The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

Tuesday 7 September 2010

Session 3

Printed and published in Scotland on behalf of the Scottish Parliamentary Corporate Body by RR Donnelley.

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END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE
4th Meeting 2010, Session 3

CONVENER

*Ross Finnie (West of Scotland) (LD)

DEPUTY CONVENER

*Ian McKee (Lothians) (SNP)

COMMITTEE MEMBERS

*Helen Eadie (Dunfermline East) (Lab)
*Michael Matheson (Falkirk West) (SNP)
*Nanette Milne (North East Scotland) (Con)
Cathy Peattie (Falkirk East) (Lab)

*attended

THE FOLLOWING ALSO ATTENDED:

Margo MacDonald (Lothians) (Ind)

THE FOLLOWING GAVE EVIDENCE:

Dr Georg Bosshard (University of Zurich and Fachhochschule Gesundheit WE'G)
Professor Martin Buijsen (Erasmus Universiteit Rotterdam)
Professor Linda Ganzini (Oregon Health and Science University)
Deborah Whiting Jaques (Oregon Hospice Association)
Dr Rob Jonquière (World Federation of Right to Die Societies)
Professor Lewis (King's College London)
Lord Mackay of Clashfern
Adrian Ward

CLERK TO THE COMMITTEE

Douglas Thornton

LOCATION

Committee Room 1

Scottish Parliament

End of Life Assistance (Scotland) Bill Committee

Tuesday 7 September 2010

[The Convener *opened the meeting at 10:11*]

End of Life Assistance (Scotland) Bill: Stage 1

The Convener (Ross Finnie): Good morning and welcome to the fourth meeting of the End of Life Assistance (Scotland) Bill Committee.

I cannot believe that people will have forgotten over the summer how irritating it is when a mobile phone goes off, but, just in case you have forgotten these simple matters, I remind everybody, including those in the public gallery, to please switch off all electronic equipment that might interfere with proceedings.

We have received an apology from Cathy Peattie.

I welcome Margo MacDonald, who is of course the member in charge of the bill and, as such, is obviously entitled—[*Interruption*.] That did not sound very promising; I hope that that was the exit sound of that particular piece of electronic equipment. Margo is entitled—as is any member—to participate in the proceedings and to put questions at any stage. Margo, you are welcome to do that as we go through the witnesses' positions.

Our only item on the agenda is to take oral evidence on the End of Life Assistance (Scotland) Bill. Today, we will hear from three panels. We will hear from two panels this morning then we will suspend the meeting and wait until our time zone is more in synch with Oregon, so that we can have our meeting with witnesses from there, which should take place nearer 5 o'clock.

The first panel will address the existence and development of other jurisdictions in Europe. I welcome Dr Georg Bosshard, who is a lecturer in medical ethics at the University of Zurich; Professor Martin Buijsen, professor of health law at the institute of health policy and management at Erasmus Universiteit Rotterdam; Dr Rob Jonquière, former chief executive of the NVVE—the Dutch right to die association—and communications director of the World Federation of Right to Die Societies; and Professor Penney Lewis, professor of law at the school of law and centre of medical law and ethics, King's College London. You have been kind enough to provide us with submissions, therefore I hope that you will agree that we can move straight to questions from the committee.

10:15

Ian McKee (Lothians) (SNP): Thank you for coming to give evidence. Two themes have come out of a lot of the submissions that we have received. The first is a concern that the bill could be a slippery slope: we might introduce legislation that is fairly limited now but which over the years will inevitably encompass more and more people and will have consequences that we do not foresee today. The second is a concern that there might well be pressure on subjects to apply for end of life assistance for reasons with which we would not agree, such as that they are worried about being a burden on their relatives or they want to leave their relatives some money early. I know that you can give evidence about what is happening in countries where such legislation already exists. How real are those worries? Has there been a slippery slope and is there undue pressure on people to agree to end of life assistance?

Dr Rob Jonquière (World Federation of Right to Die Societies): The two issues that you highlight are real: they are the issues that confront me every time I talk about the Dutch law.

The first issue that you mentioned was the concern about the slippery slope. Of course, it depends what you consider to be a slippery slope. Up till now, I have heard it formulated that once you give the doctor the right to euthanise a patient, next time he will do it more easily and, in the end, everybody who says, even for a short time, that they would rather be dead than alive will be killed by euthanasia. I can assure you that that kind of slippery slope does not exist in the Netherlands. The Netherlands can serve as good proof, because although we have had the legislation for only eight years, we had about 30 years of tolerated practice before that, so you could say that our situation has existed for more than 30 years. We do not see that kind of slippery slope.

If you look at the figures that I submitted in my evidence, you will see that the percentage of euthanasia cases is staying more or less the same. On the issue of doctors terminating life without request, which I consider to be the most dangerous part of a slippery slope, the slope is going in the right direction—towards less termination of life without request.

The third thing I have to say about the slippery slope is that a slope is slippery when no light is shining on it—the surface is wet and you can slip away. One of the advantages of regulating euthanasia with legislation is that the sun shines on the slope, so we know what is happening. Our reviews have always shown exactly what has been happening in the Netherlands.

The second issue that you raised was about people being under pressure. I can give evidence on that on the basis of my experience, because I was a general practitioner and I have practised euthanasia. I know from my former colleagues that the request for euthanasia is the most difficult request that we ever get. When a patient tells a doctor that they would rather be dead than alive, the first thing a doctor does is frighten them off and say, “Let’s look and see whether we can do something else.” Only by having that relationship do you develop the insight that tells you that euthanasia or assisted dying is the only way. It is not a criterion that can be written down in law, but it is, certainly in my view, one of the best criteria: doctors do not like to do it. That is against the pressure argument.

Margo MacDonald (Lothians) (Ind): To pick up on Dr Jonquière’s comment, we have tried to encompass what he has just described in our bill. It is a requirement, after the requesting patient has approached a doctor, that the doctor must discuss alternatives. That is why we have choices in our bill.

Dr Jonquière: The difficulty in legalisation processes—I have seen this in different countries—is that it always seems that in writing down the law, you try to go away from the arguments that opponents may use, and by writing that into your law you at the same time include new exclusions and new points of discussion. The thing that I like most about the Dutch law is that it is a cadre: it more or less says, “These are the limits of what you as a doctor, with your patients, are allowed to do, and together you make your choice within those limits.” Some people say that that is the danger of our law: that there are no strict criteria in it, or not too many strict criteria. That is the discussion.

Margo MacDonald: The two ways of approaching the matter are bound to come out in the discussion.

Professor Lewis (King's College London): I want to talk a little bit about how the slippery slope arguments are made and how the data are used by opponents and proponents of legalisation.

One argument—that legalising euthanasia or assisted suicide will inevitably result in an increase in non-voluntary euthanasia or what the Dutch call, as Dr Jonquière has said, termination of life without request—faces two problems. The first is the establishment of a causal link: you need to be able to look at the evidence and establish that evidence of or an increase in termination of life without request is caused by legalisation. The other problem is that you need to look at other jurisdictions to see whether the prevalence of termination of life without request in jurisdictions where euthanasia is permitted is higher or lower than in jurisdictions where it is not permitted. If you do that sort of analysis with the Dutch data, you discover that there is no evidence in the Netherlands—or indeed in any other country—of the prevalence of termination of life without request prior to effective legalisation in the Netherlands, so we do not know whether there was any kind of causal reaction to the courts’ decisions to permit the defence of necessity in the Netherlands. In Belgium, where we have a little bit more data from pre-legalisation, there does not seem to have been an increase in termination of life without request post-legalisation; in fact, there seems to have been a decrease.

The comparative evidence is mixed. Some jurisdictions that are prohibitive, which do not allow euthanasia or assisted suicide, appear to have a higher rate of termination of life without request than the Netherlands. Other jurisdictions, including the United Kingdom, appear to have a lower rate. Because that comparison is not uniform, you cannot conclude that legalisation has had the sort of effect that the slippery slope argument is said to demonstrate. There are problems both with causation and with the comparison.

Dr Georg Bosshard (University of Zurich and Fachhochschule Gesundheit WE'G): I completely agree that for that question you have to make clear what kind of slippery slope you are talking about. I try to explain it by saying that other words that are often used in that context are “abuse” and “misuse”. I think that everyone in the committee room agrees that there should be no abuse in that field, but if you were to ask all the participants what they think abuse is, there would be a broad range of opinions. Some people basically think that any kind of assisted suicide is abuse. Some think that there is no abuse when assisted suicide is allowed only when people are dying and at the very end of life. Other people think that as long as someone has a clear wish, that that wish persists and that there is no doubt that the individual involved has decision-making capacity, there is no abuse. There is a wide range of opinions on the issue, which makes all discussions about the slippery slope argument a bit difficult.

The most accepted type of slippery slope is the slippery slope from voluntary towards non-voluntary euthanasia. I think that we have no evidence at all from all the jurisdictions, including Switzerland, of such a slippery slope. However, other evolutions can be seen to be critical. There is some evidence about that from the Netherlands, for example, from discussions about assisted suicide and euthanasia for people who are tired of life. We have similar developments in Switzerland.

We started with basically end-of-life cases: people who were terminally ill. As you know, it is not a legal requirement in the Netherlands or in Switzerland that people who ask for assisted suicide or euthanasia have to be terminally ill. The percentage of people asking for assisted suicide who are not terminally ill has increased in Switzerland. In the 1990s, 20 per cent of individuals with granted requests for assisted suicide in Switzerland were not terminally ill; now, 33 per cent of individuals with granted requests in Switzerland are not terminally ill.

That makes it particularly difficult for doctors, because the more that you move away from clear medical symptoms at the end of life, the less clear it is what the medical question is in the case. I can give you a narrative example of that. I am a general practitioner, and I have never carried out assisted suicide, but I know colleagues who have. I have a colleague who was quite engaged in that field for a couple of years, but during the last three years she came under more and more pressure from individuals who wanted to die but who were not terminally or even seriously ill. She even had a meeting with the right to die organisation Exit, at which people were saying, “Doctors like you are to blame for patients like me having to have a gun at home.” She was not happy with that discussion and in the end she decided not to engage any further in that field. She does not carry out assisted suicides any more, because she felt that pressure from the population.

Professor Martin Buijsen (Erasmus Universiteit Rotterdam): You must not forget that in the Netherlands, euthanasia and physician-assisted suicide is strictly limited to patients and doctors. Nobody is seriously discussing, in the Netherlands at least, the goodness or badness of our euthanasia law. I agree with Dr Bosshard that there is no evidence of a slippery slope in reality, but what you do see is certain developments at the fringes, for example non-physicians assisting in suicide and practising euthanasia. In the Netherlands, those people are always prosecuted.

Another kind of slippery slope is that a discussion is now going on politically about whether people who are not patients but who are tired of life can go to a physician and ask for euthanasia or a physician-assisted suicide. That discussion has appeared since we introduced our law.

10:30

Helen Eadie (Dunfermline East) (Lab): Among all the papers that we have received, we have been given a copy of the report of the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill. I draw particular attention to page 46 of that report, where paragraph 123 deals with the whole issue of competence, which is defined as the patient having

> “the capacity to make an informed decision”.

From reading that paragraph it is evident that there seems to be a consensus—the report mentions people at the department of psychiatry at the Royal Free hospital, the Association of British Neurologists and others—that

> “the ‘gatekeepers’ in regard to applications for assisted dying could not be expected to spot impairment of judgement in all cases.”

That concerns me. The narrative in the report tells us that patients can despair of their illness at different times, but that can be cyclical and they can move on to have hope during their illness. How do we guard against that problem? As the report points out, the fact that therapies are developing all the time raises the possibility that such patients might have a longer life.

One concern must be about those patients who find themselves at their lowest ebb. Indeed, we heard one very striking case from a witness who told us that she had been determined for some time to take her own life and had sought assistance to do so, but she then met a partner and, ultimately, no longer wished to end her life early. How would we guard against that issue by ensuring that those gatekeepers could spot any impairment of a patient’s judgment?

Professor Buijsen: In the Netherlands, it is up to the doctor—the treating physician—to see whether there is such an impairment. When there is a request for euthanasia or physician-assisted suicide, he has to consult another doctor. That is the safeguard that we offer in the Netherlands.

Helen Eadie: That is interesting, because the report suggests that a multidisciplinary team, rather than a single consultant, should come to the conclusion. Does that happen in any of the other jurisdictions?

Dr Bosshard: I think that that is a problem. The issue is also to do with the fact that the Government usually has no interest in really engaging in such cases. In principle, we could conceive of a commission that was provided by the Government to consider probably not all cases but at least those cases that were difficult for GPs. However, at least in Switzerland, we do not have such a commission that would be willing to do that beforehand rather than after the death.

It is also to do with the organisation of the whole field. In my experience, GPs are usually pretty lonely in making that decision. They might seek help, but it is difficult for them to get it. The SCEN network—support and consultation on euthanasia in the Netherlands—is good for that, but at least in Switzerland things could be better. GPs are alone.

There is literature on how to assess decisional capacity for assisted suicide, but GPs are not aware of it.

Professor Lewis: On the issue of other regimes, all those that we have looked at—the Netherlands, Switzerland, Belgium and Oregon—have a consultation requirement whereby another physician must be consulted to confirm that the legal requirements have been fulfilled. That is one attempt at a safeguard to ensure that capacity is established.

However, if I may approach the question from a slightly different angle, we should really have that concern about all end-of-life decisions that patients make. Even in jurisdictions where euthanasia or assisted suicide is permitted, we are talking about a tiny proportion of the decisions that patients make that result in their death.

The scenario that Helen Eadie described—in which a patient makes a decision out of despair that results in their death when medication or treatment might have prolonged their life—could also apply to a refusal of life-sustaining treatment. The decision to withdraw or withhold such treatment is far more common in all jurisdictions than assisted suicide and euthanasia.

The scrutiny of capacity is important, but we should not forget that we should scrutinise capacity for every decision that patients make, particularly those that result in their deaths. That applies not only to euthanasia and assisted suicide. There is a group of end-of-life decisions in which we should worry about capacity, voluntariness and pressure from friends and family. I sometimes worry about the overscrutiny of decisions in the context of euthanasia and assisted suicide. They deserve scrutiny, but so do those other sorts of decisions that have similar ramifications.

Dr Jonquière: I will come back a little on what I said about pressure. When we discuss euthanasia laws, it often looks as though we are discussing sudden decisions—as if nothing was wrong yesterday but I go to the doctor today and say that I want euthanasia and want it performed tomorrow. One of the advantages of having a legal possibility of euthanasia is that there is a culture of transparency, openness and talking about it.

Most of the instances of euthanasia in the Netherlands are performed by family doctors, which means that, in the large majority of cases, it was discussed long before the patients became ill, so doctors know about their patients' ideas. The right-to-die societies in the Netherlands promote to their members talking about their future choices with their GPs. When those discussions have not taken place and a doctor gets a sudden request, even if they are prepared to perform euthanasia, they will have difficulties with doing it.

In her book, Frances Norwood said that the biggest advantage of the Dutch law is that everybody can talk about euthanasia. We should certainly not forget that advantage when we talk about legalisation.

Helen Eadie: Your written submission talks about

"The existence of both law and guideline"

and goes on to discuss the fact that the legislation has been reassessed and has evolved at each stage. Will you give us some idea of the lessons that have been learned along the path to where you are now, so that we can learn what to avoid should the Parliament decide to legalise euthanasia?

Dr Jonquière: If I understand correctly, you are asking about the evaluation that we had a couple of years ago.

Helen Eadie: Yes.

Dr Jonquière: One of the points that we learned from that evaluation is that the due care criteria that we formulated in the law could be divided into formal and informal criteria. It turned out that when doctors did not comply with the informal ones, the review committees hesitated about whether to hand the doctors over to the prosecutor because they had not followed the criteria. They saw that the prosecutors would say that it was not a reason for prosecution.

Based on those signals, my interpretation is that that cadre of law gives a chance to the doctor and patient together. It is a doctor's law in that it defends the doctor, because he or she is the one who survives the euthanasia, but it is also a patient's law, because the patient must ask, and if the patient does not ask nothing will happen. It turned out that the evaluation provided lessons only on very small details, which it would not be valuable to discuss now. Perhaps Professor Buijsen wants to add to that.

Professor Buijsen: The law came into effect in 2002 and was evaluated in 2006. The evaluation report has an excellent summary in English that is freely available; indeed, I have it in front of me. The law will be evaluated again in 2010 or 2011.

The philosophy of the Dutch law is entirely different from that in the proposed legislation. Some say that the law on euthanasia is a doctor's law. The first objective of the law is to provide doctors with legal certainty. If you are seeking an explanation for the on-going process of protocolisation, it has to do with the fact that the law first and foremost tries to provide legal certainty for doctors.

Helen Eadie: Was the legislation in the Netherlands born from a member's bill or a Government bill? How clear was the majority in the Parliament in the Netherlands when it was being determined whether the bill would proceed?

Professor Buijsen: If I remember correctly, an initiative by a member of Parliament was taken over by the Government.

Dr Jonquière: Yes.

Professor Buijsen: I do not know about the majority. I would have to explain everything about the Dutch political system to explain the process, but I think that the coalition at the time voted for the bill. However, I cannot recall any numbers. I remember that the bill was hotly debated in the Senate at one point.

Nanette Milne (North East Scotland) (Con): Given that it is very difficult for anyone to know what goes on in families behind closed doors, I have a concern about undue influence. With your experience, how confident can you be that no undue influence has been exerted on people who request assisted suicide?

Dr Jonquière: I will be honest. I think that I am confident, but one never knows, because the patient is dead after the event. That is not just a kind of trick. A patient does not ask for euthanasia because he does not want to know what his life will be like in four weeks' or six months' time; rather, he will talk about his situation at that moment. I agree with my colleague Dr Bosshard. The concern is about abuse. Everybody is afraid; even the doctor is afraid that he will terminate the life of a person who may have got better the next day. However, decisions are not taken on the spur of the moment. For example, I discussed the issue—not in general but in specific terms—in a terminal situation for around four months before the patient finally said that the moment had come when she could no longer bear the suffering. Nobody can tell whether, if we had continued treatment, she would have been cured a month later.

10:45

Professor Buijsen: It is not part of the requirements of due care, but according to Dutch law the patient does not have to be terminally ill. If you look at the practice, however, in almost every case in which a doctor provides euthanasia or physician-assisted suicide, the patient is terminally ill. The figures show that it is almost always about patients with cancer, who have a life expectancy of a few weeks at most.

Dr Bosshard: I agree with what has been said. It is impossible to read minds—one can never really know what happens in the depths of somebody's mind—but one can feel what happens in that person's family and the process that they go through. In the normal course of events, that starts with an individual expressing the wish to die. Normally—I think that my colleagues would agree—the family is not happy at all with the patient's wish and they need several months to accept that their father or mother wants to die. Anyone who has experienced that course of events will know that it is pretty unlikely that, behind what one can see, it is completely the opposite and there is pressure from the family. Of course, in some exceptional cases there is a danger that that could be the case; therefore, we should be very careful.

Real cases in Switzerland involve huge responsibility not only on the part of the doctor but on the part of the volunteer from the right to die society, who usually has much more experience of assisted suicide. The doctor is probably involved in it for the first time, but the volunteer from the right to die society will have experience of five, 10 or 15 other cases. Furthermore, not only a doctor can stop a case; a volunteer from the right to die society can stop a case and say, "I have a bad feeling that there is pressure." The process therefore relies not just on the doctor, but on the right to die society handling the case sensitively.

Professor Lewis: All that one can do is put oneself in the best position to assess voluntariness and capacity. One factor that helps in that regard is the length of the relationship between the patient and the physician. The better that the physician knows their patient, the more likely they are to be able to assess whether the decision is out of character and whether the patient appear to be acting in a way that just does not sit right.

Originally, in the Netherlands the person who provided euthanasia had to be the patient's treating physician. Now the review committees tend to look in a more purposive way at whether that relationship is one in which the doctor is in a position to assess whether the due care criteria have been met. The Belgian law is slightly more specific and talks about several conversations that the doctor must have with the patient, which must be spread out over a period of time. All of those are ways of ensuring that the doctor is in a position to assess voluntariness, capacity and where the request is coming from.

Something that you may want to explore with the witnesses from Oregon is the concern that has been raised there that, in some cases, although certainly not all, there appears to be a very short relationship between the doctor and the patient of zero weeks or one week. One worries slightly about how easy it is for the doctor to assess capacity and voluntariness when they have just met somebody.

Michael Matheson (Falkirk West) (SNP): I have a question for Dr Bosshard about some of the material in his evidence. You have helpfully provided a section on attitudes to end-of-life assistance within which you demonstrate that the acceptance of end-of-life assistance is greater among the general public than it tends to be across the medical profession. Can you explain why that is the case? Can you also explain why it appears that acceptance is lowest specifically among doctors who specialise in caring for those who are dying?

Dr Bosshard: There is evidence from a couple of studies, but it is also my personal experience. It is to do with the fact that, as my colleague said, it is a very difficult decision for doctors to make.

In one way, you could say that a doctor who engages in assisted suicide can only lose. The only motive that you have for doing it is compassion, but you can get into trouble with the law, with relatives and with your colleagues, and you will be lonely. Why should you do it? I believe that that is why many doctors are restrictive in that field. They say, “At least I would never engage in that field” or, “The profession as a whole should never engage in a field where we can only lose.”

Perhaps it can be compared with the field of abortion, in which there is a certain pressure from society on doctors to carry out the procedure. A gynaecologist can only lose by performing an abortion, but they still do it because they realise that it is the least worst solution. To have backstreet abortionists would be even worse. The same holds for assisted suicide. Doctors will never be happy with assisted suicide and euthanasia, and it is important that they are not. As my colleague said, that is an important safeguard. That is how the field works.

Michael Matheson: I find that interesting, because the objective of introducing legislation is to create that legal certainty for doctors, so that—as is the case in many other areas of medicine—there is no legal question as long as they follow the law. I find it surprising that there appears be a high level of resistance to participation in end-of-life assistance.

Dr Bosshard: The way that the political development works in most countries is that society, including many laws, puts pressure on doctors to engage in that field. Doctors are not happy, because it is a difficult field: it goes beyond medicine, but they are still responsible. I understand why they are not happy. I feel, however, that we must at least engage in the discussion and the same holds for abortion.

Michael Matheson: Has there been any change in the attitudes of doctors in the Netherlands, where the process has been in place for several years now? Are they more accepting, or does that level of resistance continue?

Dr Jonquière: I do not know the exact figures, but I know from some of the reviews that have been carried out, such as those by Van der Wal and Van der Maas, the Remmelink report, and the reports in 1995 and 2000, that the level of permissiveness—that is a difficult word for me, but perhaps you understand it—among doctors is going down.

In the beginning, doctors were more permissive in saying, “All right—this is part of my job.” During the period in question, however, doctors became more and more restrictive in their ideas. As a doctor, I am aware of the difference between a layman talking about euthanasia and saying that the patient should have the right to choose to end his life, and the position of a doctor. Whenever someone chooses, he must come to me as a doctor and I am the one who has to do it. I am not of the opinion that my duty as a doctor is to preserve life whenever possible, but terminating the life of a patient is not something that you have learned—it is not inside your system—so it needs a lot of emotional, rather than rational reasoning. When polls ask people, “What do you think about having a choice?” they will say, “That is a good idea”, whereas a doctor immediately realises that if he agrees, he has to do it. My own experience is that doing it is an emotionally heavy duty, but I will not make it sound too bad. When I have helped patients with euthanasia, afterwards I have been happy that I could help them with their most intimate question. It is not an easy step to take. That is why there is a difference in the polling between doctors and patients. [*Interruption*.]

The Convener: I will take Professor Buijsen first and then I will let Margo MacDonald come in.

Margo MacDonald: I apologise if I came in too early in the first place, but I think that committee members have all had a shot. Are there any more questions?

The Convener: Professor Buijsen wants to contribute on this particular point. I will then check whether Michael Matheson wants to ask a supplementary, then it will be over to you.

Professor Buijsen: If you have a law like the one that we have in the Netherlands, it is extremely important to educate physicians. One problem seen by the researchers in the first evaluation was that if you asked the ordinary Dutch person in the street whether he, as a Dutchman living in the Netherlands, had a legally enforceable right to euthanasia, almost everybody would say, “Yes, we do have that right.” That places an enormous amount of pressure on the medical profession. It is clear that performing euthanasia and assisting in suicide is not normal medical practice. A doctor is asked as a physician to help in that way, but the decision that he makes is as a human being. He is not guided by his medical professional standards or his medical ethics; the only ethics that he has is whether he thinks that such things are in accordance with his own fundamental beliefs. He has access to certain drugs, but that is not the point.

Michael Matheson: My final point is on an issue that has been raised with me, which is the impact that legislation such as this can have on the relationship between the patient and the physician. I was interested in your comments that the majority of those who practise euthanasia in the Netherlands are family doctors—general practitioners—who often have the closest relationship with their patient. Has any research indicated, or have you picked up on anything by way of a change in patient attitudes to doctors who have chosen to engage in euthanasia? For example, have individuals in your practice who did not like the idea of their family physician engaging in euthanasia changed to another practice? To your knowledge, is there any experience of that in the Netherlands or in any other jurisdiction?

Dr Jonquière: I cannot remember any patient leaving my practice because he knew that I was practising euthanasia and I cannot remember any colleague saying that he was keeping his euthanasia practice secret because he was afraid of patients leaving him. I know that in some nursing homes the management does not want to make it open that euthanasia is practised, because they are afraid of the effect on the other inhabitants. At the same time, I know that when you go into that sort of nursing home and give information to the public, there will be a big audience in the hall and the majority of them will agree with the right to make a choice at the end of life.

I do not know where those stories of people running away, or the trust between doctor and patient being lost because the doctor is practising euthanasia, stem from. I heard the strangest stories when the Dutch law was being debated. One of them was the one about trust being lost. I do not have the data for the scientific side of it, but you might know some research by Margaret Pabst Battin and others about the effects of a euthanasia law. I think that the doctor-patient relationship is one of the issues that was looked into. The research also found that it was not only the poor or the weak in the population who got the euthanasia, but maybe even the other way round—if you have a good mouth and can talk to your doctor, you get your euthanasia. Do you know that research?

11:00

Professor Lewis: I know the article that you are referring to. I agree. In all the literature that I have looked at, from the Netherlands and from other jurisdictions, I have never seen any evidence in support of the argument that people change doctors. In fact, the evidence is the opposite. In some jurisdictions—not in the Netherlands but certainly in Oregon—there is some evidence of doctor shopping: people go to a number of doctors in order to find one who is willing to write them a prescription for the medication for an assisted suicide. That is the flip side.

The paper by Battin and colleagues looks at the Netherlands and Oregon, and considers 10 different categories of possible vulnerability. It is mentioned at the end of my briefing note. Those categories included older people, people with certain kinds of conditions and people from lower socioeconomic or educational backgrounds. All the evidence appears to indicate that those groups are underrepresented among those who seek euthanasia and/or assisted suicide or obtain it. There is an exception. There is some concern that people with AIDS seem to be slightly overrepresented. However, all the other categories appear to be underrepresented. That chimes very much with the evidence from Oregon. In the annual reports, year after year, it appears to be younger people, in fairly high educational and socioeconomic brackets. I am not aware of any evidence that suggests that people leave doctors on the basis that they practise euthanasia and/or assisted suicide.

Dr Bosshard: I do not think that there is direct academic evidence of the issue raised by Michael Matheson, but there is indirect evidence. There are some studies on how good the doctor-patient relationship is in different European countries. As far as I know, compared to other European countries the trust of the Dutch population in their GPs is very high. There is no evidence that the open practice of euthanasia has damaged the doctor-patient relationship in the Netherlands.

There is narrative evidence. I have a couple of colleagues who have engaged in assisted suicide. Most of them do not want it to be widely known that they have done that. That is not because they fear that patients would leave them. The fear is the other way round. They fear that more patients would approach them with a request for assisted suicide and they do not want that to happen.

Margo MacDonald: I apologise to the committee for nipping in earlier.

We have spent a long time on discussion about the possible development of a slippery slope. I agree with the witnesses. I see no evidence for it. I do not think that that is how human nature works.

However, I have no doubt that we will come back to that issue.

I am interested in an issue that we have not discussed here, which is the syndrome that is being observed—at the very early stages in the Netherlands, I think—of people who are simply tired of life, who say that they would like to end their lives sooner than nature would intend. Some would say that that is a slippery slope. When you discussed the matter with the members of the committee, you did not mention any requirement for psychiatric assessment. You did not go into any details on that. I would be interested to find out whether there is a move to deepen the examination of someone who presents himself or herself as being tired of life—although, sometimes, I can quite understand that feeling.

Another question that arises is whether there are any moves to dump or amend the legislation in any of the jurisdictions that allow assisted suicide. Is there much debate about that? Professor Buijsen said that there had been fierce debate in the Dutch senate when the law was introduced but that he could not recall much debate since then. From that, I assume that the law is now accepted.

Professor Buijsen: Yes, as I have said, there is no serious debate—political or otherwise—going on about whether the euthanasia law is good or bad. In fact, we have a pax between the proponents and the opponents of such practices, and it is remarkably quiet on that front politically. Everybody seems happy with the law and the practices when they are restricted to doctors and patients, but the political debate has shifted outwards to include persons who are not, strictly speaking, patients—people who are simply old, lonely and tired of life. That political debate is going on and has been initiated by right-to-die groups.

Margo MacDonald: So, no conclusion has been reached. I wanted to ask specifically whether there is any evidence of what the public opinion on that development is.

Professor Buijsen: A year ago, there was some kind of initiative by opinion leaders who wanted to amend the law in that way, but without success.

Margo MacDonald: They wanted to amend the law positively.

Professor Buijsen: Yes.

Margo MacDonald: I have another question. You have talked about the fact that some doctors are unhappy about having to provide the service. Obviously, we would not expect them to be happy about it, but what is the attitude among doctors to the withdrawal of treatment? Do they see that, philosophically, in the same way as assisting someone to die?

Dr Jonquière: The debate always returns to that point. In the Netherlands, if a hospital team that is caring for a patient who is on permanent ventilation turns the knob to stop the ventilation and the patient dies, that is considered to be a normal medical decision. As long as the team has discussed the matter with the patient’s family and there is agreement that because no good will come from continuing the ventilation they should stop the treatment, there is no problem for the doctors. Doctors do that in the same way as they remove an appendix or stitch a wound. However, when they assist the suicide of a patient who is as terminally ill as the patient on ventilation, that takes an action by the doctor—that is the emotional difference. To give euthanasia, a doctor fills their needle with medication that will stop the person’s life. Every time, the doctor will want to look the patient in the eye and ask, “Is this really what you want?” If the patient says, “Yes”, the doctor will give the medication and the patient dies at their needle. That sounds dramatic but, emotionally, for the doctor, giving the injection is very different from turning the knob of the ventilation machine, and that is not to be regulated in the law, I think.

Margo MacDonald: I think that everyone is concerned about the emotional, philosophical and moral aspects. Is there any evidence that some doctors, if not all, prefer to get to know the patient and finally, perhaps, agree to their request, knowing that the alternative could well be a botched suicide attempt on the part of the patient?

Dr Jonquière: I think that you can say that, yes. Of course. Certainly, in the course of the whole debate about this final decision, one aspect that might be important for the doctor is that the patient has let it be known that, if the doctor does not help him, he will try to look for another way. Again, that is a moment where the doctor should be very careful about whether that is good, positive pressure or negative pressure. If the doctor feels that it is negative, the only thing that they can say is no. They can say what their limit is and why they will not help the person. They can give the arguments. Is that what you were asking about?

Margo MacDonald: Yes. I am just trying to clear up some of the areas of dispute that have arisen here when we have discussed the issue.

Another area of dispute concerns the allegation that, if a country introduces such a law into its jurisprudence, it somehow coarsens its society and changes into a less humane, less caring society.

Dr Jonquière: I do not recognise that at all in the Netherlands.

Professor Buijsen: In the Netherlands, we had very poor palliative care in the decades before the euthanasia law, but since we introduced the law attention has shifted to palliative care and a lot more money has gone into it. We did not have the evolution that the Belgians had. They had excellent palliative care but they recognised that there were certain situations in which they could not prevent people from asking for euthanasia. That is not the development that took place in the Netherlands. We had poor palliative care and locked positions with regard to the euthanasia law, but once that was cleared, money went in to palliative care.

Margo MacDonald: That is excellent.

Dr Jonquière: May I add a comment on palliative care and the euthanasia debate? The idea has been expressed that Mrs Els Borst, the minister who introduced the law in the Parliament, said that she introduced it because the Dutch had poor palliative care. That is not true. She started the development of palliative care before bringing the bill to the Parliament. There was Europe-wide development of palliative care in the 1980s, although we did not call it palliative care in the Netherlands. We had other terms for it. She started a programme for that. The euthanasia discussion had been going on since the 1970s, so it was a process that she had to continue. The two things were more or less parallel. Indeed, palliative care got a great boost after the law was installed in the Netherlands, and we can say that that happened because the law was there. Discussions with patients and doctors about the end of life and looking for alternatives made it possible and necessary to have more palliative care available. The independent doctors who were consulted said, “Actually, we do not have enough knowledge to give a good consultation. We need more knowledge of palliative care.” That is the train of thought that was going on.

Margo MacDonald: I have a final question. Dr Bosshard, I would be interested to learn what the attitude of people in Switzerland is to Switzerland being a sort of centre that people from other countries go to because their countries have no law that would accommodate their wish to end their lives.

11:15

Dr Bosshard: Could you specify your question? I do not understand what you really want to know.

Margo MacDonald: I think that it is taking advantage of Swiss hospitality for people to go there because their own countries do not have a law that would allow them to end their lives with assistance.

Dr Bosshard: So your question is basically about the attitude of the Swiss people to what we call suicide tourism.

Margo MacDonald: Yes.

Dr Bosshard: Funnily enough, just a few days ago, the University of Zurich’s institute of law published a report about the attitude of Swiss people to many questions in that field. It showed that the population is divided. A bit more than half of the population is quite critical of suicide tourism. On the other hand, during the past few years, we have had about six political attempts—particularly in the canton of Zurich—to stop suicide tourism but they all failed. Regardless of what lawyers say and politicians do, in the end the practice has not been stopped. The argument is basically this: if Swiss people have certain rights, why should people who travel to Switzerland not have the very same rights? All law is local, so why have different laws for those living in Switzerland and those who travel to Switzerland?

Margo MacDonald: You are very nice people; that is what it is.

The Convener: This has been a helpful evidence session. I thank all four of you for your contributions this morning. Time has moved remarkably swiftly, but we have had a full exposition. Of course, in addition to the verbal evidence that you have given this morning, we have your written papers, which we have studied and will give due consideration to.

We will have a two-minute interval while the members of our second panel come to the table.

11:17

Meeting suspended.

11:23

On resuming—

The Convener: Our second panel comprises two witnesses. The first is Lord Mackay of Clashfern, the former Lord Chancellor. The important point in relation to the bill is that he chaired the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, which Lord Joffe introduced. Lord Mackay has—helpfully—ensured that we have the relevant material from the House of Lords committee and has prepared initial and further submissions. It is clear that the select committee elicited several important principles, which Lord Mackay has helpfully summarised, as I think members will agree. It is fair to say that, without taking a position, Lord Mackay has put to us those issues as principles for consideration as to whether they apply to Margo MacDonald’s bill.

The second witness is Adrian Ward, who is the convener of the Law Society of Scotland's mental health and disability law sub-committee. I understand that he is here as a legal expert on matters that relate to mental health and disability but that his views—we get all these caveats from lawyers—do not necessarily represent those of the Law Society of Scotland, from which we have not had a submission and which does not appear to be taking a position on this important bill.

I invite committee members to commence questions.

Ian McKee: Lord Mackay, thank you for the helpful material that you have presented to the committee, which is readable and interesting. You gave us a statement that the Director of Public Prosecutions in England and Wales issued in February this year entitled "Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide". Do you present that just as a fact or do you support the conclusions of the Director of Public Prosecutions?

Lord Mackay of Clashfern: All that I seek to do is to give the committee as much information as I can about the position in England and Wales, in the legal setting that existed and now exists. The report of the select committee to which I have referred and which I was honoured to chair dealt with the law as it was when the committee operated. We had an authoritative opinion from the Attorney-General on the law and its bearing on the bill that we considered.

Some relevant cases have taken place since then, but the only substantially significant change of which I know is the issue by the Director of Public Prosecutions of guidelines in response to an opinion of the supreme court in its last judgment as the House of Lords—that coincidence is rather significant. What is now the Supreme Court said that a person was entitled to have some information about the basis on which the prosecution would exercise its prosecutorial discretion in respect of the Suicide Act 1961 and the offences that were created under it. Of course, as members know, that act applies only to England and Wales. That is the only significant development, so I thought that I should draw attention to it.

I have submitted evidence to your committee in my capacity as the select committee's chair, so I have taken no position. Of course, I have a view about such matters, which I expressed in a debate in the House of Lords. However, as the select committee's chair, I felt that it was right to have no personal view on how the law should develop. I simply examined the evidence with the experience that I have had as a judge over a year or two now.

Ian McKee: I understand that.

The advice from the Director of Public Prosecutions applies only to England and Wales. Towards the end, the document lists "Public interest factors tending against prosecution". As a sort of codification, that is a strong hint that, if those criteria were satisfied, someone would be extremely unlikely to be prosecuted. I think that a case came to court—perhaps after the policy was issued—in which a judge wondered why the prosecution had been brought, because he felt that the criteria in the document were met.

11:30

As I see it, the trouble with these criteria is that the person who is helping the victim, if I may use that legal term, to end their life is likely to be totally unaware of any medical way or efficient way of doing it. We could end up with terribly botched help being given because we have not given people more comfort in law such that a professional can provide aid when the moment comes. Is that a reasonable criticism?

Lord Mackay: It is certainly a criticism that is open to you to entertain. So far as I am concerned, I just have to take the criteria as laid down. I think that you will notice that the guidelines from the DPP do not allow the person who is assisting to be the medical practitioner, so there is a question about how that will work. However, they are the rules on the exercise of discretion that are laid down for the time being, and I would expect the prosecution in England and Wales to go by them. Of course, they apply only to assisted suicide; they do not apply to anything that could be regarded as murder—not even so-called mercy killing or anything of that sort.

Ian McKee: Right, but it seems that you are ruling out the people who could have the professional knowledge to do it properly, if I may put it that way.

Lord Mackay: That is the way that the DPP decided it should be. He had quite a large public consultation, and all I know is that the current guidelines are what came out of it.

Ian McKee: I turn to your helpful summary of the elements of the House of Lords committee's report that affect Ms MacDonald's bill. Page 5 of your submission goes into some detail on conscientious objection and makes the point that the bill does not

> "make any provision for doctors who may have a conscientious objection to assisting a suicide or administering voluntary euthanasia."

Surely there are precedents—in the law on abortion, for example, and certainly, in practice, on matters such as contraception. There are all sorts of occasions when a doctor can have a conscientious objection. The right of such doctors is not enshrined in law, but there are rulings from the General Medical Council. For example, in the case of abortion, the GMC laid down that it is a doctor's duty, if they are morally against abortion, to refer the patient to a doctor who is not. In the cases that we are discussing, why does that need to be enshrined in law rather than being part of ordinary medical practice?

Lord Mackay: In relation to abortion, it is of course enshrined in the statute.

I draw attention to the fact that such a right was proposed in Lord Joffe's bill but not in Margo MacDonald's bill. It may be that in Scotland it would be thought that that right existed whether or not it was expressly conferred in the statute, but I just draw attention to that point for the committee's consideration.

The Convener: Do you have a view on that, Mr Ward? We are focusing on the point simply because Lord Mackay has been good enough to write it down on a piece of paper and direct our attention to it. Broadening it out, the question that Ian McKee has asked is relevant, in that we now have a bill before us and either you as an individual practitioner or the Law Society may have a view on the matter.

Adrian Ward: First, may I clear up one matter? The Law Society does not have a view. I am before the committee as an individual practitioner, and advisedly so. The Law Society has not made a submission and does not have a collective view on the principle of the bill, although as individual lawyers we have views on particular points in it. How wide is your question? Is it just on the immediately preceding discussion?

The Convener: Yes, it is on the immediately preceding question.

Adrian Ward: There is always a question, in dealing with any profession, about the extent to which you constrain that profession by law and the extent to which you leave matters to professional regulation. There has to be professional regulation.

I am not really subject to any constraints of law if I decide to decline to act for someone or to cease to act for someone. What my code of conduct tells me is that I must not unreasonably cease to act for them once I have accepted them as a client. Of course, a lawyer will not be asked to participate in something quite as extreme as we are envisaging. If you are asking me for a view, it is that we are probably getting into the area of professional regulation and what a professional should do when his conscience is against doing something that he knows that other doctors might be willing to support, which is very different from being asked to do something that no doctor would do.

The Convener: That is helpful.

Helen Eadie: My question relates to issues that have been drawn to my attention through the Scottish Parliament information centre briefing that we have received and follows on from the discussion that Ian McKee started about the difference between Scots law and the law south of the border and the fact that, in Scotland, there is no published prosecution policy. Page 11 of the briefing points out that, following the Purdy case, England was required to have a code, under the European convention on human rights. Would it be possible to argue that there should be such a code in Scotland as well, as we are also subject to the ECHR? What are the views of either witness on that point?

Lord Mackay: The law of Scotland does not have the Suicide Act 1961. The decision that caused the DPP to issue his guidelines was a decision of the court in relation to the law of England and Wales, and particularly the 1961 act. The reasoning of each of the various judges who were involved is different, but the ECHR certainly played a part in their decision that a person who was going to be affected by the law was entitled to know, in fairly reasonable terms, how the law might be applied when there was a discretion that was as important as the one that we are discussing. Those judges thought that it was right that the DPP should issue guidelines and he agreed to do that.

In Scotland, there is nothing in this area quite as clear-cut as the 1961 act. It is for the Lord Advocate to decide what seem to be the relevant considerations in relation to any discretion that she might have in related matters under the law of Scotland.

Helen Eadie: It was interesting that the Lord Advocate issued a statement after that pronouncement to say that

> "The Crown Office and Procurator Fiscal Service will give careful consideration to the implications of the DPP's guidance, the outcome of his public consultation and developments in other jurisdictions."

Given that we do not have any published prosecution policy specifically relating to suicide cases, that must feature somehow in our deliberations around Margo MacDonald's bill.

Lord Mackay: It is certainly an important consideration. Precisely what the outcome of that consideration will be might be for you to say, rather than me.

Adrian Ward: I should add that I have not found it unduly difficult to approach the Lord Advocate to ask whether she could give us guidance on when she would consider it appropriate to prosecute on certain matters. I had to do so on one occasion, in relation to a different matter. Many years ago, when the Mental Health (Scotland) Act 1984 contained certain offences to do with encouraging people with what we now call learning disabilities to engage in sexual relations, I was approached by those who were concerned with providing sex education and by those who were concerned with providing housing. I cannot remember whether the Lord Advocate at the time was yourself, Lord Mackay, but we certainly received a helpful piece of guidance about when, in general terms, it would be considered appropriate to prosecute and when it would not be.

There is always a question about when it is in the public interest for a public prosecution to be brought, after all the other hurdles have been overcome. Any prosecutor will always think about that, and it is not impossible for a citizen to seek guidance, as I did.

The Convener: I am glad that we have established that we have had a long succession of helpful Lord Advocates. We could record that officially—Margo could introduce it into her bill.

Nanette Milne: Lord Mackay's submission mentions that the House of Lords select committee was concerned that the actions that a physician might take to give effect to an approved application for assisted suicide were not specified in Lord Joffe's bill. Those actions are not specified in Margo MacDonald's bill either. To go beyond that, it is not merely the physician who might be involved in those actions; it would also be other members of the team, notably pharmacists, nurses and so on. Was that a concern of the select committee?

Lord Mackay: Yes, it was.

Nanette Milne: Do you have any views on that?

Lord Mackay: If something is to be authorised that takes the action outside the law as it is at present, it needs to be fairly clearly defined. Therefore, it is important to set out in detail what people are entitled to do in pursuance of the new principle, if it is introduced. We felt that that was not really set out in Lord Joffe's bill and that there would have been advantages in doing so.

Lord Joffe introduced a bill in the next session of Parliament, in which he changed quite a lot from the previous bill. One change was that he restricted the bill to assisted suicide and took out the voluntary euthanasia aspect, which relates to the cases in which a person is not able to avail himself or herself of assistance to commit suicide because they are too weak or frail to do so. Lord Joffe had allowed for voluntary euthanasia in his earlier bill. It is fair to say that the select committee considered that those were two distinct issues and that the justification for one might not be as strong as the justification for the other. Therefore, the select committee considered that the bill would have to be considered in committee so that the two issues could be separated.

Unfortunately—or fortunately, depending on how you look at it—when Lord Joffe introduced his bill in the next session of Parliament, he cut out the voluntary euthanasia aspect altogether. The reason for requiring a committee stage, rather than just a second reading, had passed and the House decided the matter in the second-reading debate.

It is important to set out the detail for doctors because, after all—and as was said in the previous evidence session—the purpose of such legislation is primarily to indicate to doctors what they may do and that they do not run a legal risk by doing it. Therefore, it is important to let them know, pretty precisely, what they are allowed to do that hitherto they have not been allowed to do. Even with that, as our colleague from the Netherlands said, there is still difficulty in deciding what is to be done. Without reasonable details of legal protection, it is a little difficult to see that it would be wise to legislate.

Nanette Milne: As a medical practitioner in my previous life, I have a concern about the lack of a conscience clause in the proposed legislation. I am also concerned about how that would affect the rest of the team, beyond the medical practitioners.

11:45

Lord Mackay: I agree that it is important to make the position clear regarding the rest of the team. You mentioned the team, and an important point about the development of medical practice both in Scotland and in England and Wales is that there is now much more team practice than there used to be. It is now common for a patient to see a different doctor on a succession of occasions. Therefore, there is not quite the same relationship between a patient and a doctor that might have obtained at an earlier time here and which may obtain in other countries such as the Netherlands. There, the doctor gets to know the patient—their family, their circumstances and so on—over a period of years. Here, particularly when a patient is in hospital, a full team is often involved and it is quite difficult for any one member of the team to get to know the patient so well. Indeed, some of the evidence suggests that the nurses are subject to conversations about what should happen more than the consultants and other members of the medical team.

Nanette Milne: Thank you for that. That is important to note.

The Convener: Do you wish to comment on that, Mr Ward? I am not encouraging you, necessarily; I am just affording you the opportunity.

Adrian Ward: My only comment is that, as a practising solicitor, when somebody wants to make a power of attorney I have to assess whether they have capacity to do that and whether somebody is pushing them into doing it. It is much easier to make those judgments with clients and families whom I have known for a long time professionally than with somebody who has come into my office only that day. The difference really is huge.

Ian McKee: I have a question that follows on from Mr Ward's comment. I am sure that you and Lord Mackay are right in saying that the greater the continuity, the better qualified your advice will be. However, I imagine that the number of people who see their lawyer frequently is not huge. Most people see their lawyer when they move house or something like that, whereas people see their doctor often, especially the people whom we are talking about, who have probably been going to their doctor time and time again before they consider making such a request. On the other hand, if we accept that what Lord Mackay says is correct, just about any element of treatment could be vitiated on the ground that the doctor did not have knowledge of the patient's background. Surely, if someone has been ill enough to reach the point of making the request, there will be enough knowledge of them within the practice for a proper appreciation of the request and a proper judgment to be made on it.

Lord Mackay: I would think so. However, there is perhaps a slight difference in terms of intimacy between the knowledge that one gathers from reports of what one's partners have found on examination and so on and that which one gathers oneself from being the person with whom the patient has the relationship. That is simply a point for consideration—it is probably not critical one way or the other.

Michael Matheson: Lord Mackay, your committee's report shows that you gave quite a lot of consideration to the qualifying conditions in Lord Joffe's bill—in particular, his use of the term "unbearable" among those criteria. In your report, the committee suggests two terms as alternatives to that, which would provide a more objective medical assessment. In considering that matter, did you consider the word "intolerable", as it is defined in Margo MacDonald's bill, to be sufficiently objective?

Lord Mackay: I do not think that "intolerable" was suggested specifically, as far as I remember. It was five years ago, so I am treading on rather dangerous ground. We canvassed a number of different possibilities, and the ones that we ultimately came up with as looking to be the most objective were the ones that are included in the report. There is quite a range of possibility in that respect, and I commend the issue to the committee as something that has to be thought about with a degree of care, given the possibility that a doctor might rely on the criterion in defence or in support of what he or she has done.

Michael Matheson: From a legal perspective, can the term "intolerable" be readily defined?

Lord Mackay: "Intolerable" simply means that one cannot bear something. Of course, the question whether one cannot bear something is itself somewhat subjective. Then again, it is very difficult to formulate a completely objective standard, but we tried to produce the best wording in that respect.

The Convener: The specific terms that you recommend are "unrelievable" or "intractable", which set out an interesting concept that I had not come across before. Following on from Michael Matheson's probing of the use of the word "intolerable", I think that such a phrase moves us into a more objective field. Does either of you wish to comment on the specific recommendations of the House of Lords?

Lord Mackay: Our committee was attracted to that type of word because it is capable of being verified without relying on the patient's feelings—unlike the term "intolerable" and other possibilities along that line, which are quite difficult to determine in a way that would necessarily stand up to subsequent criticism.

Adrian Ward: I entirely agree. I have written down the two pairs of words. "Unbearable" and "intolerable" are substantially synonyms—they really mean the same thing—and are entirely subjective. Only I can tell you what is intolerable to me, whereas with the terms "intractable" and "unrelievable" there is an outside objective element—yes, we can do something about what someone finds intolerable, or no, we cannot. There is a significant difference between that kind of objective outside view and the purely subjective.

Ian McKee: I do not really understand your point, because I do not see how you can avoid a subjective element if you are dealing with someone in pain. Obviously if you get rid of someone's pain, that is fine, but at the end of the day pain is something that a person experiences and there is no painometer or some other machine that can detect it objectively. As a result, you will have to rely on what the patient—or, in legal terms, the victim—tells you when you ask those questions, your past experience and how things develop. Surely any view is bound to be subjective rather than objective.

Adrian Ward: Indeed, and that is what I said with regard to the terms "unbearable" and "intolerable". Only I can tell you whether the pain I am feeling is intolerable. However, I think that someone else can judge whether it can be relieved or treated or whether it is unrelievable and intractable.

Ian McKee: Surely only the patient who experiences the pain can tell you whether it has been or cannot be relieved, which brings us back to the fact that such views are subjective.

Lord Mackay: In that case, though, we are talking about a report on the effect of what you have done to relieve the patient's pain. If the pain is unrelievable, the patient will say, "I'm no better", but the question is whether anything can be done to make him or her better. If you have tried something and the patient says that it has not worked, that is a completely objective matter. You have to accept his or her verdict in that respect.

I agree that pain is very much a matter of subjective experience but, on the other hand, there are criteria by which relieving pain can be judged. Those of us who have been involved in personal injury cases will have been used to dealing with back pain, for example. Sometimes, the back pain is very severe, but it allows the person to do marvellous things off the record. Pain is certainly subjective to a substantial degree, but the means available to relieve it are objective.

The Convener: I seek clarification, perhaps from Mr Ward. Curiously, we are not trying to define pain; instead, we are trying to assess whether, in Ms MacDonald's bill, there are criteria against which to judge whether a person should be eligible to satisfy the conditions for assisted dying. The issue is whether people should self-certify or whether there should be objective criteria against which the decision is made. Is that not the territory that we are in?

Adrian Ward: Yes, and I think that there must be a combination of both. If a person had not in effect self-certified, they would not have raised the question but, after that, it is relevant to hear what others have to say.

The Convener: I apologise to Michael Matheson for interrupting his questioning.

Michael Matheson: That is fine. It was a helpful discussion.

Concerns have been raised about the assessment process for patients who wish to exercise their rights under the bill. The bill requires a psychiatrist's assessment to be carried out, but we have received evidence that the bill must be much clearer in its definition of a psychiatrist and that it should set out the necessary qualifications to perform that type of assessment. Given Mr Ward's expertise in the field of mental health legislation, I ask him to say whether it is necessary to be specific about which individuals should be responsible for performing such assessments.

Adrian Ward: We really must start with considering what is being assessed. Section 9(4) states:

> "a person has capacity to make a request for end of life assistance if that person is not suffering from any mental disorder which might affect the making of such a request and is capable of"

various things—there is a list that members who are familiar with the Adults with Incapacity (Scotland) Act 2000 will recognise.

However, there is a curious reversal of the 2000 act. On issues of capacity and incapacity, validity and invalidity and related issues of discrimination, we want to be sure that we screen out people who cannot make a decision but do not exclude those who can. If, simply because of the presence of some disorder we exclude someone who could in fact deal with something, we are discriminating. Reading section 9(4) carefully, we find that it tells us that the gateway is that a person has a

> "mental disorder which might affect the making of ... a request".

So if one has such a mental disorder, even if one is in fact capable of making a request, one is excluded. Obviously, this discussion is not about the principle of whether there should be such a procedure; it is about how such a procedure, if there were to be one, should be applied and what should be the gateways.

A depression could affect someone's ability to make a capable decision but, upon assessment, it might be found that it does not and that they can make such a decision. Those people should not be excluded. The Adults with Incapacity (Scotland) Act 2000 requires incapability—defined rather similarly to the way in which it is defined in the bill—that is caused by a mental disorder. That is the other way round, and it is quite different. It does not say, "If you've got a mental disorder at all, you are out." Even if someone does not have a mental disorder, are they capable? I suggest that the bill puts matters the wrong way round.

12:00

The issues that are addressed in section 9 are simply capacity and undue influence. I mentioned certifying a power of attorney. Solicitors, advocates and medical practitioners can grant a certificate that becomes part of a power of attorney document, and only with such a certificate can the power be registered and operate after loss of capacity. We have to certify that there is not only understanding, capacity and a lack of undue influence, but a lack of any other vitiating factor. There are a range of things in law that can knock out what might otherwise be a consent. One has to address all those carefully in one form or another under the legislation.

On how one screens out, if I am not confident about certifying a power of attorney, I speak to someone who has relevant skills or knowledge and narrate that I have done so. For certain medical treatments, such as electroconvulsive therapy, the Mental Health (Care and Treatment) (Scotland) Act 2003 says that even if someone consents to the treatment, there must be certification by one doctor that the person is capable and consents. Someone who wishes to consent voluntarily to what is usually termed psychosurgery needs much more—they need a doctor to certify that they are capable of consenting and that they consent. Interestingly, they also need at least two other people who are not doctors to certify that.

The issue really comes back to the task. Capacity is task specific. Many people have capacity for some things but not for others and capacity at some times and not at other times. Therefore, the capacity has to be task specific to a decision of the nature that we are discussing. Given that we set the bar rather higher and require rather more input for psychosurgery, the committee might feel that the bar should not be a great deal lower for the subject matter that we are addressing. However, it has to be task specific.

The expertise that we need is in assessing capacity. There are psychologists and experienced mental health officers who are trained social workers who do that very well. So in one respect, we might not need to be too narrow but, in another respect, we must be sure that we take people who have the specific expertise to assess capacity and to do so in the circumstances covered by the bill and for those purposes.

The Convener: I want to pursue that point and to pick up on points in Lord Mackay's written submission. He drew attention to the fact that witnesses to the select committee

> "warned that 'the desire to die covers a spectrum of intent' and that 'far more people express a desire to die than actually make an attempt to kill themselves'".

The paper goes on to refer to episodic reactive depression. If I read the submission correctly, the select committee's conclusion was to recommend a much broader requirement for psychiatric evaluation than was proposed in the Joffe bill. By inference, Lord Mackay is making a similar comment in relation to Margo MacDonald's bill. Would either or both of you care to develop that point in the context of the select committee's comments on capacity in its report?

Adrian Ward: You make a number of points. It is correct that people express one view of what they would want in a situation and that their view is sometimes different when they actually find themselves in that situation. That is well known and well documented.

As a practising solicitor, a well-known client came to me and said. "Look, I have been diagnosed with a terminal condition. I know it's going to get very nasty towards the end. I may well want to end it. If I wait until I cannot do that without assistance, would someone who helped me be committing a crime?" I had to say yes. The client said, "Therefore, you are telling me that, if I decide that I wish to end it, I must be constrained to do that before I get to the point at which I cannot do that unaided."

I am simply reporting that as it is representative of something that one has to address. In proposing legislation of this nature, it is appropriate to consider not only how many people might actually avail themselves of this procedure but how many people might be comforted by knowing that the procedure is available, even though many of them, I suspect, would never follow it. For example, the last time that I spoke to the client whom I just mentioned, he was doing well, and that was well beyond the length of time that had been predicted for his survival.

Lord Mackay: The issue of the estimate of how long someone has left to live is a separate problem, as that is not an exact science, by any means.

The fact that, although people might have a settled resolve that they want to die, they might decide, when it comes to the bit, that they do not want to carry it out, is evidenced by what we know from the example of Oregon. I understand that, in Oregon, for a lethal prescription to be given, the person to whom it is given is required to have exhibited a settled desire to end his or her life. However, the evidence shows that quite a number of people who got that lethal prescription did not use it. It is possible for a view that is settled today not to be settled in the future, until the end of someone's life. Any legislation of the kind that is being contemplated here needs to take such matters into account.

As Adrian Ward said, however, in Oregon, people who got that lethal prescription received a measure of assurance that, if things got too bad, they could take it.

It is quite important to consider the issue of the sort of explanation of one's point of view on which final action should be taken, because that might have a considerable bearing on the amount of time that the person will have in this life.

The Convener: Lord Mackay, your report draws our attention to the fact that the committee that you chaired recommended that, if a future bill should include terminal illness as a qualifying condition, that should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis. Are you able to assist us by developing that important point, which has become rather relevant of late?

Margo MacDonald: Mr MacAskill will look forward to hearing from you.

Lord Mackay: It is difficult to do what you ask. I need not remind this committee that it is not particularly easy to make such an estimate with regard to a period of months

We said that if the prognosis is that life is coming to an end, it is, on the whole, easier to estimate how long that will be if a much shorter period of time is involved, as over a longer period the developments can be remarkable. We did not attempt to say how that should be done; we just drew attention to the need to do it, which is perhaps not as helpful as it would have been if we had said what should happen—

The Convener: Which was why I asked the question.

Lord Mackay: Quite. We would, if we are looking at terminal illness on that basis, tend to go for a period that is shorter than six months. The precise period of time that might be best would be down to the medical professional evidence that you receive, but our evidence suggests that the time period would need to be quite short for estimates to be really reliable.

The Convener: Mr Ward, would making that a qualifying condition, as the bill proposes, give rise to any particular difficulties?

Adrian Ward: There is considerable difficulty in trying to make a prediction and hanging a great deal on it. Medical people can try to give you an idea, but—this issue is probably more for the committee’s medical witnesses—medicine is not an exact science. We are not machines that can be taken apart and told exactly what has worn and by how much, and what is there.

I have come across many cases in which people have been in great pain that is apparently due to a degenerative condition, and it has then been discovered that something else—such as an infection—is present and can be treated, which makes the situation a little better.

I agree with Lord Mackay on the great difficulty of asking doctors to make a prediction over several months and hanging a great deal on that.

The Convener: The point about other illnesses was raised at the House of Lords committee, and—to pick up on the previous question that we were discussing—was another reason that was advanced for more exhaustive medical examination.

Margo MacDonald: I realise that how long someone should live after the doctors have said that they are going to die is a delicate subject, and we should not try to come up with an answer that is not an answer. Every person is an individual, and if the doctor says, “This person is dying and they cannot return from that position; there is no way back from this illness,” I would not be too concerned if he was out by a month or two, or even six months.

In proposing the bill, I am most concerned about the requesting person—in other words, the patient. This rests on the patient’s autonomy, and there is bound to be subjectivity with regard to what a patient considers to be intolerable. The issue is not just intolerable pain; most of the people I have spoken to who have progressive degenerative conditions, as we have described them, are at least as concerned about the slow descent into complete loss of control and choice in relation to how they live out their lives as they are about pain.

That must be taken into account, and it should be respected. I accept that other people do not believe in taking as individual an approach to the matter as I do, but we can start from what I believe and what is reflected in the bill.

I ask Lord Mackay and Adrian Ward whether it is satisfactory that the DPP guidelines are not equitable, in that they do not treat everyone in the same way. A subjective opinion is reached by the DPP, who decides whether or not an action that resulted in the death of another person came about through compassion, care and love. He has said that if it is an act of compassion, there is unlikely to be a prosecution. How can he judge that? If you are going to give someone the legal protection of not being prosecuted, the condition that is laid down must be a bit more objective.

Lord Mackay said that we have to accept the criteria that are set down. I know that but, if you are here in an individual capacity at all, Mr Ward, I would be interested to know whether you, as a lawyer, think that approaching such a thing in such a way makes good law. The overwhelming view of people who have considered the issue seriously is that we must have legislation and cannot leave an official to interpret guidelines, as that is not equitable. I thought that equity was one of the principles of our law making.

12:15

The other issue that I want to tackle is that of conscience. The committee members said that they would have preferred there to be a conscience clause. We have not included one, and we have a reason for that. We have tried to ensure that no one—including those who work in the team that supports someone with a progressive degenerative condition, such as medical social workers, psychiatrists and physiotherapists—is compelled to assist in a procedure and that any one of them can opt out. We have made it as fluid as we can. Any of those people have the right to say no, because they have consciences, too. This piece of legislation is at the very interface of personal conscience and public policy. I accept that it is difficult to ensure that the situation is equitable in one respect and highly individualised in another respect, but that is what is required.

We spent a long time talking about the word “intolerable.” Yes, it is subjective; it involves the patient’s feelings. Someone who has a progressive degenerative condition might well have to wait for a very long time before they are into the period in which they are terminally ill, but they can find the lack of control and the lack of their wishes being acted on to be intolerable long before they reach the very end stage, and they might want to miss that stage of their condition because that death can be terrible. We hope that that does not happen, but it is a comfort to have the insurance policy of knowing what, for example, Debbie Purdy wanted to know: that your husband or wife will not be prosecuted if they help you.

It is an insurance policy. In Oregon, 44 per cent of the people who get a lethal prescription—which I always imagine sitting on their mantelpiece—do not use it because they do not reach the stage at which their condition is absolutely intolerable. However, they like to know that, if their life becomes absolutely intolerable, they have the choice to end it.

The psychologists and psychiatrists to whom I have spoken do not have the trouble with the determining of capacities that it has been suggested might be encountered. They say that that is their stock-in-trade, they do it every day of the week and it is what they are paid to do; so they do not find it as much of a trial or a difficulty as I think Adrian Ward was suggesting it would be. However, if we can improve on the legislation, I would be delighted to try to amend that part of the bill.

That is probably all that I wanted to say at the moment. I would like to hear people’s comments.

The Convener: I think that they are just drawing breath.

Adrian Ward: On determining capacities, I can only report that I have had fairly frequent experience of situations in which there has been a quick and clear determination of capacity or incapacity that, for one reason or another, has not quite rung true and, on further consideration and careful examination, has proved not to be correct for a particular purpose, perhaps because a person has been approached on a bad day or has been approached in a difficult way. The determination can be wrong either way. I have had situations in which people have been certified as capable but there has been no way in which I could take instructions from them. It is not always easy to determine someone’s capacity.

I think that I covered Margo MacDonald’s point about the long wait until one is terminally ill in my previous answer. There is a comfort factor, but I have a degree of reservation about the idea of the prescription—if she means the actual drug that is prescribed—sitting on the mantelpiece. If it sits there for a long time, it could be used impulsively.

More valuable, to my mind—I base this view on clients I have dealt with and people with whom I have discussed these things—would be the knowledge that the procedure was there, and that the prescription could be obtained. That largely answers Margo MacDonald’s point about loss of control.

Margo MacDonald: That is the point that I was making: the idea of an insurance policy, so that if it does get too bad, you can do something about it.

Adrian Ward: Doctors with whom I have spoken tell me that people who can self-administer pain relief—by pressing a button, for example—generally use less of it than those who cannot, because they know that it is there.

Margo MacDonald: Oh no, I did not—I used it all.

Adrian Ward: I am told that—apparently—people often tend to use less than those who do not have that degree of control. I am not competent to say that; I am just reporting it.

Margo MacDonald: You are actually saying what I have discovered from speaking and listening to people; that is the sort of thing that they say.

The Convener: I would like Margo MacDonald to clarify something. In the bill, you introduce the question of whether or not a condition is “intolerable”. However, you are saying—unless I am mishearing you; I would like you to clarify the matter so that I do not get the wrong end of the stick—that someone might qualify by being deemed to be in an intolerable condition, and then not use their prescription because they are not in an intolerable condition. Is there not an inherent conflict between having to meet the criteria and deciding whether or not one wishes to use them?

Margo MacDonald: Can I be anecdotal on that? I know people who have conditions that can deteriorate to the stage at which no amount of palliative care is satisfactory. They know that that is possible, and they can reach a position where life is just intolerable to them, although we hope that that does not happen. Everyone can change their mind. A case was reported to me of a Scot who went to live in the Netherlands. Because he had oesophageal cancer, he took advantage of the law there, which he was quite entitled to do as he had been living there for long enough. His friends went over from Scotland to be with him, and he wanted a dignified peaceful end with all the ends tied up. However, he changed his mind twice after the date had been set.

The friends were a bit nonplussed, and they asked his doctors about it. The doctors said that it showed that the Dutch law was working, because it is the patient who determines when and whether their life is going to end, as they make the request. I do not know whether that conveys some of the feeling of control and of autonomy for the patient who is working with the medical practitioner.

The Convener: I will not express a view on that; it simply brings us back, in a circle, to the point that was discussed earlier about whether we should use subjective criteria, or more objective criteria that use terms such as “unrelievable” or “intractable”. We have rehearsed that well enough; I apologise to Adrian Ward for interrupting him.

Adrian Ward: I was going backwards through the points. The first relates to the DPP guidelines. In all the British systems of prosecution, the question is whether there is evidence that a crime has been committed that looks as if it will stand up. As I understand it, only after that point must the prosecutor ask whether it is in the public interest that he prosecutes.

All the elements of the issue cannot be prescriptively laid down, because if that could be done clearly, it would move to the level of legislation, which would state that in certain situations something should not be a crime. There must be an element—which seems to be what Margo MacDonald is criticising—that comes down almost entirely to making a judgment and weighing things up.

The earlier witnesses talked about this being a law for the protection of doctors. We have a slightly unusual legal situation here, in that if I assist someone to commit a crime, I am probably committing a crime. Here, the assistance that is being provided is a crime but the act that is being assisted is not a crime. I cannot think of another situation where that is so.

Margo MacDonald: I do not think that the Lord Advocate said that she would be persuaded by the DPP guidelines. She said that she would keep an eye on them, but she did not say that they would be persuasive in Scotland. I would prefer your comment on this. If we are going to opt out of the law in this way, is it not better to have a standard that everyone understands will apply equally? The DPP has kept people waiting—he kept Dr Libby Wilson waiting for months before he said whether she would be prosecuted for having been judged to have given advice on how to commit suicide to someone over the phone. Is that good law?

Adrian Ward: That is where I would have to turn the matter back to you as legislators; it is for legislators to determine the level at which something should be a matter of judgment and practice, and the level at which there should be the reassurance of clear law. As I understand it, that is probably what this process is all about.

Lord Mackay: Shall I comment on Margo MacDonald’s points?

Margo MacDonald: Yes, please.

The Convener: Please do not feel inhibited about going forward or backwards. A precedent was not necessarily being set by Mr Ward on that matter.

Lord Mackay: I will take the points in the order in which Margo MacDonald made them, in the hope that that may be helpful.

As Adrian Ward pointed out, the essential nature of guidelines is that they are guidelines. The DPP is not authorised to change the law. The legislation—the Suicide Act 1961—stands. The DPP was asked by the now Supreme Court to say what the factors were that would be taken into account in deciding whether a particular prosecution should go ahead. He has done that, as a result of consultation and to the best of his ability. Mrs Purdy concluded from the guidelines that what she wanted to do would be all right. However, the guidelines cannot alter the legislation. The DPP was dealing with a situation in which the legislation stands and he was illustrating and setting out the way in which he would use his discretion in the prosecution.

The second question was about the conscience clause. I entirely agree with Margo MacDonald that everyone involved in the system of giving this type of assistance may have a conscientious objection and should, on that basis, be entitled to opt out. Of course, it depends on whether you think that the law that would be enacted would confer on people who are, for example, national health service patients, the right in some circumstances to go down that road. If that is the situation, and depending on what the legislation says, a doctor who was asked to take part in this would have, under the NHS arrangement, a duty to do so unless he or she had a conscientious objection. Abortion is rather like that; it is subject to express conscientious objection, in a clause provided in the Abortion Act 1967. All I am doing is drawing attention to that to see whether the committee and, ultimately, the Parliament would want to take some account of it in its deliberations on the bill.

12:30

The next point was about intolerable, and not necessarily intolerable, pain. That question is not really for me to answer. I just draw attention to the point that if you are to allow an entirely subjective way of considering the issue as the basis of a law that protects doctors, you have to make that pretty plain.

The last point was about capacity. I do not profess to have any knowledge of or ability in that; all I want to say is that the committee needs to hear the medical evidence on that and what doctors say about what they can or cannot do based on a single interview or whatever. That was discussed in the select committee on Lord Joffe's bill. I have no doubt that the capacity question is important and difficult. As the witnesses from the Netherlands pointed out, doctors who actually do such procedures are in a pretty difficult situation if it turns out that the decision was wrong in some way or another.

The select committee drew attention to evidence from pathologists that about 5 per cent of post mortems that are done in respect of terminal illness turn out to give proof that it was not the terminal illness that caused death at all, but something else. A few moments ago, Adrian Ward mentioned the possibility of other kinds of curable infections. The question of capacity is a matter for doctors and the evidence that the committee may take from them. All I say is that it is an important question that needs to be considered.

Margo MacDonald: Just to follow up that point, I agree that doctors need the protection, provided that they adhere to the law. However, you said that post mortems can show that a wrong decision was arrived at on the cause of death. In essence, is there any great difference between the case of a doctor agreeing to assist a suicide and somehow, post mortem, the decision being made that the person might have been suffering from a spike of depression and should or could have been treated, and the case of someone who is on an artificial ventilator and a decision being made to shut down the ventilator? Every so often, somebody comes out of a coma after being in it for a long time. Do not doctors have to make such decisions?

Lord Mackay: The decision about shutting off the ventilator is certainly a difficult matter. Before one shuts it off, one would want to be pretty sure that that was the only effective way of dealing with the matter. As part of that decision, one would have to be sure that no treatment could help relieve the patient's suffering. As you know, the House of Lords exercised itself fully in the case of Bland in that area. All I can do is commend that judgment to you. It is not easy to summarise.

Margo MacDonald: But those are questions of professional judgment, and professional standards and guidelines are laid down by the profession to try to ensure that the judgment that is exercised by individual practitioners is likely to be as correct as possible.

Lord Mackay: That is true. All I am saying is that, if I was a doctor who had carried out such a procedure and it turned out that what I had done was on a false basis, I would be rather troubled.

Ian McKee: Lord Mackay mentioned that 5 per cent of post mortems of people who were thought to have died from terminal illness showed a different illness as the cause. However, does he accept that, as the vast majority of people who die from terminal illness do not have post mortems, that might well be a skewed figure? In those cases, there might have been some sort of suspicion, whereas most people would not have a post mortem at all. So the figure is probably a lot smaller than 5 per cent.

Lord Mackay: I cannot tell how much it would affect the figure, but I hope that I was careful to say that it was in cases in which post mortems had been done. Needless to say, the figure does not apply to other cases. All that I am pointing out is that, in the cases that we know about, there is a risk. As I said, if I was a doctor who had carried out the procedure and it turned out after a post mortem that what I had done was on the wrong basis, I would feel at least rather uncomfortable.

The Convener: I thank Lord Mackay and Adrian Ward. Mr Ward, you said that you struggled to think of a case in which someone assisting in something would be committing an offence, whereas the actual provider would not, but that might indicate that, although you are an undoubted expert on mental health and disability, you have not necessarily considered the law on prostitution.

Margo MacDonald: Oh that is good—are we starting on that?

The Convener: We might find that it is an offence to give assistance for something that is not an offence.

Adrian Ward: There are some other things that the prostitute might be doing that would be an offence.

The Convener: Anyway, given the risk of encouraging the member in charge of the bill, we will not go there. I thank both the witnesses very much for their evidence.

I now suspend the meeting. The meeting will resume at 5 o'clock. I ask members to be in their places a little in advance of that, because we will have a video link with Oregon. It is important to be able to commence the meeting at 5 o'clock and to assist those who are dealing with the transmission to do so in an orderly way.

12:37

Meeting suspended.

17:01

On resuming—

The Convener: I welcome everybody back and again remind people to turn off their mobile phones or other electronic instruments.

As you are all aware, our final panel of witnesses is giving evidence via a videoconference link from Portland, Oregon, in the USA. Both our witnesses are experts on different aspects of Oregon's assisted suicide law and have informed us that they are neutral with regard to the law, being neither for or against it.

On the panel, we have Linda Ganzini, who is a professor of psychiatry and medicine and a senior scholar of the centre of ethics and health care at Oregon Health and Science University; and Deborah Whiting Jaques, the executive director and chief executive officer of the Oregon Hospice Association.

Professor Linda Ganzini (Oregon Health and Science University): Thank you for having us.

Deborah Whiting Jaques (Oregon Hospice Association): It is delightful to be with you.

The Convener: It might be helpful if I introduced the members of the committee. On my right—your left—at the far end, is Nanette Milne. Next to her is Helen Eadie; next to Helen is Michael Matheson; and next to Michael is Ian McKee. Sitting beside me is the adviser to the committee, Alison Britton. I am Ross Finnie. At the other end of the table is the member whose bill we are discussing, Margo MacDonald—she is a bit of a limelight case, as you might have gathered from the way in which she is waving at you.

Margo MacDonald: I am just saying hello.

The Convener: I invite members to ask questions.

Helen Eadie: I am pleased to have the opportunity to ask you about the circumstances in Oregon. From reading the report of the House of Lords select committee, I understand that 30 to 40 per cent of people in Oregon remain to be persuaded by the legislation. I also understand that the legislature voted to pass the legislation. As the report was published in 2005, it is a little dated, so I wonder how things have changed in Oregon since then. The report said that, in a sense, the jury was out, as the law in Oregon is on the specific issue of assisted suicide, but there is the wider issue of the euthanasia debate as well. Could you expand on that aspect?

Professor Ganzini: As you know from reviewing our law, Oregon is a place where a group of citizens can put a measure on a ballot for the state to vote on. In 1994, the ballot on assisted suicide was introduced, and around 51 per cent of Oregonians voted in favour of the measure.

Our legislature—this is not meant to be a criticism of legislatures—was concerned that the citizens of Oregon did not really know what they were voting on, so the measure went back, unchanged, to a vote a few years later. The second time round, Oregonians voted by a larger percentage—60 per cent to 40 per cent—not to repeal the law.

There have been no substantial surveys of the general population since then, but smaller groups of people have been surveyed. In general, around a third of people oppose the legalisation on assisted suicide; we do not have any evidence for or against that figure changing over time.

Deborah Whiting Jaques: It is interesting to note that the state of Washington, which is just north of Oregon, passed almost exactly the same bill last year. While Oregon has had an environment in which assisted dying is possible for 12 years, Washington now has nine months of data to report. The public support and perception in Washington reflects that in Oregon. From a hospice perspective, it is perceived in the state of Oregon that the Death with Dignity Act is the law and is available to Oregonians—the few who choose to use it—as an alternative.

Professor Ganzini: From studying smaller populations such as physicians, hospice social workers, hospice nurses and patient groups, it is evident that the core people—the third I mentioned—who oppose the law often do so on a moral and ethical basis. Whether the law is successful or problematic would not really impact on their views, which are determined by ethics.

Helen Eadie: I understand that the number of people who opt to take the decision is in the region of 36 people per year. Is that still the number that we are talking about, across the whole population of Oregon?

Professor Ganzini: Assisted suicide currently accounts for around two in 1,000 deaths, which is a very small number; it has increased slowly from around one in 1,000. I will ask my colleague to tell you what the absolute number is.

Deborah Whiting Jaques: In total, 406 people have availed themselves of the law since 1998. In 2009, 95 prescriptions were written, and 53 individuals ended their lives using the medication.

Helen Eadie: I have a question about the prescriptions. Are they written, filled by the pharmacy and left with the patient indefinitely?

Deborah Whiting Jaques: Yes, that is true. Some pharmacies in the state of Oregon choose not to participate, but others do. One of the most interesting aspects about the Death with Dignity Act in Oregon, and one of the issues that stuck out in my mind as I read the bill today, is the timeline available for the bill to be effective. In Oregon, for every 10 people who get a prescription, only seven use the medication. Having the medication available in the patient's home seems to be an important component in the psychological and social aspects of the law.

Helen Eadie: Is there any risk to other individuals in the household of having the pill in the household? Does it get kept in a secure place?

Professor Ganzini: The law does not say that the patient and family need to keep the prescription in a safe place. There are some physicians who do not want the prescription around. In some cases, they pick it up and bring it to the patient's home. We do not have any evidence of adverse outcomes because of someone else getting hold of the prescription, although it is a potential concern because these are highly lethal medications. On the other hand, people with terminal illness have lots of potentially lethal medications in their homes. There is a difference between Great Britain and the rest of Europe, and the United States, in that most hospice care and end-of-life care here is delivered in patients' homes. Only about 20 per cent of people die in hospital in this area, whereas in Scotland I think that it is about 60 per cent. There is a strong ethos here of de-medicalisation of death, and of death occurring in people's homes. There are many aspects of the dying process over which the physicians and the medical system have less control; there are good parts to that and bad parts.

Michael Matheson: You gave us figures for the number of patients who are issued with a prescription but who, in the end, do not use that prescription to end their life. It struck me as being a fairly high number who go down that route. Is there any evidence on why those patients have chosen not to use the medication, having gone through the process of deciding that they would like to have such a prescription issued to them?

Professor Ganzini: In some cases, people make a voluntary choice not to take the medication. More often, in my experience, they lose the ability to take the medication because the disease overtakes them unexpectedly, and they develop confusion, delirium or swallowing difficulties. Some wish to have the medication just to have a sense of control. However, I am more impressed by the number of people who take the medication than the number who do not. Sixty to 70 per cent of people who get these medications are quite determined to use them and to have that be the method at their life's end.

17:15

Deborah Whiting Jaques: It is interesting to note that when people who had got a prescription were asked why they were seeking to use that legal alternative in the states of Oregon and Washington, nearly 97 per cent of Oregonians and 100 per cent of Washingtonians said that the primary reason was the loss of autonomy. The individuals who choose to use the option are highly independent and have great self-determination. That is the demographic. Given the primary stated reason for using the medication, once the medication is obtained or people are able to have it, they certainly feel that they are in control of their own destiny. As a hospice professional, I agree with Professor Ganzini that, because of the way in which Oregon's law is written and the fact that the individual must be able to take the medication themselves, some patients simply lose the ability to use the medication that they have received.

Michael Matheson: Obviously, in progressing the proposed legislation in Oregon, a conscious decision was taken at the outset not to include euthanasia, which would have clearly addressed the issue of patients who lose the physical capacity to administer the medication themselves. When the law was being framed, why was there a deliberate decision not to include euthanasia?

Professor Ganzini: We were not involved in that particular decision, but I think that the people who supported the legislation politically thought that the inclusion of euthanasia would result in the law not being passed. It was thought simply to be politically inadvisable to add it.

The second reason has to do with the nature of the north-western United States. There is a strong ethos of rugged individualism here. People have a strong desire to remain independent; they want to be in charge of what is going on with them and do not want doctors to be in charge.

It is also true that end-of-life or palliative sedation is a reasonable alternative to euthanasia for people whose symptoms are uncontrollable—who have uncontrolled pain or who vomit uncontrollably, for example—in the final days of life. Since the law was passed, there really has not been a need to push for euthanasia because there are alternatives for such symptoms. There are not good alternatives for people who wish to be in control in the way that people who want assisted suicide wish to be.

Michael Matheson: There is another issue that I want to raise. If an individual is in a hospice environment or a federal health care facility that meets the criteria set out in the legislation, can they have a prescription issued in that facility and administer things themselves or must they be in their own private home or another private facility?

Deborah Whiting Jaques: I am not aware of deaths that have occurred inside a facility. As we have stated before, hospice care is primarily provided in a household environment—in patients' homes. I am not aware of an instance in the past several years in which I have been involved with the Death with Dignity Act and hospice care of an assisted suicide occurring in a hospital facility. Do you have experience of that, Linda?

Professor Ganzini: No. One important reason why people want assisted suicide is that they do not want to die in the hospital—they really want to die at home—so it would be unusual for somebody to go into hospital and request assisted suicide there.

The federal facilities in our state are small—they include Department of Veterans Affairs facilities, which take care of just a small group of patients who have served in the war, and federal prisons. A physician who was employed by either of those groups would not be able to write a relevant prescription; if they did, the associated pharmacies would not fulfil it. However, veterans can get assisted suicide by going outside the veterans system, so there is no problem of people being affiliated to one system and being unable to use a private or different system.

Deborah Whiting Jaques: One point that I have seen in the comprehensive work that has been done on the bill and in the House of Lords report from 2005 is that the faith community has moral and ethical issues with hastening death. It is significant to note that, as Linda Ganzini mentions, just as veterans have the option to seek alternatives outside the veterans programme, the same applies to patients in a hospital-based system that has physicians who are faith based and which chooses not to allow its physicians or staff to prescribe under or participate in the Oregon Death with Dignity Act. Individuals who find themselves in such situations have alternatives, too.

Michael Matheson: That is helpful. Has the state Government taken a policy decision not to allow patients in state facilities to use the legislation and does it require them to leave those facilities to use it? It appears from what you have said that such patients who wish to use the legislation must opt out of the state system—is that correct?

Professor Ganzini: That is correct, but less than 5 per cent of the population is served by a federal system. There are not really any state systems.

Deborah Whiting Jaques: Linda, does an opt-out actually exist? For instance, does a veteran have to say, "I am opting out of my Department of Veterans Affairs provision so that I can go to another physician to acquire a prescription under the Death with Dignity Act"? I do not believe that people have to say that—the process is additional.

Professor Ganzini: Right. A veteran could continue to receive all their other care through the Department of Veterans Affairs, for example.

Michael Matheson: That is helpful. Health care is different in Scotland, where the state provides 99.9 per cent of health care, and I pursued the question because I was interested in understanding the position in Oregon. I recognise that a very small percentage of people there receive state support.

The Convener: I will follow up Michael Matheson's point. Will the witnesses outline the amount of palliative care—I presume that it is private—in Oregon? Having described what is available, will you tell us whether that has changed for better or worse since the 1997 act was introduced?

Deborah Whiting Jaques: I have a question for clarity, as the terms "hospice" and "palliative care" are used interchangeably. Are you talking about end-of-life care in general—about how many more programmes exist or about whether detrimental effects or occurrences as a result of the 1997 act have damaged end-of-life care?

The Convener: Let me try to be helpful. I was following on from Michael Matheson's question about provision. I am interested in what you regard as the state of development of palliative care. We heard this morning from witnesses from the Netherlands, Belgium and elsewhere. We learned that in some cases there was a poor level of palliative care but that there has been quite an improvement in provision since death with dignity legislation came into being. I am not trying to be too specific about the nature of the care; I am interested in the quantum of provision and the general quality of care.

Professor Ganzini: When the assisted suicide law passed in 1994, Oregon was ahead of many other states in the provision of hospice care. It had one of the highest rates of hospice utilisation at the end of life. However, palliative care in other, non-hospice settings was poorly developed. Since that time, there has been a dramatic increase in Oregon in both hospice and palliative care. Almost all the major hospitals have separate palliative care teams.

However, hospice and palliative care have improved across the country—although we are still somewhat ahead of the curve. It is hard to say that the assisted suicide law caused the improvement in Oregon; it is more that we were already ahead of the curve. It could be said that it is more likely that people felt comfortable about passing the law because they were more confident about their ability to access hospice. There are 50 hospice organisations in Oregon, and there is broad coverage, so there is no evidence that anyone who wants hospice at the end of life would not be able to get it.

It is true that many people who want assisted suicide initially decline hospice, because they see it as an affront to their independence to have people coming into their homes delivering a lot of care that they do not want. However, there has been a great push to ensure that people understand that hospice is an opportunity to improve their independence, not the reverse. Overall, Oregon's hospice and palliative care has improved dramatically, but it would be hard to say that that is because of the assisted suicide law or that the law either promoted or undermined that development.

Deborah Whiting Jaques: I agree. It is more the case that Oregonians' interest in and comfort with grappling with end-of-life issues is responsible for the passing of the Death with Dignity Act than it is the case that a causal effect of the act has been to increase the amount of hospice care that is available in the state of Oregon or the state of Washington.

As of today, 46 other states provide less hospice care than does the state of Oregon—and the states that provide more hospice care have a higher concentration of elderly individuals, so that is not necessarily surprising. I would not draw a direct correlation between improvements in the quality of hospice and palliative care or the number of agencies that provide such care and the presence of the Death with Dignity Act.

Ian McKee: I want to put this beyond doubt. Do hospice physicians in Oregon regard the legislation as a threat or an opportunity, or do they regard it neutrally?

Professor Ganzini: A crucial difference between our system and yours is that in Oregon most patients who go into hospices retain their personal physician, whom they might have had for a long time. Hospice nurses, social workers and other personnel come into their home to deliver care, working with the person's personal physician.

There is also a hospice medical director, but that person is not the one who writes the orders. For example, it is quite possible that a person in Oregon could receive a prescription from their personal physician and die through assisted suicide, and the hospice or the medical director would never know. Some people feel that it is a very private thing and so do not, for a variety of privacy reasons, want their hospice to know. That does not happen very often, but it shows how things are different here.

17:30

Deborah Whiting Jaques: Another important point to consider is that physicians, hospitals and hospice agencies across the state of Oregon have different policies, perceptions and levels of implementation and availability of the Death with Dignity Act 1997. As Linda Ganzini has said, some hospices have policies that specifically do not allow the hospice employees to be present when the medication is ingested. Hospice personnel may arrive after that, but they may not be present when the medication is being taken.

Professor Courtney Campbell, the director of the department of philosophy at Oregon State University, has just completed a study in which 59 separate hospice agencies in different locations responded. He found that there are vast differences across this state of urban and rural, metropolitan and suburban areas, and that people—physicians included—have very different ideas about what they want their practices to be involved in; hospices are the same.

The important point is that there are alternatives for individuals whose hospice says that it will not be involved in being with them when they take the medicine, and that it will not prescribe it for them, but it will refer them to a group called Compassion & Choices. That group is the public benefit charitable organisation in Oregon and elsewhere that helps people to go through the process as prescribed by the law. Many hospices, hospitals and physicians will refer a patient to Compassion & Choices for consultations and threshold events that must occur for the law to be administered.

Professor Ganzini: By the same token, it would be highly unusual—I am not sure that it has ever occurred—for a hospice to discharge a patient because they were pursuing assisted suicide.

Deborah Whiting Jaques: No—we would not do that.

Professor Ganzini: A hospice would see non-abandonment as being a higher principle than not wanting to hasten death. It would continue to care for the patient and to do all the things that hospice does but, in some cases, it would not be involved in issues around obtaining and taking the prescription.

Deborah Whiting Jaques: A hospice will not discharge a patient because they wish to avail themselves of the law. That would be abandonment, and we should make it very clear that Oregonians have the right to have hospice and access to the Death with Dignity Act 1997.

Ian McKee: Thank you. You have made that very clear.

What medication is used, how does it work, and is it always successful straight away?

Professor Ganzini: The medication is one of two short-acting barbiturates called nembutal and—what is the other one?

Deborah Whiting Jaques: They are called secobarbital and phenobarbital.

Professor Ganzini: Those are old sleep agents that are now very rarely used for other purposes in the United States because of the lethal risk if people use them as a sleep aid. The patient receives about 10g of the medication. It is in a capsule and is put in a sweet slurry, because it apparently tastes awful. The patient needs to consume it in a short period of time—less than five minutes. The majority of patients fall asleep immediately and then die within a couple of hours. However, there have been cases of patients who have lived longer than 24 hours, which was very hard for the family. In one case out of the 406, a patient woke up after three days and then died several weeks later from their underlying disease. The concoction is very unpleasant tasting, so some patients are at risk of throwing up. That happens in about 5 per cent of cases, although usually there is enough medication in their system so that they die.

Deborah Whiting Jaques: The median length of time from ingestion of the medication to unconsciousness is five minutes, and the range is one to 30 minutes. From ingestion to death, the median time is 45 minutes and the range is two minutes to 104 hours. So, there is a range, but the medians are that people fall asleep in five minutes and die in 45 minutes after ingestion of 5oz of sweet liquid with the secobarbital or phenobarbital.

Professor Ganzini: For those of you who are grasping in their minds to remember your elementary statistics course, the median means that half the people take more time and half the people take less—the median is different from the average.

Ian McKee: Thank you. One thing that has concerned us in our deliberations is about working out whether someone will survive six months or less. We have had a particular problem with that in Scotland in another field, about which you might know. There is plenty of evidence that it is extremely difficult for the medical profession to say whether someone will die within six months, although it is comparatively easy if it is going to be a few days. However, I note that the six-month period is built into your legislation. Will you comment on the practical implications of that?

Professor Ganzini: That can be fairly difficult to predict; it depends on the disease process. It is easier to predict shortened life expectancy for those who have cancer than it is for people with a variety of other diseases. A study in the United States by Nick Christakis showed that physicians tend to overestimate life expectancy five times more often than they underestimate it. However, there will always be an outlier, because it is not a fine science. It is a bad comment on medicine in the United States that one of the problems in hospice care is how many people—particularly those who do not have cancer—get better in hospice care when they have good, basic, everyday nurse-focused care. That is particularly the case with people with neurological diseases such as Parkinson’s disease. So, there are cases in which people live longer, which is often because they get good hospice care.

Deborah Whiting Jaques: Prognostication is an issue in the United States. The six-month threshold that is included in the legislation mirrors what our Medicare system does as a financial model for hospice care. Under our Medicare system, which is the only nationwide Government programme for medical assistance to individuals over 65 years of age, individuals are not eligible for hospice benefit unless two physicians—their doctor and the hospice doctor—agree that the patient is likely to die of their disease within six months. That is a challenge in the United States.

There are tools that hospice medical directors use to prognosticate, and training is available for that purpose to physicians who are board certified in hospice and palliative medicine, but it is an art, not a science. We see in hospice that physicians overestimate the length of time that people will take to die. In many instances, we have patients in our hospice service not for six months but for two weeks—very short stays. Those patients could have benefited from the comfort and care of hospice for six months, rather than two weeks.

Ian McKee: If you admit someone with a prognosis of less than six months to hospice and they live longer, your miscalculation is obvious. However, if you give them a lethal prescription on the basis that they will live for less than six months, your mistake will never be discovered, because the lethal prescription will have taken effect.

Professor Ganzini: That is true, but most of the patients who choose assisted suicide have cancer. Such patients are rarely discharged from hospice.

Deborah Whiting Jaques: About 80 per cent of individuals who avail themselves of the Death with Dignity Act 1997 are cancer patients; last year, the figure was 80.1 per cent. We are not seeing Alzheimer's and dementia patients, who are unable to meet the criteria that the law sets, or heart disease patients, who—as Professor Ganzini pointed out—do much better once they have hospice care and whose disease trajectory tends to be pointy, consisting of peaks and valleys, unlike that which is associated with cancer diagnosis. With cancer, we see decline in a very distinct way. Individuals with dementia take much longer to die. I am not sure that the 1997 act hides whether physicians have or have not been accurate in their prognostication, because we know more and are able to predict better with cancer than with other diseases.

Ian McKee: I have some more questions, but Nanette Milne may want to question the witnesses first.

Nanette Milne: I want to touch on the eligibility requirements under Margo MacDonald's bill. Section 4 of the bill stipulates:

> "A person may make a formal request for end of life assistance under this Act only if the person ... has been registered with a medical practice in Scotland for a continuous period of at least 18 months immediately prior to making that request".

I understand that that is not the case in Oregon and that patients can have a much shorter doctor-patient relationship before they are prescribed lethal medication. Can you enlighten me on that point?

Professor Ganzini: About a decade ago, we carried out a study of the experience with the law of 4,000 physicians in Oregon. At that time, about 5 per cent—144—of those physicians had received a request for a lethal prescription. Of those 144 requests from patients, only four of the patients had come to Oregon in the previous six months. Of those, three had come because they had family here—that was about their end-of-life decision, not about assisted suicide—and only one had come in order to get assisted suicide. Therefore, people are not coming from out of the state to avail themselves of the law in Oregon.

17:45

The second issue was whether people were changing physicians in order to avail themselves of the law. We know that about a third of Oregon physicians would not prescribe a lethal medication for any purpose. If a patient happens to have had such a physician for many years, the patient would need to change physician in order to get the lethal prescription, which the law states must be prescribed only by the physician who is caring for the patient's total end-of-life care. People have changed physicians in order to get the lethal prescription.

Deborah Whiting Jaques: It is interesting to note that, in 2009, only 55 prescribing physicians were involved with the Death with Dignity Act—those 55 physicians wrote the 95 prescriptions in the state of Oregon during 2009. Linda, I cannot remember how many docs we have in the state of Oregon, but 55 seems a very low number compared to the number of physicians in the state.

Professor Ganzini: Yes.

Nanette Milne: One concern that has been put to us is the risk of undue influence on a person's decision to request assisted suicide. My concern is that a short doctor-patient relationship might not allow the physician to understand the circumstances behind the patient's request. Have you any comment to make on that?

Professor Ganzini: The law requires that two physicians assess the patient as having decision-making capacity, as not having a mental illness and as being terminally ill. The patient is also required to show that the decision is not impulsive, so the patient must make three requests over a 15-day period. My interviews with physicians support the conclusion that physicians go the extra mile to try to understand what is behind the patient's decision.

However, the law requires that the patient meet a certain set of criteria. Many others besides the physician are involved in the patient's end-of-life care. For example, hospice providers will see the patient several times a week in the last few weeks to months of life. In many cases, they probably have a better understanding of the patient than the physician has. I honestly think that they often have better psychosocial training than the physicians and that they are the more important group for understanding the patient.

Deborah Whiting Jaques: I wonder whether the opposite effect might also happen in relation to the idea that we have spoken about this afternoon. We said that an individual's personal perception and beliefs drive how they feel about the Death with Dignity Act. In my experience, that is true across disciplines. Whether you are a physician, a layperson, a hospice professional or a medical professional, your personal perceptions and your personal frame of reference drive how you feel about this. If I see a physician for years who has taken excellent care of me but has a different personal philosophy to mine, I might be dissuaded in another way from doing what I believe is important.

It might be better for me to seek the advice and counsel of a physician who will interview me in a professional session and ascertain whether I meet the criteria that are established under the law. Those criteria include understanding the alternatives that are available to me, meeting the residence application, being terminally ill and having made the necessary requests. Therefore, there is the opposite risk: knowing your physician has its own set of circumstances, as does seeing a physician who is different from the one who has been your family physician for years. There may be valid points to make at both ends of the spectrum.

Nanette Milne: Thank you.

Ian McKee: Will you expand on the statistic that in 2009, 25 per cent of people who died after ingesting lethal medication had cited the burden on family, friends and carers? I see that between 1998 and 2008 the figure was higher—38.3 per cent. That does not particularly surprise or worry me if it is incidental to the other reasons that were given, but it would be a great concern if it was a prime factor in people’s minds. People have said in evidence on the bill that they are worried that individuals could ask to end their lives because relatives are pressurising them in some way. Can you reassure me that that is not the case here and that the figures show the natural feeling of someone who does not want to lose autonomy, a corollary of which would be becoming a burden on their family and friends?

Professor Ganzini: In my research, I have interviewed physicians, hospice nurses, hospice social workers, and patients who want a lethal prescription and their family members. What really comes across from all of them is that this is a group of people for whom being independent and in control and not having other people take care of them has been a lifelong value. Everyone who knows them says that it has permeated every decision that they have made since they were in their teens.

When I interview patients about not wanting to be a burden, what frequently comes across is their lack of value of the dying period, because that is a period in which someone is dependent on other people to take care of them and they find that an anathema and an appalling idea. When I ask them whether they feel a burden, I frequently see the family in the background saying that they would be honoured to take care of them and would like the opportunity, but the individual does not want it.

It is often the case that the patient simply cannot imagine that being taken care of in that way would be of value to anybody, because they do not value it themselves. It is a lifelong perception. I have not seen cases of coercion or in which there is a sense from the family that the individual is a burden. The patients are just too independent—they are usually the matriarchs or patriarchs of the family, not dependent people who need care.

Deborah Whiting Jaques: My experience is the same. We are not talking about the disenfranchised meek who are requesting to use the Death with Dignity Act 1997; these are rugged individualists who are used to being in charge of their lives. They have driven and been in charge of their life from the beginning, whether they are men or women. The family is not pushing them; usually, the family is holding back. They are happy to take care of them and are saying, “Don’t do this.” I do not see coercion as an issue.

In respect of the slippery slope that we were concerned about in 1997 when the law came into effect, the demographic picture that arises in Oregon and, interestingly so, in Washington is that the people who use the law are not the disenfranchised, the poor, the uneducated or non-Oregon residents. On the contrary, they are about half men, half women; in their mid 70s; highly educated—most have a bachelors degree; the vast majority have health insurance; they are white; they have cancer and they die at home. That is the demographic of the individuals who have used the Death with Dignity Act 1997 over the past 12 years.

Professor Ganzini: Let me give you an example. We were doing a study of patients who were in the process of requesting lethal prescriptions, and I was working with a psychologist called Betsy Goy. She was going into patients’ homes to have them fill out information about their depression and their views. I remember that after about the tenth interview she came back and said, “We can’t do the study.” I said, “Why not?” and she replied, “They refuse to fill out the forms. They take the forms, and although we have used those depression questions a million times they say that they are stupid questions, they cross them out and rewrite them. I can’t get through these interviews. These are people who want to be in control. They can’t even fill out an interview questionnaire without changing the language on it.” That gives a sense of the demographic.

I remember interviewing an extraordinary woman who lived in a very rural area in southern Oregon and had advanced cancer. The day that I saw her she had just got off her roof where she was putting on new shingles. She had gone deer hunting to get her deer for the season. She was a survivalist and she told me that one of her friends had said, “If we ever get to the end of the world, we all want to come with you.” She was seen as the most competent person among them. The problem is that in Oregon we really admire these very independent, individualistic people as part of our history. Some people may come across them and say, “They are control freaks,” but in Oregon we admire them, so that makes it difficult to say that their request is pathological. You cannot really admire somebody’s life history then, on the day that they ask for assisted suicide, say, “That is psychologically disturbed.”

Michael Matheson: I am struck by the way that the legislation works in Oregon. The mechanism is very straightforward: a person has to meet set criteria, which do not have many caveats or qualifications. The bill that is before us is somewhat different, in that the threshold is much higher: two doctors must be involved, there must be a psychiatrist’s report, the condition has to be intolerable, they have to be within the last six months of their illness and they have to have been registered with the doctor for 18 months in advance of the request. Given the criteria in the bill, is there a danger that we are setting the bar so high that many patients like those who utilise the legislation in Oregon would be prevented from utilising the legislation here in Scotland? Is the potential downside that the threshold in the bill is too high to allow patients to make use of it?

18:00

Professor Ganzini: There always has to be a balance between having a series of safeguards that prevent impulsive or incompetent decisions that many people would say are not the right ones and making it so difficult that no one could meet all the criteria. We were not involved in developing the law; we work with the law that we have.

In my experience, the process that we have appeals to people who are long-range planners and who can make an effective and convincing argument. In Oregon, if someone is to do what they need to do to meet the criteria, they cannot wait until their disease has progressed so much that they can no longer get over the various hurdles. Your proposed law would be similar, in that people would be required to be well enough to make all the necessary appointments and to be verbal enough to be convincing. Is that setting the bar too high? That is a highly political decision.

Deborah Whiting Jaques: The balance between the rights of the individual and the rights of society seems to be significant here. As I read the bill, the 18-month window caused me concern, because it seems a very long period. It is hard for individuals to know with any kind of certainty that their life may end within 18 months because of a given disease. We have spoken about the difficulty with prognostication at six months, and I think that it would be extraordinarily difficult for an individual to say, “All right, I will do this 18 months from now,” which they would have to do if it was a requirement that they had to have been with their doctor for 18 months before they were eligible to use the bill. That seems to be an extremely long interval.

Helen Eadie: I am interested in the processes that have been followed, the scrutiny and monitoring that have taken place, and the lessons that have been learned after such legislation has been passed. We have learned that in the Netherlands, regional committees were set up to monitor how the legislation there was implemented and to ensure that the criteria that had been laid down were met and accorded with. I am interested to know what lessons you have learned in Oregon since the passing of your legislation. Have you adopted the monitoring committee approach of the Netherlands?

Deborah Whiting Jaques: We do not have a monitoring committee approach. Physicians are responsible for reporting death with dignity to the Department of Human Services. The Compassion & Choices of Oregon agency produces the reports, collects the data and provides them to the state of Oregon, which ensures that the data are published and made publicly available on an annual basis. The state of Washington has implemented similar monitoring processes after passing legislation last year.

Professor Ganzini: The health division gets information from the physician concerned, and the pharmacist has to report, too. If the division is concerned that the correct law has not been followed, it will look into the case and will refer the physician to the Oregon Medical Board, which is the licensing and disciplinary board that deals with such concerns. That has happened. It usually happens if there are issues around witnessing and other criteria. What was the other thing that was more common?

Deborah Whiting Jaques: I am trying to remember.

Professor Ganzini: No physician has lost their licence or their ability to practise because of a problem around the law.

Deborah Whiting Jaques: I am not aware that there has even been disciplinary action surrounding a death with dignity event.

The Convener: I want to clarify a point before I bring in Margo MacDonald. You referred to the period of 18 months when the person might contemplate seeking assistance under the bill. Perhaps that is slightly erroneous. If you decide that you wish to avail yourself of the provisions of the bill, the doctor whom you approach must be a doctor with whom you have had a relationship for 18 months; it is not that you have been thinking about seeking assistance for 18 months, after which the whole process carries on. We might have got our wires crossed a little in relation to the length of time for which the individual contemplates seeking assistance. I will hand over to Margo, who has further questions.

Margo MacDonald: Good afternoon, ladies. Given that I am one of the meek ones, I intend to inherit the earth. Just in case I do not, does Professor Ganzini have the address of the hospice that made Parkinson's well again please, because I would like to go and visit it?

Professor Ganzini: Not making Parkinson's well but, rather, causing it to stabilise and causing the patient to improve their function is not uncommon. Something like half of patients with Parkinson's disease who go into a hospice are discharged because they stabilise or do not decline.

Margo MacDonald: That says a lot for your medical services, but it does not necessarily negate the need for the Death with Dignity Act 1997. I am sure that the very name implies that there is an acceptance in Oregon of patient autonomy and an understanding that it is about more than pain at the end. Am I right?

Professor Ganzini: Yes. It would be highly unusual for a patient to choose assisted suicide purely because of pain that they were experiencing that could not be treated. Interestingly, the majority of patients who pursue assisted suicide in Oregon have very low symptom burden when they pursue it; they are anticipating symptom burden in the future, such as pain, that will undermine their autonomy. It is really not about pain.

Margo MacDonald: I can certainly understand that, because people whom I have spoken to here have told me that if they know that they have a degenerative condition, it is good for them to plan ahead.

Professor Ganzini: Yes.

Deborah Whiting Jaques: Absolutely.

Margo MacDonald: You said that the hospices were up and running in Oregon before 1994. Does that indicate that there is an acceptance in Oregon, in your legal and medical systems and I suppose in society generally, that there will always be a small number of people for whom hospice care is not adequate, because it just does not meet their needs?

Professor Ganzini: Something that we have learned from the law is that there is a group of people whose needs are not met by hospice. Although hospice is expanding and is now taking more of a variety of different patient types, and although it can help people to be more independent, it cannot really ensure that a person leaves this world in the driver's seat. That is not sufficient for some people.

Margo MacDonald: I certainly do not mean to downgrade the hospice movement's contribution in any way, because I admire it very much indeed. However, my point is that people are very different.

I share your concern that we might not have got the timings right with regard to the period in which we might ask someone who has decided that their life is intolerable to them and would like to end it. However, in our parliamentary system, we can dig into and change the legislation, if we need to or want to. I am certainly very grateful to hear your evidence about what has happened in Oregon.

I have a final question. How did the bill come about? Did you say that it was a citizens initiative?

Professor Ganzini: Yes. A group of citizens who believed that this option should exist organised themselves, developed the bill and then went out and got signatures on a petition. In Oregon, a petition needs a large number of signatures—about 80,000, I think—after which it goes to the Secretary of State's office for verification, then the whole state votes on the proposal. In some years, the citizens of Oregon have voted on 20 to 30 different citizens initiatives, which is what the bill was.

Deborah Whiting Jaques: As was the statute that was passed last year in Washington that resulted in the implementation of the Washington Death with Dignity Act 2008. In Montana, however, the process was different: someone who was terminally ill and wanted to ingest lethal medication brought a lawsuit, and the issue went straight to the Montana Supreme Court. As a result, there is a legal precedent in that state. In Oregon and Washington, the measures came about through citizens initiatives to the legislatures.

Margo MacDonald: Are you willing to comment on whether the fact that in all three states the measures came about as a result of citizens initiatives indicates that the people are sometimes ahead of their politicians?

Deborah Whiting Jaques: I suppose that it is another illustration of the independence of Oregonians that we have been talking about.

Professor Ganzini: As for the question whether such initiatives are generally good or bad, I have to say that that would be a political decision. Several have been passed that I have found appalling.

The Convener: On a technical point that we should have raised earlier, are you concerned about the way in which your medical practitioners are recording the deaths that have resulted from applying the legislation?

Professor Ganzini: As outlined in the law, if a person takes a lethal prescription, their death certificate will record their underlying cancer, for example, not that they died of that particular medication. That arose as a result of concerns about confidentiality, given the number of people who can access death certificates. To protect the privacy of the people involved, the matter goes to the health division, and although it knows the patients' names it would never include them in anything that it published. Does that answer your question?

18:15

The Convener: Yes, I think so. I do not wish to prolong the meeting but, going back to your earlier comments about the House of Lords inquiry into the Joffe bill, I should point out that the inquiry report indicated a number of difficulties in assessing the accuracy of the number of deaths recorded in Oregon and said that the state authorities were a bit concerned about the matter. Given that that was five years ago, can you update us on the current position and say whether there are any residual concerns in that respect?

Professor Ganzini: Are you asking whether any assisted suicides or deaths as a result of euthanasia are still taking place outwith the safe harbour of the law?

The Convener: Or whether such deaths are still being underrecorded.

Professor Ganzini: It would be very difficult to know whether that is happening. In our survey—which involved 4,000 physicians, was anonymous and indeed had a special National Institutes of Health certificate of confidentiality to ensure that no one could ever access the information—of the 144 requests for assisted suicide that were reported, the physicians who wrote lethal prescriptions said that they reported it to the state. As a result, it does not appear that illegal assisted suicides still take place. By the way, any physician found to be involved in such practices would suffer enormous negative repercussions. Physicians who go outside the law take a huge risk, given that there is a way of staying within it.

The Convener: On behalf of the committee, I thank both witnesses for taking the time to give us very helpful evidence that has added hugely to our knowledge and understanding of the operation of the Oregon Death with Dignity Act 1997 and will play a part in our consideration of our bill.

That concludes our formal business. I remind members that we meet again next Tuesday.

Meeting closed at 18:17.

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