The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 27 January 2015

Session 4

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HEALTH AND SPORT COMMITTEE
3rd Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Dr Salah Beltagui (Muslim Council of Scotland)
Ephraim Borowski (Scottish Council of Jewish Communities)
Dr Pat Carragher (Children's Hospice Association Scotland)
John Deighan (Bishops Conference of Scotland)
Baroness Finlay of Llandaff
The Rev Sally Foster-Fulton (Church of Scotland)
The Rev Dr Harriet Harris (Scottish Episcopal Church)
Patrick Harvie (Glasgow) (Green)
Mark Hazelwood (Scottish Partnership for Palliative Care)
Dr Stephen Hutchison (Highland Hospice)
Dr David Jeffrey (University of Edinburgh)
The Rev Dr Donald MacDonald (Free Church of Scotland)
Richard Meade (Marie Curie Cancer Care)

CLERK TO THE COMMITTEE

Eugene Windsor

LOCATION

The David Livingstone Room (CR6)

Scottish Parliament

Health and Sport Committee

Tuesday 27 January 2015

[The Convener opened the meeting at 09:46]

Assisted Suicide (Scotland) Bill: Stage 1

The Convener (Duncan McNeil): Good morning and welcome to the Health and Sport Committee's third meeting in 2015. I ask everyone in the room to switch off mobile phones, as they can often interfere with our sound system. I also ask everyone to note that some of the committee members will use tablet devices instead of hard copies of our papers.

I welcome again Patrick Harvie MSP, who has joined us for item 1.

Our first agenda item is continued stage 1 scrutiny of the Assisted Suicide (Scotland) Bill. This morning, we have two round-table sessions. The first is on palliative care. As usual with a round-table session, we will do the introductions ourselves because they are much too long for me to do them.

We also have with us Dr Mary Neal, who is the committee's adviser on the bill.

I am the member of the Scottish Parliament for Greenock and Inverclyde and convener of the committee.

Bob Doris (Glasgow) (SNP): I am deputy convener of the committee and an MSP for Glasgow.

Dr Pat Carragher (Children's Hospice Association Scotland): I am the medical director of the Children's Hospice Association Scotland.

Rhoda Grant (Highlands and Islands) (Lab): I am a Highlands and Islands MSP.

Baroness Finlay of Llandaff: I am the palliative care lead for Wales, but I am also in the House of Lords and involved in the debates about Lord Falconer's Assisted Dying Bill. I was also on the select committee that considered Lord Joffe's Assisted Dying for the Terminally Ill Bill.

Dennis Robertson (Aberdeenshire West) (SNP): Good morning. I am the MSP for Aberdeenshire West.

Dr Stephen Hutchison (Highland Hospice): I am a recently retired consultant in palliative medicine at the Highland Hospice in Inverness.

Colin Keir (Edinburgh Western) (SNP): I am the MSP for Edinburgh Western.

Mike MacKenzie (Highlands and Islands) (SNP): I am an MSP for the Highlands and Islands.

Mark Hazelwood (Scottish Partnership for Palliative Care): I am the chief executive of the Scottish Partnership for Palliative Care.

Nanette Milne (North East Scotland) (Con): I am an MSP for North East Scotland.

Dr David Jeffrey (University of Edinburgh): I am a lecturer in palliative medicine at the University of Edinburgh.

Richard Lyle (Central Scotland) (SNP): I am an MSP for Central Scotland.

Richard Meade (Marie Curie Cancer Care): I am head of policy and public affairs for Scotland for Marie Curie Cancer Care.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I am an MSP for Mid Scotland and Fife.

Patrick Harvie (Glasgow) (Green): I am the member in charge of the bill.

The Convener: Thank you all for that. I welcome you all. We will move directly to our first question, which is from Richard Simpson.

Dr Simpson: I declare an interest as a member and past chair of Strathcarron Hospice.

All of the witnesses are, if I do not misrepresent them, broadly against the bill, although some are more definitely against it than others are. I challenge them to say, if the Parliament agrees to the general principles of the bill at stage 1 and decides to proceed to stage 2, what changes could be made to the bill to make it work and be appropriate.

Baroness Finlay: I worked at Strathcarron Hospice many years ago as a doctor and was a general practitioner in Maryhill for five years. The way the bill is written, most of my patients in Maryhill and Possilpark would be included automatically because their life expectancy was much shorter than that of people who lived up the road in the wealthier areas of Bearsden and Milngavie, so there is a fundamental problem with who it tries to include.

The second point is that the bill attempts to take the matter out of medicine. That is a good thing to do but, by involving medicine at all, you create a fundamental problem. Only 4 per cent of licensed palliative medicine doctors are prepared to have anything to do with assisted suicide and 96 per cent are not. With that resistance among doctors, which is resistance for good reason, the bill will not work. I suggest that you seriously consider taking any processes for the adjudication of eligibility completely outside medicine. The bill has a concept of licensed facilitators on which you could build.

The title of the bill is honest and to be commended for its honesty. We had a big debate in the Westminster Parliament about Lord Falconer's bill, which uses the euphemism "assisted dying", but the Scottish Parliament is being clear about what it is. However, you need to specify who would issue the lethal drugs, because they are not medication or treatment—they are nothing to do with treatment—and the dose will not be in any formulary, because there is no evidence base for it. That needs to be in the bill.

You also need to clarify the interface between suicide prevention policies and when the Mental Health (Care and Treatment) (Scotland) Act 2003 would kick in. I do not see how a doctor could turn anyone down under the bill, so there is a problem with the interface between the person who seeks assisted suicide with lethal drugs and the person who is suicidal and would currently be managed, supported and helped through mental health services, often working in conjunction with the main medical services.

The other important thing for doctors is that the power to create a conscience clause is reserved, as far as I understand it, so you cannot create one in Scotland, but all the professional guidelines about conscience are probably not worth the paper that they are written on. We have seen that with midwives being involved in managing patients who have had abortions. Actually, a conscience clause would not hold water. The medical profession knows that and has no faith in any talk about a conscience clause because it knows that it will get caught up in it.

My advice is that, if the Parliament is serious about the bill and wants a system that might work, it should put the adjudication with the court to decide who is or is not to be provided with lethal drugs by a court-appointed person and a complete court system.

I will stop there, but I could go on for longer.

Mark Hazelwood: I have a point of clarification. Richard Simpson characterised all the witnesses as being opposed to the bill so, before I say anything else, it is important for me to be clear about the Scottish Partnership for Palliative Care's position. In our submission, we said that we were

> "not able to adopt a position on the principle of whether or not assisted suicide should be legalised. This is because the topic raises issues of a moral, personal and ethical nature upon which many of our member organisations"—

I am thinking particularly of the Scottish health boards—

> "are institutionally unable to hold a position."

Therefore, the partnership has adopted an approach of providing information. With regard to the interests of vulnerable people and the provision and practice of palliative care, our approach is to suggest to MSPs areas in the bill where there might be a need for particular consideration.

I appreciate that that is a slightly nuanced position, but I want to be clear that we are not in the black and white category that Richard Simpson characterised us as being in.

Dr Carragher: Dr Simpson asked an interesting question to draw us out. I represent those who are younger than 25, as that is my area of expertise. I would have considerable concerns if the bill were to become law. Children are different from young people and young people are different from adults. We know that maturing rates are different. There is an issue about somebody who is 16 or just over making this sort of decision and having the required capacity and full understanding. An increasing amount of work is available to show that young people, even up to the age of 25, do not fully understand the absolute significance of death and do not understand that death would be final for them.

In my work, twice in only the past couple of weeks, I have had experience of that. Some youngsters decide that we should not attempt cardiopulmonary resuscitation in the event of an acute deterioration, because they do not want that intervention. In the past couple of weeks, when push came to shove, if I can use that phrase, two youngsters who had been very clear in their mind about that elected for full resuscitation. Of course, they were able to go for that—I do not need to follow through that discussion.

I could go on, but I will stop there.

The Convener: Baroness Finlay wants to come back in, but I will first take those who have not yet made a contribution. In these sessions, we always defer to our panellists and ask the politicians to be patient. I will bring them in when there is a lull.

Dr Jeffrey: To build on the comments that have been made, it is not just doctors and the Association for Palliative Medicine that are opposed to the bill; all the major colleges are also opposed, such as the Royal College of Physicians and the Royal College of General Practitioners, as well as the British Medical Association. They are all against legalisation of assisted suicide, or assisted dying as it is called in England.

I want to put that in the context of the huge problem that we face in Scotland with recruitment of general practitioners. I would like the committee to think about the influence that the bill would have on doctors. Whatever the complicated ethical arguments that we have about euthanasia, the bottom line is that doctors have a gut feeling or intuition that they should just not be involved with it.

Dr Hutchison: One of my concerns, which might seem to be about rather tedious dictionary definitions, is that the bill is said to be founded on the principle of autonomy. If that principle is important enough to state that the bill is founded on it, it is important enough that we should address and challenge it. I wrote extensively about that in my written submission. Autonomy is the wrong word and the wrong concept. As I understand it, the concept has caused problems in Belgium, where in essence the patient's autonomy is the driver and it seems to supersede the professional judgment of other people, and there has therefore been a widening of the criteria for assisted dying in Belgium.

Rather than talk about autonomy—when I think about it, I do not personally believe that autonomy actually exists—we should talk about choice with responsibility. We function as a relational and interdependent society. That is how it works; it does not work with autonomy. Therefore, we need to look at choice with responsibility. To me, that puts a completely different emphasis on the issue, as it is then not about what the individual chooses and demands. That is part of the equation, but it has to be balanced with careful scrutiny of the implications for the rest of society and, in particular, for the vast numbers of frail, vulnerable and frightened people whom we look after.

10:00

Baroness Finlay: I will build on what has been said. To illustrate the age issue—graphically, I hope—I will give an example of a patient of mine. He was a young man in his 20s who had his third testicular tumour and was adamant that he did not want any treatment and he wanted to be helped to die. The discussion went on for not just weeks but months. Then, when he was unable to sit up in bed and was, I thought, in the last 24 hours of life, with his parents sitting at his bedside, he asked me, "Is it too late for me to try the treatment?" We had had weeks and weeks of discussion, but it was not until death was staring him in the face that he really believed that his treatment refusal and desire for death were going to result in his death.

Actually, there was a happy outcome. I phoned the oncologist and, within an hour, against all odds, we started him on oncological treatment and debulking surgery. That was many years ago, and he is still alive today. I see him fairly regularly socially when out walking. He is glad to be alive. However, his desire for death and to have his life shortened went on not just for weeks but for months and months, whereas the bill allows a period of two weeks. The age is important. There is really good psychological and developmental evidence that youngsters up to the age of 25 do not understand the issue.

Another problem is that laws send messages. There is a public safety issue about those who are vulnerable to coercion and pressure or to feeling that they are a burden. Dr Hutchison made a clear point about autonomy, which was a concept that came from the Greek states and was to do with having rules within their society. Autonomy as a concept is about the fact that we have responsibility to others so, actually, it is relational. I am concerned that there is no requirement in the bill to think about the effect on others. What is the effect on a child of a parent taking their life and deliberately foreshortening it and being assisted in doing so by the medical clinical services on which that young person would then be dependent in bereavement? We know that young people can have a lot of problems with a lack of support with grief. How can a grieving young person go to their GP, when that is the person who signed the forms? I put that out as a question for the committee.

Dr Simpson: The issue of autonomy is interesting. Maybe the witnesses would like to expand on one of my concerns, which is about vulnerability. My experience as a doctor is similar to that of Ilora Finlay. I had at least three patients who changed their minds when confronted with the absolute reality and when it dawned on them what was going to happen. When their denial that they were going to die stopped, they suddenly realised that, actually, they wanted to live, and they were prepared to accept treatment at that point.

I am particularly concerned about the relationship between the family and the individual. Again in my experience, individuals told me that they did not wish to be a burden on their family. I then got the family to explain that the person was not a burden and they did not have to go into a hospice or hospital, as they could stay at home and they would be looked after. When people are really quite ill, they feel that they become a burden.

I want to explore a little further how the bill, if passed, could deal with those circumstances of vulnerability. Given the psychological problems that are associated with terminal care, which are not fully understood by the public—or really by any of us until we face that situation—how do we protect those who are considering assisted suicide when in fact they would be doing it not to relieve an impossible burden for themselves but because of a vulnerability to pressure by others, which may or may not be expressed?

Dr Hutchison: In the paper that Dr Martin Wilson, who is a consultant in the care of the elderly at Raigmore hospital, in Inverness, and I have submitted, we cite the issue of elder abuse in our society, which is a major problem. The concern—which I understand from family situations that I have been in—is that there could be a spoken or unspoken pressure, with people thinking that it would be good if so-and-so was no longer alive because their suffering would be over. Such thoughts could be altruistic or they could possibly be malicious—the bill leaves itself wide open to families having malicious reasons for wanting to see the end of an older person's life, perhaps because of their inheritance, the costs of care or whatever.

The issue of someone feeling that they are a burden is interesting, and I have approached it in a way that some people might find surprising—occasionally, my patients and their families have found it so. It is common for me to speak to a husband and wife, one of whom is ill while the other is caring for them. If it is the husband who is ill, he will often say to me, "I don't want to be a burden to my wife." We know that the fear of being a burden is a significant driver for assisted suicide in Oregon, so it is a relevant issue. My response to such a suggestion—perhaps to the person's surprise—is to say, "Well, you are a burden to her." Care is a burden, and I do not believe that we can realistically say, "Of course you're not a burden." We are burdens to each other—that is part of the relational nature of our society—and I contend that, in a responsible society, we carry each other's burdens. I therefore say to the husband, "You are a burden. It is a burden for her to look after you. There are demands, and she needs the opportunity for respite and a break. If the tables were turned, would you do the same for her?" I cannot think of anyone who has said no to that.

The Convener: However, that burden sometimes weighs heavy on carers and it sometimes results in the premature death of carers. The carers who are looking after older people are getting older themselves, and it seems to me that the person in your story is not able to give care freely. The burden cannot just be dismissed as some sort of duty; in itself, it has an impact on the other person's health and quality of life. I do not think that it can be pushed away as some notional thing.

Dr Hutchison: I am not pushing it away. The substantial burden on that person means that they also need to be supported. One of the lodestones of the high quality of palliative care that we have in this country is that we care not simply for the patients but for their families, carers and relatives. We look at the social, financial and spiritual issues—we look very holistically at the situation.

The Convener: I hope that we can get to that in this evidence session. We will deal separately with the limits of end-of-life care, because we know that that support is not available throughout Scotland. We know that the appropriate staffing levels are not always available in Scotland, and we know that caring levels are under strain and that people are sometimes supported in the community in a way that is not satisfactory.

Baroness Finlay: You have highlighted eloquently the problem of carer fatigue, which exists and is real, but there is early mortality among those who are bereaved rather than among the carers. It is important to remember that, because however somebody dies, the loneliness, loss and grief seem to impact on the immune system of the person who is left behind, and there are physiological reasons why they then become more prone to infection, diseases, illnesses, loss of concentration, accidents and so on. There is a significant rise in mortality among such people in the year after bereavement.

Picking up on your comments about palliative care provision, I note that in its independent review of palliative care services around the world *The Economist* rated the United Kingdom at the highest level. I agree that there are gaps, but I think that Scotland, like Wales, has much better provision across the whole country than England has. For a start, both Wales and Scotland have much less variability in the provision of services and outreach. Huge efforts have been made in education; indeed, people sitting round this table have for many years been trying to raise the level of education of healthcare professionals precisely to ensure that they are sensitive to patients' needs and that they look at, for example, early intervention and what else can be done.

However, one must remember that palliative care is not a universal panacea. The question is not whether it works; it is not like taking a dose of antibiotics for a urinary tract infection and, if those antibiotics do not work, we try different ones and redo the cultures. Palliative care requires a whole-person approach and, as the convener has rightly said, it covers not just the physical but the emotional, social and, indeed, spiritual domains. By "spiritual", I do not just mean religion; it goes wider than that and seeks to respond to people who are asking, "Why is this happening to me?" and the impact on the whole family.

That is the strength of palliative care, and that is why, particularly in palliative care circles, there is a very strong feeling that deliberately foreshortening a life flies in the face of all the acts that we undertake to try to improve quality of life on a day-to-day basis. Usually, when we find the thing that is really getting people down, we realise that it is not in the clinical domain but is what might be called the trivia of life. Those things can really undermine people and their sense of personhood and personal worth.

The Convener: The committee looks forward to hearing evidence on palliative and end-of-life care, given that, according to our papers, the last review in Scotland was carried out in 2008. We just do not know what is happening out there, and I think that others will testify to that.

Richard Meade: I want to make two comments. First, we know from studies that Marie Curie has funded in partnership with Edinburgh university and NHS Lothian that access to palliative care can be very variable. For those who have cancer, the figure can be as high as 75 per cent, while for those who have non-malignant diseases, the figure can be as low as 20 per cent or only one in five. Moreover, they are accessing that care only in the last couple of weeks or months of life, and many professionals, including people round this table, would argue that they should be accessing it much earlier than that.

Secondly, we also know that carers, particularly those who are caring for people at the end of life, can often be overwhelmed as the patient deteriorates. Because many patients are close family members, a lot of carers do not see themselves as such; instead, they see themselves as husbands, sons or daughters, and they do not identify themselves as carers. As a result, carers do not reach out for the support that might be available for them, and we need to look at some of the statutory responses to supporting carers and ensure that they get the support that they need to look after terminally ill loved ones.

In short, we must focus more on palliative care and make a higher priority of ensuring that people get it when they would benefit from it.

Mark Hazelwood: I want to say a couple of things about access to palliative care. It is easy for confusion to arise on the issue of specialist palliative care. I find it interesting that, at this round-table evidence session, there are mostly palliative care specialists. The fact is that most palliative care in the health and social care system is not provided by specialists. Across Scotland's acute hospitals, one in three beds is occupied by someone who is in their last year of life and they are usually in general wards, not in specialist palliative care beds. We need good care for people towards the end of their lives, and palliative care is a core function of our health and social care systems. Indeed, it is one of the main things that our hospitals do.

10:15

When we think about access to palliative care, we can think about whether somebody gets to see a specialist or perhaps goes to a hospice, but that is quite a small part of the picture. Whether somebody has access to palliative care will depend on things such as whether their GP has the skills, knowledge and confidence that might lead to the person being able to indicate their preferences for care in the eventuality that their condition deteriorates. Access to palliative care might come down to whether the person is admitted to one of the many hospital wards in Scotland where the team that is in charge of their care has the skills, knowledge, behaviours and attitudes to deliver good care towards the end of life or whether they are admitted to one of the other wards where those behaviours and skills and that knowledge are not yet in place. I wanted to paint that picture of the wider context. End-of-life care is a huge part of what the health and social care system does across all settings.

I think that Richard Simpson was starting to look for information about the extent to which people get access and the quality of care. From what I have said on access, you will have a sense that that is quite a difficult question to answer. As Ilora Finlay said, some things, such as the management of symptoms and pain, may be relatively easy to identify and quantify, but the extent to which somebody's psychological and spiritual needs are met is perhaps a bit more complicated. There is an urgent and important need for us to develop better systems to measure the experience of patients, their carers and families in Scotland, in terms of the care that they receive towards the ends of their lives.

Dr Carragher: I would like to build on those remarks and return to Dr Simpson's question on what could make the bill more fit for purpose.

I have significant concerns regarding young people. The general population and the parents of the children whom I am looking after—children aged 14 and 15 at Children's Hospice Association Scotland—do not necessarily understand that if a child reaches the age of 16 and has moderate to significant cognitive abilities, their parents would have to apply under the Adults with Incapacity (Scotland) Act 2000 to be able to make legal decisions on their behalf. I am not sure that the bill gives me any assurance that parents could not take that one stage further and decide that what was in their child's best interests was assisted suicide.

We know that support for looked-after and accommodated children usually lasts up to the age of 25. Would that allow local authorities to make such decisions? I do not think that anybody I know would want to do that, but I have a real concern that if the bill is passed it might allow a degree of decision making that arguably would not be in those children's best interests.

Dr Jeffrey: I return to Dr Simpson's questions about safeguards. I believe that safeguards in this area are totally illusory. We are kidding ourselves, because of the complexity of dealing and working with patients at this stage of life. We talk about patients feeling that they are a burden: that could be an early symptom of depression. We know—there is hard evidence to show—that we are not good at detecting depression in this particularly difficult group. Linda Ganzini has shown elegantly in her studies that depression in patients whom she had identified as having depression and who had assisted suicide was not picked up by their clinical carers. These are people with treatable depression.

If we cannot diagnose depression, all safeguards disappear; there is no safeguard there. We have missed the thing altogether and the patient will move forward, because people do not have the time, skills or ability to make psychiatric referrals to find out whether a patient has depression.

On psychiatric referrals, you will note that psychiatrists, in Oregon and here, are not keen to do the capacity work. They admit their limitations. I would like to get the message across from clinicians to you that this is a very difficult area that we struggle with, and it is not possible to have the black and white answers that are required for the law.

Rhoda Grant: We seem to be picking up the concerns of people who are looking at the bill and looking for assisted suicide, because they assume that they will have little control over their last weeks and months. There is the fear of pain and of not having the assistance that they require. The palliative care that is available is of good quality, but such care is not always available.

How do we empower people, equip them with a knowledge of what is available, and give them choices that will allow them to make decisions about themselves and to retain autonomy and control over their own lives? The lack of control over their pain, treatment and where they will be based can mean a lack of autonomy. If the only choice then is for the person to take their own life, that is surely not a choice at all. How do we ensure that people have the access that they need and the choices that we should make available to them?

Mark Hazelwood: There are many ways within existing legal frameworks in which people in Scotland can exercise choice and control and increase the chances of arriving at the sort of care at the end of life and at death that they might choose. I am thinking of advance directives and wider choices such as funeral planning, making a will and writing a power of attorney so that, if a person loses capacity, somebody whom they trust can take decisions for them.

It is interesting that the level of uptake of the vehicles that currently exist in Scotland is quite low. Therefore, we have a wider problem. There is a cultural reluctance to talk about end-of-life issues and, as a result, there are low levels of public knowledge and awareness. There are also quite often high levels of professional discomfort in initiating discussions in the area.

Leaving aside the issue that we are here to discuss, we have an issue that we need to tackle. We need to create a much more open dialogue about death, dying and bereavement. That has potential benefits for the 220,000 people who are bereaved and the 40,000 people who die each year in Scotland. End-of-life issues are much bigger than the particular, narrow issue that we are here to discuss.

Dr Hutchison: I want to draw together one or two threads. We are coming back to one of the things that the convener said he wanted to address—the accessibility and availability of palliative care more widely. We seem to be focusing on that at this point. Rhoda Grant asked how we can ensure that. I guess that that is in the hands of our politicians, but it is quite well articulated in the Scottish Government's "Living and Dying Well: A national action plan for palliative and end of life care in Scotland".

Bearing in mind what Professor Finlay said about our leading the world in the quality of palliative care, my contention is that rather than pursuing assisted suicide for the few, it would be far more productive if the Government did not focus our efforts, care and investment only on people who have cancer. Palliative care for people who have cancer is good, but there are big gaps in palliative care for people who have other chronic degenerative conditions, for example.

I would encourage one particular thing. The money that we have should be invested in community care—that is where there is a big gap—so that people are supported in their communities. We should increase the profile of palliative care issues, as Mark Hazelwood and Dr Jeffrey have said, and ensure that people have access to care and support in the community rather than in hospitals. I know that there are gaps there, but care and support should not necessarily just be in hospitals or hospices. We will get far more bang for our buck if we invest in the community rather than in buildings.

The Convener: I take Mark Hazelwood's comment that he cannot say that his organisation is generally opposed to the bill.

We are considering those who offer palliative care as an alternative to something that is considered unacceptable, which takes us to the question of the limits of palliative and end-of-life care, and access to that care. According to the submissions, there has been disappointing progress in achieving the actions associated with “Living and Dying Well”—progress has been slow. Fifty per cent of people still die in hospital and that has been the case for the past 10 years. There is unmet need for palliative and end-of-life care. Who gets it? Who does not? If you are putting it to us that the system that we have is much better than what is proposed in the bill, those are important issues. We must examine them, which is partly what we are doing this morning.

Dr Carragher: I concede that too many people die in hospital. According to figures from my organisation, a third of youngsters die at home, a third of youngsters die in hospital and a third die in a children’s hospice. There is progress, although I would like it to be quicker.

My first postgraduate training was as a general practitioner. I very much agree that primary care services are the ideal environment in which to provide good palliative care—not specialist palliative care, because not everybody needs such care.

Baroness Finlay: Dying is ubiquitous so it is important to think about the generalist being educated in core palliative care skills as well as having specialist services available. That is the availability that I was talking about. You have to start education in medical schools and expose every medical student to being with someone who is dying. That is not happening at the moment. You have to incorporate education and end-of-life care into all of your nursing curricula, which does not happen at the moment. You should also have seven-day services, because disease does not respect the clock or the calendar. People have crises out of hours and they have to be able to access care.

If as a jurisdiction, we seriously want to address the needs of patients who are facing end-of-life care, we must make seven-day services available so that, whenever a problem arises, patients can rapidly access support and they know who to go to. I agree that there has to be open discussion. Good palliative care is about empowering people to have choices—choices about the care that they receive, where they are looked after and who looks after them. We have to listen to what they need and help them to find a way through and to adapt to the ever-changing situation of their disease.

Speaking as a clinician, I would say that when patients have expressed a desire for death that has not been related to the quality of services available to them, that is a different construct internally. It is often because they have been unable to see a way past the fears that were so clearly laid out by Rhoda Grant. Fear of the future can be crippling and it is not until people experience what can be done and are confident in those around them that they will see a way through. I would not want the committee to believe that it is either/or. We look after patients who express a profound desire for death that evaporates when they get the care that enhances their dignity and their sense of personal worth.

The Convener: Could somebody say something about identifying people who may require palliative or end-of-life care? Before the access problem, there is the issue of identifying which people may benefit from such care.

Richard Meade wanted in.

10:30

Richard Meade: I want to return to the issue of Government policy and leadership in that area. Audit Scotland’s report on its palliative care review and the Government’s “Living and Dying Well” document were published in 2008, so both those documents are quite out of date now. As we know, health and social care has moved on significantly in both policy and organisation.

The Scottish Government’s current 2020 vision for healthcare—which is our guiding light for health and social care in Scotland—makes no reference whatever to death, dying, terminal illness or palliative care. That issue needs to be addressed.

The Scottish Government has committed to producing a new strategic framework for action on end-of life and palliative care, and we have been promised that it will be published in spring this year. We will need to scrutinise it carefully to ensure that it is fit for purpose and that it will help to support all the people throughout Scotland who might need palliative care, and we will need to ensure that they get that care regardless of their condition.

Dr Hutchison: I have one further comment. I think that all of us who practise palliative care—indeed, anyone at the table with any general practice experience—will acknowledge that we cannot fix everything. However, it is important that we do not get drawn into the frame of mind in which we feel that we should be able to sanitise the messy by ending people’s lives.

Palliative care is a very difficult specialty. We are dealing with people who are in a lot of distress, and we acknowledge that: we do not pretend that it can all be fixed. We take a holistic approach to tackling their distress, and we must be careful to ensure that we do not sanitise the situation and make everything fine just by ending some people’s lives or making that option available to them.

Rhoda Grant: That is interesting.

I want to talk about the availability of palliative care in the community. One big issue for people is pain control. How do you ensure that people in rural communities such as those that I represent can access pain control quickly in order to manage their own pain?

They must be able to do so quickly. If someone is in a lot of pain, they do not want to wait hours for an on-call person to arrive, especially as their case might fall in priority given that their life cannot be saved.

Baroness Finlay: We have a huge rural problem in central Wales, and we have put in place just-in-case boxes and anticipatory prescribing. Early on, when someone clearly has a disease that may be unstable, the family or whoever is there are taught what to do, and it is made clear to them what they should give somebody in the event of a crisis.

If the drugs are in the house, it is possible for someone to talk the process through over the phone if they know the patient, while somebody else is on their way to see the patient. I agree with Rhoda Grant that it is unacceptable for people to wait, and it is completely unacceptable if an area does not have seven-day services. I cannot stress that strongly enough. Why should somebody who is in pain on a Sunday have to wait because no one has thought ahead of time? We need to anticipate such situations and ensure that the drugs are in the house.

I am talking about medication that is given at a specific dose. However, the bill is concerned with a massive lethal quantity of drugs, which it seems might be left in the house for the person concerned. I am not sure how, under the bill, you would ensure that somebody was not, in extremis, or just because the family was fatigued at the weekend, coerced into taking their lethal drugs.

I am trying to return to the bill that is before us. It does not have a system in which the drugs are taken out at the time when someone determines that they want to end their life. That is another problem, and I do not see any safeguard in the bill or any way of detecting coercion.

I have been taken in by certain families, as other people will have been. I had one case in which the family kept on saying that this woman’s pain control was inadequate. Each time I went to her, she said that she was fine and comfortable. Her birthday came and they had a muted birthday celebration. You would not say, “Whoopee, it’s your last birthday, mum,” so we all understood why it was a quiet celebration, but after that, the family did not visit much. One night, when she could not sleep, the nurse gave her a hot chocolate and sat with her, saying that it was a pity that the family did not get in to visit so much. She said, “No, because my fixed-term life insurance policy expired on my birthday and they’ve lost out on £11,000.” We all believed that that was a loving, caring family, and we were all completely taken in. I have been completely taken in by other families because I believed that they were loving and caring.

We have already heard about elder abuse. The issue of coercion is real and I see it as a danger with the bill.

Dr Carragher: I concur with Baroness Finlay. We are working with young people across Scotland and doing increasingly good anticipatory care. We are putting in just-in-case boxes of medicine. In my experience, areas in rural and remote Scotland often have quicker response times than inner city areas because people are prepared to cross boundaries to do their jobs. I see that nearly every day.

To build on what Ilora has said, as a practitioner who works with young people in palliative medicine, I sometimes have to use really high doses of medicine—sometimes higher than adult doses—to control or manage symptoms. If the bill is passed, what sort of doses will be required to achieve suicide? If suicide is not achieved, where will the person be if the available dose does not actually do the job that it was—I am not sure that this is the right word—prescribed for? I have real concerns on that front and we do not seem to have any evidence base about the doses of medicine that will need to be used for anybody, but particularly for young people.

Bob Doris: I want to turn to the situation in which someone, for whatever reason, feels that they cannot go on living with a chronic or life-limiting condition because they feel that their quality of life is beyond the pale. I was struck by Baroness Finlay’s comments about being a GP in Maryhill. I stay in Maryhill and I want to check the suicide rate figures for that part of north Glasgow because they are significantly higher than the Scottish average. The prescribing rates for treatment of anxiety and depression in Maryhill are 44 per cent above the Scottish average. In Springburn, the rate is 44 per cent above the Scottish average and it is 58 per cent in Possilpark, for example.

I give those figures because I feel that those who are most likely to seek assisted suicide might be led towards it because of other factors or poor outcomes in their lives that are separate from their physical health or the condition that they have. Those factors might impact differently socially across the country. I would appreciate hearing some comments on that.

To follow a line of questioning from last week's committee meeting, I wonder whether medicalisation of the assisted suicide process is unavoidable. Let us take the example of someone who goes to their GP in Maryhill, Possilpark or Springburn with heart disease or diabetes or whatever, with a considerably poorer quality of life and a life-limiting and progressive condition. Many people are in that situation. If the bill is passed, should the GP have the responsibility of telling the patient that they have a variety of options? Richard Meade spoke about statutory obligations. The bill does not say that at all, but then it is slimline and does not have much additional guidance. Should it be those working in palliative care, or GPs or those who provide the care who are responsible on a statutory basis?

If the bill is passed into law, would the natural progression of its provisions mean that there should or could be an obligation on statutory partners, including the medical profession, to say to individuals that they have another option available, which is assisted suicide? I am thinking back to the figures I gave earlier. In other words, who would be left to suggest to someone, "You have an option, and that option is assisted suicide"? Should anyone ever be allowed to do so? If so, what safeguards will we need? If not, how will an individual get the knowledge and information to empower them to make the decision to end their own life?

Baroness Finlay: I hesitate to come back in, but I am just brimming over.

My practice covered Possilpark, and I know it well. You are absolutely right: the interface with mental health services is really important and must be addressed. That is why I said right at the beginning that this issue needs to be taken out of medicine.

It is really hard to look after the population there; they have multiple co-morbidities and might see very little future ahead of them. I would be very worried about a doctor ever suggesting to a patient that they think about ending their life. That would give people the message, "I believe that you would be better off dead," and it would reinforce their sense of hopelessness and despair. As the Royal College of Physicians said very eloquently—and I am paraphrasing this, because I cannot remember it verbatim—the doctor's duty of care does not include being in any way part of a patient's suicide.

The Convener: I wonder whether I can press that point a little bit. On the difficulties that you have referred to and which are highlighted in the evidence, what about those sometimes necessary decisions about the end of a person's life that GPs and medical professionals have to discuss? We know that it is a difficult process, but could not the same principle be applied so that a doctor might say, "Well, we can't really talk about your terminal illness, because that would be me giving up on you"?

Baroness Finlay: That is not the case at all—

The Convener: Well, what is the difference? Please help me.

Bob Doris: Before you answer that question, I should point out that although the line that I have taken in my questioning illustrates my concerns, I, like Dr Simpson in his initial question, asked at the tail-end of my own question about what safeguards might be built in. The job of this committee is not just to have our individual views on the bill but to seek to improve it and to make it more robust as it goes through the parliamentary process. I have significant concerns about the bill, but my question is about how we build in safeguards.

Baroness Finlay: Perhaps I can try to answer the question.

Nowadays, when you have a patient in front of you whom you believe has a terminal illness, you have a duty to be completely open with them. Instead of the old collusion-type medicine that was around when I qualified, you talk openly with patients and listen to their concerns. Part of our job, day in, day out, is to listen to people's views and fears about death and what they feel they want. If you want to improve the bill, I think that you should not make the doctor the person who sits in judgment over whether they are suffering enough to be eligible for assisted suicide. Instead, you should maintain the doctor's duty of care to do everything they can to improve the person's quality of life and to carry on providing care.

If you have a system that sits within a legal framework, a person intent on having an assisted suicide can apply to a court, which can take evidence on the person's medical condition and its predicted pathway. A prognosis is impossible to predict—and, as we know, it will be fraught with inaccuracies—but you can say what you think is likely to happen to someone. As with any court case, evidence can be gathered. In the England and Wales system, the family division of the High Court already takes decisions on, for example, treatment cessation; the management of the Siamese twins situation, where one was going to be sacrificed; and difficult Jehovah's Witness blood transfusion decisions. While the evidence comes in, the doctor is left to carry on providing the care. So, the concept of the licensed facilitator is already there, and letting that function sit with the courts would be safer than letting it sit with the campaign groups, which is where it could sit under the bill as currently written.

The campaigners in Oregon describe themselves as guardians of the law. I find it very worrying that a campaign group could see itself as a guardian of the law, because that should be the responsibility of the legal jurisdiction.

10:45

Licensed facilitators could be contained and monitored. A monitoring commission could be established that would examine the processes and collect data about what happened when somebody died. Such data is picked up in the existing systems but it is not done adequately. The Dutch system attempts to do it, but the Oregon system does not have a monitoring commission and just collects data. However, even from that, we know that some patients have woken up after they have had their lethal drugs and have not gone on to commit suicide later on, which raises interesting questions. We also know that the time from taking the lethal dose to death is on average 26 minutes, but it can be up to 102 hours, which is a very long time.

So, we should take the whole thing out of the area of medicine. I remember well from my own experience that very vulnerable population; they live with all kinds of co-morbidities and social problems and have poverty ingrained in how they live. We should not allow doctors to suggest to them that things look so bad; we should ensure that mental health services and others support such patients. However, if they are determined to end their lives, they should be able to apply to a court for that.

Dr Jeffrey: I want to return to Bob Doris's very pertinent question about the social issues. At present, the law that bans doctors from being involved in any way in hastening a patient's death protects us as clinicians, because we have a duty with patients who we suspect might be suicidal or depressed to explore actively whether they have had suicidal thoughts. We might ask whether things have got so bad that they think that life is not worth living. Today, that is a very safe question for me to ask, because the patient in front of me knows that I am asking it because I am concerned to see how depressed they are and not because I want to know whether they want to have their life ended.

Once in law ending one's life is one of patients' choices, we cannot really have the conversation about whether they have had suicidal thoughts, because the patient is going to think immediately that the doctor does not think that they are worth bothering about. We also need to be aware of Chochinov's work on dignity—the committee might have heard of it—which shows that people sometimes say "I can't go on any longer. Will you help me to die?" as a test question for the doctor; they are asking whether the doctor thinks that they still matter and they are looking at the doctor as a mirror to see reflected that they are still of value and worth.

Currently, we can explore difficult issues with a patient because we are protected by the law. If we bring in a law on assisted dying, such conversations will not be possible.

Dr Carragher: I hear what Bob Doris is saying. I, too, live in Maryhill and popping into the supermarket there lets me see people who are in all sorts of situations. It is very difficult to raise the profile of medicine and palliative care, but I suppose I have two points on that front. One is that, as I understand it, the bill states that a person should have a terminal prognosis. I know from my own field of medicine that that is very difficult to do for younger people and with palliative care. As the baroness stated a few minutes ago, and as I think the convener tried to point out a little earlier, the question is how we decide whether somebody has a terminal condition and how far down that disease trajectory they should be before they are considered as coming under the provisions that the bill proposes.

If the provisions applied to people with terminal prognoses of one to two years, although that would probably place them outside the bill's provisions, that would reduce further longevity in communities in Scotland that, as Bob Doris said, already have the lowest longevities. There is a huge disparity in longevity between the populations in different communities.

Dr Hutchison: To emphasise one of Dr Jeffrey's points, we have been able to enjoy a safe and supportive environment in which to raise issues with patients or respond to issues that they raise with us—that has happened countless times throughout my career.

Do I understand all the legal and technical nuances of the bill? No, I certainly do not. Do I have a full grasp of all the moral and ethical issues involved? No, I do not. I have some appreciation of all those issues, but certainly not a full grasp. However, please hear this: if you ask me whether I am absolutely 100 per cent cast-iron sure that assisted suicide, if it had been available, would have compromised the care of the patients whom I have been looking after over the past 20 or 30 years, my answer is yes.

Dennis Robertson: Dr Hutchison used the term "burden", and mentioned issues to do with autonomy and definition. I am not quite sure what the definition of "burden" is at present, but the term is very emotive. I wonder whether, as a society, we actually adjust to situations in which the provision of care impacts on how we live our lives. Sometimes when we are doing so—as parents or family members, for example—we look to the wider community to assist us in that.

Baroness Finlay spoke about coercion and fear, which brings me back to the submission that referred to the twins in Belgium who were deaf and faced the prospect of going blind. I suspect that they may have had Usher syndrome—the submission does not say—but they opted for euthanasia.

My concern, to return to the point about burden and fear, is that we do not want to convey the message that people with recognised complex needs, especially those that are associated with disability, are a burden. We do not want to convey fear with regard to them living their lives. How do we get over that?

Dr Hutchison: I hope that what I said about being a burden was not taken as an isolated and rather dismissive phrase. I was speaking in the context of the deep and meaningful discussions that we have in palliative care about the need to recognise the issue of being a burden. Our work is aimed at helping patients to see that the carer also needs support, and that it is perfectly legitimate for that care to continue at home or wherever.

Dennis Robertson: My point is that there are a lot of people in society at present who could, if the bill is passed, fall into the category of being burdensome. They are not really, of course: they are living their lives and they require additional support to do so. That is why I introduced the point about people with disabilities who may have complex needs. I am trying to ensure that we do not affix a term to a group of people who may be very positive about their outcomes and about living with their conditions.

Dr Hutchison: It is the people who do not feel very positive who often raise the question about being a burden.

Dennis Robertson: Absolutely. One example from the submissions was the young girl with anorexia. People with anorexia often ask to die; it is quite normal—if we want to use that term—for people with such conditions to say, “I really want to die.” They do not really want to, but the condition itself is so prominent that that is how they feel at the time.

I am trying to explore the issue of how we provide safeguards. I am not sure that we have safeguards in the bill to help us to move away from the danger of coercion and to protect people with long-term conditions. I am trying to explore the fear aspect.

The Convener: Let us see whether we can get a response on that. A couple of other people have questions.

Mark Hazelwood: One of the major points that we make in our submission with regard to the groups that Dennis Robertson mentioned is that the eligibility criteria that the bill sets out for assisted suicide should be very clear, so that it is possible to see who would be eligible and who would not.

We make the point in our submission that the terms that are used in the bill—a “terminal or life-shortening” illness and a “progressive” condition—are not really precise enough to form part of clear eligibility criteria. The bill does not define either “terminal” or “life-shortening”, and it is also not clear what the intended difference between those two terms is. If the terms are not clear, the Scottish public and health professionals will be left not knowing who is eligible and who is not eligible, and then there is the potential for inconsistent application of different people’s conceptions of what those terms might mean. I do not think that it matters whether one is for the change in the law or against it; everyone needs to be clear about what the eligibility criteria are and what the scope of the legislation is.

Baroness Finlay: I thank Dennis Robertson for raising that question, because there is a real danger in taking a utilitarian approach and believing that a so-called able-bodied person is somehow better than someone who has a disability.

It may help the committee if I pull out the speeches by Baroness Campbell and Baroness Grey-Thompson on the bill that is before the House of Lords. For most of her life, Baroness Campbell has fitted the definition of being terminally ill within the ambit of either Lord Falconer’s bill or the Scottish bill. She is now on a ventilator and has her ventilator with her when she is in the chamber; she can speak while she is on her ventilator. Those people with severe disability are frightened of any legislation along these lines, because they already find that it is difficult to be viewed as being of equal worth in our healthcare system. Baroness Campbell has had it suggested to her many times that she should give up, particularly a few years ago when she was already in the Lords but people thought that she was at the end of her life. She contributes greatly.

There is, sadly, a prejudice in our society against particularly severe disability. I have heard people say—Tanni Grey-Thompson has spoken openly about how people say to her—such things as, “It must be awful to be incontinent.” Actually, she has less sensation from the waist down and would be classified as such, but lots of able-bodied people have a bit of incontinence and it does not make them of any less worth. However, if people behave badly towards somebody and make them feel that they are of less worth, as

Harvey Chochinov's research has shown, that undermines their sense of personal worth and can make them feel that the only option is that they should be dead and that somehow they have a duty to be dead.

That is behind some of the powerful messages that have come from those with severe disability. If it would be helpful to the committee, I will extract those speeches and send you a copy, because I think that my colleagues put it far better than I can.

The Convener: Thank you for that offer.

Colin Keir: Nobody said that this session would not be interesting. I was particularly taken by some of what Baroness Finlay has said. The key word is "some". Some people may feel whatever it is that they feel; it is not exact. The example that was given—was it of Baroness Campbell?

Baroness Finlay: Yes, Jane Campbell.

Colin Keir: She obviously made a conscious decision to fight and to live her life as she wished to. That would not bring her within the Assisted Suicide (Scotland) Bill, simply because of the fact that suicide is what it is. It is not euthanasia. We are not asking for someone else's input. That is my take on that.

11:00

Baroness Finlay: Can I say something on a matter of fact?

The Convener: I will bring you back in.

Colin Keir: I will continue if I may. I am partially deaf, so I may not have cottoned on correctly, but at one point in the discussion we seemed to be looking at an either/or situation—I think that somebody else mentioned that—in terms of palliative care and assisted suicide. I believe that if the bill was enacted it would not be a case of either/or. Surely palliative care is what it is. I would not expect anyone who worked in the palliative care sector to suggest suicide to anyone. I say that from my experience as a carer of someone with a relatively long-term degenerative illness.

I hear reasons why we cannot do this, but I find the way in which the generalisation has been put across quite off-putting. The person who I dealt with, who had received care for an extremely long time, went into palliative care and even at that point contemplated suicide towards the end. It is not the same for everybody; some people who have the same care that my relative had would not contemplate suicide.

Perhaps I need to think about this more before we take the bill wherever it happens to go, but I find it rather worrying that we have very general considerations. Maybe we have to have those considerations because of the type of debate that we are having, but the individual is the one who might decide, during their period of palliative care, "I am sorry—I've just had enough of this." At what point do we help someone to go forward? I would expect palliative carers to do everything that they could, but at some point, somewhere, a patient will say, "No, I really have had enough." I would like to see some consideration of how that would be dealt with.

The Convener: Baroness Finlay, you wanted to clarify a point.

Baroness Finlay: I wanted to make a point of fact. I am sorry; I should have explained this. At times in her life, Baroness Campbell has spoken openly about feeling suicidal, giving up and believing that she had no purpose in life. That was some years ago. She would have fitted the definition in the bill.

While I have your ear, convener, I will tell you that my mother was in a situation similar to the one that Colin Keir described. She was in a hospice bed when I was opposing Lord Joffe's bill and she was extremely angry with me for doing that, because she was desperate to have assisted suicide. That went on for weeks. It had nothing to do with the quality of her care, which was excellent; she just did not want to carry on. She had been fiercely independent all her life and she did not want to be a burden.

An argument that my mother had with the chaplain made her suddenly realise that her brain worked. He had the sense to say, "You're a very interesting lady. Can I come back and talk to you tomorrow?" They argued about philosophy that she had been interested in and she began to think that perhaps she still had something to offer, thanks to his intervention. It was nothing to do with faith, because that did not come on to her radar. She then came home, against all odds.

Four years later, having been at home and lived independently, my mother wrote about her experience and was very clear that she was glad that she had had those four unexpected years, which in some ways had been the richest years of her life. However, when she was in that hospice, she definitely would have gone for what is proposed in the bill, irrespective of what I felt. Later on, she was glad that she had not been able to do that—she also made a radio programme about it.

Dr Hutchison: I thank Colin Keir for his comments, but I would go further than him. It is not just that people on occasions reach a position where they contemplate the end of their life, wish that it would come sooner or say that they have had enough; in fact, that happens with a huge number of the people whom I look after. They are the people whom I am concerned about and who might come under pressure and influence if the bill were to become law.

As I engage my patients in supportive conversations in the course of their care, many of them say that they have had enough. However, in 25 years or thereabouts of working in palliative care, how many people can I count who have had a determined and fixed wish that somebody would end their life? I can think of one when I worked in Edinburgh, but I am hard pushed to think of any others since then.

To remind the committee of what I said earlier, we cannot make everything nice and rosy and pink in palliative care. It is messy, horrible and distressing. However, the vast and overwhelming majority of the people whom I have looked after, even those who have expressed that they have had enough, will testify at the end—their families will confirm this—that good palliative care, individual involvement, listening, attention to detail and hard work made the difference to them. That is what they appreciated and that is what they thank us for. That could be repeated endlessly by those in this room. We all receive testimonials from our patients and their families.

Dr Carragher: I echo Stephen Hutchison's point. I have worked in children and young people's palliative medicine for 18 years and exclusively for the last eight years, as a full-time job. I ask lots of open questions to try to find out where people are and, in those 18 years—this is almost a surprise to me—no young person has said that they want me to help them to end their life and no parent has said that they want me to help their child to end their life. It is worth putting that anecdotal evidence on the record. Nobody has approached me in that way.

The Convener: Mark Hazelwood and Richard Meade, are there any nuances in your positions? Mark, you gave a caveat that you are not necessarily opposed to the bill, or that it should not be presumed that you are. Will you explain that?

Mark Hazelwood: I have set out why we have that position. It is to do with the fact that we are a membership organisation and many of our members, particularly the national health service boards, are institutionally unable to adopt a position on the bill because it covers moral, ethical and personal dimensions.

The Convener: What is Marie Curie Cancer Care's position?

Richard Meade: We do not seek a change in the law at present. We would like the focus to be on ensuring that the kind of palliative care that Dr Hutchison just described is available to everybody who might benefit from it. At present in Scotland, it certainly is not available to everybody and, when people get it, it often comes much too close to the end, when they could have benefited from it for far longer.

Dr Jeffrey: I have a brief comment on what has been said about dealing with intractable or unrelieved suffering, which is of course very difficult. One privilege of being a palliative care physician is that very difficult cases are referred to us by our colleagues.

Another dynamic that I want the committee to be aware of is that it is not just carers who feel affected by the situation. Through mechanisms of transference and counter-transference, doctors themselves can perceive the situation to be hopeless and can feel helpless. The patient's feeling of helplessness can be transferred to the doctor, who begins to feel helpless. When a patient feels that the situation is hopeless and that it is not worth going on, the treating team, particularly if they are not experienced in such work, can begin to feel that the person is right and the situation is hopeless. Someone from outside might come in and have another look at the situation and say, "Maybe there's a different way of doing this—maybe we can't make everything right, but let us look at some of the things we can do." The promise that palliative care provides—of "I will not abandon you; I will be with you"—is perhaps also undermined. That might sound rather feeble in the context of high-tech medicine, but to have someone alongside when one is suffering is a huge boost, and it makes an enormous difference in this type of work.

Colin Keir commented that he was disappointed about the generalities. All palliative care physicians and health workers round the table could give you lurid individual cases, but we are bound by confidentiality even after death, and I cannot tell you about the people who changed their minds. I cannot make such cases identifiable, but just trust us: it happens day in, day out in our practice.

Richard Lyle: I could not agree more with Dr David Jeffrey, but I also have to agree with Colin Keir. I have listened intently to the comments that have been made—I respect every one of you, the way in which you have handled your evidence, and what you do in your respective fields.

Let me turn to a point that Mark Hazelwood made earlier. None of us wants to talk about death. When my mother-in-law and father-in-law were nearing the end of their lives, they did not want to talk about how I would see to their burials, make arrangements and so on. When my mother-in-law died, we put my father-in-law into an excellent home. We wanted him to go on but, unfortunately, three months later he did not. As he was being taken to the hospital one night with a heart attack, in his 90s, he said to the nurse, "Don't resuscitate me." He was ready to die, although we did not know that at the time. If we had known that, we would have said to the nurse, “No, we want to keep him,” but he did not want to go that way.

A lot of people do not want to make a will. I made a will about 20 years ago—I have not changed it recently—but basically people do not want to make a will. Nobody thinks about power of attorney. I have a friend whose mother is currently receiving palliative care in a home, and they are trying to get power of attorney. That is very hard—the person needs to confirm that they want their relatives to do that but, sadly, their mind is not there now.

Referring to the point that Colin Keir was making earlier, I agree with your point, Baroness Finlay, about people who can and want to change their mind. However, there are people who do want to die.

I was not at the committee last week; I was attending a funeral of a family friend. Prior to Christmas, when she was in hospital, she told me that she wanted to go home. Medically, she could not go home, even though there were people there to look after her. She said to me, “I just want to go.” Sadly, she did go, and I attended her funeral last Tuesday morning.

There are people who want to go, so why should we not let them go?

Dr Hutchison: Because we live in a society where we relate to each other. Can we legislate safely to allow the people you have described to have a legal right? My view is that we cannot and that it has not been legislated for safely anywhere else in the world so far. We have to ask what the availability of that right for the group of people you are talking about does for the vast majority of other people in society.

There are numerous things on which we could say that individuals wish to be able to do certain things. For instance, I might wish not to pay the level of tax that I do pay. I would like, on occasions, to be able to drive down the middle of the road, not on the left—and maybe I could stipulate which road and which time so that you could police that. However, you would say, “You’re crazy—of course you can’t do that.” What I think are my rights and the availability of such things to me must be constrained by the effect on wider society.

11:15

Baroness Finlay: To Richard Lyle, who asked why we should not just let people go, I would say that we do let them go. We do not impose futile treatments on people. I have had people for whom it was not medically appropriate to go home, but that was what they wanted. It was their home; however messy it was, however sticky the carpets were, that was where they wanted to be, and they went home. I facilitated a patient’s flight back to Africa, because he wanted to die on African soil; he died shortly afterwards.

That is what we do: our job is to support people in what they feel or want—and when they want to let go, we support them in letting go. However, that is quite different to changing the law and allowing people to access, through medical care, lethal drugs with which they can foreshorten their lives by months or even years. Your background paper makes it very clear that some people will foreshorten their lives by years, and you will have no idea what they would have done in that time.

I have permission from a patient to tell you a story. When he was referred to me in 1991, the GP said, “The only reason I’m referring him is because I cannot give him a lethal overdose.” I—and, indeed, the oncologist, the surgeon and his GP—thought that his prognosis was three months. I looked after him, but it was not easy; he was very difficult. The first night, I was at his house until 11 pm. Eleven years later, he phoned me. His wife had been diagnosed with cancer and was dying. She died, and he was left to bring up the children on his own. Against all odds, he is still alive, and when we discussed this issue he said, “Ilora, don’t go there. What would have happened to my kids? They would’ve gone into care.”

You have to remember that we cannot have everything that we want in society. We have a duty to provide care and accept death—after all, death is an inevitability for everyone—but we do not legislate to allow doctors to bring forward in time as part of so-called clinical treatment the ending of someone’s life. Deliberately ending life is not treatment.

I have already said that I am really worried about the interface between mental health legislation and all the other bits, but just on the grounds of public safety I do not think that this bill is fit for purpose. It is dangerous and leaves things wide open. It will lead to confusion; it will lead to people, not through malintent but through their not really understanding the issues in depth, deliberately being part of a person’s suicide; and it will lead to people feeling that at that time in their lives their only option is assisted suicide. In our interrelated society, that is a step too far. It is just too dangerous.

Dr Carragher: I concur with Baroness Finlay. I wish that I could give the committee a few specific situations, but confidentiality will not let me do so.

What I can say is that the Royal College of Paediatrics and Child Health, for example, very clearly states when I do not need to continue treatment and when I can withdraw treatment. I am involved in those decisions with young people, and we allow them to go. From my point of view, that situation is totally different from giving them some form of prescribed medication that finishes their lives. Although the bill has some strengths, there are areas, certainly with regard to young people, about which I have significant doubts.

Nanette Milne: I have found the whole discussion extremely interesting. What about people such as those in the terminal stages of motor neurone disease or multiple sclerosis who are totally and utterly incapacitated and who can do absolutely nothing for themselves? Let us suppose that this bill becomes the law of the land. I would be interested in people's comment on the role of facilitators, the very fine line between assisted suicide and euthanasia, and the impact that there could be on facilitators in particular but other people as well.

Dr Hutchison: I am very concerned that there is the latitude in the bill, and in the whole ethos of assisted dying, for a society that permits assisted suicide to move on to euthanasia. The original sponsor of the bill made it clear that she saw the two as being the same thing, and the policy memorandum makes it clear that she expected that things would progress so that other groups of patients would be included.

You cite somebody with motor neurone disease who, at the end, can do absolutely nothing for themselves. They can certainly be very frail, but it would be unusual for them to be so completely incapacitated that they could not do anything for themselves. I think that you mention that group of people because they would need more assistance than they expected to commit suicide, but where is the line between that and ending a person's life?

What would you do? The policy memorandum talks about lifting the cup to the patient's lips. Could you be sure, when that was happening, that the patient had not suddenly had a change of mind? No, you could not—such things are unknowable. It is areas like that which make a law to enable the deliberate ending of human life dangerous.

Baroness Finlay: I want to pick up on the wording of the bill. In section 19(b), the wording is

"to provide the person with comfort and reassurance".

Reassurance of what? Reassurance that they are doing the right thing? I am not sure what that reassurance is meant to be.

The bill also does not define exactly where the limits of assistance should be. What about the person who is on percutaneous endoscopic gastronomy feeding or on intravenous feeding, who cannot put the drugs into the bag themselves or who does not have the strength to pour the drugs down their own PEG tube? There is no clear definition of what is and is not assistance.

When I visited Oregon and we took evidence, the view was that, if someone could not take the drug themselves, it was too bad—they were no longer eligible. However, I have a sneaking suspicion, from conversations that I had outside the committee, that the line is blurry: it is difficult to draw and it is not policed. There is no provision in the bill for a monitoring commission to examine, after the event, exactly what happened, and I would be very worried about that.

Dr Jeffrey: I am concerned that the facilitators would be people who are pro assisted suicide. In fact, the whole system would be administered by people who are pro, so who would perform the check and say, "Hang on—I think you're worth while. Do you think that there might be another way of dealing with this?" I have great concerns about the role of the facilitator.

I would also have great sympathy for the people who would suffer the stresses of that job. If that was their work, it would be an extremely stressful job. Palliative care has built into our job support the availability of people we can relate to and talk to. We have to have that supervision in our work and I hope that, if the bill is passed, such provision will be made for the facilitators as well, because it will be very stressful work.

Mike MacKenzie: I have read a number of accounts of palliative care in which the whole thing is described as being of such high quality and such a rewarding experience that I can hardly wait to have the experience myself. However, most of us have had experiences that suggest that that is not strictly true for everyone.

I want to understand the status quo of palliative care. We have heard that 40,000 or so people die in Scotland every year. What proportion of those people might enjoy the kind of experience that we hear of in the best-case scenario, in which things are as good as they might be? At the other end of the spectrum, what proportion of those people experience the end of life as suffering, both physical and psychological, that we would all agree to be unacceptable? In terms of those 40,000 people per annum, can you give us a feeling for where we are on palliative care and its effectiveness?

Mark Hazelwood: I think that I said earlier that there is a really urgent need for better data about palliative care in all sorts of domains. Richard Simpson made the point that it is now more than six years since the Audit Scotland review of palliative care services in Scotland was published, and some of the data that it was based on came from 2006. There is a need for data that characterises the sector.

I was going to come into the discussion earlier and talk about anticipatory prescribing and the roll-out of just-in-case boxes in Scotland, and I was thinking about where I would go to give you current data on how far that has progressed. It has progressed a long way and it is a success story, but if somebody had come back and asked me to give the percentage of access for the Scottish population, I would not have been able to do that. There is a real need to develop data.

We have heard about the complexity of palliative care. There is pain control, and we have heard powerful stories about the importance of human relations and spiritual care, but how would we know whether people have accessed that? It is a difficult question to answer, but I will have a go. It is interesting to look south of the border, where there is a systematic survey with large samples. Bereaved relatives are asked in the period following their loved one's death about their reflections on the care and support that their loved one received. That is not a perfect system, but I think that the bereaved relative provides a unique locus of information about the experience.

People who are nearing the end of life will typically move across different settings. Surveys can be run in general practice or in hospital wards, but we will get only part of the picture from that. In Scotland, we have an opportunity to start to ask people systematically and on a national basis what the care that their loved one received towards the end of life was like for their loved one and also for them. If we had that data, we would be in a much better position to be able to answer your question.

Others might have other ways of trying to answer the question. We heard about people having a preference to die at home, and we heard that the latest data shows that 53 per cent of people in Scotland will die in hospital. Hospital is an appropriate place for some people to be cared for and to die at the end of their life. Although, in general, people say that they wish to die at home, if we unpack the data, the answers tend to be different for different people. For example, some of the older population and, interestingly, people who have had experience of caring for a loved one at home have less strong preferences to die at home.

We can look at the data that tells us the percentage of time that people spent at home or in a community setting during the last six months of their life, which gives us an idea of where care is taking place, and we can look at the data on where people die. I note that 53 per cent of people die in hospital, 25 per cent at home or in a non-institutional setting, and 22 per cent in a care home. Relatively small percentages die in Scotland's hospices, but hospices are not primarily places that people go to die. Most of the work that hospices do is about enhancing quality of life and is delivered out in the community.

I have not given you a definitive answer, but I have given you some suggestions about how we might start to answer the question in Scotland.

Richard Meade: I reiterate Mark Hazelwood's point about the need for data. NHS Quality Improvement Scotland has produced palliative care indicators, but to the best of our knowledge there has been no published assessment against them. England has a national survey of bereaved people, which is called views of informal carers—evaluation of services, or VOICES, but we have no such survey here in Scotland. That survey asks bereaved relatives about the care that their loved ones received at end of life. Something similar in Scotland would certainly help.

Mike MacKenzie: Can I intervene to seek some more honest answers to the question? A friend recently held a party very close to the end of her life, and it might be described as a very good death. I can easily think of nine other people who had deaths that I would not describe in any way as good deaths. Is that proportion—nine to one—about correct, or am I completely wrong?

11:30

Dr Hutchison: We do not know.

Baroness Finlay: It depends what they died of, how old they were and what happened. You have to remember that people die in road accidents, of complications from illness and of infections. Whether or not you are talking about people who have come to terms with everything that is going on and with their own dying, it is spurious to try to pluck a figure out the air.

I return to the statement that Mark Hazelwood made earlier: palliative care is provided by specialist palliative carers who are specially trained and are there to support generalist services. To even begin to answer the question of how many people access palliative care, you would have to look at whether each GP is practising with a good palliative care approach or whether that GP lacks knowledge.

We have outlined the pressure that you need to address—regarding the availability everywhere of healthcare professionals who have good core education—if you want to improve the standard of care for people who are dying. That means having in A and E people who are well educated in how to manage dying, because a lot of people die in A and E. You also need them in many other parts of the system, such as nursing homes and so on.

Dr Hutchison: I am proud of healthcare in Scotland. It is not perfect, but I am proud of the quality of care that I have seen that we have been able to provide and the testimonials that I have heard from patients who have come from elsewhere and commended what we have here. We should be looking at a far more wholesome way to deal with issues rather than proposing assisted suicide. We have the opportunity to affirm our lead and make sure that the level of care that we provide for people with a range of conditions is brought up to the standard that is available for people who suffer from malignancy.

Mike MacKenzie: Thank you very much. You have made that abundantly clear, but I would have preferred it if you had answered the question.

I will move on to another area. We heard from Baroness Finlay about a young man suffering from cancer, who subsequently recovered. At one stage, he refused treatment. We generally accept that patients have a right to refuse treatment, even if that is tantamount to suicide. We accept that right. I am struggling to see the difference between somebody refusing treatment, which is a right that we as a society condone—in fact, it is sacrosanct—even when it is tantamount to suicide, and our allowing somebody to assist proactively in a suicide. I am not quite sure of the distinction. Given that we accept—indeed, condone—one and not the other, I ask the question in medical terms, in clinical terms or even in terms of public good or individual good: is refusal of treatment better in some way than some kind of active suicide process?

Baroness Finlay: I would not put a value judgment on one or the other. You have to remember that death will happen to everybody. When someone refuses treatment for whatever reason, their view is that the risks to and burdens on them of their treatment outweigh the potential benefit, as they see it, as they are dying of their disease. Their disease process carries on.

The bill talks about deliberately foreshortening life before the disease process progresses. We are saying that the doctor's duty of care continues right on through while somebody is dying, whether or not they have had a treatment. Do not forget that some treatments do not work: people can go for treatment that turns out to be futile.

A very good study from the United States by Temel and colleagues showed that people who had early palliative care intervention had a higher quality of life and lower depression scores, and, interestingly, lived longer than patients with lung cancer who were going through the treatment pathway but did not have the palliative care intervention. However, the bill is not about accepting death, accepting the course of treatment or refusing treatment; it is about somebody deliberately foreshortening life by giving a person lethal drugs to assist their suicide, irrespective of how long their life would have gone on for.

The Convener: Can we get some other responses to that? We have had some discussion about the idea that doctors would be shortening people's lives—that is not necessarily part of the bill, although it is a principle against it—but the point is being made that, if we agree to withhold medicine, the outcome will be that the person's life will be shortened.

Dr Jeffrey: I reiterate what Professor Finlay says. If I was on a ventilator and the ventilator was switched off, I could start breathing. However, if I had advanced cancer, my chest was filled with fluid and I could no longer breathe, and the intensive care specialist realised that continued ventilation was futile and stopped the ventilator, the underlying disease would shorten my life and I would die.

There is a huge moral and clinical difference here. We can be reasonable and say that certain treatments are no longer beneficial to a person, that they are, therefore, futile and that we will withdraw them, provided that the patient has agreed and chooses not to have treatment. However, it completely alters the situation once other individuals are brought in. Once somebody has asked for assisted suicide, they are involving the autonomy of doctors, nurses and pharmacists.

One of the points that we have not dealt with in the discussion is the fact that this is not just a doctory thing because, in palliative care, we work as a team. Most palliative care is done by nurses. How would they feel about assisted suicide? All members of the committee have a clear idea of the sort of pressure that hospitals in Scotland and the UK in general are under. Imagine the pressures of working in a team in which one person agrees with assisted suicide but the pharmacist does not want to dispense the drugs and the nurse does not agree with it. Imagine the disruption that that would cause the team. It is a huge problem. It might prove very difficult to get moral consensus in such a team in some cases.

I reiterate that there are clear differences with the situation that Mike MacKenzie came across. He also said that we were not being honest in our responses because we were trying to pretend that all suffering could be relieved. One message that we have all tried to get across is that we have the humility to accept that we cannot relieve all suffering. We realise that. Dr Hutchison has reiterated that several times. There are all sorts of areas in medicine in which we do not relieve suffering. We do not terminate mothers' lives when they scream to have things ended in the middle of childbirth because their pain is intolerable. We do not do that at that end of life. We stay with people and do our best to relieve the pain.

It is spurious to suggest that, because we cannot relieve all suffering, it is not important to do our very best to do as much as we can. We are sitting around a table in a country that is rated number 1 in the world in that regard, and we do not acknowledge it.

Richard Lyle: Convener, I have a small comment.

The Convener: I am reluctant to let people in. I will be guided by committee members. It is now 20 minutes to 12 and we have not heard from the member in charge of the bill. I ask for committee members' co-operation so that I can bring in Patrick Harvie and give him some time. We will then close this round-table session. We have another panel of witnesses to go, as well as further business.

Patrick Harvie: Thank you very much, convener.

On Dr Jeffrey's last comment, I do not think that I have heard anybody in this evidence-taking session or at any other point in the discussion of the bill suggest that we should not give the best quality of palliative care that we can. Clearly, some people believe that that is compatible with having the option of assisted suicide, but I do not think that anybody has argued that we should not provide that level of care, stay with people and provide the greatest relief of suffering that we can.

I will try to identify some common ground between proponents and opponents of the bill although, given the evidence that we have heard, that might be a tough call—I understand that. I wonder whether I could suggest something that we might agree on. Whatever Parliament chooses to do with the bill—whether it passes the bill, rejects it or amends it—if simply debating the bill prompts greater focus of mind on and consideration of palliative care, the end-of-life situations that people may face, health inequalities and the need for decent, respectful and inclusive treatment, that would be of benefit. If simply debating the bill encourages a more open and discursive culture in relation to death, that would be of benefit.

If the bill was passed, the preliminary declaration mechanism would be one such opportunity for discussion, and I would like to hope that there might be some common ground about the benefit of that mechanism. It might become normal for us, when we are fit and well, to have a discussion with our doctor and have our general attitude to such issues recorded in our medical records. Would that create opportunities for a better and more open culture in which we could discuss the issues and make our wishes clear?

Baroness Finlay: That is an apposite summary. We all want to improve care, and these debates are important because they open up discussion in the political arena and within medicine and society as a whole, and because they raise awareness of dying.

You referred to schedule 1, on the form of preliminary declaration. If you wish to stick with that, I plead with you to change the wording so that it does not refer to

"WILLINGNESS TO CONSIDER ASSISTED SUICIDE",

because that makes it sound as if it is a matter of being willing or unwilling. It should be a declaration of intent "to possibly wish to consider assisted suicide", if you are going to leave that determination with the individual. Otherwise, the way that it is worded makes it sound as if assisted suicide is to be offered.

In terms of consensus and a way forward, it is the politicians and the legislative bodies that make the legislation, but in the bill you are talking about involving another group of people—doctors, nurses, pharmacists and so on. The problem is that the very people whom you want to involve are the ones who are saying, "This is too dangerous."

When I suggested at the outset how the bill could be improved, I did so not to be in any way flippant. I have many other suggestions as to how the bill could be improved and I would willingly share them with you, although I know that we do not have time to do that now. However, I honestly feel that, if you really want to find common ground, you need to consider a system whereby you take the decision out of medicine, so that medicine carries on providing care for people in their distress, their long-term illness and their dying, and for their families after death. You then set up a completely separate way in which those who are determined to end their life can access lethal drugs without needing to think about getting them off the internet illicitly or going abroad, and you ensure that such a process is adequately policed.

Patrick Harvie: Does Mr Hazelwood want to comment further?

Mark Hazelwood: I want to respond to your comment about openness. All of us this morning have shared a position on the value of open discussion in informing people and enabling them to plan and think ahead. In Scotland, we have an alliance called good life, good death, good grief, which involves 800 individuals and organisations that are doing all sorts of things to promote a national conversation about death, dying and bereavement.

I offer a personal reflection on something that we did not cover in the partnership's formal evidence. You asked whether the preliminary declaration would promote openness. I am not sure that it would. I guess that, as far as the model that you have presented is concerned, people might well have a discussion upstream, long before their death, and I agree that such discussions need to take place at that earlier stage, when they will be easier to have. After all, no one knows how long they have. Nevertheless, there is an alternative way of looking at this.

11:45

I do not know what the answer is, but, as we have seen, the discussion about end-of-life issues is dominated by assisted suicide. It is possible that people might have that discussion, tick the preliminary declaration box and think, “Job done.” I can see why people would want to do that; as we have heard, the end of life can be messy, complicated and difficult, and it requires us to engage with some difficult questions.

The other side of the coin and a possible concern is that although people might think that they have dealt with everything well upstream, we have heard this morning how, as we age and our death becomes imminent, our preferences and perspectives can change. People might think that they have dealt with everything, but when they get to the hospital ward they might wish that they had learned a bit more about this stuff, dealt with the power of attorney and had a conversation with the GP about whether they even wanted to be admitted to hospital once their health had deteriorated. I am not sure, but I think that there are two ways of looking at the issue.

Patrick Harvie: Surely that is why the multiple-stage process after that is an additional benefit. We are not saying in the bill simply that a person makes a request, the request is granted and the thing is done. The process is more involved than that.

Mark Hazelwood: Yes. I was simply commenting on the fact that, having ticked the box well upstream, people might be less engaged with wider issues about planning and preparing for the end of life. That is all. I am not saying that I am sure that that will happen, but I think that it is a possibility. I am sure that the situation will be different for different people.

The Convener: Do you wish to comment, Dr Carragher?

Dr Carragher: I think that what Patrick Harvie has just set out would be very valuable and good. I am concerned that we almost need to have this debate as a result of what in palliative medicine is called the double effect. Here it is unintended, and I would like it to be a primary conversation. It would still be very useful. However, I still have profound concerns about the bill’s provisions being applied to, for example, those under 25.

Patrick Harvie: Do I have time for another question, convener?

The Convener: Yes.

Patrick Harvie: Arguments have been made about practical consequences, such as the risk of someone being subject to coercion and the perception that passing the bill would undermine political support for palliative care. However, other arguments have clearly been about fundamental principles, and I would like to explore the balance between the two.

The bill clearly envisages a range of circumstances in which people might request assisted suicide, and I invite people to consider what I might call the most clear end-of-life end of that range. We might be talking about someone who has had access to good-quality palliative care and who might well have a long-standing and clearly defined and articulated principle and attitude with regard to the concept of assisted suicide. They might no longer be contemplating other options because their death is imminent—they are dying, and that death is coming quickly—and their clear will is to say their goodbyes and die on their terms and at a time of their choosing. Is there a clear, principled reason why they should not be able to exercise that decision, or is it entirely a question of practical consequences, whether for society or other people or in relation to the risk of coercion? In short, I am talking about the balance between principle and practical consequences.

Baroness Finlay: But you come back to involving another person in deliberately foreshortening that person’s life. That is a matter of principle, because you have to consider the effect on that person of the system that you have set up. With due respect, I think that your bill is not just about the very end of life at all—

Patrick Harvie: I accept that.

Baroness Finlay: It is not worded in that way. We could talk for hours about theoretical considerations, but we have been trying to highlight to you the dangers of the legislation as drafted and how it could be improved.

Patrick Harvie: I understand that. I simply want to explore the balance between the arguments about principle and the arguments about pragmatism.

Baroness Finlay: There is a public safety issue for society. You will never have a society in which everyone has everything that they want all the time, but you have to set the boundaries somewhere. I think that it was Onora O’Neill—it might have been Elizabeth Butler-Sloss; please forgive me—who said that laws are like nation states, in that they are safer when they rest on clear boundaries. The bill would fudge that, and you have to think about what Lord Carlile called “collateral damage”. I cannot speak for others, but certainly my concern is about public safety and who will get caught up in this—and, indeed, how you will ensure that people do not get caught up in it. Lord Falconer admitted on “Today” that there would be mistakes and that no legislation was watertight. That worries me, because once someone is dead, they cannot come back again.

Dr Jeffrey: Professor Rob George has referred to this as the Rubicon. We are standing on one side of the Rubicon, and we can decide to cross it into this other world. However, by taking their professional oath, doctors stay on this side, because they know that they cannot kill patients. Our confidence in that respect enables us in all sorts of ways, not just in these difficult conversations, to feel confident about using large doses of drugs when necessary to combat pain. We feel confident, because we are protected by the law.

A funny thing is that when a friend of mine who takes the completely opposite view—he remains a friend—heard that I was to give evidence, he said, “I really agree with assisted suicide, but I wouldn’t want to be looked after by a doctor who did.” That encapsulates the dynamic here. We want doctors who are on our side, who will care for us and who will say, “Hang on a minute. Is this the right thing to do?”

The Convener: Does anyone else wish to comment? Patrick?

Patrick Harvie: I think that I have raised the issues that I wanted to explore, convener.

The Convener: It remains for me to thank the witnesses very much for their attendance, their written evidence and the evidence that they have given this morning. I apologise to Richard Lyle and Richard Simpson for not being able to let them back in.

I suspend the meeting to allow a quick turnaround for the next panel of witnesses.

11:52

Meeting suspended.

11:58

On resuming—

The Convener: We continue with agenda item 1, our scrutiny of the Assisted Suicide (Scotland) Bill. This is our second round table of the morning, with representatives of religious and faith groups.

We are sorry that we are a bit behind schedule, but I am sure that you all found the previous session as interesting as I did.

As we normally do with a round-table panel, we will each introduce ourselves, and we will then go to our first question, which will be from Dennis Robertson.

With us today is Dr Mary Neal, who is a committee adviser on the bill.

My name is Duncan McNeil. I am the MSP for Greenock and Inverclyde and convener of the Health and Sport Committee.

Bob Doris: I am deputy convener of the Health and Sport Committee and a member of the Scottish Parliament for Glasgow.

The Rev Sally Foster-Fulton (Church of Scotland): Good morning. I am the convener of the church and society council for the Church of Scotland.

Rhoda Grant: I am a Highlands and Islands MSP.

The Rev Dr Harriet Harris (Scottish Episcopal Church): I am convener of the doctrine committee of the Scottish Episcopal Church.

Dennis Robertson: Good morning—I think that we are still just there. I am the MSP for Aberdeenshire West.

12:00

Ephraim Borowski (Scottish Council of Jewish Communities): I will have to say good afternoon. [*Laughter*.] We have crossed the Rubicon.

I am from the Scottish Council of Jewish Communities.

Colin Keir: Good afternoon. I represent the Edinburgh Western constituency.

The Rev Dr Donald MacDonald (Free Church of Scotland): I represent the Free Church of Scotland.

Mike MacKenzie: I am an MSP for the Highlands and Islands region.

Nanette Milne: I am an MSP for North East Scotland.

Dr Salah Beltagui (Muslim Council of Scotland): I represent the Muslim Council of Scotland.

Richard Lyle: I am an MSP for the Central region.

John Deighan (Bishops Conference of Scotland): I am the parliamentary officer for the Catholic Bishops Conference of Scotland.

Dr Simpson: I am an MSP for Mid Scotland and Fife.

The Convener: Thank you all—

Patrick Harvie: I am a member for Glasgow and the member in charge of the bill.

The Convener: Sorry, Patrick.

Patrick Harvie: It is just because I am so quiet sat here, convener.

The Convener: I know—you are quiet—and my view was more towards the other side of the table during the previous evidence session. Feel free to bring me back to central focus.

Dennis Robertson will ask the first question. We will see where the responses take us, and we will have other questions as we go on.

Dennis Robertson: In many of the submissions that we have received, the sanctity of life seems to be quite prominent. I would like to explore with the panel what is meant by the sanctity of life, and whether you would ever envisage a situation in which assisting someone in suicide would not be totally against that or in which you would perhaps see it as being respectful of the sanctity of life.

Dr Beltagui: I am not a doctor of medicine, by the way, just in case anyone thought so.

I am not a scholar in Islam, so I had a gathering of imams—scholars—and I asked them whether there was any situation in which the sanctity of life as we know it could be relaxed or we could do something about it. They very clearly and openly said no: there is no excuse for changing the time of death. We cannot change it anyway, but there is no permission at all to interfere with life.

Of course, there are situations that are legal and so on, but that is a different story.

The Rev Dr MacDonald: The sanctity of life rests on our belief that we are made in God's image—in other words, that we are different from the animals and that there is a spiritual dimension to our beings, which makes life different for us. We have a responsibility to maintain not just our own lives but the lives of others, to respect their lives and to care for one another throughout our lives.

You may have noticed that, in our submission, we said that we have no right deliberately to end an innocent human life. There might be other debatable things such as just war but, leaving that aside for the moment, we are dealing with people who are going to die anyway, who are facing problems because of suffering and who want help to end their lives.

We believe that the best way to respect a person's life is to help them face up to life, to relieve the suffering and to show compassion. We believe that compassion means that we feel with the person in their situation, we understand them, we go alongside them and we suffer alongside them—if possible and to some extent—relieving that suffering and preparing them for their death. As Christians, we believe that there is life beyond death, to which we point them, too.

On the question of sanctity of life, if someone does not believe in God and just believes, say, in a materialistic view of the universe, where all that we are is matter, they have to account in some way for the importance that we give to human life. We all realise that we are different. We have responsibility, and we have creational and aesthetic gifts. Because of all those things, we know that we are different.

People have to find some way of giving importance to our lives. Some people say that it is a matter of autonomy: they wish to make their own decisions and make their own life. That is why many people go on to say that, because it is their life and they make their own meaning to life, they want to have control over their death, too, whereas those of us who come from a faith perspective say that God has given us life and God will take away life. We are responsible, while we are here, to maintain that life and to help others to maintain it in the best way possible.

We believe that there is never a good and sufficient reason for ending someone's life, even if they themselves wish to do so. They are free to do so, although it is not something that we would encourage.

On the other hand, looking at things from a medical point of view—I was a doctor and surgeon for 20 years—if a person says that they do not want to go on living and they refuse treatment of all kinds, perhaps even refusing food and water, we would still support them through that. That is their autonomy. However, we believe that they have no right to demand that we, as their helper, carer or doctor, deliberately help to end their life.

Sanctity of life is extremely important, but it must be taken into consideration with personal autonomy and human dignity.

The Rev Sally Foster-Fulton: Thank you for asking the question, Mr Robertson. Sanctity of life is not exclusive to those around this table who hold to a religious faith. Sanctity of life means the set-asideness or specialness of life—that fleeting, fragile, extraordinary experience that we share. Indeed, "share" is the word that I would like us to focus on for a minute. It may be my life, but I share that life with others, and that is what makes it special and sacred.

The thing that concerns us about the bill stems from the same thing that concerns the folk who support it. It starts with dignity and dependence and how we see those two things interrelating. It is also about human rights and compassion.

Everyone is dependent. That does not take away dignity. In fact, it enhances it. We all need to be concerned when it comes to anything that erodes that idea or says that if someone is dependent or if they, at times, place down their burdens so that others can help them to carry them, that is a loss of dignity, a loss of the person's humanity or a loss of the sacredness of life. That is our concern about the bill, especially for those who find themselves vulnerable, marginalised, afraid and coming to the end of their life. Saying to them that their life is somehow less worthwhile than that of somebody who is healthy, fit, coherent, cognisant and able to be eloquent erodes everybody.

The sanctity of life is very complex. It is not a stark, black-and-white question—"Thou shalt not". It is about how a decision about my life will impact on the others with whom I share my life and this planet. That is where we really need to grapple with the issue, and that is where our concerns lie, essentially.

Ephraim Borowski: I would like to answer Dennis Robertson's question by referring to a question that Patrick Harvie asked at the end of the previous evidence session. He drew a distinction between issues of principle and mere practical questions. I think that that is a false dichotomy. If there are sufficient practical questions about absolutely every aspect of what is proposed, it becomes an issue of principle. It is not just a matter of knowing when the proposed criteria might be satisfied; it is a question of knowing how we could know that those criteria are satisfied. That seems to be at the heart of legislating about such issues.

This is not theology; this is law. Law is in the practical domain. Therefore, the committee and the Parliament must address all the practical questions in considering the bill.

The Rev Dr Harris: Within and outwith the faith context, paths can be chosen in relation to which it is known that death is likely to be involved—whether that be the difficult decision to go to war or to stand in the way of a careering bus that is about to hit somebody else or to go ahead with a pregnancy that might well end the woman's life.

Assisted suicide feels different because it feels as though death is being chosen for the sake of death rather than saying that death might well come but it is for the sake of life. What makes the difference is that it is death chosen for its own sake rather than death being embraced because it will mean life elsewhere or for others.

John Deighan: I concur with all the previous answers. The nub of the argument is the difference between recognising the inalienable right to life that we all have and seeing that as the foundation of ensuring that everyone in our society is safe. The point beyond which we cannot go is that at which we deliberately hasten death or choose death as the outcome.

It is right to point out that we should respect the autonomy of individuals and support them in that autonomy as far as we can, but that is within the context of having a safe society in which human dignity is always upheld.

Accepting death is a natural part of life does not breach the sanctity of life or the recognition that we have a fundamental human right to life.

Dr Beltagui: We are not just talking about the bill from the theological viewpoint that is relevant to us. We are asking whether there is a reason to believe that the bill will benefit society in any way.

The bill will do a lot of things that will not be of benefit to society as a whole. It will create mistrust between the medical profession and the general public. It will create a culture of suicide as one option for the treatment of a person, which will be attractive to many young people especially if they have depression or are in a bad way. There was a recent case in Belgium, where they have moved from, as this bill postulates, assistance to euthanasia. Someone who was in jail for life asked to have assisted suicide. The request was granted but the communities took action and the minister responsible for justice reversed the decision.

There is an interesting question there. Is ending someone's life in such a case a punishment or a treatment? Would it benefit the person or society? That could come; we could reach that stage.

The important thing for us is how the bill will affect society's behaviour. The main problems are the culture of suicide, with it becoming a normal part of treatment, and the mistrust between the patient, the medical profession and the family. We have heard about the burden on the family being a real concern for someone who is in a difficult situation. We have to consider all those issues.

The bill is not tight from beginning to end on the practical points, although there might be other questions. From the beginning, no advice is to be given to the person before he decides that he wants to be assisted. We ask for help with any transaction or process in our life—we ask a legal expert, a financial expert, even a car mechanic for example—but the decision about ending one's life is put in the hands of the person. They decide that they want to end their life and everything follows on from there. That is just for a start.

As we move through the bill, we find no monitoring process for the procedure. There is just the signing of a paper; there is no monitoring or follow-up. There is no way of ensuring that everything is good. Things could go wrong.

I am reminded of something that I have been involved in that concerns the certification of death and a new law that came in two years ago—I have been involved in discussions on that for some years now. The issue is all based on one person, Dr Shipman, who was trusted by his people but killed so many of them.

If we have this kind of bill, with a group of people called facilitators—we do not know if they are medical people, normal people or what—and give them a way to proceed without any monitoring or follow-up, that seems very strange. We are not just crossing a principle; we are going from a principle to an open system, and nobody could say that that is tight enough.

As was referred to earlier, Lord Falconer himself said that no safeguards are watertight, and the proposed measures are not something that can be repaired if they go wrong. We stopped capital punishment because we thought that, once it happens, it cannot be corrected. The bill is similar, in a way.

12:15

Dennis Robertson: I have a couple of points to make. We have heard about compassion, suffering and sharing. At some point, would we accept that the person and their family have mutually come to a decision? If the family respect the will of the individual, accept that they do not want the person to suffer any longer, as the person has made clear themselves, and the family's compassion is to agree, is it not then right that that person should be facilitated towards the end of life?

John Deighan: The problem is that the choice made by the individual—albeit that it might come from a sincere belief that they are better off dead—has an impact, in that it creates a universal categorisation of human beings in our society. The law would enshrine their belief as right and would endorse someone's decision that they are better off dead. It is protection in that regard that we have to bear in mind.

We should also bear it in mind that advances in medicine and technology afford us the opportunity to give care in better ways than at any time in our lives. That should perhaps make us think about why at this time in history people are wanting to choose to die. That is an existential question that perhaps needs to be addressed, too.

Assisted suicide would partly involve a breakdown in the bonds that we have in society. When there is a breakdown of bonds in that way, when people are isolated and when they feel that they are not worth anything or do not mean anything to anyone else, they are more liable to feel that they want to die.

Assisted suicide puts a finality on the decision and says, "Yes, we are breaking all our bonds with you, and you are breaking all your bonds with society." That is something that we cannot do.

The Rev Sally Foster-Fulton: We heard from the previous panel compelling stories in support of assisted suicide and compelling stories against. There are stories on both sides, but compelling stories do not make good, safe legislation, and we need to make that distinction.

We have heard a lot of evidence from people who work in the relevant areas day to day. We cannot safeguard against the slow erosion of the understanding of the dignity and worth of human life. We cannot safeguard against the most vulnerable, for example an old person in a home, feeling that, because he or she is spending all of his or her children's inheritance, it would be a really good, honourable thing to agree to assisted suicide—for all those good reasons—even though they do not want to go. There is no way to safeguard against that. It might not be intentional pressure from families; it might be internal pressure from the people themselves.

When you say that there is a set of circumstances in which a person's life, or a certain type of life, might not be worth living, that plants a seed and it begins to change things. You will have walked from one way of looking at things to another, and it is then very difficult to walk back. Once that legislative genie is out of the bottle, you cannot get it back in.

Ephraim Borowski: I support that. The premise of the question is that, in a sense, it is always compassionate to say yes. However, we all know that it is not compassionate always to say yes to children when they say that they want something, and the same may well be true at the other end of life, too.

Today, as everybody knows, is Holocaust memorial day. It is now a well-known cliché that the Holocaust did not begin in Auschwitz—it ended in Auschwitz. I mention that in connection with the distinction that Patrick Harvie made between practicalities and principles. In terms of principle, the Holocaust began with the belief that some lives are not worth as much as others. That is precisely what we are faced with here, and that is the point that Sally Foster-Fulton has just made, too.

The Rev Dr Harris: We always have to give full recognition to the decisions that people have reached and to hear them out fully on their assessment of their situation—how they are feeling and how their relatives are feeling. If people, as a family unit or as a more extended group, have come to a decision to give full recognition to that, it does not necessarily follow that we say that that route is possible for the person. However, allowing that to be said and recognised brings a kind of healing and opens up other possibilities, as is the case when people say that they feel they are a burden. To some extent, it is valuable to acknowledge that. It might be helpful and it might relieve anxiety if family members say, “Actually, yes, you are a burden—but you are a burden that we want to carry. We don’t want to not carry you.”

Someone might say that they want to end their life, and you could let them explore that fantasy, as you might—although it is not the same—with a sibling who says, “I hate my sister. I want to kill her.” You might respond, “Okay, tell me a bit more about that.”

I do not mean to trivialise this at all. When people have been allowed to say that and have been able to go that far, they have let themselves explore the idea in conversation and have then pulled back from it. It is really important to give full recognition when people reach such a decision, and we should let them explore it. That does not necessarily mean that we should allow it in law but, if we let them explore it, that can address some of the issues and they will pull back from wanting to go that far.

The Rev Dr MacDonald: There is another point about the situation in which somebody says, “I want to end it all now.” The family might acknowledge that he is suffering terribly and he should go now. That is obviously a case where there should be further consultation, especially a palliative care consultation involving discussion of all-round, holistic means of treating the person, so that they will probably change their minds after some time. We should not just take that first declaration of “I want to end my life” as the person’s fixed will, by any means.

Let us consider the figures from Oregon, where the legislation has been going for some years now. By far the biggest reason given for people taking death under the Death with Dignity Act is the loss of autonomy, independence and enjoyment of their usual activities and so on—not unbearable pain, which is very far down the list. Being a burden to others is perhaps in the middle of the list. Usually, a strong person, who hates being dependent on others, is involved. He or she wants to keep control of his or her life. He wants to be able to say that he wants to end it now, on his terms.

Proponents of the bill often talk about unbearable suffering, or pain that cannot be controlled. There is perhaps a very small percentage of people for whom that is true, but there are other means of dealing with that situation, through holistic care, sedation and pain relief. Generally speaking, however, unbearable pain—which we must feel along with the person—is not involved; it is more about the loss of control and the loss of independence. That is the main reason why people persist in seeking assisted suicide. That is not an adequate reason for changing the law, which is currently there to protect the vulnerable.

The Convener: We heard earlier about the distinction between assisted suicide and the withdrawal, on request, of treatment for an illness. Do the witnesses see a distinction there?

John Deighan: Very much so. As I said, we will all die, and we recognise that dying is sometimes a relief for a person who is suffering and for their family. We try to support people in the lives that they have, alleviating pain as best we can do. Sometimes that means weighing up options and concluding that a particular treatment is not worth the effort, because it would be too burdensome for the individual. Therefore, forgoing the treatment is completely in line with the position that the person has inalienable dignity; it is about ensuring that they see their way out of this life as comfortably as possible.

The Convener: But it brings on death earlier.

John Deighan: It is about accepting death. Perhaps something that motivates people who support assisted suicide is fear of an endeavour that is not worth the effort and which causes further, unnecessary suffering—it is the approach that is known as vitalism, whereby any effort to keep someone alive is pursued, simply because people think that life must be maintained, even if it is a life of suffering. That is a misunderstanding in people’s minds that needs to be teased out, so that people accept that deciding to forgo further treatment is a completely licit approach, legally and morally.

Dr Beltagui: The issue is to do with the understanding of ourselves as families—it is partly about compassion and so on. On the question of dying with dignity, if someone is really suffering there is dignity in seeing himself or herself looked after and seen by their family—children, grandchildren and so on. That is dignity, I think. Just leaving the person alone to finish it is not really dignity.

There is a complete cycle—a father, a grandfather, children and so on. We should look after our parents as much as they looked after us. It is not as though our parents just bring us up until we go to university and then forget about us, while we forget about them. Human beings should look after one another—it even happens in the animal world sometimes. It is about living as human beings, not as commodities, as some might say. If someone is the recipient of their family and friends' visits and compassion, that changes things. We have heard lots of examples of that.

No one knows exactly when death will happen. Even assisted suicide might not work. Why put ourselves through that? No one knows exactly what will happen and in many cases there will be failures.

According to the statistics from Oregon, about 50 per cent of the people who have been prescribed poison have not used it. People can change their minds very quickly, perhaps because things around them have changed. Perhaps people around the patient changed their attitudes when they saw that the person wanted to die. It is about this human feeling, together. We should not say, "Forget it, there can be a better or easier way."

I think that when a person is close to death, whether they are healthy or not, they always know that they are near the end and can decide, without poison or anything, "This is it. That's finished." I have seen that in many cases. Why do we have to interfere in something that will happen anyway?

The Rev Sally Foster-Fulton: There is a profound and distinct difference between assisted suicide and making an informed and supported decision not to have treatment that can be incredibly invasive and can have a profound impact on the quality of the life that someone has left.

For example, someone might say, "I have terminal cancer. There are things that will impact the length of my life but take away from the quality of my life, and on balance I have made an informed decision, with my physicians and family, that that treatment would impact the quality of my life negatively, even though it might increase the quantity." That is very different from saying, "At a determined time I will take a lethal dose of medication that will end my life", which is a proactive move to end their life, rather than to take advantage of most of what is left of that life.

12:30

Mike MacKenzie: I am interested in exploring the idea of the sanctity of life and the concordant idea that such an idea has a constant value. We are all aware of deaths that are talked of as being particularly tragic—perhaps a child or a young mother—and at the other end of the spectrum those that are not, for example someone who is very elderly, has lived a fulfilling and rewarding life and has died peacefully in their sleep. At one level, at least, we confer a differing value on lives and on death. Do the witnesses believe that the value of life remains the same, or is it subject to change?

Ephraim Borowski: I would make a distinction, which was not made in the question, between two different senses of the word "life". When we evaluate lives in the way in which Mike MacKenzie described—someone who had unfulfilled potential as opposed to someone who has achieved a lot—we are evaluating their life in the sense of their passage through this world from birth to death. When we talk about the infinite value of human life, we are talking about the state of being alive. That is a distinction that needs to be kept in mind and which, if I may say so, the question elided.

The Rev Dr Harris: I think that the two examples that Mike MacKenzie gave do not contradict one another. If someone has lived a full life, their death is not regarded as a tragedy—it might be sad news, but it is not bad news necessarily, and what is being valued is the culmination of a very full life. When a life is cut short in a way that seems unnatural—say the life of a child or of a mother of young children—the tragedy is that their life has not had that fullness. Those contrary reactions are both consistent with a valuing of the sanctity of life.

The Rev Sally Foster-Fulton: In every life, and all through our lives, there are times when things are really good and times when things are really challenging. That is true of every life, whether it is at the end, beginning or somewhere in the middle. It is about how people walk with us through all the times of our lives—there are always good and bad times. There have been times in my life when things have been really hard; looking back on them, it was how people walked with me that defined the difference. It will always be qualitative.

Again, there are unexpected joys and pains in every life. One of the things that concern me about assisted suicide is the fact that it curtails any unexpected joys. In taking a decision to end their life, people are preventing joys that we do not know about from happening.

Mike MacKenzie: I am grateful for those answers.

Colin Keir: I have just been changing my question a little bit following what has been said. Mr Deighan mentioned the acceptance of death and the fact that someone will be asked to help someone else curtail their life. Let us face it, suicide is not illegal, as such, and some people, for whatever reason, will commit suicide.

My concern is for people who are seriously considering that course of action. If someone has a seriously bad illness, is having problems, or is coming towards the end of their life, and they are one of that small number of people—I believe that it is a small number—who think that they are at the end of their tether and want to end their life, is it fair for us to deprive them of some help, without which they might head in their own direction and take their own lives in a less pleasant manner, which would be particularly harrowing for their families? Would it not be better for the families if the issue was resolved properly beforehand, so that there was an acceptance that it was going to happen, as against suddenly finding that their nearest and dearest or their family friend has taken their own life in some degree of solitude and in a situation that is not quite as pleasant?

John Deighan: The thing about suicides is that they are a tragedy involving people who are desperate, and we have to offer some help and stand by them when they are desperate. That is why we have suicide prevention measures supported by the Scottish Government and by many charities. The issue of bereavement is huge. We heard about that earlier, and I do not think that a bereaved family are going to be helped by the fact that a person chooses to end their own life with the help of a doctor. The problem is that it undermines the foundation of the laws that protect us all and ensure that there is no discrimination against certain people because we think that they are of less worth than others.

By all means let us support people, but hastening their death does not help them in any way. We are capable of giving support, as far as we can, and of supporting the families, to ensure that they have as good a death as possible. One of the initiatives mentioned this morning was good life, good death, good grief. We want to allow people to do that naturally and to accept death, and to support them as best we can. There is a deep instinct of self-preservation within every human being in every culture.

In the past, it was decided that suicide should no longer be illegal, but I would not say that it is lawful. If you look at some of the debates at Westminster about that—although I know that they referred only to England and Wales—you will see that people were saying that people who wanted to die actually had some sort of problem, that they had a level of depression or desperation in their lives, but that they did not need to be prosecuted after attempting suicide. That is why the Suicide Act 1961 was introduced. The decision not to prosecute arose out of compassion. That is why assisted suicide had a penalty of 14 years—almost the same as murder.

We must recognise that suicide is a tragedy, and we must help people through their lives to have as full a life as possible and not to end in a desperate situation where they feel that they have to sever all their bonds with society and with their family.

The Rev Dr MacDonald: I would like to pick up on something that John Deighan said about the incidence of depression in those who are suicidal. Depression is very common in young people—among young men in Scotland, particularly—and that is why we have an anti-suicide strategy. It is the same towards the end of life. People who are in terminal illness are often depressed and it is often difficult to reach that diagnosis from a medical perspective. That is where a specialist examination of such patients is needed. A practical aspect of the bill that bothers me is that there is no necessity to have that psychological or psychiatric assessment of the person who asks for assisted suicide.

Many people get depressed towards the end of life, and perhaps people do not recognise it. The family might not even recognise it, because they put the person’s withdrawn state or their refusal to face the future down to the physical suffering, pain and weakness. That is part of it, obviously, but when the mind gets depressed it affects the whole of a person’s system. With proper psychiatric help, and probably with anti-depressants, they can get through that and then perhaps be prepared for a better death than just being put to sleep by their own action.

The Rev Sally Foster-Fulton: It is important that we return to the idea that we are talking about law and, any time that something is legislated for or against, it is about a balance between the benefits and drawbacks for an individual and for society. What about all the people who are not articulate, are not well supported and are vulnerable but who desperately want to live with dignity until they die? We have to focus on them. Any time that we begin to erode the level of support for them, even in the way that they are perceived in society, we are on a dangerous path.

I return to some of what the previous panel of witnesses said about palliative care. We have a great system of palliative care in the United Kingdom but it is not perfect and it is patchy. If somebody has a non-malignant disease, their chances of having good palliative care are less. Before we move to plan B, why not exhaust plan A and do absolutely everything that we can to ensure that good, consistent, deep palliative care is offered throughout Scotland? Until we have exhausted that, and we can put up our hands and say that we have done absolutely everything that we can do in palliative care, why should we move to plan B?

The Convener: I should point out for the witnesses who sat through the earlier evidence-taking session and are here now that we have been involved in a number of areas. The Assisted Suicide (Scotland) Bill is one. We have also considered access to new medicines, which is another aspect of end-of-life care. We intend to consider palliative and end-of-life care, too. We are trying to consider the bill in a broader setting.

Dr Beltagui: Assisted suicide does not involve only one person doing something awful by killing himself; it involves someone else to do the process. If something like that goes ahead, it will have difficult repercussions because you will have to try to find a way to ensure that you do not discriminate against doctors and other medical staff who do not agree with it. Although there is usually some conscience clause, it does not always work easily. That is another addition to the difficulties.

Palliative care is not completely funded by the Government like the NHS. A lot of it depends on charities, so why not put some support into it? That needs to be considered more than anything else.

Richard Lyle: I am very impressed by the number of churches and faiths that are represented. I respect them all, but I also have to ask the question. We all know when we were born—we can say what day it was—but none of us knows or can predict when we will die. The previous witnesses went on about people being given more days and years. The mother of a friend of mine was told that she had cancer and had only six months to live, but actually she lived three years.

We all go to cemeteries to visit our relatives who, sadly, have gone. We need only go to local cemeteries and see the flowers to see the respect that everyone has. However, I have never heard so many scare stories about how we should let people go on and not let them die. No one wants their relatives to go—we all want to keep them, as I said to the previous witnesses—but, if a relative wants to go, why should we not let them? I know the answers that I will get but, if someone is lying there dying and says, “I want to go”—we have all gone into hospices and hospitals and seen friends or relations who have said that—why should we not let them go or even help them go?

The Convener: I am sure that we will get some responses to that.

12:45

John Deighan: I think that you have heard some scare stories because there is something to be scared of. Since the second world war, secular authorities have created a human rights regime that has put the right to life as the foundation for all other rights. That has been increasingly recognised, with more positive obligations on states to ensure that people realise their right to life.

That was founded on recognition of how dark things get when people have the power to decide over life and death, and how easily that is abused. Not only can it be abused—and we can recognise that directly, perhaps after it has happened—but it degrades the fundamental recognition that every human life is special and is to be nurtured and protected as much as possible. It also leads to temptations that undermine everyone’s right to life.

We have seen in other jurisdictions people being refused treatment because caring for them was too expensive, or it was cheaper just to give them a concoction that would kill them. We have heard of people such as Tom Mortier in Belgium, for example, whose elderly mother was suffering dementia. He got a phone call to say, “Your mother has been put to death yesterday”, and he knew nothing about it. We have heard of the case of Kate Cheney in Oregon, whose daughter was coaching her on what to say so that she could get assisted suicide. That was recognised by a doctor, but the family were able to take her out and find another doctor who had her life put to an end.

We have now seen the development of that, with people nominating themselves for death in Switzerland just because they are tired of living. This morning we heard about the twins who were going blind and who wanted to die. We have also seen the extension of that in Holland and Belgium, where children can now be put to death.

That is why you are hearing scare stories. It is something to be scared about when a foundation is taken away that has been recognised throughout our religious traditions, which testify to it as well, but also in our secular institutions, which have tried to uphold it. It is dangerous to take that platform away.

Ephraim Borowski: I am not going to justify scare stories. I am going to address the question again. It seems to me that the question that Richard Lyle asked would be appropriate if, today, we were discussing making suicide illegal or making it illegal to strive officiously to keep people alive, but that is not the question that is before us. The question is about assisting suicide. In other words, the boundary that is being crossed by the proposed legislation is not to do with people dying but to do with what their agents do. We heard that loudly and clearly from the medical profession in the previous panel.

To some extent, it is a question of language, again. We are calling this “assisted suicide”. We might just as well refer to it as “requested euthanasia”, in which case I do not think that it would have quite so many supporters.

Dr Beltagui: As I said before, this is about involving someone else in the act. With those who commit suicide, people do not stop them. If anyone says, "I'm not having any medicine any more", nobody stops them.

The Rev Dr MacDonald: The question was, "Why keep people alive when they don't want to live?" There is a lot of misunderstanding among people—especially people who are well at the moment. I have heard a good Christian man—a member of the church—say, "When my time comes, I want you to let me go. Don't keep me alive unnecessarily." I hope that nobody would do that.

People seem to think that, because doctors nowadays are so specialised and so keen on doing experiments, they keep people alive when they do not have to. That is a complete misunderstanding. When a person is ill and their life is at risk, they want treatment—they do not want to die. It is only later, when they realise that the end is coming, that they might say, "Well, just end it now." However, as we have heard from the palliative care specialists, if people are given proper palliative care, they change their minds.

We need a whole lot of education of people, while they are still well, about end-of-life issues. We need to get them talking about the subject. It is not a question of keeping people alive against their will. When somebody says, "I refuse treatment," we must respect that, unless of course the person has a severe mental illness and can be certified, as they say. That is a different situation.

If somebody who is in their right mind says, "No, I cannot take any more—just withdraw treatment," we should respect that and let them go. That is not the same as giving somebody a lethal dose; I would be very much against the medical profession having any involvement whatsoever in that.

It strikes me that it is a good thing for people to talk about death and dying, perhaps even when they are young, but we must remember that there is a great risk of increasing the tendency towards suicide in young people. I am worried that the preliminary declaration in the bill can be made from the age of 16. At that age, would a person have to be told, "It is a coming of age at 16, so now you can sign a declaration"? That is the wrong time to bring up the idea of suicide—of ending their life.

Young people can talk about death, especially when they see friends dying, as sadly happens, such as when somebody dies in an accident. That ought to be talked about, but it has to be done in the context of affirming life and giving them a mechanism to deal with the thought of their own life ending, and not of having them think of suicide—the deliberate ending of their life—as a way out of a problem. That is the big problem here.

The Rev Dr Harris: Letting people go is important, and sometimes, helping people to go is important—that is an important and very skilled ministry. An aspect to helping people to go is like midwifery.

The bill would address that by providing drugs that kill people, but often what stops people from dying is not medical as such. There are other reasons why they might be holding on. Their bodies might be ready, but they might be holding out for a critical conversation that they need to have with somebody, or something has really bothered them and they are not sure what it is, but a skilled conversation brings it out—then they relax and let themselves go.

There is an awful lot of skill in helping people to die, and it would be great for there to be more resources to enable that to go well. If that were people's experience generally, there probably would be less concern to see a bill such as this passed in Parliament.

The Rev Sally Foster-Fulton: I think that Richard Lyle heard not scare stories but real stories, some of which are scary. We need to listen to all the stories that people tell, because they have something to add to the conversation. This is such a complex conversation to have. It is not black or white but grey, and grey areas are where people tend to get lost. I repeat that my concern—I will keep saying it—is about the people who might get lost if the bill is passed.

Richard Lyle: As I said, I respect the faiths on the panel, but the point is that we are told that, if we smoke and do not eat healthily, we will cut years off our lives. As I said, we know when we were born, but none of us knows when we will die. The bill is about people who are really, chronically sick and getting near the end. What I heard from the panel was, "We still want to give you more days." If people want to go, my view is that we should let them. That was a comment more than a question.

John Deighan: Is it possible to ensure that the process applies only to the cohort that Richard Lyle is talking about? That is the problem that is being explored. It is not possible. The process spills over and puts the weak and the vulnerable most at risk. Surely the law of the land should be not enabling the powerful or the articulate but defending the weakest.

Dr Beltagui: Suicide happens everywhere. We just take it as not being a crime. When suicide happens in custody in prisons, which is where it can be expected, there is a big noise and a big inquiry.

In our hearts, we all think that suicide is not really something good. Somebody committing suicide is one thing, but helping someone with it is another thing. That is adding a load on to someone else.

The Convener: Richard Lyle, Mike MacKenzie and others have said that there are people who do not share your faith or your view on assisted suicide and who would exercise a different conscious decision on that. We have heard examples of horror stories regarding assisted deaths, but not every family is looking for an inheritance from the death of a family member. Many families would see assisted suicide as an act of love and respect for a person. I am worried that the adversarial nature of the strong views being expressed might make us forget that.

Everyone would wish that, if they were requested by a loved one to assist their suicide, they would be able to say, “Don’t be so daft. You’re not a burden.” However, we know that some people leave the country with their loved one to seek help elsewhere for an assisted suicide. They are motivated by their love for the person, which is not necessarily a bad thing. Do you perceive no situation in which assisted suicide would be anything other than a violation of that feeling of humanity?

John Deighan: People can have good intentions, but not only intentions count. We must consider the consequences of assisted suicide and what action society might be legalising. If the bill was passed, a power would be granted to some people to bring a person’s life to an end.

You referred to our faith tradition, but I tried to point out that our objection to assisted suicide is not just about faith; it is about a natural instinct in every human being and therefore every human society. Our human rights regimes have endorsed the fact that we must protect the foundation of ensuring that every person’s life is inalienable, and we have the complete recognition that there should be no discrimination against anyone in society. Our society needs that foundation.

The Rev Dr MacDonald: I have a comment on what the convener said about respect and the loving attitude of a family who want to help a loved one to end their life. What concerns me is not just the decision of the person involved but the effect on the person who gives the help and prescribes the lethal drug or provides the lethal apparatus. As a doctor and a Christian, I firmly believe that it would not be right for such a person to provide the means whereby someone can end their life.

That is particularly my view as a doctor because it has always been the tradition of the medical profession, from the time of Hippocrates, to protect life, care for people until the end of their lives and not do anything deliberately to bring about the end of a person’s life. The bill attempts to distance the medical profession and the caring professions from the act of suicide, but it does not achieve that.

When a doctor prescribes a drug, he has to say how much is to be taken and how to take it. If the drug was to be lethal, he would be instructing a person in how to end their life—he would be giving them an order to end their life. To be fair, the person might not take the drug. However, once he took it, the doctor would be involved and any carers who were around would also be involved—they, too, would have conscientious objections, which are not mentioned in the bill. The facilitator would be involved, and he or she would have severe psychological results from aiding a person to end their life.

I believe that it is not a loving thing to do to give people the means to end their life. The means are not specified in the bill, but they could involve anything—a mask and an inert gas such as nitrogen could be used, or there could be a lethal injection; if a person was on a drip, stuff could be provided for the drip and the person who wanted to end their life could just flick a switch to take it or perhaps could start the process by moving their eyelid if they could not move anything else—that could be arranged. However, that would be so close to euthanasia that I believe that it would be euthanasia.

The principle is—I believe—that we should never aid people to end their lives. We can agree with people who want their lives to end naturally because there is no further treatment and the illness—or perhaps even dehydration—will kill them, but they will still get supportive treatment all the way through. Even when they are dry, they can have their mouth moistened, which relieves a lot of their suffering. However, deliberately ending a person’s life should be completely outlawed and the idea should never be entertained.

13:00

The Rev Sally Foster-Fulton: I firmly believe that the vast majority of families do what they do out of intense love and concern for the person who is dying, but that does not change what the law would say. It would be making a qualitative judgment about life. In broad terms that are quite hard to define—that is another issue that we can discuss—it would say to folk who are terminally ill or who have one of the many life-shortening illnesses, such as diabetes, that some lives are not quite as worth living as others are. How does that impact on those who suffer from those debilitating illnesses, diseases or life-shortening conditions, who would like to live and be supported in doing so? We would be making a judgment—inadvertently and unintentionally, but that is what the law would do.

The Convener: No other committee members have indicated that they want to speak, so we move to Patrick Harvie.

Patrick Harvie: I hope to explore the issue that we have just discussed: how we respond to the reality that—as people have acknowledged—the act of assisting someone to commit suicide might sometimes be undertaken entirely out of love and compassion. The witnesses will be aware that, as well as attempts to change the law in this jurisdiction, south of the border and elsewhere, there have been repeated attempts to clarify the current law. There are now guidelines on prosecution south of the border, which we do not have. There is a lack of clarity in Scotland on whether there are circumstances in which someone could be prosecuted even for arranging for a relative to travel to Dignitas. The current law lacks clarity.

Given that situation, if someone assisted the suicide of a relative or someone close to them, there would be inquiries and perhaps a police investigation and a court case. If all the facts lent themselves to the conclusion that someone had acted out of love and compassion, and with complete respect for the autonomy and the decisions of the person involved, is it the witnesses' view that they should be prosecuted, convicted and sentenced for a very serious crime? Does the recognition of compassion come into the question at all?

The Rev Dr MacDonald: The decision would be up to the court. At present, the Crown Office and Procurator Fiscal Service would have responsibility for deciding whether to prosecute, and it need not do so. That is a legal matter; I am not making any moral or ethical pronouncement about it. COPFS has to decide whether there is a case and whether proceeding is in the public interest.

Once a case is before the court, the court can decide. There might be extenuating circumstances for any crime. Assisting suicide falls under the homicide law, which I think is common law—I do not think that there is a statute on it. The court would be free to do what it could, but the moral and ethical question is slightly different.

Patrick Harvie: All of which leads to—

The Rev Dr MacDonald: I would not support what the person did, but it might not be a prosecutable offence under law.

The Convener: We will get all the responses, and then I will give Patrick Harvie time to come back in.

Dr Beltagui: The question relates to the guidelines that were issued three years ago by the director of public prosecutions in England—

Patrick Harvie: South of the border.

Dr Beltagui: Yes—south of the border. The main point in the guidance is that a prosecutor should look at whether proceeding is in the public interest.

Decisions should be taken case by case, because assisting suicide is considered to be an offence at present. Your bill would make it not an offence, which is a different situation.

Ephraim Borowski: This is another question that seeks a yes/no answer and presupposes that all cases are identical and have to have the same answer—either they are all prosecuted or none are. As a couple of people have said, there is a judgment for a number of public officials before a case gets even as far as prosecution. I do not think that anybody around the table suggests that that is in any way wrong. In fact, it is implicit in that position that we do not need a new law that says that people in such circumstances should never be prosecuted, although that is the proposal before us.

The Rev Dr Harris: The on-the-ground situation for all faith groups and their ministers is that, if someone knows the family, they will support the family. That is why ministers do not serve on juries, because their job is to stand alongside people. We sit with people on the mourning bench or give them our compassion, whatever they have done and regardless of whether we agree with it.

Patrick Harvie: It strikes me that we are not fully expressing the compassion that we are talking about if we are leaving people with that complete lack of clarity about whether an action that they take is legal or illegal, regardless of whether they will be prosecuted or whether it is culturally and socially sanctioned. Do you think that the current situation is satisfactory?

John Deighan: My understanding is that, following the guidance that was issued by the director of public prosecutions in England, the Lord Advocate commented that the law is quite clear in Scotland.

Patrick Harvie: I am not sure that that is the precise phrase that was used. There have been many views put forward suggesting that the current situation is not clear. Perhaps I can come on to another question—-

The Convener: I think that Donald MacDonald had an answer to the question about whether the current situation is satisfactory.

Patrick Harvie: I beg your pardon.

The Rev Dr MacDonald: I believe that it is satisfactory. There should be more information for the public about end-of-life issues. As I was saying earlier, people have many misunderstandings about this, which is why they get so het up and say that people are being kept alive artificially and that there should be legislation on the issue. When the situation is explained to them, their opinion changes. That is why we cannot rely on public opinion polls, because they change depending on what question is asked and what the person's understanding is. Once end-of-life issues and palliative care have been explained, the number of people in favour of legalising assisted suicide comes way down. It is not straightforward.

The Rev Sally Foster-Fulton: Any time that people are suffering, struggling and feeling that they do not have the support that they need, it is not satisfactory. What might help is earlier intervention and people who can walk alongside them in their early struggles, allowing them to make those explorations, and who ask not just the person but the whole family, "How can we best help and support you as you walk through this?" One of the things that faith groups, communities and healthcare professionals can do is get in there early and walk alongside folk, so that they do not have to suffer and struggle by themselves.

Patrick Harvie: I appreciate that and I have great respect for the sentiment. However, I still worry that we will be asking, "How can we best support you?", while at the back of our minds thinking, "There is one answer to that question that I will not help you with."

The Rev Dr MacDonald mentioned opinion polls and the balance of views. Some people will place a lot of importance on opinion polls and others say that questions lead one way or another or that people have not considered the question in depth, but there is very little evidence to suggest that the balance of views is particularly different between the population at large and the major denominations.

It is also clear that, albeit not among the witnesses who have been invited to speak today, there is a range of views on the issues among the religious communities, including among people who are very committed and involved in their religious organisations. The Rev Scott McKenna spoke at the launch of the bill when Margo MacDonald published and introduced it. He talked about the bill as

"an attempt to bring peace of mind"

and said that he regarded it as

"an act of Christian compassion".

We have also heard, elsewhere in the UK, from a former Archbishop of Canterbury, Lord Carey. He said:

"those arguments that persuaded me in the past"

not to support a change in the law

"seem to lack power and authority now when confronted with the experiences of those suffering a painful death ... there is nothing anti-Christian about embracing the reforms that Lord Falconer's Bill offers."

Rabbi Dr Jonathan Romain said:

"the debate is not—as is often thought—a battle between the religious and secular camps, but is within the religious community too. There are many who have both a deep faith and a desire to see assisted dying legalised in Britain as a voluntary option for the terminally ill ... There are also a growing number of clergy like myself who are only too familiar with those dying in pain"

and want to see them allowed

"the option of assisted death if they so wish."

At a global level, perhaps one of the most famous religious figures in the world, Desmond Tutu, has also written about the issue. He states:

"I revere the sanctity of life—but not at any cost."

He acknowledges many of the issues of context that have been reflected in today's discussion and states:

"I think a lot of people would be upset if I said I wanted assisted dying. I would say I wouldn't mind actually."

Can the witnesses reflect on why none of the organisations has chosen to acknowledge the range of views that exist both among those who subscribe to a religious affiliation and among those who are extremely active and have given the matter great thought in that context? Ephraim Borowski's submission acknowledges that there is a range of views, but the submissions from most of the others and the discussion have not reflected that.

Ephraim Borowski: I thank Patrick Harvie for acknowledging that we acknowledged the range of views within the Jewish community. It is fair to say that there is what one might call a denominational split within the Jewish community. The orthodox community is steadfastly opposed to the proposals; the liberal community is by and large in favour, with caveats; and I think that the reform community is making its mind up. I acknowledge that, but where there is—I am cautious about saying unanimity, because I am talking about the Jewish community—well-nigh unanimity is on the need for far greater safeguards in the current proposals.

You referred kindly to our written submission, which goes through a large number of issues on which we feel that there is a need for considerably greater safeguards, although now is not the time to go through those one by one. That takes us back to practicalities as opposed to principle, but the principle of the bill is one that I think the Jewish community, by and large, would be opposed to.

Patrick Harvie: Would any other witnesses like to comment?

The Rev Dr Harris: Our submission states that there are diverse views within the SEC, and many individuals probably feel quite conflicted. We made reference to Hans Küng, an important Roman Catholic theologian who has made a case for dignified dying in this kind of way. It is important that there are voices that enable the arguments to become very good arguments—it is iron sharpening iron if you can have such a debate within a faith community. I am a great follower of Desmond Tutu, so it is influential when he says something like that.

What concerns me about the context of this conversation is that, as we heard from the last panel, our cultural context is one that tends not to look at death and not to feel very comfortable around death. We know that the writing of wills, powers of attorney, advance directives and so on is very low and that there is an increasing trend towards people not wanting to have funerals. There is in some way a denial that death will come, a denial that death has happened and a discomfort about looking at death. That lack of familiarity with death makes us frightened of death and I am conscious that we have, on the one hand, a kind of denial of death and, on the other, a strenuous effort to allow us to choose it and have other people kill us. It is that context that troubles me.

13:15

The Rev Dr MacDonald: The voices that Patrick Harvie mentioned are really minority voices in all the Christian denominations; they certainly are in our small denomination, which is a conservative—with a small c—denomination. I do not know of anybody who would support assisted suicide. No doubt there are individuals, but I do not know about them. I think that the majority of the faith communities would be against it in general. Sadly, I think that many of those who are in favour of it have not studied the issue in enough detail, as we are doing at the moment and as the committee is doing, which I am glad about; I am very impressed by the deep interest that the committee has taken in the issue. I encourage the committee members to weigh up all the evidence that they have heard, because I think that the evidence is very much against legalising assisted suicide in any form whatsoever.

The Rev Sally Foster-Fulton: The Church of Scotland is a broad church and so, on almost every issue, there are going to be different opinions. That is a good thing because it makes for good discussions. Not that long ago, this issue came to the general assembly and this is the policy that we have. At the last general assembly, the church and society council was asked to reflect again on the issue and we embraced that opportunity. There will be a round table in the next couple of months and we will continue those conversations quite widely and deeply.

Again, it comes down to the way in which we look at death as something very personal and private—as “my death”. If we look at it that way, “my right to decide” seems completely and utterly sensible. It is when we dig a bit deeper that we see the community aspect of all our lives and how my life and my death and what I choose may have unforeseen implications for others. I think that that is one of the main reasons for the Church of Scotland’s decision to oppose this legislation. Also, so many safeguards need to be put in place with this particular piece of legislation that it is quite troubling.

The Convener: I thank you all for your attendance, for your written evidence and indeed for your oral evidence today. We very much appreciate the valuable time that you have given us. Thank you.

13:17

Meeting continued in private until 13:27.

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