



The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE

Tuesday 14 September 2010

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Printed and published in Scotland on behalf of the Scottish Parliamentary Corporate Body by
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END OF LIFE ASSISTANCE (SCOTLAND) BILL COMMITTEE
5th 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 Iain Brassington (University of Manchester)

Mark Hazelwood (Scottish Partnership for Palliative Care)

Stephen Hutchison (Highland Hospice)

Professor Graeme Laurie (University of Edinburgh)

Professor Calum MacKellar (Scottish Council on Human Bioethics)

Professor Sheila McLean (University of Glasgow)

Katrina McNamara-Goodger (Association for Children's Palliative Care)

Elaine Stevens (Independent Association of Nurses in Palliative Care)

Dr Chris Sugden (St Andrew's Hospice)

CLERK TO THE COMMITTEE

Douglas Thornton

LOCATION

Committee Room 1

Scottish Parliament

End of Life Assistance (Scotland) Bill Committee

Tuesday 14 September 2010

[The Convener opened the meeting at 10:20]

End of Life Assistance (Scotland) Bill: Stage 1

The Convener (Ross Finnie): Good morning. I welcome everybody to the fifth meeting of the End of Life Assistance (Scotland) Bill Committee. As always, I remind everyone to switch off mobile phones and any other electronic equipment that might interfere with transmission.

We have received an apology from Cathy Peattie; otherwise, we are all present. As will be the case throughout the evidence taking, we welcome the bill's promoter Margo MacDonald, who is perfectly entitled to ask, and no doubt will ask, questions of witnesses after the committee members have done so.

There is only one item of business on the agenda—evidence taking—and there are two panels, the first of which is assembled before us. It comprises Dr Iain Brassington, lecturer in bioethics at the school of law at the University of Manchester; Professor Sheila McLean, professor of law and ethics in medicine at the centre for applied ethics and legal philosophy at the University of Glasgow; Professor Graeme Laurie, professor of medical jurisprudence at the school of law at the University of Edinburgh; and Professor Calum MacKellar, director of research at the Scottish Council on Human Bioethics.

On behalf of the committee, I welcome you and thank you all for the comprehensive papers that you have supplied to the committee. On the basis that the committee has had the opportunity to read those papers in advance, and the benefit of doing so, I propose to move straight to questions.

Helen Eadie (Dunfermline East) (Lab): Good morning to our panel; I thank you for being here. I want to ask you about an issue that comes up in more than one paper—the idea of general practitioners or others in the medical profession being gatekeepers, and the power of doctors to impose their morality on the issue. Would any of the panel like to expand on that and to give a view on who, if they believe that the legislation should go ahead, the gatekeepers should be?

Professor Sheila McLean (University of Glasgow): I certainly raised that question, partly because we have seen situations in the past in

other very sensitive areas, such as abortion, in which the doctor as gatekeeper assumed a significant role, arguably sometimes in situations in which the woman satisfied the legal requirements for having an abortion. It is not possible to dispose of doctors in such situations—that is the case even in Switzerland. For example, someone would at least need access to prescription medicine, so there would obviously be medical input.

The point that I was trying to make is that, if we use doctors as the gatekeepers to what could otherwise be seen as someone's right under the legislation—if they qualify for it—we should ensure that the role is as disinterested as it can be. In other words, the role should not be affected by individual morality. If the person qualifies, they qualify. That was my point: it was not so much that we do away with doctors in this arena but rather that we ensure that their role is sensitive to the underpinning principles of the legislation.

Helen Eadie: That is helpful. The age of 16 is a deciding factor in all of this. Do members of the panel wish to expand on what they said on the subject in their submissions or give their view on the matter?

Dr Iain Brassington (University of Manchester): I addressed the point about why 16 was chosen as the cut-off point in my submission. From a pragmatic point of view and for the sake of drawing up a workable bill, it makes sense to set a lower boundary. Sixteen is the age that medical law in other fields seems to think is important. Consistency demands that it works in this context, too.

The more important point is that the people who ask for assistance should know what they are doing. It is possible to have a very smart 15-year-old, just as it is possible to have a very stupid 30-year-old—someone who is above the age that is set out in the bill but who is not capable. Capability is more important, and if you want age to be a cipher for that, that is legitimate for all kinds of practical reasons. However, from a purely moral point of view, I think that the age limit looks a little bit arbitrary. It has to be made clear that it is competence, not chronology, that does the work.

Helen Eadie: In your submission, you talk about maturity testing. How would you set about doing that testing?

Dr Brassington: Pass. Medics have to make that kind of decision fairly frequently in deciding whether a patient has given valid consent—whether they are capable of making a given medical decision. This kind of judgment is not so vastly different from that. I suspect that doctors are fairly good at recognising when someone is competent—and when someone is not competent.

Whether we can give them a rubric with boxes to tick is another question. Indeed, I am not sure whether doing so would be desirable, because people work in different ways. I would have to say that we should trust medical judgment in such cases.

Professor Graeme Laurie (University of Edinburgh): Children are protected under Scots law from decisions that may not be in their best or better interests. In our submission, we give the example of a contract that a child enters into between the ages of 16 and 18, which can be nullified up to the age of 21 if it is thought to be against the child's interests. In the context of the bill, it would be possible to take a different position with respect to children in order to protect them. If we want to treat children as they are treated in the context of consent to medical treatment, 16 is a clear cut-off point. We also argue in our submission that we might want a minimum level nonetheless, if we are looking to recognise competence. We are talking about a sliding scale; nonetheless, for protection reasons, we might want a minimum cut-off point of, perhaps, 14. Such a cut-off would reflect the traditional Scottish view of pupillage.

Professor Calum MacKellar (Scottish Council on Human Bioethics): When you talk about the age of consent, you must also look at the problem of people with mental disability for whom, even although they are adults, the issues are similar under medical law.

As we have heard, sometimes it is clear when someone has consented or has not consented. However, when people have a mental disability, the issue becomes extremely difficult. I know of psychiatrists who talk about capacity in this field as a sort of holy grail—they can never really find it. That is why, in these circumstances, it is probably better to have a group to look at the matter. Even with a group, it will be extremely difficult to know whether the person can consent or not to such decisions.

Helen Eadie: Are you suggesting that we need not one or two general practitioners but a case conference?

Professor MacKellar: Exactly. In such cases, we would need a psychiatrist and so forth. That would not solve all the problems, but it would make the system a lot more robust.

10:30

Nanette Milne (North East Scotland) (Con): I return to Helen Eadie's first question. I want to tease out what Professor Laurie said and Dr Brassington's comment at the top of page 2 of his submission that

"If no one is available or willing to assist a person in bringing about his own death, then he has no moral right to compel assistance; nor ought he to have the legal right. Hence the right to assistance takes the form of a permit rather than an entitlement."

How does that sit with what Professor McLean said about taking morality out of the situation? Do you agree with the bill's suggestion that, if a doctor has a conscientious objection to what is requested, he must refer the patient to someone else? Alternatively, would a conscientious objection relieve a doctor of the burden of passing a patient to someone else?

Professor McLean: If a person satisfies the terms of the bill—if we assume that it becomes law—a health care professional's conscientious objection should not stand in the way of that person's achieving what the law entitles them to achieve. The professionally appropriate action would be to refer the patient to someone else.

I mentioned abortion. In the British Medical Association and in other places, we have debated for many years what the doctor's obligation should be in such circumstances. By and large, we almost agree about the situation. For example, the vast majority of cases of euthanasia in the Netherlands are carried out by general practitioners, who are most people's first port of call. If a general practitioner were not willing in any circumstances to fulfil a request for assisted death, even when that satisfied the terms of the law, my view is that that GP should make that clear to all patients as they join the practice, which would give them the option of going to a different doctor.

Because of the influence of some medical practitioners on the accessibility of abortion, the BMA advises doctors who have a conscientious objection that they should refer patients to others and that they should make that objection clear to patients. We could ask for no less than that in the situation that we are discussing.

Ian McKee (Lothians) (SNP): I have a question for Professor MacKellar, but I am interested in hearing other people's views, too. Your submission was interesting. I see that your organisation does not have a religious background. If it did, I would understand its points completely, because I respect the views of people who say, "God made you and God should decide when you leave this earth"—that is a matter of someone's belief.

I am interested in your arguments about the relative status of autonomy and dignity. I understand your argument to be that autonomy is something that people consider about themselves whereas, although people consider their own dignity, that is also given by society. You argue that someone does not just have the right to attempt to end their life, because their dignity is

determined by what other people think about them.

Before becoming an MSP, I was a general practitioner. I can think of people—not a huge number—who would have been strongly in favour of the right to end their lives. The micro-society around such people would have been totally in accordance with those people's belief. Given that, how far do we go in taking on board wider society's views when a decision that is highly specific to a person and their micro-environment must be made? Why should the law be involved? There are plenty of other ethical points. For example, infidelity in marriage is probably destroying the dignity of marriage in the eyes of others, but we have not yet said that someone who breaks up a marriage commits an illegal act. Will you give further observations on such situations?

Professor MacKellar: Thank you very much for the question. It is crucial, as human dignity is a really important concept in this policy area. There has been much misunderstanding about it and there is much confusion: people discuss it using different definitions, so they basically discuss past one another.

I subdivide the concept into two. The first concept is that the way that somebody behaves displays a certain amount of human dignity. That kind of dignity comes and goes; sometimes people have it and sometimes they do not. There is an in-between state, in a way; there are different degrees of human dignity. That is how dignity is understood under the State of Oregon Death with Dignity Act 1997. It is also included in the understanding of dignity with which Dignity in Dying—that is the new name of the Voluntary Euthanasia Society—operates. That is the first way of defining human dignity.

The second is the way that the United Nations Universal Declaration of Human Rights defines human dignity as being inherent. The preamble says:

“the inherent dignity ... of the human family is the foundation of freedom, justice and peace in the world”.

That is the foundation of the whole declaration. That kind of dignity cannot be lost. It is equal among everyone and is not variable, but the most important thing is that it can never be lost.

However, I argue that the bill says that inherent human dignity—the inherent value, meaning and worth of a life—can be lost. I also argue that the bill sort of says that some lives may no longer be worth living because they have lost their inherent dignity. There is such a thing as the concept of a life unworthy of life. It was coined in the 1920s in continental Europe and used in the first part of the 20th century. However, on the basis of inherent

human dignity, Scotland should never say that there is such a thing as a life unworthy of life. That is why the Scottish Council on Human Bioethics, which bases all its positions on the United Nations declaration, is concerned about the bill.

On the comparison with the dignity of marriage, we could say that divorce undermines the dignity of marriage, but we are talking about something different: the inherent dignity of human life. It is the foundation of democracy. The Parliament is built on it, hospitals are built on it and doctors work because of it—they do not simply put down people with broken legs as they put down horses with broken legs. Inherent human dignity is one of the foundations of a civilised society and it can never be lost.

Graeme Laurie and Professor Mason indicated in their submission that inherent human dignity is difficult to understand. It is not scientific. I am a scientist and, from a scientific perspective, everybody present today is a just pile of cells made up of 70 per cent water and a few other biochemical compounds. From that perspective, we have no dignity, but human dignity is an important belief, which the UN declaration of human rights supports. It is a declaration of human rights, not a scientific proof of them.

Dr Brassington: I accept the idea that dignity is an important concept and plays an important role in such debates. However, I do not entirely recognise the picture of it that has just been drawn.

For one thing, I worry slightly about the claim that inherent dignity is not scientific. In reading the written evidence from the Scottish Council on Human Bioethics, I got the feeling that Professor MacKellar was playing a little bit fast and loose with the definition of human dignity on the basis that there is no scientific consensus about it.

The general consensus in the bioethical debate is that dignity arises from self-determination. We have dignity qua moral agents or human beings because we have the capacity for self-determination and to give our own lives value. That is the foundation for dignity. It seems to follow that, if a person freely decides that they do not want to live this life any more and would rather that it ended, that does not undermine their dignity; it is a statement of their dignity. It follows that people appeal to UN definitions and understandings and the way in which dignity gets associated with things such as liberty if they think that dignity arises from self-determination and people's ability to run their own lives as they see fit. There is then no conflict between dignity, as it is used to defend assisted dying, and liberty and the valuable things that we might think that dignity protects. Those things are completely compatible.

To that extent, limiting someone's liberty would be an erosion of dignity.

Professor McLean: I agree with Dr Brassington, but will take what he said a step further following Dr McKee's question. It will come as no surprise to members to learn that I profoundly disagree with Professor MacKellar and his paper. There is another issue in it that has been touched on: the attempt to build a notion of relational autonomy. We often understand a person's autonomy as being simply their right to make their own decisions. Professor MacKellar has rightly referred to the fact that there are other considerations that we take into account, or should take into account, when we make decisions. However, the relational account of autonomy does not, as I think his paper suggests, imply selfishness. It is possible for a person to be independently autonomous and also concerned about people around them.

For example, there is some interesting research—a small amount, as not much research has been done on this matter—that suggests that the families of people in this country who have been able to achieve an assisted death found the grieving process to be considerably easier, because by the time it happened, the families had talked the matter through and even family members who did not approve of the assisted death nonetheless came to terms with the death.

I will use an important legal example. If it is the case that a person loses dignity because they choose to die or somebody else allows them to die, I would want to see the argument being developed that patients who are currently legally entitled to refuse life-sustaining treatment should be prohibited from doing that, as it is clear that they have also made a choice that will result in a chosen and knowing death. Doctors participate in such decisions; indeed, if they did not agree with the patient in those circumstances, they would be guilty of an assault. Those patients have made the same choices that the patients whom Margo MacDonald is attempting to reach have made. At the moment, not only is that legal but it would be an assault to interfere with those decisions. That is an important point.

Professor Laurie: Referring to dignity is a powerful rhetorical device, but the reality of using dignity as a legal concept is very different. Legal instruments notoriously and determinedly avoid defining what is meant by dignity because we cannot agree on what we mean by it. A good example is the UN's attempt to ban cloning. Ultimately, the only agreement that it could reach was that whatever each country defines as being undignified is undignified. That is not useful in law.

It is possible to make both objective constructs of dignity, as Professor MacKellar is doing, and

subjective constructs of it, which are being made elsewhere and lead it to look like autonomy. If the bill is about autonomy and choice, I do not think that we need to refer to dignity at all.

Professor MacKellar: We make laws first by looking at ethics, and we are looking at ethics right now. The way in which we look at ethics relates to our understanding of human dignity. We all have different understandings of human dignity, and I hope that every one of us here understands dignity—especially in this case—as being inherent, at least in some way. Inherent human dignity is

“the foundation of freedom, justice and peace in the world”.

Of course the concept is difficult to define, but we must accept that, otherwise what are we building our laws on, and what kind of ethics do we have?

10:45

Autonomy is extremely important, and we who work in the field believe that it is one of the key issues in medical ethics. However, autonomy cannot take priority over everything else. We should never fall into the trap of autonomy fundamentalism.

There are issues even now, even in Scotland, in which inherent human dignity trumps autonomy. A person cannot sell their organs or give a heart to their relative voluntarily, and they cannot sell themselves into slavery. That is not because of autonomy, but because of inherent human dignity.

To return to a point that was made earlier, there is a big difference between letting a person die—for which, in a way, nature is responsible—and taking active steps to end a life. In the second case, another person is making the decision.

If we legalise assisted suicide, it does not affect just the micro-society to which Dr McKee referred. If the Scottish Parliament agrees that some lives have lost their inherent meaning and worth, the whole of Scottish society accepts it.

It is not an issue that can be sorted out in the micro-society of a family. It affects the whole of society, and that is why we are here today to try to make a law on it.

Dr Brassington: I have two points in response to that. First, if it is true that we all have our own definition of dignity, I struggle to see what objection there is to the bill on the grounds of dignity. If we all have our own understanding of dignity, that is great—we should pass it to the patients and let them decide. That seems to be pretty much what the bill says.

Secondly, I am not sure that the point about autonomy holds water. I do not want to turn the

meeting into a philosophy seminar, although I would love to—

The Convener: I am not sure that I will permit you to do so.

Dr Brassington: I will try not to. One can generate an account from autonomy of why people cannot sell themselves into slavery. On the issue of organ donation, perhaps autonomy means, morally speaking, that someone could say, “I’ve got a spare kidney and a mortgage”. Dr MacKellar’s picture of autonomy does not seem to be all that compelling.

The Convener: I do not want to curtail that debate unnecessarily, but the important thing is whether Dr McKee is satisfied in relation to his question.

Ian McKee: My question served the purpose of allowing several views to be expressed, but it is not worth trying to come to a conclusion.

As a small observation from my life as a doctor, the common refrain that I heard when I came across people who had been in this type of situation was, “They would treat animals better than they treated my father”, so there are two ways of looking at it.

We took evidence last week on societies where the right to an assisted end has been put into law. Have you seen any effects in those societies—in the Netherlands, for example—that show that there has been a deterioration in the way that people feel about one another?

Professor MacKellar: I watched the debate last week, and in particular the evidence from the witnesses in Oregon. I was quite disturbed by the number of times they talked about autonomy, control and independence. They even said that some of the people who want assisted dying are “control freaks” and—I was even more surprised at this—that

“in Oregon we admire them”.—[*Official Report, End of Life Assistance (Scotland) Bill Committee*, 7 September 2010; c 65.]

I do not believe that that is the type of society that we want in Scotland.

Ian McKee: But is society created by the law, or does the law reflect society?

Professor MacKellar: The law always reflects society, which is why we have to be very careful.

Ian McKee: I am asking whether the change in the law in countries such as the Netherlands has changed society. Your example is that Oregon is a different society from ours, and that is reflected in the law. I am asking whether the introduction of the law has made society worse.

Professor MacKellar: This relates to the debate about the slippery slope, which you also had last week. Slippery slopes can take a long time to go down—they go down either steeply or slowly. The point about any slippery slope, however, is that it goes down. Sometimes, we do not immediately see the effects.

If we consider the effects of euthanasia and assisted suicide only in the Netherlands, we might not see a strong effect, or hardly any effect at all. If we start to undermine inherent human dignity, however, I can assure you that you will eventually see effects—perhaps not where you are looking, but in a completely different area of law. Where that concept is being undermined, there will eventually be an effect—but not necessarily where we expect to see it.

The Convener: Professor McLean?

Professor McLean: Dr McKee has indirectly said what I was going to say, so I will pass for the moment.

The Convener: That is very agreeable.

Professor McLean: It is not like me.

The Convener: I could not comment.

I take the panel back to the general principles of the bill and, in particular, its scope. In other jurisdictions, attempts have been made to draw distinctions between a physician-assisted suicide and euthanasia; some have been more successful than others, as I do not need to tell you. On certain readings of it, the End of Life Assistance (Scotland) Bill gives the impression that we are seeking to break new ground by broadening and encompassing both those aspects, which means, of course, that the sections that follow seek to support that proposition.

I am interested to hear your views on that. Do you think that it is sustainable to embrace both concepts in a single bill? Might there be some difficulties in trying to widen the scope? The matter was raised with us last week, and it is raised in some of the papers before us.

Professor McLean: The original bill that Lord Joffe presented to the House of Lords was intended to cover both voluntary euthanasia and assisted suicide.

The Convener: My apologies.

Professor McLean: Some commentators have indeed made that point, but that was actually what Lord Joffe intended. If we read carefully the reports of the House of Lords select committee on his bill, we see that he was given a strong hint by the committee that he would be more likely to succeed if he restricted the bill to assisted suicide rather than voluntary euthanasia. I believe that to have been a political judgment. It strikes me that

one of the logical points in the bill before us is the inclusion of both voluntary euthanasia and assisted suicide.

It is interesting that the first challenge to the law in Oregon came from the disabled rights lobby, which argued that some of its members who might have wanted an assisted death were precluded from that because they would have to ingest the medication themselves and, in some cases, they were unable to do so.

If we accept the fundamental principle of choice at the end of life, it would be illogical to limit the bill to assisted suicide. I know that there are differences. The doctor's role is less active in one case than in the other case. I remind you, however, of what Lord Mustill said in the case of Anthony Bland, a young man who was injured in the Hillsborough disaster and ended up in a permanent vegetative state. On the so-called difference between acts and omissions—an omission is supposedly not nearly so bad as an act—Lord Mustill said that that distinction was simply not applicable in the circumstances and carried no moral weight. If the bill were to cover only assisted suicide, those who want to die but who need the simple assistance of a doctor would be deprived of that assistance on the basis of a legal rule that even the highest judges in the land do not think is applicable in such circumstances.

Professor Laurie: Professor Kenyon Mason from the University of Edinburgh and I suggest in our submission that, although the bill purports to be about assisted suicide, it blurs the distinction between assisted suicide and euthanasia. Section 1(2) refers to

“assistance, including the provision or administration of appropriate means”.

I take on board what Professor McLean said about whether it is valid to make that distinction but, if you want to try to draw the distinction in order to help people who are physically unable to help themselves, the text could be amended to read:

“assistance includes the provision of appropriate means ... or in the event of the requesting person being physically unable to utilise such means, the administration of appropriate means so as to enable”

them to die. That would help patients such as those who are incapacitated because of neuromuscular disease.

The Convener: You suggested an amendment, but do you agree with Professor McLean on whether the concepts can comfortably be accommodated in a single bill, or indeed whether they should be so incorporated? I am driving at the principle; we will get to drafting changes at a later stage.

Professor Laurie: Yes. From a principle point of view, it is difficult to draw the distinction but if one wants to do that, we have given the example of how one might do so.

The Convener: Indeed.

Professor MacKellar: I agree with Professor Laurie that it is difficult to draw a distinction between assisted suicide and euthanasia. The three countries in Europe where both euthanasia and assisted suicide are legal are Luxembourg, Belgium and the Netherlands. On looking at the statistics, it is interesting to note that it is mainly euthanasia that is practised in those countries—the doctor killing the person. In a way, medics are more uncomfortable with assisted suicide because things can go wrong. That is why euthanasia is seen as preferable in the three countries that I cited.

Michael Matheson (Falkirk West) (SNP): I seek the panel's views on safeguards in the bill such as the length of time that the person must be registered with their general practitioner, the second formal request and the need for psychiatric assessment. Are those safeguards sufficient to ensure the person's competence in making a decision, or are they too onerous? Could they compromise individuals who are diagnosed with a condition that leads to a very short life expectancy? Surely such individuals would be unable to access the provisions.

From the evidence that we received from Oregon last week, I was struck by the fast-track approach there. It is clear that the intention of the bill that is before us is for someone to have a relatively long-term relationship with the doctor to whom they make the first approach.

Professor McLean: Any sensible person who attempted to draft a bill of this sort would almost certainly want to have as many apparent safeguards as possible. I understand the reason for that, but I have a little bit of difficulty with some of them. In an ideal world, it would be nice to think that the GP who is involved throughout the process is someone whom the person knows very well and who knows them very well. That said, how long the doctor has known the person has nothing to do with competence to make a decision. The provision asks a great deal; it is perhaps a hurdle too far. The issue should be about competence, not how long the doctor has known the person.

In reading the policy memorandum, I was a bit concerned that the intention appears to be to automatically preclude people who are mentally ill. That might sound odd, but there is at least law that suggests that even those who are mentally ill may nonetheless be competent to make certain decisions. It is taking too broad a sweep to say

that a person should not necessarily be able to participate in making a decision about the end of their life simply because they are mentally ill.

I am also a bit concerned that there seems to be a tight time limit between the time when a person is advised that they could have an assisted death and the time when they have to die. Margo MacDonald will tell me if I am misreading the bill. There are no such time limits in Oregon. It seems to me that the perverse interpretation or consequence of such a time limit might be that people will take the medicine or have an assisted death sooner than they might otherwise have done. Every year in Oregon, a substantial percentage of people are given access to prescriptions for assisted death, and they sometimes wait for years before they use them. The evidence seems to suggest that they are reassured by the fact that they know that they can have an assisted death, but they do not necessarily want it until the last conceivable moment.

Any requirement on people to act quickly would be a difficult burden. Professor Laurie and Professor Mason have proposed that we might extend the period by 28 days, but that would still give people only two months to act, otherwise they would have to go back to the beginning and start all over again. It seems to me that that is an unnecessary constraint on people's right to make such decisions.

11:00

The Convener: I have a small supplementary question, on a tiny point. There are other issues relating to the criteria that you would apply. We will not go into whether the word "unbearable" is right; rather, we will take the generality of the presented criteria. If a person meets the criteria that require to be established, how would you square that with an almost unlimited period possibly being needed in which their right can be exercised? That might be more of a criticism of introducing the criteria, but I am interested in your view. There seems to be a conflict.

Professor McLean: I think that that point was made clearly in Dr Brassington's paper. The vast majority of people in Oregon and the Netherlands who seek an assisted death suffer from cancer. I understand that the figure in the Netherlands is around two thirds. Most of them are therefore aware of their prognosis and that they will not get better, and they are often aware of the kind of emotional or physical suffering that they might endure.

It makes perfect sense to me to say that the real meat of the question will be missed if we want to use words such as "intolerable" and "unbearable".

If suffering is only physical, their suffering may not be unbearable, although they may be suffering enormously emotionally. The real meat of the question is that people are able to predict that they will suffer in future in particular ways. People in Oregon most often cite the loss of dignity, whatever dignity means. I am not sure that a person needs to be suffering intolerably at the time. In the Netherlands, those who are refused access to assisted death tend to die quite quickly anyway, but a person does not need to be in that situation to understand what their death might be like. It seems to me that in some ways they might be even more competent when they are making a decision that is based on that than they would be if the pain was simply too much for them.

The Convener: Dr Brassington should bear in mind Michael Matheson's question.

Dr Brassington: I would like to expand on the point about intolerability. It seems to me that if a person is suffering intolerably, that at least gives a *prima facie* reason to suppose that their request or consent might not be valid. It seems to make perfect sense to say that people in pain might not think straight, whereas we would have reason to think that someone who is not yet suffering has thought about matters and is coming at them in as clear headed a way as possible.

On time limits and the criteria relating to terminal illness, let us imagine a situation in which an illness has been diagnosed and there is a reasonable prognosis that the person will start to suffer at some point in the foreseeable future. Let us imagine that I have been diagnosed with Matheson's syndrome and I know that I will be struck by a terrible illness in five years' time and will have a month of suffering followed by a grim death. Imagine that I know as well as anyone can know that that will happen. It would not seem unreasonable for me to say that I am not suffering now and would prefer not to start suffering, so I would like assistance before the symptoms start to manifest. Going against that seems to be parallel to telling a gambler that they cannot leave the casino until they have lost the house—I think that I have used that analogy somewhere. It seems to me to be perfectly sensible to allow people to say, "Obviously, it would be better not to suffer, so if I can avoid that by assisted death, that is up to me." Therefore, the criterion seems to me to be a little bit iffy.

Professor Laurie: Time limits are important, as Professor McLean said. We suggested in our submission a further cooling-off period of 28 days. Extending that or making the time indefinite could begin to call into question the validity of the original competence assessment of the individual, so we felt that building in some time limits was important.

By the same token, a time limit is not built in for obtaining the second approval from the medical practitioner. Having such a limit would give the individual who makes the request a reasonable expectation about when they would receive an answer or a decision.

Professor MacKellar: The safeguards in the bill are probably better than those in the Oregon act, but there is still a lot to do, as has been said. However, it is impossible for the bill to be 100 per cent safe. If the bill could enable a person to be killed against their will—involuntarily—it should not be passed. Death is irreversible; other conditions are reversible. If one person could die involuntarily because of the bill, the bill should not be passed.

Professor McLean: I have two quick points. I will follow up what Dr Brassington said. In his hypothesis about the onset of an illness, having a much longer period between the agreement that a person can have an assisted death and the time when the action must be carried out makes sense.

I must respond to Professor MacKellar. The whole point of the bill is that any death that occurs under it should be voluntary. No logic of which I can think leads to any suggestion that a bill that was based entirely on competent autonomous decisions would lead to doctors turning into murderers. I simply do not see that and to suggest it is rather rude about the medical profession. Without such a law, we know that people die with assistance at the moment, so we can draw no links at all between a voluntary scheme and involuntary killing.

Professor MacKellar: I did not say that doctors were murderers. We know that involuntary deaths are taking place in the Netherlands. They are rare, but statistics show us that they are taking place.

Professor McLean: They do not.

Professor MacKellar: That is why I believe that the bill should not be passed.

Michael Matheson: Professor McLean said that we know that assisted deaths are taking place at the moment, although they are illegal. If it is clear in law that assisted death is illegal, but it is happening, could changing the law to legalise the procedure in some situations open up even more the possibility for the legislation to be interpreted in such a way that it could be misused, as happens at the moment?

Professor McLean: Technically, there is no legislation at the moment—there is a common-law rule about murder, which is clear and brooks no exceptions, other than for self-defence and so on. The drive for doctors to help their patients to die comes from compassion—as Dr McKee described in his initial question—and is not an attempt to break the law. As members will know even from

media coverage, some doctors have felt compelled to break the law. We criminalise those doctors.

I agree with Professor MacKellar that nothing is fail-safe, but I see no logical link between passing a relatively closely knit bill and people thinking that it is all right to do something illegal. The doctors who help their patients to die do not think that it is all right to act illegally, but they are driven by what they see as a more powerful principle—compassion. The bill would allow doctors who are prepared from compassion to assist their patients to assist them. People cannot be prevented from breaking the law—there is no law that is never broken. However, I see no link between drawing up a permissive regime that is well safeguarded and people thinking that it is all right to kill.

Michael Matheson: My next point is also on safeguards, one of which is the involvement of a psychiatrist in the competence test. Professor Laurie's written submission raises concerns about the lack of a definition of the term "psychiatrist" in the bill. I ask him to expand a little on why it is important for there to be a definition. Specifically, he suggests that the person should have experience and a background in the field. Why is it so important that that is included in the bill?

Professor Laurie: That is probably a reflection of the way in which the regulation of the medical profession has been going. For example, we now require medical practitioners to have a live licence. The point about experience is really to ensure that we have somebody who can get to grips with the complex notions of assessing competence; who knows all the factors that need to be weighed in the balance; and who can draw on that experience to ensure that they provide a robust and valid assessment of a person's ability to make the request. That would be a further safeguard.

The suggestion that the psychiatrist should be certified by the Scottish ministers is really to deal with the diversity of approach that we might see in the European Union or elsewhere. Psychiatrists from other countries and different cultures might take a different view of what it is to be competent to take the decision. Our submission gives the example of somebody from the Netherlands who has a different experience of decisions to die that have been allowed on the basis of mental illness or other conditions. We are trying to build in a provision that reflects the cultural practices and values of Scotland. We want to ensure that the psychiatrist draws on their experience when judging issues such as competence.

One of our concerns is that we could end up with two psychiatrists who come to different opinions about the appropriateness of a decision to help somebody to die. We are not clear why two psychiatrists are needed. If that provision were to

be included, we would at least want some sort of mechanism to provide a resolution if there are different opinions or decisions.

Michael Matheson: I understand the importance, if the safeguard in the bill is to be sufficient, of ensuring that the person who carries out the assessment has the competence to do so. However, your suggestion could be interpreted as a form of regulating the profession of psychiatrists, which is not within the competence of the Scottish Parliament.

Professor Laurie: That is certainly not our intention. Our suggestion is very determinedly about ensuring that the assessment of the individual's competence is robust.

Michael Matheson: I understand that, but I am just keen to explore your reasons. I have a concern that it might not be within the Parliament's competence to do what you suggest.

Nanette Milne: I have a couple of questions. I think that I can find a very subtle difference between someone giving a drug that will have lethal consequences with the intention of relieving suffering, and someone giving a similar drug with the intention of killing. It is a subtle difference, but there could be one. I am interested in any comments on that.

Another issue that concerns me is how we can be sure that a person who decides that they want to end their life prematurely, as we might say, has had no undue influence, however subtle, on them. No one knows what goes on within families behind closed doors. That perhaps ties in with what Professor MacKellar said about unintended consequences.

Professor MacKellar: As I said, we can never be sure all the time. Sometimes we can be sure, but we will never be sure all the time in every single case that is presented in the future.

I agree that intentions are sometimes difficult to see in a doctor or nurse who is working in a hospital. When intentions are difficult to determine, the only recourse is to go to court. A court is all about trying to figure out what people's intentions were. That is what takes place right now, and it works well. As you say, intentions are sometimes difficult to determine, but they are extremely important. Intention can be the difference between a person being condemned as guilty or found not guilty, for the same act.

Professor McLean: I think that I understand your unease about the question of intention.

Nanette Milne: I should say that I have a medical background, which puts my questions into context.

11:15

Professor McLean: So you know exactly what the problem is.

Let us move away from assisted dying and look at something that is accepted at the moment: the doctrine of double effect. The presumption there is that the person is increasing analgesia with the intention of easing pain, but the death is foreseeable. That is perhaps the kind of thing that you have in mind. Legally speaking, when something is so foreseeable that it is inevitable, it is the same as there being intention. I can see that there might be a psychological distinction, but whether that translates into law, or even into ethics, is another matter.

The second question, which concerns a great number of people, was how can we know that people have not been subjected to some subtle pressures. All I can do is take you back to the example of the patient who refuses life-sustaining treatment. It is possible that they are subject to pressures, too, but we do not require them to jump through hoops. If you try to treat them against their wishes, that is it. We do not even inquire too hard into their competence in most cases, although there have occasionally been cases in which competence has been looked at.

There might well be pressures. Indeed, if we adopted the relational account of autonomy, you would imagine that there would be pressures, because people are part of a group, family or community. The chances are that there will be pressures on people, but such pressures could be to live. If the pressures are subtle, I do not see a way of being able to assess whether they exist.

We also need to take account of the fact that what someone else might see as pressure might not seem like pressure to the person. For example, I could imagine clearly being in a situation where my continued existence, which would be unpleasant for me, would also be an enormous burden on my family. The fact that I would be a burden would be a relevant part of my consideration, taking account of all the other circumstances that might influence me to ask for an assisted death, but that does not mean that that is a bad thing. I could be taking account of the effects on my family of what I did either way.

Nanette Milne: The other issue ties in with palliative care where people foresee that they will have a very nasty experience and a very unpleasant death. I am sure that palliative care would be discussed with all those people. Do you think that it should be written into the bill that people should experience palliative care, rather than just discuss it? So often, people who think that they want to end their lives change their mind once they are in good palliative care.

Professor McLean: I do not claim any expertise here at all, but it seems to me that there are some situations in which palliation can be enormously successful. I do not think that it would be a bad idea to have a trial of palliation to see how people then feel. However, there are also some reasons for dying that palliation can relieve only by sedation. If I am a person who wants to end my life in a manner that I approve of, that might not be the way that I would want to go. There might be some reasons for seeking an assisted death that do not lend themselves to palliation, except for what I believe is called terminal sedation, of which you could not easily have a trial. Pain seems to be one of the lesser reasons why people ask for an assisted death, because palliative care is so good nowadays. Where the source of the request is pain, a trial of palliation would make perfect sense to me, but I do not know that pain is the major reason why people ask for help.

The Convener: We will move on. I call Margo MacDonald.

Margo MacDonald (Lothians) (Ind): There are a number of points to follow up. Having read the submissions, for which I thank you—even though I sometimes felt as though I was in an ethics tutorial—I have already decided that section (4)2 could stand being amended.

I turn to the point that has just been made about palliation. When the bill was drafted it was assumed that if the discussion resulted in the doctor advising and the patient agreeing, palliation would be tried in any case, although that should not be prescriptive. So there is no problem there. The comment on the experience of the psychiatrist was perfectly reasonable. Given that the psychiatrist has to be licensed, the suggestion that was made would occur. There is no problem with that.

I turn to Professor Laurie's point on adjudication between psychiatrists who disagree. I am inclined to say that, if there is no agreement, the doctor should decide. If the patient agrees with that, we start the process again. That is the only way in which to resolve the matter. Obviously, I will be thinking about and talking over the issues before returning with amendments to strengthen the bill.

I turn to the point on pressures. I was at great pains to ensure that no one is coerced or pressurised, always remembering that all of this rests on the basis of autonomy. None of the witnesses last week said that they had observed any pressure or coercion. It delves into people's souls to say what someone can or cannot say inside their family. We should not try to do that. No one piece of legislation will change things all that much.

I come to the business of age. I am interested that the minimum age was considered. We will look again at that. I am not stuck on 16 being the age but—

The Convener: I do not wish to interrupt you, Margo, but there is a danger here. I am anxious that you have an equal opportunity to question or cross-examine each panel of witnesses that appears before the committee and addresses our questions. The slight danger is that you give us a running commentary on how the bill is developing in your mind. I am not against that, but the purpose of the session is to give you, as the promoter of the bill, the opportunity to test the evidence that the witnesses have led. Indicating to the committee that you have in mind a number of changes is helpful, but we must try to ensure that the answers that the witnesses give in response to committee questions are tested by you, as the promoter of the bill. That will give the committee a balanced view on matters. If we have put a question in a way that was slightly prejudicial to the subject matter, or that was constructed as the Latin *num* and *nonne*—in other words, expecting the answer no or yes—you as the promoter can pick us up on that and force the witness to give their view. In that way, we will get a balanced view. It would help the committee if you would address questions to the panel.

Margo MacDonald: I was trying to do that. On a number of occasions, I would have liked to come in on the committee questioning. I would have liked to have followed up on Professor MacKellar's assertion that, if one wrongful death were to result from the bill, it should not go through. In that case, what about car driving? I wanted to take issue with elements of the philosophy that he was expounding, but I did not want to crash in on the questions that others were putting.

The Convener: With respect, there was a minor and very civilised disagreement between Professor McLean and Professor MacKellar on the point. Unless I missed something, both sides of the argument were exposed fully before the committee. I am interested in your questions. The panel are still at committee. We are anxious that you should ask questions of them.

Margo MacDonald: I do not have any more questions at the moment.

Professor MacKellar: Let me respond to the point about driving. In medical ethics a lot of our work involves balancing advantages against risks. Driving is legal in every country and I agree that there are lots of deaths, but we balance the advantages against the risks. On the issue that we are discussing, I think—other people who are here do not agree with me—that the advantages and risks do not balance out.

Margo MacDonald: Because?

Professor MacKellar: Because of the risks involved. There is the risk of people dying involuntarily and the risk of undermining the whole concept of inherent human dignity. There is a risk of saying that society accepts that in some cases a person's life is unworthy of life. For me that is an important risk. Of course I see the advantages of euthanasia and assisted suicide, but I do not think that the risks and advantages balance out.

Margo MacDonald: What advantages do you see in euthanasia and assisted suicide?

Professor MacKellar: There is the advantage that it is possible to end suffering for a certain person, be it physical suffering—although I agree with Professor McLean that physical suffering can now be appropriately addressed, especially in the United Kingdom—mental suffering or existential suffering. All that suffering can stop with euthanasia and assisted suicide. I agree with that. I understand that. However, I also see all the risks involved, and for me the risks do not balance out.

Dr Brassington: We must be careful to distinguish between involuntary dying and non-voluntary dying, which I suspect have been conflated. I hope that no one will come out in favour of involuntary dying. Non-voluntary dying can be a little more of a grey area, for example in cases such as the Bland case.

As far as I have understood it, the bill is specifically about voluntary death, so the worry about the risk of other stuff happening does not strike me as being all that powerful. The objection that has just been articulated seems to be that voluntary euthanasia is perhaps okay but we are worried about something else. In that case, let us concentrate on the something else. If we can tell the moral difference between act A and act B, it makes no sense to say that we ought to forbid A because we are worried about B; we can just ensure that B remains forbidden.

Professor McLean: I want to pick up on something that Professor MacKellar said. It seems to me entirely misleading to suggest that legalising assisted suicide and/or voluntary euthanasia means that society has decided that some people's lives are not worth while. The individual person has decided that they do not want to continue to live, and if that means that they have decided that their lives are not worth while I do not know who else's choice that should be. It is not society saying, "Your life is not worth living"; it is the individual saying, "I do not want to continue in this particular condition", and society is respecting their dignity by allowing them to make that choice.

Margo MacDonald: That is what I had in mind when I said that people seem to have forgotten that the bill rests on autonomy.

Professor MacKellar: We are here in the Parliament not just to talk about respecting people's wishes but to look at how valuable, worth while and meaningful a life is. I believe that the Parliament should never say that a life is unworthy of life. It is the Parliament that decides. That is why euthanasia, murder and assisted suicide have been prohibited in society so far.

The decision that a person makes on whether to eat ice cream or to eat chocolate cake does not really matter, but the decision that a person makes in this area—the area of inherent human dignity—has consequences for the whole of society. That is inherently so. As Lord Walton pointed out in the 1994 House of Lords select committee report,

"dying is not only a personal or individual affair. The death of a person affects the lives of others, often in ways and to an extent which cannot be foreseen. We believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole".

I agree with Lord Walton on that.

Professor Laurie: This is an example of what might be called principles-based regulation. I completely agree with Professor MacKellar that we need to be absolutely clear about the principles upon which the legislation would be based and the relative weight that would be given to issues over which—as can be seen in this panel—people legitimately disagree.

However, the bill also raises some really important issues about procedure. Where the bill talks about a person who provides end-of-life assistance, it is not clear whether that person needs to be a medical practitioner, whether it is envisaged that such a person could be a medical practitioner or what the qualities or characteristics of that person should be. It is interesting that the ultimate act of assistance is not actually the subject of procedural safeguards or procedural scrutiny. I suggest that that is an important issue to consider as well.

11:30

Margo MacDonald: I am taking that on board.

I want to ask a question of Professor MacKellar. To be honest, I ask this out of interest. When someone is sent to war, is your justification set aside?

Professor MacKellar: Sorry, I do not understand. Can you develop your question?

Margo MacDonald: You said that there was no real autonomy for people to decide on the worth of their life and whether their life should continue. When people are sent to war, is it just accepted that they have no right to say no?

Professor MacKellar: In the past, if you were a member of the Army and you were sent to war, you had your orders to go. In that sense, people did not have any autonomy to say, “I don’t want to go to war.” In a way, war is an interesting case. In war, people suffer incredibly because they want to defend their country and to defend the inherent human dignity of the British people. That is why British soldiers are going to war and are suffering. That suffering of the soldiers is a measure of how important the concept of the inherent human dignity of the people of Britain is.

The Convener: I think that I am in danger of having to award degrees in moral philosophy at rather a late stage in the morning’s proceedings. I think that we have exhausted our questions, so I thank each and every one of the members of the panel both for their written submissions, as I said earlier, and for their contributions this morning.

11:32

Meeting suspended.

11:38

On resuming—

The Convener: I welcome our second panel this morning, which comprises Mark Hazelwood, the director of the Scottish Partnership for Palliative Care; Elaine Stevens, chair of the independent association of nurses in palliative care; Katrina McNamara-Goodger, head of policy and practice for the Association for Children’s Palliative Care; Stephen Hutchison, a consultant physician in palliative medicine at the Highland Hospice; and Dr Chris Sugden, medical director at St Andrew’s Hospice.

As with the first panel, your organisations have kindly supplied us with detailed written submissions and, as the committee has had the opportunity to study those with care, I intend to proceed to questions.

Michael Matheson: I turn to the paper provided by Mark Hazelwood. In the early part of that paper, you raise a number of concerns about terminology and practice in palliative care and the way in which the terminology in the bill is framed. You raise concerns about the way in which that could impact on practice within palliative care. Can you maybe expand a little further on that issue? Given your concerns about the use of the terms “end of life”, “dignity” and so on, what would your suggested alternatives be?

Mark Hazelwood (Scottish Partnership for Palliative Care): I preface my comments by saying that the Scottish Partnership for Palliative Care is not able to hold a position in principle on the legalisation of assisted suicide or euthanasia,

because our membership includes organisations—the most notable example being the Scottish health boards—that are institutionally unable to hold a view on matters of that sort.

We put in a submission grouped around two areas on which we felt MSPs could usefully focus. The first is the protection of vulnerable people and the second is possible damage to the practice and provision of palliative care. It is in that context that I come on to your question.

Our submission refers to issues, particularly in section 1(2) of the bill, which is the section in which “end of life assistance” is defined. The partnership feels that that is a broad piece of wording. In fact, when you read it, that definition would be consistent with the ordinary practice of palliative care, so we were concerned about whether the wording was precise enough. Section 1(2) states:

“‘end of life assistance’ means assistance, including the provision or administration of appropriate means, to enable a person to die with dignity and a minimum of distress.”

I am not a clinician—obviously, you have clinicians available to you—but my understanding is that a lot of the practice of palliative care physicians is about exactly that: it is about enabling a person who is dying to maintain their dignity and to have a minimum of distress. The partnership’s submission suggests that, given the ambiguity that we felt there was in that wording, MSPs consider the use of alternative terms that are clearer and better understood; the obvious terms are voluntary euthanasia and assisted suicide.

Michael Matheson: I can understand some of your concerns about confusion. Is it your view that, in order to take some of the edges off the debate, the bill has tried to hide under the idea that what it proposes is a bit like palliative care and is not so much about assisted dying and voluntary euthanasia? Is it your concern that that will start to become confused with the role of palliative care in hospitals and hospices in Scotland?

11:45

Mark Hazelwood: We are not trying to impute a particular intention to the bill and the way in which it is worded. We have drawn attention to what we regard as a real lack of clarity in a concept that is at the heart of the bill and have suggested that MSPs think about what consequences that might have for the practice and provision of palliative care.

In our submission, we give some illustrations of the sorts of difficulties that have the potential to arise because of the ambiguity of the bill’s wording. We have talked about the level of sensitive and nuanced communication that goes on between clinicians and patients in certain

situations. Clinical colleagues will be able to describe that at first hand. For example, in order to try to understand the feelings and needs of a patient in such circumstances, a clinician may ask the patient whether they have feelings that their life is worthless. The partnership's submission makes it clear that we are concerned that, given the vagueness of the bill's wording, it will be possible in such situations for the patient to infer that the clinician's communication is signposting them towards consideration of euthanasia or physician-assisted suicide.

Helen Eadie: Is it reasonable to assume that the driver for Margo MacDonald's bill may be a perception among the public and, perhaps, some MSPs that palliative care is not adequately funded in Scotland? I have dealt with cases of constituents to whom palliative care was not available. Sometimes palliative care is needed at very short notice, but one health board cannot deal appropriately with other boards or respond quickly enough to patients. Are such issues the driving force behind the bill and why some people in Scotland think that it is important?

Mark Hazelwood: Some research that has been carried out in other countries shows that when people are asked why they have pursued a request to access such a service, often they are motivated by a future-looking concern and anxiety, which may be grounded in a lack of knowledge about what is likely to be available in future circumstances.

I have a number of points to make about the specifics of availability of palliative care in the Scottish context. In June or July, the Economist Intelligence Unit published an international survey called the quality of death index. Although the subject that it addresses is a bit narrower than palliative care, the United Kingdom comes right at the top of the table for access. However, the issue is a bit more complicated than that.

It is helpful to think of access as having a number of different dimensions. We can think of it in terms of people's diagnoses: access may differ depending on whether someone has a malignant disease, a respiratory disease or a neurological disease. There are differences in access depending on the setting of care, and patients may be in different settings during the course of their illness. The average levels of service and support that are available in a hospice setting, for example, may differ from those that are available in a busy ward of an acute hospital.

There is another way in which it is important to think about access. Palliative care is a multifaceted type of care—it is a determinedly holistic approach to meeting patients' diverse needs. We have had quite a lot of discussion this morning about the extent to which symptoms such

as pain can be addressed, but palliative care is broader than that: it aims to address people's spiritual and psychological needs and to address the needs of the families involved. Therefore, there will be variability in access depending on those dimensions, as well.

I am sorry—I have not given a very definite answer, but I hope that I have illustrated some of the complexities that are involved.

Elaine Stevens (Independent Association of Nurses in Palliative Care): I will add a comment on equity of access to palliative care from my professional background as a palliative care educator. There are huge constraints in Scotland in relation to the training of health care professionals. Some people cannot access adequate palliative care because the staff in the area where they are being cared for do not have the knowledge and skills to provide it.

Stephen Hutchison (Highland Hospice): I will make a point that covers both the questions that have just been asked. What we call the bill is more than just a matter of semantics—it is really important that we be absolutely crystal clear about what law is being proposed. To that end, I suggest that such a bill should be called the physician-assisted suicide bill, the voluntary euthanasia bill or something similar that leaves absolutely no doubt as to what we are talking about.

People get confused about what exactly we mean. For instance, we know from a study that was done two or three years ago that less than 20 per cent of the British public have a full, complete or well-developed understanding of what palliative care is. We know that many people are anxious—for understandable reasons—about being referred to a palliative care service. People do not understand exactly what we do and there are many misconceptions about how we treat our patients and what can be achieved. We have touched on some of them, such as double effect. Therefore, it is important that we be crystal clear in what we call the bill and that we do nothing that obscures the issue for the general public.

Dr Chris Sugden (St Andrew's Hospice): I agree with the points that Stephen Hutchison made. The vast majority of the patients who come into a hospice's in-patient unit—or even an out-patient clinic, for that matter—are extremely vulnerable and very anxious, especially at first contact. The bill uses the term “End of Life Assistance”; in our specialty, we use the word “assistance” quite often. A vulnerable person may latch on to that, become confused and mix up our assistance with the wording of the bill.

Helen Eadie: The submissions—in particular, Mark Hazelwood's—raise issues about

"the standards of diligence expected in regard to the roles of practitioners"

and ask that there be some clarity on those. Will you expand a little bit on that?

Mark Hazelwood: That was one of three themes that the partnership raised in its submission. We felt that it was really important that practitioners be left in no doubt about what they were allowed to do and not allowed to do. Within that, we also felt it important that they know the standards by which their conduct might retrospectively be judged, were there to be a complaint or investigation for some reason.

We raised a couple of matters of particular importance under that heading. First, the bill talks about designated practitioners and psychiatrists, but most health and social care these days is delivered by a team. Therefore, it is important that MSPs have regard to making clear what the roles of different members of the team would be and what the information flows within the team might require to be.

The other point that we made, which you have referred to, was about standards of diligence in relation to practitioners. We gave the example that practitioners will be required to make a judgment about the extent to which a patient is acting without undue influence. There might be a great range of measures that one could take to establish whether someone was acting under undue influence, from simply asking them whether anyone was putting pressure on them, right through to undertaking a series of interviews with different family members. I am talking about a more forensic examination of the dynamics of the family, which might involve looking at the state of the finances of people in the family and the wider circumstance.

Our position is not that one approach or the other might be correct but that, from the point of view of practitioners who will be required to say that someone has acted without undue influence, some more specific guidance ought to be provided for them on what would be judged in retrospect to have been reasonable measures for them to have taken in reaching their conclusion.

Helen Eadie: I would like to press you a little further on that. You are saying that if a GP does not feel able to advise on forensic or other matters, he or she should take advice from another expert. Who might such an expert be?

Mark Hazelwood: As we said in our submission, the bill talks only about the medical practitioner and the psychiatrist, whereas some of the matters of judgment in question seem to be ones that do not necessarily fall within the expertise of those practitioners. I am not sure that we have a suggestion to make about who else

might be able to undertake such investigations. In a way, it would depend on the standard of investigation or diligence. If, for example, it were deemed necessary for the practitioner to have an understanding of any financial pressures or circumstances surrounding the request for assistance, I suppose it could be possible that the GP or medical practitioner might wish to take advice from an accountant. We did not get to that level of detail; as an organisation, we wanted to highlight the fact that the bill does not contain the detail that would give guidance or reassurance to a practitioner who had to make such decisions.

Helen Eadie: I can see that the process would be relatively easy and straightforward if we were talking about a criminal records check, but it would be a lot more complex if it involved the social dynamics of the family background. I, too, find it difficult to think who such an expert might be.

Ian McKee: I would like to discuss the wider issue of the relationship between palliative care and the proposals in the bill. My background is that before I became an MSP I was a general practitioner for many years. In fact, I sent Derek Doyle some of his first patients when St Columba's Hospice opened in the 1970s, and I worked in close contact with Macmillan nurses in the practice. No one is more convinced than I am of the benefits of palliative care and its ability to transform the lives not just of patients, but of relatives. It is a wonderful development, and it is quite strange to think that it did not exist at all when I started in practice. I am entirely on the side of palliative care.

In my years of experience there were a handful of people whom palliative care could not help, for one reason or another, despite the very best efforts of the people in palliative care. Both they and their relatives wished to put an end to life, but that was not available. For many years afterwards, relatives would come to me and say that they wished they could have helped their father and that they felt they had let him down. That is the sort of attitude that I have encountered. What is your reaction to such situations in palliative care?

12:00

Stephen Hutchison: One of my concerns is that what relatives say might reflect their own distress and not necessarily the distress that the patient is experiencing. We find that that is quite common, so we have to be careful how we interpret what a family member says.

I recognise that palliative care does not conclusively answer every problem that might be raised in the care of a patient in such a setting. However, it is extremely rare that we are not able to offer something. On the suggestion that

situations arise in which we can do nothing, in my 20 years in palliative care I can think of one patient—it was a recent case—for whom my perception was that we could do nothing. We tried a number of interventions and different means of support for the patient, but our perception was that we were achieving nothing. I do not think, however, that that was the patient's perception or the family's perception, and it is interesting that the whole issue of accelerated dying never raised its head.

There are times when we have the impression that we are not doing anything much, but if we ask the family they often recognise that care is being delivered in a context of compassion, love and understanding. They acknowledge our attempts to empathise as closely as possible with the patient and their experience, our attempts to address physical issues and to acknowledge other issues, and our attempts energetically and tirelessly to control things, sometimes in very imaginative ways. When we are doing all that, it is difficult to find a person for whom we can say that we can do nothing.

Ian McKee: That was not quite my point. I accept that you can do a lot for lots of people. However, sometimes what you can do is not enough. I have come across the issue in my practice—not often, but I have come across it. Do you not have a concern that there are people whom you cannot help further?

Stephen Hutchison: Of course I have a concern about that. The patient whom I mentioned gave me a lot of heartache, because I did not feel that I was able to do anything for him. My heart would sink when I visited him, because I felt powerless to help him.

I do not know what the answer is. It is a problem for someone like me, who opposes legislation such as is proposed in the bill. How do I address a level of suffering that I do not seem able to address with the skills that I currently have? However, I do not think that the right answer is to take that patient's life.

Dr Sugden: In 25 years of practice I have come across a few patients for whom palliative care could not address every need. I acknowledge that. What is the alternative? I have come away from patients' houses or hospital ward visits scratching my head. I have concluded first that the number of such patients is—thankfully—quite small, and secondly, that if we were to introduce a law for the few patients that we are talking about it would run the risk of being at the expense of the many anxious and vulnerable patients whom we see day in, day out, who would be affected in some way, particularly given that the bill involves doctors as participants in end of life assistance. That would far outweigh the current situation, in which we

occasionally scratch our heads and agonise about whether we could have done something better or taken another avenue.

Ian McKee: We heard from witnesses from other countries last week and we heard evidence about what happens in countries from which we did not have witnesses. The picture seems to be variable. In Belgium, which brought in a law on euthanasia, there is a fairly good palliative care structure. In the Netherlands there is no such structure, but we were told that the palliative care system improved enormously in the years after assisted suicide was permitted—I am not saying that it was cause and effect. We heard the same story in relation to Oregon. Does that not show that, in countries where such legislation exists, palliative care clinicians do not have as much to worry about as you are concerned that they might here, because palliative care services can improve or stay good despite the introduction of such legislation?

Stephen Hutchison: We have to be careful to ensure that we are comparing like with like. In a number of the countries that you have mentioned, the palliative care services are quite unlike what we have here. Mark Hazelwood has already mentioned the paper that states that the United Kingdom leads at least 40 other countries that were included in the survey in terms of quality of palliative care, and we are privileged to work in that environment. The situation is not the same elsewhere.

I do not know whether Oregon uses the term, "palliative care", but it certainly uses the word, "hospice". I think that the situation is changing a little bit but, by and large, when someone is admitted to a hospice in Oregon, they decide that they will not have any further active treatment of their disease, as hospice care is, essentially, terminal care at home. Ann Jackson, who was the executive director of the Oregon Hospice Association, spoke at a meeting that I attended in London in 2007. She told us that Oregon has two in-patient units, had 23 palliative care beds in the whole state and spent around £1,000 on the care of each patient and that care plans were reviewed once every two weeks. That horrified me. We are way ahead of that. We review our care plans several times a day; we spend a lot more than £1,000 per patient; and we have 23 beds in one hospice, let alone the whole country.

That demonstrates why we have to be careful that we are comparing like with like. Some people say that palliative care in certain places has improved. Perhaps it could not have got worse, and had to improve.

Katrina McNamara-Goodger (Association for Children's Palliative Care): I wonder whether the developments in palliative care are a sign of a

society's maturity. The fact that the issue of death and dying is raised in any way might be why people start to think about the associated services, which might lead to the development of the palliative care services. However, the UK has a long history of palliative care, and initiatives such as the living and dying well strategy give us the opportunity to develop palliative care further. We do not need the End of Life Assistance (Scotland) Bill to take us there; we already have those opportunities.

Ian McKee: One or two of the submissions said that not many of the people in your care ask to have their lives terminated. Might that not be, at least in part, because how you feel on this is well known? At the start, the hospice movement was based very much on religious grounds. I know that things have changed now, but I believe that one of the three founding principles of the organisation that Elaine Stevens represents is to fight against the introduction of legislation of the sort that we are discussing today. Is that correct?

Elaine Stevens: The principle is to oppose its introduction, not fight against it. I appreciate that that might be semantics.

I represent the independent association of nurses in palliative care, which is a small organisation, and I obviously do not have a mandate to speak about other nursing organisations or nursing in general. However, the members of the steering group on specialist palliative care in the hospice movement, of which I am a member, say that they do not hear many determined requests for euthanasia. In the 30 years that I have been in palliative care, I can probably count on the fingers of one hand the number of patients who have made such requests.

Some people who come into palliative care are distressed, demoralised and lacking in dignity and will say, "I wish it was all over". However, if you sit down and talk to them using skills of communication, you find that distress, pain and other issues are leading them to think that. After a period of quite specialised intervention, you can move people forward and reduce the amount of requests for it to be all over. Such people often go on to have a very good quality of life with their families. People have expressed thanks for what we have done for them, saying that the time that they have had has been precious and has allowed them to do many things.

Stephen Hutchison: The case of another recent patient illustrates that well. We are exceptionally rarely faced with serious requests to have a life terminated, but we are commonly faced with people who express that level of distress. Two or three weeks ago, I tried to engage a patient in that sort of discussion, in the confidence that he would not think that I was trying to steer

him down that path—I believe that I could not have that discussion if the bill became law, but I can have it now—and I was able to ask him about his level of distress and whether, if we were able to do something to end his life, he would wish us to do so. He did not answer me verbally; he held out his arm as if to say, "Give it to me now." He was clear about that, and his circumstances were such that you might think that that was legitimate.

Just last week, I saw the patient at home and asked him if he felt the same way, and he said that he did not, because his issues had been addressed. His situation might not be completely to his satisfaction, and he might change his mind again, but the point is that we had addressed some of his serious issues, and he had changed his position.

Ian McKee: The submission from Elaine Stevens's organisation says that it would be a good idea to ensure that if the bill became law, the patient was given the kind of palliative care input that you are talking about.

I agree that many people who have been low and have felt like ending it all have been helped by palliative care. My question was really about the people who, despite that process, still feel the same. However, I think that you have answered the question.

Stephen Hutchison: It is perhaps a legal point, and I am not qualified to discuss legal issues, but how right is it that, in society, we should introduce legislation with such great potential if we are going to use it in only a very small number of cases? I am not asking you to answer that now, but it is an issue that law makers need to bear in mind.

The Convener: I will take it as a rhetorical question.

Michael Matheson: One of the things that I have struggled with when considering this bill is its practical implication for hospices and those who deliver support, care and advice to individuals who require palliative care. A number of months ago, I met people from the hospice in Strathcarron, in my constituency. I was left in some uncertainty about how staff in a hospice would react if a patient who had been an out-patient for several years and became an in-patient decided to exercise the rights that this legislation would give them. Would the person physically have to leave the hospice? Would the hospice and social work withdraw care if the person returned home? To what degree would the practical support that hospices normally give to people be withdrawn in such circumstances?

12:15

Dr Sugden: It would impact hugely. In our submission, the board of management and medical team at St Andrews Hospice in Airdrie make the point that we oppose the bill. We would feel very uncomfortable if it were to pass into law. That said, we have to treat and look after our patients without prejudice. If the time came when someone wanted to follow through the process and wished end of life assistance, we would have to find a mechanism to discharge the patient from the hospice. The burden that would be placed on the other patients and staff is huge. I have not yet done a poll of all hospice employees to determine their stance on the bill.

As a management board, we would have to put in place a contingency to cope with this—one that sees the patient outside the hospice. Doing so would not prevent us from assessing and treating the patient until they were about to carry this out. As our protocols stand, the person would have to leave the hospice. We have had to draw up a protocol in anticipation of a bill such as this becoming law. I hope that that makes sense. We would care for the patient without prejudice but, when it came to a decision being made for end of life assistance, we have agreed that that would have to be given elsewhere.

Michael Matheson: Just—

The Convener: Both Mr Hutchison and Mr Hazelwood want to respond to the question.

Michael Matheson: Before they do so, I seek clarification from Dr Sugden. Let us say that someone has a 28-day window in which to exercise the right to end their life under the legislation, if the bill is passed. If someone chose to exercise that right on day 26, could they remain in the hospice for the intervening 25 days?

Stephen Hutchison: The question raises some of the extremely challenging issues that those in palliative care face. One reason why those of us in palliative care oppose the bill is because the provisions are fundamentally at variance with the principles and practice of palliative care as it is defined by the World Health Organization. They are also at variance with the concepts that Cicely Saunders, the founder of hospice care, elucidated. This sort of action is fundamentally at variance with those principles.

I am sure that the committee has looked at the Highland Hospice submission, which references a paper from Jose Pereira that answers exactly the question. The paper looks at the range of issues that hospice people face and the dissonance, problems and crises that can develop when attempts are made to introduce this measure into palliative care settings. I am happy to expand the

point if requested. For the sake of brevity, I direct the committee to the paper.

Mark Hazelwood: I have two points to make. The first point is the practical issue of arrangements for staff who have a conscientious objection to being part of the process. We mentioned that in our submission. We ask MSPs to consider the fact that the bill is silent on the matter. The second point does not form part of our submission but arises from my reading of the National Health Service (Scotland) Act 1978 in relation to the Palliative Care (Scotland) Bill that the Health and Sport Committee is considering. The End of Life Assistance (Scotland) Bill is a bill that grants rights to individuals; the extent to which NHS boards and voluntary hospices will be mandated to provide such a service is unclear. I think that the assumption that is made in the bill is that NHS boards will pick up such assistance—it will be a service that they are obliged to deliver. I am not a lawyer, but my reading of the 1978 act prompted a question: to what extent is end of life assistance, or steps towards such provision, consistent with the 1978 act?

The Convener: The committee anticipated the question. We will write to the Government to seek clarification on whether the provisions of the 1978 act are consistent with end of life assistance as it is envisaged in the bill. If and when we receive an answer from the Government, we will place it on the public record. We can then have the debate that you propose in a more informed context. The question is an interesting one. We do not know the answer. As I said, we are actively pursuing the matter.

Dr Sugden: I will finish the answer that I was giving. The bill does not mention conscientious objectors—our hospice, as an organisation, would come under that.

Katrina McNamara-Goodger: The point is not covered in our submission, but on the concept of conscientious objection and of services withdrawing from providing palliative care because of a fear that they might be asked to move on to provide end of life assistance, I reiterate that young people—16-to-18-year olds—who are moving from children-focused services into adult-focused services already find the transition and getting appropriate services quite difficult. The legislation will bring added complexity to a difficult phase of their lives.

Michael Matheson: Dr Hutchison mentioned another paper that is referenced in Highland Hospice's submission. Would it be fair to say that hospices in Scotland are uncertain at which point they would withdraw care should the bill be enacted and that you would have to give further consideration to that should it be enacted?

Stephen Hutchison: Absolutely.

Nanette Milne: Dr Hutchison, will you elaborate on your response to a previous question? You hinted that some of the conversations that you currently have with terminally ill patients might be different if the bill were enacted. In the Highland Hospice submission, you state that your work

“includes sensitive exploration of and support for ... psychological or spiritual distress”

and discussion of sensitive issues in the safe knowledge that your only response will be to optimise the end of life for your patients. Would you find it difficult to continue your current practice if the bill were enacted?

Stephen Hutchison: I would find it extremely difficult because, inevitably, if I were to raise that sort of issue with a patient, or if they were to raise it with me, by definition assisted dying would have to be on the agenda, which I would find very uncomfortable. A number of safeguards have been proposed. Essentially, people would be allowed to withdraw from the process if they wished. In doing that, I believe that they should be able to discuss openly with their doctor the concerns that are in their mind, but I think that the legislation would inhibit that dialogue.

Nanette Milne: Dr Sugden, you state in your submission that the bill does not elaborate on the effect that such legislation would have on families and close associates. We heard from Elaine Stevens that families are often comforted by the palliative care that their distressed relatives receive. You are obviously implying that the reverse might happen if the bill is enacted. Will you elaborate on that?

Dr Sugden: It is currently unknown how relatives cope with assisted suicide or voluntary euthanasia, but it is fair to say that death is always messy; it is never clear cut. Things are always left behind and there is the possibility that there might be problems for relatives looking back, in bereavement, knowing the point at which a person had voluntary euthanasia or assisted suicide, and reflecting on whether it was the right thing to do. I say “might” because I do not have evidence for that.

In, shall we say, a natural death, there is an opportunity to bring closure—to use the American phrase—and to have extended spiritual input and bereavement support. My concern is about how we would support relatives in what is not a natural process. The bill does not cover that. Indeed, I am not sure whether there are any papers or evidence on how the bereaved cope in such circumstances.

Stephen Hutchison: There is very little evidence on that. I think Professor Sheila McLean in the previous panel mentioned a study showing

that a small number of people were comforted by the fact that the patient had had assisted dying. However, we are talking about one very small study. Nowadays, we normally look for rather more robust and rigorous scientific evidence.

I should clarify a point that was perhaps not as clear as it might have been. One of the safeguards that have been proposed—and quite rightly so—is to ensure that the person is not acting under any coercion or undue influence. Could raising the issue with my patient be construed as coercion or undue influence, or might they perceive there to be an expectation on my part that they might wish to pursue this course of action because of a perception that we cannot do anything else?

Ian McKee: I might be wrong, but I do not see anything in the bill that says that you would have to raise the issue. Surely it is all about the patient making a request for end of life assistance. It does not say that such an option has to be counselled as part of the services that you offer.

Stephen Hutchison: I am not suggesting that I would specifically raise with the patient the question whether they would like to have their life terminated. What I am saying is that the legislation might inhibit my ability to engage the patient in dialogue that allows them to express their distress—sometimes, perhaps, to the extent that they express a wish for their life to be over. That brings us back to Elaine Stevens’s point that we can pursue and often deal with many such matters.

Helen Eadie: Mark Hazelwood referred to one issue to which the committee is alert, as the convener pointed out—the 1978 act. I would be interested in hearing the witnesses’ views on the conflict of interest issue raised in Mr Hazelwood’s submission. Sometimes with legislation there are unintended consequences and Mr Hazelwood suggests that we might see the rise of specialist GPs or simply specialists providing such services in Scotland. What societal pressures might arise if GPs decided to make a private living from this legislation? Someone this morning cited the example of selling a kidney to pay their mortgage. Might some GPs think this to be a good area of private practice?

Mark Hazelwood: The bill contains a lot of provisions on conflict of interest and the Scottish Partnership for Palliative Care feels that to be a positive move. The point in our submission is quite narrow and relates to section 5(2)(b), which concerns practitioners not levying charges or making income that might raise suggestions of a conflict of interest. Our point is that, although there might be safeguards covering individual instances, if there were to be a degree of specialisation of practice such that an individual practitioner became involved in quite a lot of this activity and a

significant proportion of their income came from such work, it might become quite difficult to be clear that there was not a conflict of interest on their part. It is probably better to ask others about changes in societal attitudes or pressures over time, as the partnership's submission does not really go into that territory.

Ian McKee: I might have misunderstood you, Mr Hazelwood, but surely the fee would be paid for the work done, even if the doctor decided that the patient did not warrant end of life assistance. It cannot be the case, surely, that the doctor gets the income based on coming to a certain conclusion. The fee would be paid one way or the other, surely.

Mark Hazelwood: It is a hypothetical situation, obviously. The point is not made in respect of individual decisions, but you can see that someone who wanted to build a business or practice of this sort would understand that people who want to get access to the service will tend to gravitate towards a practice in which a high proportion of requests are approved. That is the logic behind the point.

12:30

Helen Eadie: This is an interesting area. What if some members of society cannot afford the fees? We do not know what level the fees might be set at. We do not know whether the 1978 act might need to be adjusted or altered. However, if it were not amended, we could have a scenario in which some GPs decided that they were only going to practise in this area, and fees could be whatever demand allowed them to be. Is that what you envisage?

Mark Hazelwood: To be honest, it is difficult to speculate about the pattern of service or how various members of the profession might respond to the opportunity.

The Convener: With respect to Helen Eadie and Ian McKee, we are involved in a discussion of a situation on which there are three pre-conditions, and we are then asking the witnesses to speculate on the basis of an undetermined opinion. I think that we should move on, as I am not sure that this is wholly—

Helen Eadie: With respect, how will we revisit the issue once we have received the clarification that we seek?

The Convener: On the point to which Mr Hazelwood alluded, it is important to determine whether the 1978 act applies. Only at that point will we be able to determine whether payment is a matter for the NHS or private practice. It is unfair to ask Mr Hazelwood to speculate about what the

basis of the fee might be before we have the information.

Ian McKee: I was following up Mr Hazelwood's statement rather than asking him to speculate.

The Convener: Indeed, but I think that we got into difficult territory.

Stephen Hutchison: I will steer away from any such speculation. However, the fact that the issue has come up is recognition of the point that most doctors are not in favour of doing this and will not wish to be engaged in it. However, it also touches on doctors' competence and case exposure. I will not go into that in detail just now, but you will find some discussion of it in the submission from the Royal College of Physicians and Surgeons of Glasgow.

Helen Eadie: You will be relieved to hear that I will move away from that topic, convener. I respect your views on that.

I am sorry to be giving you such a hard time this morning, Mr Hazelwood, but I would like to ask about reporting and monitoring and the possibility that procurators fiscal would investigate all the deaths. That raises an important point about the collection of data that will enable us to determine whether this policy is a good one.

Mark Hazelwood: I will start by saying that I know little about the operations of a procurator fiscal's office.

In our submission, we noted that the bill is extremely light on collection of data that would tell us what is going on with end of life assistance and would form the basis for monitoring and reporting. It is not clear that the potential intervention of the procurator fiscal's office would deliver that sort of data set. We have suggested that the data set would be important for monitoring and scrutiny.

As you have found, this is an incredibly controversial and contested area of public policy. We feel that when you consider the evidence in other jurisdictions—which have a little more in the way of monitoring and reporting arrangements than is envisaged under the proposed Scottish legislation—it is apparent that the bill would lead us into a new area of public policy, but without generating the sort of data set that would allow scrutiny of individual practice as well as the collection of evidence that would enable us to, for example, determine trends.

Margo MacDonald: I have six questions. Can I ask them all?

The Convener: Certainly.

Margo MacDonald: Dr Hutchison, if a hospice patient refused treatment, would he or she have to leave the hospice? Refusal would be their legal right.

Stephen Hutchison: I am not entirely sure what you mean. Are you asking about a situation in which a patient refused the interventions that we were willing to offer?

Margo MacDonald: I am asking what would happen if the patient refused treatment.

Stephen Hutchison: In that case, there would be no point in their remaining as an in-patient in the hospice.

Margo MacDonald: Would they have to leave?

Stephen Hutchison: I think that they would wish to leave.

Margo MacDonald: Do you not know? I am asking you because you work in the hospice movement.

Stephen Hutchison: In order to maintain a service—bearing it in mind that we have only a small number of beds—we have to recognise that, when people have completed the course of treatment that we can provide for them as best we can, or have declined treatment, we must discharge them, because there are a lot of other people who need our care.

The hospice covers more than simply in-patient care. I am not saying that we would abandon that person. That is one of the difficulties of the legislation, as Dr Sugden said. Would we be placed in the position of, in a sense, having to abandon that patient? We would not wish to do that. We might discharge them from the in-patient unit, but we would maintain contact with them through their GP, their Macmillan nurse, a day hospice centre or whatever.

Margo MacDonald: Let us suppose that the patient's attitude is that he or she is grateful for what has been done but has had enough and does not want any more, so goodbye, and thank you.

Stephen Hutchison: We would respect that.

Margo MacDonald: On the idea that a GP might become a specialist in euthanasia, do you agree that the proceedings that are outlined in the proposed legislation refer only to a small number of people? The witnesses are all nodding. In that case, do you think that there would be sufficient volume of cases for someone to make a lot of money by becoming a specialist?

Stephen Hutchison: I think that we would be speculating again.

Margo MacDonald: I am sorry, but you said quite definitively earlier that the proceedings referred to only a small number of people. If that is the case, what is your fear about GPs becoming specialists in euthanasia?

Stephen Hutchison: My fear would be for the health, in the global context, of the doctor who was providing that service. I have no idea what level the fees would be set at and, as we have said, we cannot speculate on that. However, the matter raises itself because doctors have to work in the context of competency, and the small number of cases means that it is likely that they would not arrive at that level of competency.

Margo MacDonald: Do you agree that there is such a small number of people involved in this issue that it would be most unlikely to throw up a new specialism?

Stephen Hutchison: I agree that the current estimates and the figures that we see in other countries are fairly low. Nevertheless, in places where such a law has come into effect, the number of people availing themselves of the option has increased. I do not know what the numbers will be. It might take many years or many generations to see how society will develop.

Margo MacDonald: What countries are you talking about?

Stephen Hutchison: I am talking about the situation in Oregon.

Margo MacDonald: How do you know what it is?

Stephen Hutchison: Annual statistics that are returned show that the numbers have steadily increased.

Margo MacDonald: No.

Stephen Hutchison: They have increased, reached a plateau and dropped slightly, but they are still higher than they were.

Margo MacDonald: So, we get back to Mark Hazelwood's comment that we could do with a bit more information on how the stats are compiled.

Stephen Hutchison: I think that he was talking about how the statistics for the monitoring of the process and subsequent monitoring should be done.

Margo MacDonald: I will not pursue the matter because, to be frank, I do not think that you are all that interested in Oregon and I am much more interested in the effects of the proposed legislation.

I have a question for Elaine Stevens. Does the specialist intervention to which she referred—talking to people—work in every case?

Elaine Stevens: No, it does not always work. We have all already said that specialist palliative care interventions do not work in every case, but that does not lead my association to offering

people assistance to die. We think that that is a step too far.

Margo MacDonald: I make it plain that the bill does not propose that you should offer assistance to die. Are you aware of that?

Elaine Stevens: Oh, yes.

Margo MacDonald: If your specialist intervention does not comfort the person, work as you want it to or have the effect that you desire, what do you do then?

Elaine Stevens: We journey along with the person as best we can and will be with them as partners in their distress and end of life care. We do not abandon them.

Margo MacDonald: Has nobody ever said to you, "I want to finish it now"?

Elaine Stevens: They have done, in the past. In the palliative care teams of which I have been a part, we have agreed with them. Obviously, assistance to die is not legal in this country so we journey along with people in their distress and look after them in all the ways that we possibly can to make the last part of their lives as comfortable and of as good a quality as we possibly can.

Margo MacDonald: However, you accept that you cannot get rid of the distress in every case.

Elaine Stevens: We would be foolish to say that we could help all the people all the time, but that does not automatically lead us to wanting to offer end of life assistance.

Margo MacDonald: You should be a politician if you think that you cannot please all the people all the time.

My next question is addressed to all the witnesses. Do you have any suggestions for amendments that would improve the bill?

Elaine Stevens: From my association's point of view, there are issues relating to conscientious objectors. Many practising nurses, although not all, would not want to be involved in implementing such legislation.

Margo MacDonald: The bill says that they would be able to refuse to take part in any procedure.

Elaine Stevens: We would like that to be strengthened.

Dr Sugden: I agree with that.

Katrina McNamara-Goodger: For us, the major issue is age. Many of the points were rehearsed this morning. We find it extremely difficult to accept that the bill makes age the determinant of the capacity to make decisions. It is not about whether 16 is too young or too old, but the whole

concept. We are concerned about the ability of those who judge an individual's ability to make decisions, the involvement of young people—and the right people—in assessment, and the ability of those involved in assessment to deal with the young person's stage of emotional development. Those are all issues that we would like to be looked at in amendments.

Margo MacDonald: Do I infer from that answer that you do not think that psychiatrists have enough knowledge?

Katrina McNamara-Goodger: I am keeping my comments to the young adolescents—the teenagers—about whom we are talking. The services that many adult psychiatrists offer will consider the pathology that relates to adults, but that does not necessarily relate to the pathology of children and adolescents. We acknowledge that child and adolescent mental health services are a specialty in mental health care that is more able to examine the emotional development of young people. However, those services will not necessarily be able to consider decisions on assisted suicide.

There is a big gap in the ability of one service to consider developmental issues and of the other to consider suicide issues. Currently, I would have concerns about the ability of psychiatrists to make the assessments that would be required.

12:45

Margo MacDonald: I will mention that to the psychiatrists when they come to give evidence.

Stephen Hutchison: I do not know whether your question was intended to identify a number of practical issues that, if they could be addressed, would gain the palliative care sector's support for the bill. I find it difficult to separate the practical and the ethical; we have to consider both globally.

In a straight answer to your question whether I would propose any amendments, I am not a lawyer or lawmaker, but there are a large number of issues about which I have considerable reservations and on which I would like to make amendments. However, even if each of those were to be addressed to my satisfaction, I would still consider the bill to be wrong because of the ethical principles that were discussed with the previous witnesses—the uniqueness and sanctity of human life.

Mark Hazelwood: We did not document proposed amendments in our submission; the thrust of our approach was to highlight areas for consideration. However, I will mention two specific areas that are highlighted in our submission. I have already been asked about the first, which is the terminology "end of life assistance". In our

submission, we drew attention to the fact that alternative and more clearly defined terms—euthanasia and assisted suicide—are available.

The second piece of terminology to which we drew attention concerns one of the eligibility criteria. Our submission asks MSPs to consider carefully whether the criterion of not being “able to live independently” is really clear enough or whether it might be liable to very varying and inconsistent interpretation. From the point of view of practitioners and somebody who might wish to access the service for which the bill provides, that sort of ambiguity is probably not helpful.

Margo MacDonald: Am I correct that Dr Hutchison identified that the basis of his objection to the bill is ethical or moral, rather than legal or clinical?

Stephen Hutchison: It is both. My point is that it is not possible to separate one from the other. I may have ethical objections to provisions that other people would consider perfectly practical and legal or I may have practical and legal objections to something that other people consider ethical. In this situation, we have to take both together; we cannot separate the two.

Margo MacDonald: I presume that you accept that somebody with a different ethical stance from your own would give me the same answer.

Stephen Hutchison: I defer to the more learned opinion about ethics and bioethics, such as you heard from the first panel of witnesses.

The Convener: I thank all the witnesses on the panel for their contributions. Before I conclude the meeting, I remind members of the committee and the public that the next committee meeting is scheduled to take place on Monday 20 September, when we will take further oral evidence at stage 1 of the bill.

That concludes the formal proceedings for this morning.

Meeting closed at 12:49.

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