoughts. Broadly, again, first is the qualification criteria. You have two broad thrusts: who may or may not qualify; and the second one is: what are the procedures and processes? Just a few thoughts on who may qualify. The most restrictive around the world, of course, is those who are terminally ill and are anticipated to die within six months. For most of the states in the USA that have legislation, that is the form of qualification. That, of course, leaves out others who may suffer just as much as those folks but for longer—say, for example, a person with a degenerative neurological condition such as motor neurone disease, Parkinson’s disease and so on. They might last considerably longer than six months but be suffering intolerably and without relief. They would not be caught by that provision, so you might want to broaden it a bit. When I spoke to the Victorian committee about this, I suggested considering starting with the most restrictive and by adding on more qualification criteria, it might be that you adjust the procedures. Say, for example, if someone has longer to live, rather than a psychiatric consultation being suggested or optional, maybe in those circumstances you would make a psychiatric consultation mandatory, or two consultations mandatory. Of course, politics being the art of the possible—as all of you are only too aware—in order to get a bill across the line, one can be precious about whether something is or is not in, but I would highly recommend consulting colleagues to see what they are comfortable with. If we are able to help a significant number of people to access this when they are suffering intolerably and without relief, that is evidently helping nobody.

That is the first part—who may qualify. The second part is the procedures and processes. You would definitely want basics such as the patient has to be fully informed; they have to understand the nature of their condition and its prognosis; and the doctor has to consider and test the veracity of the request—examining the patient, for example, in the absence of family members or other friends

who might be bringing undue pressure to bear. These kinds of provisions we can find in pretty much all the bills that exist at the moment. The Victorian bill, a recent act, is much more detailed and nuanced to the point of having provisions, for example, about whether the medication is returned to the pharmacist unused or not, so there are many details about that. But those two broad thrusts are where energies need to be concentrated: what are the qualification criteria, and what are the processes that create safety around this being enacted?

Mr J.E. McGRATH: Thank you.

Hon ROBIN CHAPPLE: Thank you, if I may call you Neil; we have met on a few occasions in the past. An issue that has come up is quite clearly one of self-administration versus doctor-administration. Do you have a view in that area?

Mr FRANCIS: I do. Thank you, Mr Chapple; that is an excellent question, and it was asked of me by the Victorian committee. My recommendation was thus, and I am a little bit tickled that they adopted the recommendation. Most folks are comfortable with the self-administration version. If a patient self-administers, it is difficult to get more clear evidence about the veracity of their intention than self-administration. But what occurs when you refuse a doctor the ability to administer is that in some cases a patient might choose to die earlier. This is the opposite of what we are intending. They might choose to die earlier because they are losing the physical capacity to administer. That is a negative; we do not want to go down that route, so my recommendation to the Victorian Parliament was: you do not have to have an either/or if you combine those two things, and my suggestion was to craft the bill in such a way that if the patient was able to self-administer, they must do so. However, if the patient was physically unable to administer, then a doctor may administer. That means that those people with motor neurone disease, for example, who would otherwise be forced to take the medication somewhat earlier than they were prepared for simply because they had to because they have to take it themselves, they could then live out a bit more of their lives before asking a doctor to administer.

Hon ROBIN CHAPPLE: Thank you. In relation to self-administration, Mr Francis, there have been indications that self-administration can come with some problems—that is, the medication is not taken properly or the correct amount is not taken, which has led to people being under-dosed, if you will excuse the expression, and finding themselves in a worse state. Do you have any thoughts around that?

Mr FRANCIS: I would agree with you except for the very last portion—the premise that they are in a worse state. That is actually not the case. We have plenty of data from Oregon where it has been in practice now for 20 years. There are a very small minority of cases where the person does not die within an hour or so of taking the medication and some regain consciousness. When they regain consciousness, they are actually, if I can put it this way, undamaged from the medication. In fact, there was one famous case of a fellow who took it and regained consciousness a day or two later and was quite *compos mentis*, to the point of saying, “Well, why the bloody hell am I still here?” Under those circumstances where dosage may not have been adjusted for body weight, so perhaps a person with significantly greater body weight needs a greater dose, it is also the case that when self-administration is not conducted with—not assistance in giving the medication, but in providing advice about how things occur that the patient does not take sufficient or any antiemetic, anti-vomit medication, because the barbiturates are incredibly bitter and are likely to be regurgitated—so in those circumstances where insufficient antiemetic has been administered, there can be some regurgitation and therefore the dosage is insufficient, but they are not damaged. They do not come out of the process being a worse-off person.

Hon NICK GOIRAN: Mr Francis, thanks for your time today. I am conscious of the fact that we are already well extended past the hearing time. I have a number of questions for you. Do you have your submission handy?

Mr FRANCIS: Yes, I do.

Hon NICK GOIRAN: If I could just take you to a few things in your submission. Thanks for its comprehensiveness; I think it is more than 50 pages and you have made some effort to reference various parts to it. On pages 9 and 10 of your submission you deal with the issue of pain and suffering. I quote —

Palliative and medical care can never address all profound suffering at the end of life, regardless of funding or organisation: some kinds of suffering have no relevant or effective medical interventions.

...

To expect perfection in every circumstance is unrealistic and unfair.

I think that is a very pertinent comment by you.

You have done a lot of research into the various jurisdictions. I think you mentioned that you have been to them all except for Canada. Are you able to inform the committee if assisted suicide has been executed with perfection in every legalised jurisdiction?

[1.40 pm]

Mr FRANCIS: I will take your verb with advice—“executed”, which I think is an unfortunate verb. Has it been conducted well? Yes, I would say largely it has been conducted. You will immediately pick on the fact that I have said “largely”, because of course I have recorded cases that are unreported. I would point out to the committee that while assisted dying occurs in lawful jurisdictions, it occurs in every jurisdiction in the world in which it has been studied, and the reporting rate in Australia is zero.

Hon NICK GOIRAN: Well, look, I think that is magnificent because that was the next area I was going to take you to, which is pages 14 and 15 of your submission. You have already jumped the gun there. There you say, and I quote —

Indeed, “euthanasia is performed worldwide, regardless of the existence of laws governing it” ... “in all countries studied” ... “albeit in a secretive manner” ... “in the privacy of their [doctor–patient] relationship” ... and with repeated involvement among some physicians ...

On the following page you argue that —

Law reform would also force assisted dying from the dark shadows, creating transparency and accountability around the process, which would then be open to discussion and improvement if required.

I thought, again, a very pertinent comment. In the study that you have done, in which jurisdictions have such improvements taken place?

Mr FRANCIS: I missed the last bit.

Hon NICK GOIRAN: In which jurisdictions have such improvements taken place?

Mr FRANCIS: In Oregon and Washington, for example. They both have palliative care systems that have improved in the period that their assisted dying laws have been in place. Indeed, Oregon and Washington are in the top 10—they might even be the top eight; I cannot remember—they are

certainly right up there in the top echelons of the quality of palliative care that is delivered across the USA states.

Hon NICK GOIRAN: Sure, but, with respect, that is not what page 15 of your submission is talking about. You are not talking about improvement of palliative care; you are talking about assisted dying and forcing it from dark shadows, creating transparency and accountability around the process, and this would then be open for discussion and improvement. We are not really looking at whether palliative care improves. You are making a point about it otherwise being underground.

Mr FRANCIS: Good point. In the Netherlands, which has the oldest assisted dying framework in the world, it has allowed doctors and patients to have open conversations. In fact, when Ken Smith and I went to Oregon, we found very clearly that physicians and patients, particularly physicians who had been somewhat opposed or concerned about the legislation before it came in said quite clearly—Dr Peter Reagan, for example, was the first doctor to prescribe under the Oregon law, and all these folks, to a person, said it helped improve doctor–patient conversations. We do not have to speak in code; we do not have to circle around issues and not make ourselves clear. They absolutely appreciated that they can talk openly about what their views are, what they are asking for, what they are not asking for, and so that quality has improved enormously. It has improved enormously in Belgium and the Netherlands. Those conversations are open and the cases are recorded and investigated by their commissions, whereas here in Australia, where assisted dying does occur, there is no referral to an ethics committee, there is no consultation with other doctors, there is no review by a board of any kind. It all happens under the covers, at the private discretion of an individual doctor and an individual patient, and I would argue that that is not an appropriate standard of conduct.

Hon NICK GOIRAN: When you say the cases are reported, I recall a slide that you showed the committee earlier, I think it was from the Netherlands, which indicates that there is still under-reporting taking place.

Mr FRANCIS: I did explain that. There will always be cases that are not reported. In Australia, as I have stressed to the committee, none of the cases are reported—nil, zero. What the law does is it facilitates a framework in which patients and doctors can converse and follow a course of action lawfully. Can a law prevent people from breaking it? Of course not—it would be silly to say we must not have a law against speeding, because people will speed. That is a similar argument here, saying that people might break the law. Harold Shipman in the UK killed many patients in the complete absence of an assisted dying law. This law does not prevent certain small numbers of people from behaving extremely badly. What it does do is give people of good record and good conscience a lawful framework to be able to choose a course of action. That is its purpose.

Hon NICK GOIRAN: Have you had an opportunity to review the Northern Territory legislation when it was in place?

Mr FRANCIS: I have, but a very long time ago. It was terminated about eight months after it came into effect.

Hon NICK GOIRAN: That is right. Is it your view that the law was broken at any time when euthanasia was legalised in the Northern Territory?

Mr FRANCIS: I do not believe so. In the eight months it was in effect, only four people used the law. Four people died under the provisions of that act. It was actually quite a difficult environment, being the first structured legislative approach to assisted dying. The number of doctors who were willing to participate in considering an assisted dying case—not even administering the drugs, but considering the case—was very, very small. The AMA in the Northern Territory was utterly opposed,

so it was extremely difficult for the four individuals who used the law to actually go through the process and follow the criteria.

Hon NICK GOIRAN: Sure. What is your evidence to the committee? Was the law broken in the Northern Territory or not?

Mr FRANCIS: I do not believe so.

Hon NICK GOIRAN: Okay. Now, at page 36 of your submission you deal with the issue of choice, and you state —

Legislation that allows those who seek or are willing to support a hastened death to do so, at the same time as those opposed may elect not to participate, permits both world views to co-exist.

That was a very good point, albeit that I would probably only agree with it in theory. When you say that, how do you define “choice”?

Mr FRANCIS: I am not sure that I follow your question—choice of participation?

Hon NICK GOIRAN: Yes, you are indicating that the two world views can coexist because, at the end of the day, people can choose to be involved, if you like, and opt into the system, but you are not obliged to participate. When you say that people can choose to be involved, how do you define choice?

Mr FRANCIS: When people can choose to participate or not?

Hon NICK GOIRAN: Yes.

Mr FRANCIS: If someone is utterly opposed to this assisted dying—let us assume that an act gets up and this legislation permits such a thing—people can decline to participate in it, while others choose to participate in it.

Hon NICK GOIRAN: I think you indicated earlier that choice had to include that the person needed to be informed. I think that was one of the safeguards you might have responded to my colleague, John McGrath.

Mr FRANCIS: Yes, they do need to be informed. They need to be informed about their illness and about its prognosis and the likely trajectory that they will follow.

Hon NICK GOIRAN: Should their choice be free from duress or undue influence?

Mr FRANCIS: Correct.

[1.50 pm]

Hon NICK GOIRAN: I think you will agree with me that we cannot provide redress to the uninformed or coerced patient after the fact. Do we have to simply accept that there are going to be some casualties?

Mr FRANCIS: No. I reject that argument entirely because it is based on a false premise in that you are saying that it is after the fact. You design the legislation so that the doctors who are assessing the case inform themselves in advance of any administration of assisted dying that they so qualify.

Hon NICK GOIRAN: At the very start I asked you if you are aware of any legislation overseas where assisted suicide had been executed with perfection. You did take exception to my verb but you did say “largely”, so it would indicate that in some places it has not been conducted with perfection.

Mr FRANCIS: This is the very point I was making—that the legislation provides facility for people to take a course of action under the law. It does not prevent people from breaking the law.

Hon NICK GOIRAN: Indeed.

Mr FRANCIS: Let me further explain that. Right now doctors break the law by assisting people to die in Australia. Doctors break the law—not all of them by any means, but a lot of doctors break the law. When you bring in legislation that permits assisted dying with restricted circumstances, doctors can operate within the law. Does that prevent a doctor from acting outside the law? No, just as a speeding law does not prevent a person from speeding. No law can ever prevent anybody from doing something. Those who are going to act illegally may still do so or they may actually switch to the legal form where you as legislators have laid out the qualification criteria, you have laid out the processes and procedures and you are satisfied that those are quite ample and satisfactory and you are happy for doctors and patients to operate in that environment. Some doctors may operate outside the law but they would do that before the law came in. It is not a consequence of the law.

Hon NICK GOIRAN: I am curious to know on what basis the committee can have any confidence that current law breakers will suddenly become law abiders after a change in the law.

Mr FRANCIS: It is quite simple. That is because there is a legal avenue.

Hon NICK GOIRAN: In the Netherlands, they still do not report anyway.

Mr FRANCIS: I explained that. Let me repeat that. It is quite important that certainly the majority—certainly, I will not claim all; that would be inappropriate—of cases that are reported are of doctors who are administering barbiturates that have no clinical purpose other than to bring about the patient's death at the patient's request. Of those other cases, they are defined as euthanasia because one of the intentions of the doctor was to hasten death. Their other intention is to relieve intolerable symptoms by reducing consciousness of the patient. In those other cases, the ones where they are not reported are almost all an administration of opioids. That is what doctors here do. That is what doctors in New Zealand do. That is what doctors in the UK do. They administer opioids to diminish consciousness and to relieve the suffering of the dying patient. Doctors, not just the public, still have a wide opinion that the administration of opioids can hasten death. When they are properly titrated doses, they do not. But the studies in the Netherlands still classify it as euthanasia because an intention of the doctor was to hasten death, even though what they did was extremely unlikely to hasten death. It was just so classified because that is the law in the Netherlands.

Hon NICK GOIRAN: I will just say, Mr Francis, because I know that I have taken quite a bit of time and there are other committee members with questions, that I just want to thank you for your evidence today.

The CHAIR: Mr Francis, I am conscious that we have run a bit over time. We do have a couple more questions. Would you mind if we detained you for a little bit longer?

Mr FRANCIS: Sure.

Hon Dr SALLY TALBOT: Mr Francis, can I explore with you a bit further the question of who is included in the provisions. You mentioned the difficulty presented, for example, by the Victorian legislation for people with motor neurone disease. The committee is familiar with that statistical evidence that people with cancer will often have quite a high quality of life until relatively shortly before they die whereas people with other sorts of diseases, particularly neurodegenerative diseases, will have a rapid decline fairly early on. One of the things that has interested me about watching the Victorian process is a concern about people with dementia and the various forms of dementia, not just Alzheimer's, so the movement-related dementias associated with Parkinsonism, your Parkinson-type diseases. Do we need to include people with those diseases in this kind of legislation? I will just start with that broad question.

Mr FRANCIS: Thank you, Dr Talbot. That is an excellent question. I would preface my remarks by saying include in a bill those provisions that are likely to enjoy the support of the majority of members on the floor of the house, politics being the art of the possible. It would be wise to consult members as to what their views were. But in terms of whether you include mental as well as physical or somatic symptoms, I guess, is the kind of question you are asking, that would be up to you as legislators. I have to say that having read in excess of 8 000 peer review journal articles about such matters, that opinion in the medical fraternity is divided. Whatever you hear from individuals before the committee as witnesses, it is important to recognise that there is an overreaction to mental illness. It still suffers a significant social stigma relevant to somatic illnesses and it is important to be clear that because a person may have an illness of a mental nature, psychiatrists agree that that does not necessarily imply a person has lost decisional capacity about end of life.

Hon Dr SALLY TALBOT: Would you mind if I just interrupt you because I did want to come to a question about mental illness. The specific question I am asking you, albeit in broad parameters, is about people—if you conducted a surprise test on them, would you be surprised if this person died within a year? They might be in the early stages of motor neurone disease and the answer to that question might be no because the person could live for another five or six years. In other jurisdictions, how can people with those kind of conditions access this legislation?

Mr FRANCIS: That would depend on the jurisdiction. In most of the USA states, for example, to qualify, the person has to have a terminal illness and be anticipated to die within six months by their doctor. That is reasonably clear. There may be some small argument about whether the person is going to die in four months or seven months, but the provisions of the law are quite clear. Terminal illness, death anticipated patient within six months, then the patient may qualify according to other criteria—an adult resident and so forth.

In terms of other jurisdictions, in Benelux, for example, the acts in the Netherlands, Belgium and Luxembourg are all very similar, and indeed in Canada, and terminal illness is not required. What is required is that the patient is suffering intolerably and without relief from any form of administration or intervention that is acceptable. So it may be that there is some rare, uncertain treatment available, but that is not acceptable to them in their last phase of life.

Hon Dr SALLY TALBOT: That leads me to two further questions on the same subject, but zoning in a bit. Obviously, one of the ways that people, certainly in the Western Australian jurisdiction—I think most other states have this option—is advance health directives. That will be up to us to sort out whether our advance health directive system is working well or not. My question to you is: have you seen examples of the specific association of advance health directives with voluntary assisted dying options?

[2.00 pm]

Mr FRANCIS: Personal examples are a problem because I do not have the patients' records, but in principal it is only in the Benelux countries that assisted dying may lawfully be requested through an advance care directive. In other jurisdictions, you may not request it in an advance care directive; either it is not provided for or it is expressly excluded. In the Netherlands, for example—the first jurisdiction by jurisprudence initially and then confirmed in the legislation that was passed in 2001 and came into effect in 2002—a patient may request assisted dying in specified circumstances in advance of their incapacity to later so request. It is important that the committee understands that doctors honouring those advance care directive requests is extremely rare. It is extremely rare. In fact, I know of only three cases in the Netherlands—this is in regard to dementia—where a patient has stipulated a request for assisted dying while competent in their advance health care directive and then later as a result of dementia becoming incompetent. I just remind the committee dementia

is a terminal illness; make no mistake, dementia is a terminal illness. Once the dementia sets in at a certain level, they have lost the capacity to understand and to request and so forth. Doctors in the Netherlands where this is lawful are extremely reluctant to honour a request unless they can ask the patient directly and look them in the eye and have that conversation at the time to say, “Is this what you really mean? Is this what you want?”

Hon Dr SALLY TALBOT: This is where I wanted to ask you your views about mental illness. It is in connection with the assessment of capacity, so I am still on the same subject of who gets included in legislation. We have heard some very strong evidence from people who will come as no surprise to you that the assessment of capacity in relation to a request for voluntary assisted dying should be done only by a psychiatrist or a palliative care specialist or perhaps a gerontologist. Clearly, what has been spelled out to us—I am not making this up—is the implication that you have to make sure that you have not got a treatable depression before you can be considered. I went to my GP the other day and asked him what his view of my capacity was in relation to this inquiry and he confirmed for me what I expected he would say, which is that GPs assess capacity every time they see a patient. Do you have a view about who is competent to carry out that assessment of capacity?

Mr FRANCIS: Yes. If I could once again just preface my remarks by saying keep in mind, as the committee making recommendations, that there is no such requirement for a patient refusing lifesaving medical treatment in order to die and there is no requirement for a patient voluntarily refusing food and fluids in order to die. So if the legislature is being consistent, then a measure of capacity ought to be consistent across all of those choices whose direct and foreseeable intended consequence is death.

In terms of who ought to assess, it is my personal view that GPs are adequate in assessing. In part, that view is informed by Ken Smith and I speaking with physicians in Oregon. We specifically asked, again, Dr Peter Reagan, who wrote the prescription for the very first assisted dying case in Oregon, “How come in Oregon the rate of assisted dying has not soared?” He literally laughed and he said, “Well, it turns out that people don’t want to die.” This is a fundamental value we have that people are in desperately dire circumstances and in a place we are not sitting right now—we are all reasonably comfortable, if I may put it that way —

The CHAIR: Mr Francis, if you would not mind, I bring you back to answering the question, because we have one more question from another member, around who should be assessing capacity.

Mr FRANCIS: I think the attending physician should be assessing capacity. There may be an extension of that. For example, if your patient is making a request in respect of a somatic illness—something physical—my personal view is that the GP’s assessment is a wholly adequate assessment. It may be that if the committee recommends that some forms of mental illness or condition might qualify, then you might put in an extra requirement that the person is to be assessed by a psychiatrist or two psychiatrists.

Mr R.R. WHITBY: Thanks, Mr Francis. We appreciate your evidence today and we have put you through your paces. I was very interested to hear you mention what happens with palliative care in jurisdictions that have assisted dying. One of the things I have found is that there is almost an either/or. Either you have palliative care or you have assisted dying. One of the arguments against voluntary assisted dying has been let us just invest more in palliative care and that will fix the problem. I am interested in this idea that where jurisdictions have voluntary assisted dying, you experience some improvement in overall palliative care. I just want to tease it out more if I can. I think you mentioned Washington and Oregon. Are there other places where that has occurred, and do you have reason to believe that similar would happen in Australia with legislation like this?

Mr FRANCIS: That is an excellent question; thank you. Yes, there have been improvements. Data from Luxembourg is very hard to come by; it is a very small jurisdiction. But certainly in both the Netherlands and Belgium, the legislature, at the same time as introducing legislation to legalise restricted assisted dying, introduced either legislation or government policy to increase the funding of palliative care. In fact, that has happened directly here in Victoria as well. At the same time that the Victorian Parliament was considering this bill, the Victorian government announced considerably increased funding for palliative care. These are absolutely not either/or things.

I might just point out very quickly also in response to your question that while you will have received fairly negative opinions from the AMA and probably from Palliative Care Australia, or the Western Australian branch of it, I inquired of the AMA and Palliative Care Australia as to what specific policies and procedures they had for their members in attending to and participating in refusals of lifesaving medical treatment and voluntary refusal of food and fluid—these are things that directly and intentionally cause death—and the answer was none. I just find it quite curious that you would have very negative input from the AMA and Palliative Care Australia on assisted dying when they do not have policies on those two parallel death scenarios.

The CHAIR: Mr Francis, thank you very much for joining us today and for letting us take up much more of your time than we had anticipated. A transcript of this hearing will be forwarded to you for correction of minor errors only. Any such corrections must be made and the transcript returned within 10 working days from the date of the email attached to the transcript. If the transcript is not returned within this period, it will be deemed to be correct. New material cannot be added via these corrections and the sense of your evidence cannot be altered. If you wish to provide clarifying information or elaborate on your evidence, please provide this in an email for consideration by the committee when you return your corrected transcript of evidence. Again, thank you very much for your evidence this afternoon. We really appreciate you taking the time to talk to us.

Mr FRANCIS: Thank you. I appreciate the opportunity.

Hearing concluded at 2.08 pm
