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 TWO

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

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Hearing commenced at 2.59 pm

Mr SILVAN LULEY
Board member, Dignitas, examined:

Mr LUDWIG MINELLI
Founder and board member, Dignitas, examined:

The CHAIR: On behalf of the committee, I would like to thank you for agreeing to appear today to continue with your evidence in relation to the end-of-life choices inquiry. My name is Amber-Jade Sanderson. I am the Chair of the joint select committee. We have Mr Simon Millman; Hon Dr Sally Talbot; Mr John McGrath; Dr Jeannine Purdy, our principal research officer; Hon Colin Holt; Hon Nick Goiran; Mr Reece Whitby; and Hon Robin Chapple. It is important that 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 you might 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.

We left off last time talking about the role of Dignitas. I want to ask you: do you think that the intermediary role played by associations like Dignitas provide a useful model for minimising concerns that people have the role of physicians would be undermined by legislating for physician-assisted suicide?

Mr LULEY: I hope I understand your question correctly. Please correct me if my answer indicates that I have not understood. Here in Switzerland, this intermediary role of an organisation like Dignitas has grown historically, because physicians did not react to the need of the public to discuss end-of-life options openly and because physicians, and especially the professional board—the professional union of physicians—did not react in time to the public need. You have emphasised this. Coupled with that, organisations were founded, like EXIT (Deutsche Schweiz), EXIT-ADMD, and us, Dignitas. In a way, it is the same effect as you have in Australia, where each state, as far as I know, has an organisation, a so-called Right to Die organisation. It is the same effect here. As our law is, this intermediary role went as far as regular, non-profit member societies like Dignitas. We are in a position to be in a triangle between the physician and the patient and his family and friends. Thus we are able to coordinate and arrange for accompanied suicides. Does that make sense?

The CHAIR: Yes, it does. Dignitas has been around for nearly 20 years. In that time have you seen a decrease in the reluctance of physicians to engage in assisted suicide?

Mr LULEY: The readiness of physicians to prescribe pentobarbital for accompanied suicides has grown consistently and slowly. As long as we have [inaudible] when [inaudible][1]. Quite often the organisation instructs the physician what to do and what to observe if they do that. In Switzerland we have, like, two approaches. If you have the situation that a patient in one of his consultations with the GP says, "GP, you are looking after me perfectly, but if I go downhill, will you help me to die in dignity?", the GP might say, "Yes. I will certainly help you. We'll see about that when the time comes." Then the time comes and the GP says, "Look, dear patient, I'm not the expert in this field of assisted dying, this field of accompanied suicide. I know that I can write a prescription for 15 grams of pentobarbital but I am not the expert of doing the accompanied suicide, of providing the medication, of looking after family and friends and so on." For this, we have organisations like

[1] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.

Dignitas. Then you will have this triangle of physician; patient and his family; and the organisation, Dignitas, where there is this combination. The GP would provide a prescription to the organisation in the name of the patient, of course—the prescription for the patient—and the organisation would be in touch with the physician and the patient, and arrange for all that. So it is kind of working together. One thing is it is a direct contact between patient and GP. The other situation might be that the GP disagrees. "It isn't right. I wouldn't write a script in your case, or I wouldn't do it," or for whatever reason, "because I don't believe in accompanied suicide." Then the patient would contact us as an organisation and we have physicians who are prepared to look into cases, to assess requests of patients who are not their regular patients. They have to start from scratch then, of course—see the patient, talk, assess their entire medical file because they have it not in advance, such as a GP has for 10 or 20 years maybe, but it is the same effect. Does that make sense?

The CHAIR: Yes, it does make sense. Thank you. Your submission refers to Dignitas' experience as one of the best means for preventing suicide and suicide attempts, and that one of the best ways to prevent suicide is to have a voluntary assisted dying scheme. Can you expand on that?

Mr LULEY: [Speaks in Swiss German to colleague.] Mr Minelli was making a comment to me in regard to your question.

We claim that assisted dying or access to the option of end-of-life choices or accompanied suicide is a good, if not the best, means for suicide prevention and suicide attempt prevention. In very simple words: if you have an emergency exit route that you know is legal, safe, dignified—however you want to define "dignified"—and you can involve your family and friends, if you know that you have such an emergency exit route in the situation of severe suffering, you are much less at risk to have to go in front of a train, jump off a high building, shoot yourself, poison yourself, stab yourself, or whatever other violent methods, to end that[2]. So the option of a legal safe "way out" is automatically making sure that people are less at risk to do violent do-it-yourself suicides. This is what you see from the figures in Switzerland. In Switzerland, the number of violent do-it-yourself suicide has decreased over the past 20 years, whilst the number of assisted suicides, accompanied suicides, assisted dying, has increased until about the year 2016, after which it levelled off, and even decreased a little bit, because palliative care has considerably improved.

[3.10 pm]

The option for a person in a suffering situation, no matter whether it is a physical terminal illness, whether it is physical suffering, whether it is a mental health issue—the option that the person can talk to someone, takes that person seriously[3] and says, "Well, we might have a way out for you that is safe and legal and without any risks" gives that person hope and reduces the risk that the person might attempt suicide. That is why we have been saying for 20 years that suicide attempt prevention and a competent suicide risk[4], assisted dying, whatever you want to call it, these two things go together. They are interlocked with each other just as much as palliative care and assisted dying are interlocked with each other. It is not one or the other. It is all together and it is all connected to each other. If people have a choice, they are less at risk to do something lonely and violent.

Hon ROBIN CHAPPLE: Just on that, I am not sure whether we have the stats from them already, but if there are statistics around that, the percentages of suicides, assisted dying, where you can actually show that suicides have decreased or stabilised, do you have that data?

[2] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[3] ibid
[4] ibid

Mr LULEY: It is available. I will have to provide[5] it for you because it is mostly, I guess, in German. It is published by the Swiss federal office of statistics. It is all on the web. You will find it, but I am not sure whether it is all available in English. But from official state statistics, one sees how the number of suicides has decreased and assisted suicides have increased. Just to give you a comparison, an interesting aspect: I shortly looked at the figures of the US state of Oregon, which, as you know, has assisted dying for 20 years. The Death with Dignity Act it is called and their law, as you are probably aware, is more restrictive than the Swiss one—only physical terminally ill with less than six months' life expectancy can access assisted dying in the US state of Oregon. Interestingly, their suicide rate has not really decreased. It has just stayed about the same over the years and, in fact, has increased just a little bit. But here in Switzerland, where we definitely have a more progressive legal situation, more open-minded, more liberal and gives more people access to assisted dying, here the number of violent suicides, has decreased and, yes, the data is available publicly.

Mr MINELLI: In the year of 2001 we had in Switzerland about 1 300 suicides and nowadays we have about 1 000, less 300.

The CHAIR: Thank you. My questions now relate to some of the arguments against assisted dying. It has often raised concerns about vulnerable people and vulnerable people dying prematurely because of duress or demoralisation, with access to voluntary assisted dying. Has that been your experience in Switzerland or do you have a comment on that?

Mr LULEY: You will find a comment on that in the submission we wrote, that the Netherlands and Belgium have done quite extensive research into that topic and they clearly studied[6] that this is not about vulnerable people being pushed or demoralised to leave their existence earlier than others. There is no evidence of that and [indistinct][7]. I would say if there really were people that we do not know of who would feel demoralised or pushed or whatever, then that is not the effect of a law—that is, an assisted dying law. That is the effect of our society not sufficiently caring for the elderly. That is the effect of our over-performance, money-orientated society, which would strive for being powerful, good looking, sexy, omnipotent all the time; when you are 50, you are hard to find a job et cetera. What will happen to the elderly people? Elderly people will feel pressured by our society not being worth anything or not being part of our society anymore. We push them into a home for the elderly. How many young people are really going to visit their 70, 80, maybe 90-year-old grandads and grandmas in the care homes when they are old[8]? I would say it is the development of our society which we should take care of—we should push that—and it is not the fact of assisted dying being an effect on these elderly people being pushed or demoralised to go earlier. There is no evidence of so-called vulnerable people being demoralised or pushed to use assisted dying. Besides that, we must be careful. When we say vulnerable people, who is vulnerable? Is it us judging these people to be vulnerable? What about them? Do they feel vulnerable? So, we must be careful not to stigmatise people from our point of view when, in fact, they might not feel vulnerable themselves.

The CHAIR: What about the slippery slope argument where those who argue against voluntary assisted dying make claims that the provisions have been expanded and the categories of people who would qualify for it have been expanded since the original introduction of any legislation? Has that been the case in Switzerland?

Mr LULEY: The slippery slope argument just as much as the[9] vulnerable people being pushed, so to say demoralised, is a pretext argument by the opponents and from all the evidence that there is

[5] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[6] ibid
[7] ibid
[8] ibid
[9] ibid

available from the Netherlands, Belgium, the US state of Oregon, here in Switzerland, there is no evidence that this is the case whatsoever. What you have, of course, and that is a development in society—when you have new needs for society coming, then you might have the situation that some people say, "Thank you for this law which gives, let us say, terminally ill people with six months' life expectancy the possibility for end-of-life choice", but then after 10, 20 years, you might have a development in society that people want more freedom of choice. Then they might call for, "Let's extend that to 12 months." That is not a slippery slope. That is a development in society where people want to have more freedom of choice. I think that our opponents mix that up to make an argument against real freedom of choice. Besides the point, these arguments are fear arguments and fear is never a good place to look for solutions for the problems in society. We must base solutions on progressive thinking—think what people need and want and not on fear.

The CHAIR: Thank you.

Hon NICK GOIRAN: Mr Luley, do you know Andreas Brunner?

Mr LULEY: Yes.

Hon NICK GOIRAN: That is Zurich's chief public prosecutor.

Mr LULEY: Ex-prosecutor. He is retired.

Hon NICK GOIRAN: Now, I have done some research on this chief public prosecutor and he has said that assisted suicide had been extended from the terminally ill to the very ill facing extreme suffering to the elderly who were suffering the effects of old age or a combination of illnesses and, finally, opened up to healthy people. I am intrigued by your comment that this is not a slippery slope but that it is a push for freedom of choice. Can you just help me understand that?

[3.20 pm]

Mr LULEY: I must first explain the character of Mr Andreas Brunner. Andreas Brunner is a man who disliked Mr Minelli and Dignitas right from the start. Mr Brunner is someone who even went as far as to do an illegal contract between the state prosecutor's office and the right-to-die organisation, Exit,[10] to try to limit the services of Exit by offering them that after an accompanied suicide, no state prosecutor would go anymore [indistinct].[11] That is the sort of legal expert and character that Mr Brunner is. The Swiss Federal Supreme Court ruled on the contract he did and found that it is undemocratic, unconstitutional, absolutely useless and has no validity.[12] Based on that, I must tell you we do not need to comment and we do not even need to look into the arguments of a man like this. Besides that point, I will still give you an answer, but I am just describing who Mr Brunner is. Luckily he has retired, but he is still spreading false information, unfortunately. I will still give you an answer. There never was in Switzerland a restriction to terminally ill people. What he says is simply not true. There never was a restriction on terminally people. We never had a change of law. Since 1942, the law—the Criminal Code—is the same, and there is no restriction to terminally ill people. So there was never a weakening or a softening of the law allowing more people, or even healthy people, to access assisted dying. The law has always been the same.

Hon NICK GOIRAN: That is very helpful. So there have never been any restrictions in Switzerland with regard to access to this. I think it is the case that some people have sought assisted suicide, or accompanied suicide, in Switzerland but been refused. Is that true?

Mr LULEY: Yes, because it is in the free decision of a medical practitioner—a physician—to decide whether he wants to give access to assisted dying; whether he wants to write a prescription for the

[10] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[11] ibid
[12] ibid

pentobarbital or not. As you can guess, every medical doctor, when a perfectly healthy person and a mentally healthy person would come and would say, "I want to have an accompanied suicide", and the doctor would say, "What's wrong with you? You probably are in a life crisis. You certainly need treatment, but you don't need an assisted suicide. Let's talk about this first and see how we can improve your quality of life so you can get back on track." No Swiss doctor would ever write a prescription for a perfectly healthy person. Theoretically, by law—just theoretically—the doctor could do so. He might get into conflict with the professional board of medical doctors, he might get into conflict with some, let us say, ethics committees or whatever, but based simply on the law, a doctor could do so, but it would be against any logic to do that. It is the same for us as an organisation. It might sound provocative to you, but we at Dignitas could do an accompanied suicide for someone who is perfectly healthy, who has no medical diagnosis whatsoever. The law would allow that, but it is understood that no—as long as the person of course has mental capacity—that is always the base; that is understood—but nobody would ever do that.

Hon NICK GOIRAN: That is very helpful. So has that ever happened at Dignitas?

Mr LULEY: I did not catch that.

Hon NICK GOIRAN: Has it ever been the case that there has been an accompanied suicide at Dignitas for a healthy person?

Mr LULEY: Never, ever.

Hon NICK GOIRAN: Never?

Mr LULEY: Never, because always every request for an accompanied suicide is assessed by doctors who are independent of Dignitas. There is a not a single medical doctor working at Dignitas. We do not employ doctors; they are all independent of the organisation. So if one of our members sends us a request, we assess it, we discuss with the member what is needed, and only if that request is sufficiently substantial, and substantial for a doctor, we forward it to the doctor and then the doctor assesses it. If the doctor says no, we cannot do anything. We cannot do the accompanied suicide. It is only on the medical doctor's agreement that the accompanied suicide takes place.

Hon NICK GOIRAN: So all of the deaths that have happened at Dignitas have been for unhealthy people then?

Mr LULEY: That is right.

Hon NICK GOIRAN: When you say "unhealthy", what does that mean?

Mr LULEY: It means that there must be some sort of medical diagnosis, a certain severeness of suffering.

Hon ROBIN CHAPPLE: Did we get that?

Hon NICK GOIRAN: If you could just repeat that.

Mr LULEY: There must be some medical diagnosis and a certain severeness of the suffering. Whether it is physical suffering or mental health suffering, it does not matter. Both have the right to access assisted dying in Switzerland. At this point I would like to add something out of the last hearing. At the last hearing you asked whether there had been any people from Western Australia that had made use of an accompanied suicide at Dignitas, and we were not able to answer that question because I did not have the statistical data ready. I looked it up and I can tell you that in July 2011 we had a lady having lived near Perth who came to Dignitas and made use of an accompanied suicide. She was suffering from severe Parkinson's disease. I would just like to, if you allow, read two or three lines out to you from the medical report by her Australian doctor of course.

The CHAIR: Yes, please do.

Mr LULEY: He says —

> Mrs Such and Such suffers from severe Parkinson Disease, with significant effect on her speech, motor function and very severe tremors associated with painful rigidity of neck, back and limb muscles. This causes her to be unable to walk without an assistant. Her posture is severely affected and flexed. It is very difficult to comprehend the speech due to the vocal weakness causing low tone and shaky voice due to tremors. Since seeing her over the two years ago she has deteriorated.

Now, by coincidence, if I look at this case, if you make a law that allows for terminally ill people with six months' life expectancy access, then someone like this would theoretically be excluded from access to assisted dying. Now, when you recall what I just read out to you from what her Australian doctor says, it is obvious that this lady is suffering terribly, and I guess you would agree that someone like that could have access to a safe, dignified end-of-life option, not being forced to jump off a high building or go in front of a train. But this lady, looking at the law which has been enacted in your neighbouring state, Victoria, would not get access to assisted dying in Victoria; she would still need to have to come to Dignitas. A law which only allows terminally ill people with a short life expectancy to have access to end-of-life options, I am sorry to say, that is not a good law because it is not taking care of people like this lady.

[3.30 pm]

The CHAIR: Thank you. I want to ask you some questions about oversight of assisted dying. Can you give us an outline of the oversight agencies and reporting obligations associated with assisted suicide in Switzerland?

Mr LULEY: There is oversight of suicide assistance by means that as soon as a death takes place, it is reported to the police and the state prosecution service—what you would call a coroner, I guess—and an official medical doctor, usually someone from the Institute of Forensic Medicine, will immediately come and investigate the case. For this, we provide a medical file of the patient that it was his or her free will[13]. If the authorities are satisfied with that, they will release the body, for example, for cremation. If they are still not satisfied with that, the body will go to the Institute of Forensic Medicine for further investigation, an autopsy, and the state prosecution might trigger a criminal investigation against the medical doctor who prescribed the pentobarbital. That is the main control effect. At the same time, the medical doctors are governed by the state health authorities. If you have an accompanied suicide, the state prosecution service would find some irregular acts, it would be told the health authorities[14], and the health authorities would then contact the medical doctor and say, "Look, we have known from the state prosecution service that you prescribed pentobarbital in a case which seems not correct. Would you please explain?" That could have the effect that the doctor, in the softer case, would lose his permission to prescribe barbiturates, and, in the extremist case, he would lose his permit to work as a medical doctor. So, in short, each case of accompanied suicide is immediately investigated, and, if they find anything incorrect, you would face severe effects.

The CHAIR: To your knowledge, has anyone ever been prosecuted for not meeting their requirements under the law?

Mr LULEY: At Dignitas, we have had one or two investigations but we never had any prosecutions. These investigations are quite normal. I mean, every case is investigated, but usually it ends with the state prosecution service saying everything has been okay. In one or two cases, they looked at it more closely and posed more questions, but it never led to prosecution. With medical doctors in

[13] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[14] ibid

Switzerland, we had one or two cases where the health authorities then made an investigation and decided to withdraw their permission to prescribe pentobarbital. The doctor did not lose his permit to work; he only lost his permit which allows him to prescribe pentobarbital. But these cases are extremely rare when you compare it to the overall number of accompanied suicides over the years.

The CHAIR: In your submission you state that the majority of those who are approved for assisted suicide do not actually use the option. Can you tell us why you think that is the case and why having access is important?

Mr LULEY: One could write a book on that, I guess!

The CHAIR: Give us the short version!

Mr LULEY: I will try to keep it as short as possible and try to give you an example. What do people want? What do you want to have in your life? Choice—freedom of choice, options. You want to choose what job you want to learn and do. You want to choose what partner you have in life. You want to choose whether you have kids or not. You want to choose how you lead your life. You do not want anyone to tell you what you have to do or not to do. In the frame of what the law allows, you want to have free choice. This extends to end of life. It is as simple as that. People want to have choice at end of life as well. As soon as they know, in a severe suffering situation, that they have access to an emergency exit that is safe and legal, that pressure, that tension, that stress of knowing that they have no option, immediately decreases to almost zero because of the option of dying with the medical doctor telling them, "Yes, if the worst comes to the worst, I will write a prescription for lethal medication for you and will make sure that you can take it, if you really cannot take any more." This stress then decreases to zero, because they know they have an option; they have choice. As soon as they have that, they have two options—either to live on, or to make use of it. We are human beings. Let us face it: we are programmed to live. We are not programmed to die. As with all living species on this planet, we want to live for as long as possible and have quality of life. When people know they have an end-of-life option, a legal and safe option, they will automatically opt to live as long as they can, and they will have better quality of life in that last stage because they know that they have a way out, an emergency exit door, as I called it earlier on. This has the effect that people then wait, and they might even have better mental health quality, and their spiritual wellbeing improves, because they know they have a way out. They do not need to worry about what their end is going to be that much, because they know they have a safe way out, and then they might live on and might even get better, and then simply die in a natural way; or, in the last few days, they go to a palliative care ward and are helped by a palliative care specialist, and maybe they will receive continuous deep sedation that lasts for two or three days, and that is all very well. In that way, for many people who have this emergency exit door, at Dignitas we see that although they have the so-called provisional green light, which is the basic consent for the medical doctor to write the prescription, only around 14 per cent actually make use of accompanied suicide. Of all the Dignitas members, and we are a small organisation, only three per cent make use of accompanied suicide.

Mr R.R. WHITBY: Can I just clarify your last comment before the bell went off. What proportion of Dignitas members actually go through the final stage and make use of that end-of-life choice? What was the percentage?

[3.40 pm]

Mr LULEY: Three per cent.

Mr R.R. WHITBY: Three per cent.

Mr LULEY: Yes. The figure, we must be careful about this. We are a small member society. We have 8 400 members all over the world and for the last five years we had on average 200 accompanied suicides. Comparing this 200 with the 8 400 members makes for three per cent. If you look at our

colleagues EXIT-Deutsche Schweiz, the Swiss organisation, there the relation is much more extreme. They have 110 000 members, Swiss only, and approximately 700 to 800 accompanied suicides a year, so their three per cent figure is much smaller[15].

Mr R.R. WHITBY: Is that because people who sign up with Dignitas may never get a disease or a life-ending situation where they would want to take that option?

Mr LULEY: I did not understand the beginning of the question.

Mr R.R. WHITBY: I am just saying, people who sign up with Dignitas as members may never get a life-threatening disease or condition, so, obviously, they would not want to avail themselves of that option.

Mr LULEY: That is true as well, yes. Some will seek membership in groups like Dignitas or EXIT, the same as in Australian organisations. Some of them see it as a commitment to support organisations which work for more freedom of choice at the end of life on a legal and political level. They are perfectly healthy; they do not need an assisted dying service, but they support organisations that they agree with the goals of the organisation. I must add that assisted dying, accompanied suicide, that was never the goal, the main work of Dignitas; that is just a side-effect of our work. The founding idea of Dignitas, of Mr Minelli as a human rights lawyer, was to improve end-of-life choices and what you would call the right to die or the right to get access to help so you can decide on the time and manner of your own end of life. It is a different approach. We are not an assisted dying organisation; we are a legal–political progression of law organisation, and suicide attempt prevention and social issues, and the accompanying suicides are, in a way, kind of a side-effect of our work. With our colleagues at EXIT-Deutsche Schweiz, that was a bit different. Their main early aim was to do accompanied suicides and to implement the living will, the advance directive. They were not so much a legal–political organisation, but have developed into a wider scope as well. So, it is a question of aim and focus, but what I can say for sure is that many people become a member also because they feel it to be like an insurance, to say, "I'm okay now, I'm healthy now. I think this organisation is doing good work, but I don't need this service now, but I might need it one day, and that day I will have access to a legal and safe end-of-life choice, but I'm going to support this organisation in the meantime."

The CHAIR: I just want to ask about your view of the Victorian laws where they have some limited provision for people who cannot self-administer to have access to physician-assisted dying. Do you have a view? Obviously, in Switzerland you have to be able to self-administer, and that eliminates a group of people who cannot do that. Do you have a view as to which is the better model?

Mr LULEY: I think there is no model that is better or worse. It is good if both are available. Personally, we think that the Swiss model of self-administration is a good thing because with self-administration, you are sure of that last act. This is the last clear expression of the will, the autonomy of the patient. It is true that there are possibly a few cases where it is very, very difficult for a patient to self-administer. Think of someone who has ALS or multiple sclerosis and is almost entirely paralysed, has difficulty swallowing, can hardly move a finger. There you can still ensure self-administration with a lot of technical help, of course, but if the person has entirely lost all bodily control, then it becomes very, very difficult. You can have a person of sound mind in a completely deteriorated body, and I think we agree that even a person like that should have access to assisted dying. In Belgium and The Netherlands, doctors do the injection on the request of the patient. We do not have that in Switzerland. I would say it might exclude one or two individuals. We were always available with technical help to make sure that even people with extremely deteriorated health were able to deal with the situation, just like pressing on a button. For example, we had one patient,

[15] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.

the only thing this lady was able to do was to move her foot like this—my hand might be her foot—[shows movement] so we installed a switch at the foot of the bed, on the side, and then the palliative care pain pump with the pentobarbital in it, connected intravenously. When she was ready and they said, "You really want to end your life? You know what happens if you activate that switch?", she was only able to blink with her eyes to say yes, and she then moved—the only controlled movement she had—her foot onto the switch, the switch activated the pain pump and the pain pump pumped the pentobarbital into her vein. So a lot of technical gear, but it was still self-administration, legally and practically, but it was of course very difficult for her and for her family and friends who were there as well. These cases are definitely more dignified; more better feeling—I do not know the right word in English—if the doctor can administer the lethal medication. Whether you want that or not is, of course, for you as lawmakers at the end of the day to decide. We think it is a good thing that both options are available. Canada has it as well, for example. They did the same thing at the beginning, of only permitting self-administration and then expanded into what is legally and technically called voluntary euthanasia; in short, the doctor administering the lethal medication.

The CHAIR: Does Dignitas have clients who have degenerative illnesses like ALS, for example, where they have opted for assisted suicide whilst they are physically able but may have had some time to live, because of that restriction in the law?

Mr LULEY: in Switzerland, with the law saying that you have to be mentally competent at the last moment, you have to be able to self-administer the lethal medication. It may be that, in effect, the patient has to go earlier than what he would want. Being that we are able to go to quite an extent, as I have described, with technical, legal and so on[16], that has little effect, because people can really wait for a long time until they are very bad off and[17] then there is the fear though that it might be too late and they want to leave earlier [inaudible] on the lost futures. It is what I explained about people wanting to live, not wanting to die, but there is one point where we have the negative effect of people having to leave earlier—that is, dementia. Someone suffering from dementia who wants to have a self-determined, self-enacted end of life definitely has to leave much earlier than what he or she would want, compared to if voluntary euthanasia was possible.

[3.50 pm]

We could say that this limiting effect is not too much if you have a good passive euthanasia regime—I mean, the advance healthcare directive. If you make sure in the law that someone can make an advance healthcare directive in which, for example, the person can rule, "if I have dementia, do not control all my bowels and bladder any more, do not recognise my family and friends any more, then I want that the doctor does not treat me any more—no food, no drink, nor any medication, nothing, so I can pass away." If you have that in the law, then, of course, the limiting factor of the person possibly having to go earlier, you would not have that, but you still would have the fact that the person who wants to determine the time of his own end in life might have to go a little earlier if the system is restricted. I am not sure if I can make myself understood in this.

The CHAIR: Yes, we understand.

Mr LULEY: Two or three things now interact; self-administration, the doctor being able to administer, and the advance healthcare directive. All link together.

Hon NICK GOIRAN: I regret that we keep running out of time. I think maybe the committee should come and visit you. Be that as it may, just a couple of quick questions.

I understand that Dignitas has had problems securing access to sodium pentobarbital because of lack of cooperation from prescribing doctors. Does Dignitas still have those problems?

[16] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[17] ibid

Mr LULEY: We did not have those problems due to a lack of doctors cooperating. We had a short problem that the Zürich health authorities from one day to the other changed their rules and said doctors had to see the patient before prescribing pentobarbital on more than one occasion, thus making it more difficult for severely ill patients, especially from abroad, coming to us, and they then had to stay longer here in Zürich to see a doctor on several occasions. That also put pressure on the doctors not to support Dignitas, not to help patients of Dignitas anymore. That was a very difficult phase, but it was never a problem that we did not have access to pentobarbital.

Hon NICK GOIRAN: So have you got access to it now?

Mr LULEY: We have always had access to it, and we always had medical doctors ready to cooperate with Dignitas and to write prescriptions. Sometimes it was difficult—there were not that many medical doctors—but we always managed in these 20 years.

Hon NICK GOIRAN: When you say that you have always had access to it, I understand that for a period of time, you were experimenting with helium.

Mr LULEY: Yes, but there were only four cases of accompanied suicide with the well-known helium method. These patients also had to see medical doctors. The medical doctors, instead of prescribing pentobarbital, agreed to assisted suicide with the helium method. It was not for a period of time, it was just four patients who actually chose themselves to have this method.

Hon NICK GOIRAN: Was this because it was during that time when the authorities had changed the law?

Mr LULEY: They did not change the law. The health authority does not have the power to set law, but they have the power to put pressure on medical doctors, to change their support for dying plans, which then frightened medical doctors, and it gave them a headache. That narrowed the access, so to say, to pentobarbital, or rather the capacity of medical doctors to help patients. It is delicate to talk about the helium method, because it is a method which works so good that if the public knew more about it—we may have to cut that out—you might have more people using that method, because it is working so efficiently. It works so perfectly well. We knew that this method was working very well, and we were offering it as an alternative and that is when four patients chose that option [inaudible].[18]

Hon NICK GOIRAN: If it is such a good method, why do you not keep using it now?

Mr LULEY: Because it is very technical with—well, I do not want to talk about it now, because this is all public. You research it yourself, then you will realise how effective and how efficient and how easy it is. But it is a very technical method, and pentobarbital is a much simpler method, and more aesthetic. If you want to take this way with helium, you must work with a hood, or with a bag over your head, and so on and so on; you need the gas. Think of Europe, where we had the thinking with some older people, going back to the German Deutsches Reich—the Nazis—triggering ideas of that. We do not want to touch that. It works, no doubt about it, it works very well, but it is better not to use that method, not for medical or technical reasons [inaudible] with having perspective[19].

Hon NICK GOIRAN: Last question: have you used any other methods, other than the helium method and the sodium pentobarbital?

Mr LULEY: We have always used the pentobarbital, and only with these four patients, the helium method; there has been nothing else. In all cases, they had to see a medical doctor who agreed to the assisted suicide beforehand.

[18] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.
[19] Information from the witness clarifying this part of the transcript can be accessed on the Committee website.

The CHAIR: Thank you very much, Mr Luley and Mr Minelli, for joining us a second time. I am going to read a closing statement to close off the hearing. But on behalf of the committee, I want to thank you very much for taking the time to speak to us today. 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 both very much for taking the time to talk to us; we really appreciate it.

Hearing concluded at 3.58 pm

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