## TRANSCRIPT

# STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

### Inquiry into end-of-life choices

Melbourne — 21 October 2015

#### **Members**

Mr Edward O'Donohue — Chair Mr Daniel Mulino
Ms Nina Springle — Deputy Chair Ms Fiona Patten
Ms Margaret Fitzherbert Mrs Inga Peulich
Mr Cesar Melhem Ms Jaclyn Symes

Participating Members

Mr Gordon Rich-Phillips

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#### Witness

Mr Neil Francis, DyingForChoice.com.

**The CHAIR** — I now welcome Mr Neil Francis from DyingForChoice.com.

Before I invite you to make a presentation, I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with a proof version of the transcript within the next week, and the transcript will ultimately be made public and posted on the committee's website.

We have allowed approximately half an hour for our time tonight. I again thank you for being here, particularly at this hour of the evening, and I invite you to make some opening remarks, and thereafter the committee will have questions.

Mr FRANCIS — Thank you, Chair, and thank you to the committee for the invitation to appear. I firstly congratulate the Legislative Council on the referral and having the wisdom to make that referral and the committee for its excellent work. We are having a little technical problem, but I want to draw to your attention something you will already be quite aware of, and that is the phenomenal number of written submissions that the committee and the secretariat have received in response to this issue. Whereas many inquiries receive perhaps a few dozen — perhaps even 60 or 100 — submissions, this one has received over 1000, and I think that indicates the importance of the referral to this committee on this issue. It is very important, and the community is deeply engaged with it.

I can also report to the committee something it may not be aware of. Of course you will understand that the terms of reference do not mention assisted dying in any way, shape or form. However — it is not up on the screen, I am sorry — 95.7 per cent of the submissions to this inquiry have articulated a point of view on assisted dying, and that says the community not only is deeply engaged with end-of-life decision-making but is very deeply engaged with the issue of assisted dying of one form or another.

I can also report that 35.3 per cent of the submissions that articulated a position on assisted dying were opposed and 60.4 per cent articulated a position in favour, so we have quite a broad representation of views amongst the submissions. The sad news is that I have my entire submission in the slide deck; the good news is that I do not intend to talk to all slides.

#### Visual presentation.

Mr FRANCIS — There are the submissions that have been received on this matter, and there are the opposition to and support for assisted dying that appear amongst all the submissions that have been published. There are a handful that remain private, to which of course I do not have access, but these are the ones that have been published.

I just want to provide a little heads-up, if you will, to the committee about biases in decision-making, and I identify three in my submission. One is the use of very strong emotional language, which appears quite commonly in opposition submissions to assisted dying. They use very strong language about Belgium, about Oregon and so forth, and when we experience very strong language we tend to disengage our critical faculties, and it is important that we re-engage them.

The second point is that repetition does not make a falsehood true, and I can say that the very great majority of those submissions that indicate opposition to assisted dying — which is very much their right, I have to say, and I respect the right of people to make those submissions — talk about Belgium and Netherlands slippery slopes. Just because that is said extremely frequently does not make it true.

The other is the use of authorities as undeserved evidence cues — that is, people in supposed positions of authority Sometimes these things are merely opinion; they are not actually empirical research facts. We need to distinguish between those.

I will skip through a lot of these — they are in the submission — but I will alight on several items. We are quite clear from multiple forms of research that there is overwhelming public support. It occurs across major religions. It occurs across the political spectrum. More than 60 000 Victorians at the 2014 state election were polled by Vote Compass, and you can see extremely strong support there — a very important issue for voters.

A little gentle reminder is that in the last decade the Youth Parliament of this state, four times out of four, has introduced, debated and taken to committee and voted up a one or other form of assisted dying bill. So this is not just a silver-haired issue, and it is not just seniors; this is of great importance to the whole community.

I critique, as you will see in the report, a number of items. I just want to highlight this one. On this chart, this is a single multi-country study, so the same methodology was used across a range of countries. This was in 2001, and so we have the Netherlands, Belgium, UK, Australia, Denmark, Italy, Sweden and Switzerland. I will point out that the very left and the very right countries in 2001 had an assisted dying law or regulation; the others did not. You can see that there is non-voluntary euthanasia occurring at various levels across those countries. For example, Belgium has the highest, but it is not caused by an assisted dying law. Belgium did not have an assisted dying law in 2001. So we need to be careful when we look at an item and say, 'We think that is unfavourable; let us tie it to something else we think is unfavourable, which is assisted dying', that we are not automatically making that connection but it is an inappropriate connection.

Looking at the longitudinal data, the rate of non-voluntary euthanasia in Belgium and the Netherlands has decreased, not increased. It has decreased since the law came into effect. If we look at Belgium, for example, this figure for non-voluntary euthanasia, that is before the law came into effect; it is not caused by the law. But when the Act came into effect the rate dropped. In the Netherlands, which has had regulation for many, many years — it became a statute in 2002 as well — the rate of non-voluntary euthanasia has continued to drop and it is now around the same level as it is in the UK, which is the world's gold standard in palliative care.

These are three charts. I just want to quickly show you these because these are not in the report. I just want to share with you what kind of illnesses folks are suffering from in the lawful jurisdictions when they choose one form of assisted dying or other. You can see from the blue line — the blue line is cancer — quite clearly that cancer is the overwhelming reason that people in the Netherlands on this chart choose assisted dying. It is the case in Belgium as well, and it is also the case in Oregon.

One thing I do want to highlight — I do know it is in the report, but I want to highlight it — is that there are three forms of end-of-life decision-making as I am conveying them here. One is assisted dying, which is a subject of interest to this committee. There are two that are legal already. One is the refusal of medical treatment. If that is life saving, that is a decision whose direct and foreseeable consequence is death. So is the voluntary refusal of food and fluids. Both those things are legal in Victoria. They have no oversight by record-keeping of a committee reporting to Parliament. On the refusal of medical treatment, the Medical Treatment Act 1988 does require the doctor to adjudge whether the patient has decisional capacity — that is about it — and there are no conditions for the voluntary refusal food and fluids. Have we had an absolute avalanche of deaths by these methods since the Medical Treatment Act came into effect in 1988? No. In fact the police statistics unit says that there have been no prosecutions for inappropriate persuasion recorded in their database.

There are various forms of misinformation. I will go very quickly through these. Professor Margaret Somerville in her public addresses against euthanasia says that Els Borst regrets the law reform she introduced into the Dutch Parliament. I interviewed Els Borst in person in Utrecht in 2012, and she quite spontaneously said, 'I am still very happy with it. I think we did the right thing, and I would like to meet this Margaret Somerville, but perhaps she would not listen anyway'. Margaret Somerville also says that the Dutch elderly are afraid of going into nursing homes; they go to Germany instead. Well, there is no empirical evidence to support that assertion. It is populist nonsense in the press. I asked Dutch Senator Professor Heleen Dupuis, who was really quite frustrated and exasperated with this suggestion, because it is really quite silly, and this kind of commentary is really not appropriate.

Paul Russell of HOPE has sent in a submission, which of course is entirely his right to do. He has published on a number of occasions that there is suicide contagion in Oregon because the data since 2000, he says — here is 2000 — the law came into effect in 97. Since 2000 the general suicide rate in Oregon has been increasing markedly, and he suggests that that is a result of suicide contagion. Well, it is not, because you have to compare the figures before the law with after the law, and you find that the average after the law came into effect is actually lower than the average before the law came into effect. And if you superimpose the unemployment figures, you will see a correlating trend. It is well established that of the variety of things that can cause people to choose suicide, unemployment is a significant factor, and we can see quite a correlation there.

Switzerland has had the world's longest standing assisted suicide law. It has been in effect since 1942. This is about Dignitas. Once societies had started assisting people to a peaceful death, did the rate of suicide go up? Was there contagion? I think the data shows otherwise.

This one is very important, because this is quoted liberally — including by academics, I have to say. In this figure here, the blue bars are Belgium. We are talking about nurses administering drugs which are said to hasten death; that is what this chart is about. Opponents of assisted dying highlight this figure — this is published in a particular paper — and say, 'Isn't it awful that Belgian nurses are hastening the death of patients without asking?'. Well, here is the rate it was, using the same methodology prior to the law coming into effect. This behaviour was not caused by the law; this behaviour is the general medical culture within a community. By the way, it also dropped; it did not go up, it dropped. If we go to the other side of the world and look at the data from New Zealand, we will find the rate is similar, and still with no assisted dying law at all the rate has gone up. This is quite unrelated to whether a patient has a choice or not; it is not driven by that.

Sadly the little bit of nonsense that the Dutch carry around a little card saying 'Please don't euthanase me' has now transferred across to Belgium. It has never been said of Belgium before; it has always been accused of The Netherlands. Professor David Jones from the Anscombe Bioethics Centre in the UK published an article not too long ago saying that the Belgians carry around a little card saying, 'Please don't euthanase me', so this has athletically jumped the country boundary from The Netherlands to Belgium. There is no evidence for this at all, and in fact Theo Boer, who you will be aware is opposed to assisted dying law reform, and the Dutch Patients Association, which is also opposed, are amongst a great number of people I interviewed in The Netherlands who say, 'This is really silly; it's just not true'.

Opponents make a big thing about Theo Boer converting from supporting the law to opposing the law. I interviewed Theo Boer in Utrecht in 2012, and he described himself as a sceptic of the law before he was appointed to a euthanasia commission. I have to say I found him a very reasonable and a very thoughtful fellow. We will differ on our points of view, and that is absolutely fine, but he was never an great supporter of the law. He is a self-identified sceptic.

Here in Victoria Nicholas Tonti-Filippini wrote a letter to all South Australian parliamentarians when they had a bill before one of their houses saying that two-thirds of those killed in lawful jurisdictions under euthanasia laws are women. I want to draw your attention to the chart on the right: the pink is girls, the blue is boys. The majority are males, not females. One only has to look at the readily available data to know that that is not true. There are enormous squads of misinformation being put, and when I visited Oregon with the former Speaker of the Victorian Parliament, the Honourable Ken Smith, we interviewed these three doctors at Providence St Vincent, and they volunteered that, no, they could not assert any causation between an assisted dying law and negative outcomes.

The committee has asked, I know in previous sessions, several questions which may or may not have been answered. If this one has not been answered, here is an indication. The question was asked, 'Well, if we were to implement some kind of assisted dying law, what kind of numbers might we expect to occur in Victoria?'. I have looked at the evidence from the Oregon, Washington and now California model and the evidence from the Benelux countries, and I can indicate that if the Oregon kind of model is the model that is adopted, approximately 120 people a year would use it — and it takes a while for that culturally to be adopted. It has taken ages for these figures to arise in their own jurisdictions. If the model adopted is Benelux — that is, active voluntary euthanasia is permitted and a doctor may administer if that is what the patient requests — it is likely to be about 1400 persons.

But I want to emphasise what is really important with these figures: these are the people who use the act. When there is choice available, a great proportion more people achieve a benefit because they know they do not have to worry about tomorrow. This is the message that Ken Smith and I heard again and again in Oregon: when people have a choice, it is not that they jump at the choice, it is that they can now pay attention to today and live today without worrying, 'If tomorrow is too awful, what am I going to do?'.

That brings me to the final part, which is the legislative options. This format is not in my submission, so it is just a little bit different, and that is I believe there are four areas that the committee and the Parliament might consider in terms of crafting a bill that affords Victorians the opportunity to make such a choice, and they are, first of all, who might qualify; secondly, how might assistance be rendered; thirdly, what processes and provisions might be brought to bear; and last but not least, what reporting and review procedures might be put

in place. I do not propose to go through these charts, but I have just indicated generally who might qualify. There are models that are restrictive, conservative, cautious and more liberal, so that the committee and the Parliament might consider on balance, 'Do we think this is the more prudent approach or is this the more appropriate approach?'. So on that note I will conclude.

**The CHAIR** — Thank you, Mr Francis, for your submission and for your presentation this evening. If I can just ask two quick questions. First of all, the analysis of the submissions you referred to at the start of the presentation, is that your own analysis?

Mr FRANCIS — Correct.

**The CHAIR** — And can you comment on the difference in the number of people who may use a voluntary euthanasia scheme — as you have described it, the Oregon model versus the Benelux countries? How do you come to those?

Mr FRANCIS — They are from the annual reports of the authorities in those jurisdictions. Every year in Oregon the Department of Human Services publishes a report. They are freely available on the web. Those charts are directly from the data from the Oregon Health Authority. In Belgium and The Netherlands they have commissions which interrogate the reports that are received, and they also publish annual reports as well as biennial in Belgium. Those all come directly from the source.

**The CHAIR** — Those figures are for those jurisdictions, not for what would be the potential — is that what those figures were — for those jurisdictions?

Mr FRANCIS — Just clarify — —

**Ms PATTEN** — By comparison.

**Mr FRANCIS** — Are you talking about these charts?

Ms SPRINGLE — The 120 versus 1400 and how you make that apply to Victoria.

Mr FRANCIS — Yes, I have calculated those in respect of the trend in growth of use of the law, because it is a cultural adaptation. It is not that the law is there one day and everybody is aware of it, understands it, wants to use it on day one. That is far from the truth. For example, in Oregon, Dr Peter Reagan was the first doctor to write a prescription under the death with dignity act in Oregon, and it took about five or six months for that to occur after the law had come into effect, so this is not a great rush.

What I am talking about is figures after a significant period of time, like a decade. These are proportional to the populations of the jurisdictions. So we have a population of 5.6 million; Oregon is about 3.6 million; Belgium is, if I remember rightly — do not quote me — about 11.7 million; and the Netherlands is about 16 million. We have got to balance those figures up.

**Ms SPRINGLE** — Thank you; it is very informative. I am curious to know if there is a model that you advocate for.

**Mr FRANCIS** — I think the model that is appropriate is the one that members are going to pass.

Ms SPRINGLE — Okay.

Mr FRANCIS — Let us be practical, and you have had practical speakers before. If one were to construct a model that did not have the support of the members in both houses, then we are not succeeding. The reason I brought forward these four questions about how one might consider the options — so who might qualify, how might the assistance be rendered, what process and provisions do we think are reasonable. Also comparing that, by the way, to the fact that people in Victoria are allowed to refuse life-saving medical treatment, no questions asked, and are allowed voluntary refusal of food and fluids, no conditions whatsoever. There is no reporting to Parliament. Let us not make patients climb Mount Everest with one hand tied behind their back to get the third form of assistance, which the overwhelming majority of Victorians want available, not that they will take it, but they want it available.

My suggestion is for the committee to take soundings. I would be very happy to assist the committee, if it were to ask, in drawing forth options for this — my example table is very simple; these can get quite complex — to think about the options, what the options are in the laws in the already lawful jurisdictions and to come to an understanding with one's fellow members as to, 'We believe we can help an awful lot of people with this approach, even if we are not helping everybody', and that will satisfy a lot of Victorians. I think 80-plus per cent of Victorians want law reform on this issue.

Mr MULINO — Thank you for your submission and also for providing evidence. I just wanted to frame it in that I think the ethical questions in this debate are very important, and these are issues that have been debated a lot, but I just want to focus in my questions in relation to your submission on some of the data because I think that is the focus of what you have looked at. I just wanted to ask, firstly: notwithstanding the fact that there are some exaggerations in your rises to some of the threats for the vulnerable, would you agree that it is still important to have appropriate safeguards in any lawful regime?

Mr FRANCIS — I would agree that forms of safeguards would be appropriate, and I would point you again at the spectrum from nothing at all, which is already legal — voluntary refusal of food and fluids, which many doctors support in Victoria — all the way through to incredible provisions which are almost impossible to qualify, which does have the patient climbing Mount Everest with one hand tied behind their back. So it is for the Parliament, I believe, for the members, to consider what it feels are a valid range of options.

In terms of these options, the Oregon model, for example, requires the patient to self-administer. There is an advantage to that in the sense that when someone self-administers, that demonstrates volition. There is nothing more clear than a patient self-administering their medication in order to achieve their death than taking it themselves, but the negative, the downside — this is where these tables get complex and need some consideration — is that a patient may have to take it sooner than they want. That is, they have to take it while they can take it, but they might not be ready yet.

But then you can formulate halfway houses. These are some of the options that are open and available. You might say, 'Look, if the patient can self-administer, the act will require the patient to self-administer, but if at such time the patient becomes incapable of self-administering, then a doctor may administer'. These are the kinds of options that might be considered.

Mr MULINO — The reason I asked is I think there is a section in your submission which talks about the logical circularity of some arguments, and I just wanted to clarify that. Notwithstanding the fact that you find some formulations logically circular, you do think it is an important policy consideration to have the appropriate lawful safeguards?

Mr FRANCIS — Absolutely.

**Mr MULINO** — Yes, that was all — just to clarify that.

**Mr FRANCIS** — I am sorry, I gave a long answer to that, didn't I?

**Mr MULINO** — No, I thought that would be the case, but I just wanted to clarify it.

Now just in terms of the data, I think the Oregon suicide graph is an interesting one. I think it is 23 in your submission. In your submission you look at the average pre and post, and it is lower post and higher pre. You critique the trend line that was submitted in one of the submissions by arguing that there could be some causation from high unemployment rates. This to me is an interesting case in point in that I totally agree with you that one has to be very careful with the statistics. So when I saw your submission, I suppose I was a little bit concerned about drawing a no trend line post, but I fully agree with you that you have got to look at potential correlations with contemporaneous social phenomena.

I guess my point is that I think this is really an example of quite a tricky phenomenon to disentangle and that I actually find the trendline the most natural way to interpret the post-reform data. Having said that, I agree with you. If there are simultaneous social changes that might be causal, then that is worth examining. But of course, as we know, correlation is not causation. I imagine we are both on the same page that one has to take care. I think that was an interesting case study in how tricky some of this data can be.

Mr FRANCIS — I saved you some charts because I have a chart for the Netherlands as well. Of course with regulation for a very long period of time there is considerably more data and the two lines basically follow each other — the general suicide rate and the unemployment rate. That is not to say that there are not other complicating factors. This is obviously a very complex area, but when you look at trends there are very clear indications. I agree with you in the sense that I am saying this is an indication that is a potential explanatory factor and it is not to be ignored, which it was. I can say that having read Paul Russell's submission to this inquiry, he now notes that he agrees that the evidence does not support his hypothesis, and yet on his website the three webpages which claim this hypothesis still appear, so they are quite inconsistent.

**Mr MULINO** — One thing that I would find useful, and apologies if I have missed this in your submission, but it seems to me that on some of the figures at least there is not a clear link back to the references in the bibliography.

**Mr FRANCIS** — They should all be. It is run by EndNote. I use a professional citation manager, so I hope — —

**Mr MULINO** — Figure 19, for example.

**Mr FRANCIS** — The reference should be in the text. The last sentence on the previous page gives you the citations for that data.

Mr MULINO — Okay.

Ms PATTEN — Thank you very much, Mr Francis. It is amazing, as was the video with Ken Smith and the Oregon, so thank you very much for sharing that. Regarding this issue of terminal sedation, as you said, we do not have any statistics on people refusing food or refusing treatment. I understand we have no statistics on implementing terminal sedation either. My question is: how is terminal sedation dealt with in countries like the Netherlands? Do they collect the data on that type of doctor-assisted — —

Mr FRANCIS — They do, and it is very complex, so I will try to be brief. This is one of the issues in understanding what the data actually means. It is really important not just to get a bunch of figures and say 'Ah ha! That's what it says'. You need to understand what questions were asked, what the context was and so forth, because, as you know, these make profound differences to how one interprets the data. The big issue with much of what you see in the non-voluntary euthanasia charts is indeed doctors administering opiates in accelerated relief of intolerable symptoms. For Belgium and the Netherlands the definition which is used by the researchers, the law and the commission is that one of the intentions of the doctor was to hasten the death of the patient. If that was one of the intentions, it is classified as euthanasia. Whereas here — —

**Ms PATTEN** — Then it is called non-voluntary.

Mr FRANCIS — If I could just take this short example. Imagine two identical beds in a hospital. In those two identical beds there are two identical patients. Standing next to those two identical beds are two identical doctors with identical syringes in their hands, and they administer to those identical patients the identical contents in those identical syringes. One doctor thinks privately to themselves — this is private — 'I am relieving the patient's symptoms, and it may well hasten their death'. The other doctor thinks, 'I may well be hastening my patient's death, and I am relieving their symptoms in so doing'. This doctor is hailed as a hero, and this doctor goes to jail for 14 years. So we can see how mixed the situation is.

Ms PATTEN — I appreciate that, Mr Francis. In some of the evidence we have heard about non-voluntary euthanasia rates in Belgium and the Netherlands. What I understand is that in those rates and in that data they are including what we would call terminal sedation or what we would call hastening death through an opiate.

Mr FRANCIS — This is why I was making the point. If you are talking about what was one of the doctor's intentions, some people would not classify it as terminal sedation. They would classify it as euthanasia because one of the intentions was to shorten life. If the intention was not to shorten life, but the two doctors did identical things, here in Australia a doctor says or thinks to themselves, 'I am aggressively relieving these intolerable symptoms, and I am hastening the patient's death', that is doctrine of double effect, which I need to say is not as simple, nice and clear-cut as people like to make out; it is problematic.

There is not a simple answer, but I can say that there is already a study available in the literature regarding the conduct of doctors in Belgium where they are considering hastening death. What did they actually do? They administered opioids. In the overwhelming majority of those cases the hastening of death was in the hours or possibly days. So in terms of action it equates to deep continuous sedation, terminal sedation, palliative sedation or whatever you want to call it, but in terms of intent the Dutch and Belgian laws are quite clear.

Mrs PEULICH — I have a few questions, if I may. Could I first of all say that your interpretation of some of the trends of submissions, particularly Youth Parliament, I would not necessarily accept the conclusions that you have reached. I have observed Youth Parliament: the way it operates, how it is selected and some of the organisations and themes that have been run. At the most recent one I recall that nearly every speaker was criticising one political party. I am just putting that on the record. I would not necessarily accept — —

**Mr FRANCIS** — Mrs Peulich, if you would mind speaking into the microphone; I am having a little trouble hearing you. Thank you.

**Mrs PEULICH** — First of all, given your interpretation of how strongly supported the proposition of voluntary euthanasia is — I assume you are talking about voluntary euthanasia?

**Mr FRANCIS** — And/or physician-assisted dying, yes.

**Mrs PEULICH** — Why is it that more jurisdictions do not introduce it? Why is it that parliamentarians are so equivocal about voting for it?

Mr FRANCIS — I can answer that very simply, Mrs Peulich, and that is because of the section that I deliberately put in my submission about misinformation. That misinformation scares legislators: 'Oh, goodness! There are doctors running around Belgium and the Netherlands putting patients to death without their request'. This misinformation is repeated often and volubly — remember the three decision-making biases that I identified right at the beginning of the address and the submission — these things make politicians fearful.

The second part of it is that there is a rule of thumb, if you will, amongst politicians that if we do not legislate for assisted dying in one form or another, then there will be no penalty at the ballot box, whereas if we legislate for it, there will be considerable penalty at the ballot box. You will see in my submission, in a national Newspoll voters were asked, 'If the candidate you would normally vote for had the opposite view from you towards assisted dying, would you be likely to change your vote?'. I will not be able to find it now, but there is a chart in there that indicates quite clearly that across-the-board it is about 4 to 1; by bringing in an assisted dying law, politicians standing in elections stand to gain four times on average more votes than they would lose by opposing it. That is what voters are actually saying.

**Mrs PEULICH** — So it is a vote winner in your view?

**Mr FRANCIS** — I am sorry, I am having trouble hearing.

**Mrs PEULICH** — Sorry. You are saying that it is a vote winner?

Mr FRANCIS — I am saying that in the short term, yes, it is a vote winner. Well, this is Australian research, and we do not expect Victorians to be considerably different from the rest of the country on this matter. If anything, they are more socially progressive — we are more socially progressive — so that is what voters are saying. And in fact this is borne out by a fair bit of evidence.

At not the last Victorian election but the previous one, Ken Smith was actively opposed by a Catholic mission in his own electorate for being vocally supportive of assisted-dying law reform. Now I do not know if you have looked at the VEC statistics, but Ken Smith achieved a significantly higher rise in his vote than other members in the coalition did at the election.

Previous to that, the member who brought the assisted dying bill into the Legislative Council in 2008, Colleen Hartland, when she was first elected, it was absolutely by the skin of her teeth. People told her ad nauseam that she would lose the next election because she had brought this bill in; she was elected by a considerably larger number of people.

Mrs PEULICH — Secondly, your physician-assisted dying regime: is it dependent upon people being able to articulate their view, and in terms of the safeguards that you have alluded to, what safeguards would be required to protect the inarticulate, those who may be illiterate, those who may not speak the language, those who may be demented, young babies and so on?

Mr FRANCIS — A clear principle of this reform is that it is only the person themselves that can articulate a considered decision for any form of assisted dying. You may already know, I will refresh your memories in any case: in the Netherlands and Belgium it is lawful for people to request assisted dying in their advance care directive; it is not lawful in Oregon. So again we have these different approaches.

What is the rate of assisted dying for those who have passed their competency in the Netherlands? It is very small. It is of the order of 1 or 2 per cent of all the assisted deaths. As people in the Netherlands told me, it is actually honoured more in the breach than in the observance, but the principle is that the person has to be able to articulate a clear decision themselves. Nobody else may decide.

Mrs PEULICH — I have one last question: given that you are into the debunking of myths and correcting misinformation — and I thought your presentation was interesting, because that is largely what you focused on, rather than advocating the positive case — the reported 1000 of those who have been accidentally euthanased in Holland, is that a correct figure, following your research?

Mr FRANCIS — Mrs Peulich, thank you so much for the question. It is an excellent question — —

Mrs PEULICH — I just thought, given you are into the debunking.

Mr FRANCIS — I can exactly answer your question, if you just bear with me one moment. First of all, you have used the expression 'accidentally euthanased'; just let me decline that premise of the question. The clear research shows that these are doctors who are administering opioids and that the shortening of life is in the order of hours or days, so we are not talking about people who have made no request and whose lives are being shortened by considerable periods. This is continuous, deep sedation.

But thank you for the question, I can point you to exactly the data. And here it is: for example, you have used the number of 1000, the panel may not be aware that on the websites of the Catholic archdiocese of Melbourne and Sydney, they say, 'We do not want to be like Belgium. Isn't it awful?'. They kill — one says 500, the other says 1000. Well, who is right? So, Mrs Peulich, here is what the data is — —

**Mrs PEULICH** — Without deriding, though, as I am just asking you to comment on the accuracy of that figure.

Mr FRANCIS — Here are the figures. This is empirical research; this is not guess work. That is the 1000 figure; that is the 500 figure. We cannot say anything about anything with a static point in time figure. We have to look at the longitudinal data, and the longitudinal data absolutely clearly shows that the rate of non-voluntary euthanasia is decreasing. That is the empirical research.

**Mrs PEULICH** — The rate of non?

Mr FRANCIS — It is classified as non-voluntary euthanasia. These are doctors who are administering opioids in considerable amounts to alleviate — aggressively alleviate — terrible end-of-life symptoms without a specific current request of the patient, and of course such things happen around the world. In every jurisdiction that has ever been studied, as I showed you on the previous chart, that occurs.

**Mrs PEULICH** — Doctors pop the patients off?

Mr FRANCIS — That is your expression. Other people would say that they are having their symptoms aggressively alleviated. These, by the way, do not happen in isolation. In Belgium and the Netherlands doctors confer with the family, they confer with other doctors, they discuss, 'Is this proportionate? Is this the best approach for this patient?'.

**The CHAIR** — We have gone quite some time over time. Are there any final questions from members? Mr Francis, is there any final statement you want to make before we conclude?

Mr FRANCIS — I do have a couple, if you would just bear with me, Chair. I noticed in a previous address — there were some excellent addresses — there was some discussion as to whether advance care directives ought to be made binding or whether they ought not be made binding. Now this is one of these binary questions where one is tossing around, 'Should we or shouldn't we?'. There is a solution to that — that is, the legislation can articulate that the person themself decides whether it is binding or not. Some people will choose, 'Yes, this is exactly what I mean; do not vary from this, please', and other people will say, 'Well look, this is a good indication, but if other things arise, please use your best judgement'. So it is not that this legislature has to decide that. It can grant that right to others.

You asked a question about advance care planning. I would urge the committee to have a look at the Oregon POLST system. It is a great system. It is in practice, so people have cards in their homes and have stuck magnets on the fridge and so forth. I would highly recommend, if you can, to travel to jurisdictions where this is lawful. Talk with people in Oregon, talk with people in Belgium and the Netherlands, as I and others have, and you will find enormous insights. If you are not able to do that, perhaps videoconferences, real conferences, with people who are at the coalface would be very, very useful.

**The CHAIR** — Thank you, Mr Francis. Ms Patten has one final question.

**Ms PATTEN** — Just one — yes or no. One of the witnesses said we need a plebiscite. Given the debate and all the data that you have collated, do you think we do?

**Mr FRANCIS** — I think the Parliament ought to consult its members as to what is an acceptable bill that will give choice to the overwhelming majority of Victorians who want it.

**The CHAIR** — Thank you, Mr Francis, for your submission and the evidence you have presented tonight.

Mr FRANCIS — Thank you.

Committee adjourned.