The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Wednesday 27 October 2010

Session 3

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

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HEALTH AND SPORT COMMITTEE
30th Meeting 2010, Session 3

CONVENER

*Christine Grahame (South of Scotland) (SNP)

DEPUTY CONVENER

*Ross Finnie (West of Scotland) (LD)

COMMITTEE MEMBERS

*Helen Eadie (Dunfermline East) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Michael Matheson (Falkirk West) (SNP)
*Ian McKee (Lothians) (SNP)
*Mary Scanlon (Highlands and Islands) (Con)
*Dr Richard Simpson (Mid Scotland and Fife) (Lab)

COMMITTEE SUBSTITUTES

Joe FitzPatrick (Dundee West) (SNP)
Mr Frank McAveety (Glasgow Shettleston) (Lab)
Nanette Milne (North East Scotland) (Con)
Jamie Stone (Caithness, Sutherland and Easter Ross) (LD)

*attended

THE FOLLOWING ALSO ATTENDED:

Gil Paterson (West of Scotland) (SNP)

THE FOLLOWING GAVE EVIDENCE:

Dr Colin Barrett (St Margaret of Scotland Hospice)
Sandra Campbell (Royal College of Nursing Scotland)
Jenny Henderson (Alzheimer Scotland—Action on Dementia)
Jacquie Lindsay (St Margaret of Scotland Hospice)
Irene McKie (Strathcarron Hospice)
Katrina McNamara-Goodger (Association for Children's Palliative Care)
David McNiven (Multiple Sclerosis Society Scotland)
Professor Scott Murray (Association for Palliative Medicine)
Dr David Oxenham (Marie Curie Hospice Edinburgh)
Dr Euan Paterson (Royal College of General Practitioners Scotland)
Dr Richard Scheffer (Dignity in Dying)

CLERK TO THE COMMITTEE

Douglas Wands

LOCATION

Committee Room 3

Scottish Parliament

Health and Sport Committee

Wednesday 27 October 2010

[The Convener *opened the meeting at 10:18*]

Subordinate Legislation

Materials and Articles in Contact with Food (Scotland) Regulations 2010 (SSI 2010/327)

Food Irradiation (Scotland) Amendment Regulations 2010 (SSI 2010/328)

Contaminants in Food (Scotland) Regulations 2010 (SSI 2010/329)

The Convener (Christine Grahame): Good morning. I welcome everyone to the Health and Sport Committee's 30th meeting in 2010. I apologise for the delay in starting and remind everyone to switch off mobile phones and other electronic equipment.

No apologies have been received. I welcome Gil Paterson MSP, who is attending the meeting for oral evidence taking on his Palliative Care (Scotland) Bill.

Item 1 on the agenda is consideration of three negative instruments that relate to the amendment of regulations regarding food safety standards to comply with the latest directives from the Council of the European Union on the issue.

Members have a cover note from the clerks that summarises the purpose of each set of regulations. As the Subordinate Legislation Committee had no substantive points to make on any of them, I do not propose to go through them one by one. If members have no comments to make on them, are they content not to make recommendations on any of the regulations?

Members *indicated agreement.*

Palliative Care (Scotland) Bill: Stage 1

10:19

The Convener: Item 2 on the agenda is the Palliative Care (Scotland) Bill. It is our first evidence-taking session on the bill and we have three panels of witnesses today. The first consists of representatives from various voluntary sector organisations. I welcome Dr Richard Scheffer, who is a board member of Dignity in Dying; David McNiven, the director of the Multiple Sclerosis Society Scotland; and Jenny Henderson, the development manager of Alzheimer Scotland—Action on Dementia. Lilian Lawson, the director of the Scottish Council on Deafness, will join us next week.

Mary Scanlon (Highlands and Islands) (Con): I will ask Alzheimer Scotland and the MS Society about something that they raised in their submissions to the committee.

I notice that, on the provisions on reporting, Alzheimer Scotland says:

> "Indicators one to four do not allow for the identification of the number of people with dementia."

It also says:

> "The trajectory of dementia is long; it would be open to interpretation when a palliative care approach was provided."

That is a matter of some concern. Would Jenny Henderson clarify those points for us?

The Convener: The microphones will come on automatically, so witnesses do not need to worry about that. Also, if a member of the panel to whom a question was not directly put wishes to speak, they should indicate to me and I will call them.

Jenny Henderson (Alzheimer Scotland—Action on Dementia): On the trajectory of the illness, we are talking about a period of 10 to 12 years. In the initial stages, someone will be fit but, at the end, if they go through the entire illness, they will become bed-bound and unable to do anything.

At which point does the person gain access to palliative care? Under the definition in the bill, palliative care is about living and dying with the illness, and we are concerned that people with dementia will not be picked up as having palliative care needs until the very last stages of the illness, when we are talking about end of life needs. That last period, when they are in a debilitated state, can last two to three years and the patient may not be picked up at any point as having palliative care needs.

Thanks to money from the Government, Alzheimer Scotland has been instrumental in producing some learning materials to try to engage the workforce in the fact that dementia is, in fact, a terminal disease. There is a huge lack of knowledge and understanding that people live and die with it.

Mary Scanlon: I will ask David McNiven basically the same question. The MS Society raises concerns about the definition of "life-limiting condition". Its submission says:

> "MS is a highly unique and unpredictable condition and as a consequence its impact differs from person to person",

but the point that really caught my eye was:

> "For others, however, improved management and treatment means that MS can be managed like diabetes".

Under the bill, "life-limiting condition" sounds like it is easy to define, but you point out that it is much more complex. Will you explain that further to us?

David McNiven (Multiple Sclerosis Society Scotland): Yes. The diagnostics and categories of the disease are distinctly different. Most people are probably aware of a relapsing-remitting type of onset, in which a patient has acute episodes of inflammation and disability associated with it and then recovers, but not quite to 100 per cent of their previous state. However, there are also primary levels of MS that are progressive and debilitating. Forecasting disability and palliative care needs in such a wide variation of clinical presentation is exceedingly difficult, even for senior clinicians.

Mary Scanlon: The two provisions in the bill are the duty to provide care and the requirement to report on provision.

The Convener: Before you move on, Mary, I invite questions on the definition of "life-limiting condition" so that we can deal with it in one.

Ian McKee (Lothians) (SNP): Mr McNiven said that multiple sclerosis is a condition that can have relapses and remissions; the progress is not even. I think that that can sometimes happen in the course of a long period of Alzheimer's disease as well. There are treatments that can help that to a certain extent for a short period of time. Is that correct?

Jenny Henderson: Yes, they can alter the course of the illness, but there are more than 100 types of dementia and the only ones for which there is a treatment that has any real effect are the Alzheimer's type illnesses. There are a range of other dementias for which there is no treatment.

Ian McKee: The point that I am getting to is that, under the bill, one criteria of a "life-limiting condition"—the sort of condition that a person would have to have to have a right to access palliative care—is that its progress

> "cannot be reversed by treatment".

Do you think that, if there is a statutory requirement on palliative care, that part of the bill could be used to prevent people whom you represent from getting such care, because someone could say that their condition could be reversed by treatment, even though it will ultimately be a fatal condition?

Jenny Henderson: One could argue that the point at which someone is eligible for palliative care is the point when the anticholinesterase medications are withdrawn because they have no effect.

Ian McKee: Would you be satisfied with that?

Jenny Henderson: I am still not sure that the dementia world is sufficiently tuned in to the idea of palliative care that people would access it.

Ian McKee: Based on my experience as a general practitioner, I am concerned that there could be many occasions on which people and families who would benefit from what we loosely term palliative care might not meet the criteria in the bill. I wonder whether the bill might actually be counterproductive, in that it might deny people treatment that would have been given in the past, because health boards could say that they do not meet the criteria in the bill.

Jenny Henderson: That might well be the case.

David McNiven: From the Multiple Sclerosis Society's perspective, we are not sure whether legislating to install the service is a good or bad thing, but we are somewhat dubious about it. There might be consequences for or impacts on other patient groups and disease categories that could cause other legislation to be made in future. Palliative care and specialist palliative care is evidence of good clinical practice. We need a bit more time to bed in the work of NHS Quality Improvement Scotland and the recent papers that have been produced and to allow the services to develop more effectively.

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I want to take that issue a little further. We are considering a proposal for primary legislation. It would be much more serious than an action plan, because we would be embedding stuff that would have to last for a long time, whereas the living and dying well action plan is much more of a moveable feast. We can update and change it alongside developments.

Let us say that a new treatment becomes available for one of the disease groups with which the witnesses are concerned. I believe that one is coming along for Alzheimer's that might arrest things and we might get new treatments for MS. For a patient with Alzheimer's who has been on anticholinesterase, been taken off it and then gone into palliative care, if a new treatment becomes available, they would no longer have a right to palliative care, because there would now be a treatment for the condition. So it is even worse than making a judgment at a given point in time. The judgment could change at a future date, because new treatments might become available.

The bill is about giving palliative care patients a right that is greater than the right of other patients. I believe that the only group that is mentioned specifically in the National Health Service (Scotland) Act 1978 at present is that of mothers and children. Otherwise, there is a general duty to provide care and treatment. How that is provided and the priority with which it is provided is a matter for the health minister through directives to the health boards. The bill would place palliative care patients above all others, except the group that I mentioned, and that would mean that resources would have to be applied to them. If those resources were applied, they would be withdrawn from other services. Are you comfortable with that?

Jenny Henderson: Not really, no. Could the situation not be the same for many cancers now? They are becoming far more chronic conditions.

10:30

Dr Simpson: Yes, absolutely. The point applies to every condition and that is one of my concerns. I just wonder what your views are. Cancer is a huge priority in terms of the Government’s actions—it is one of the top four priority groups—but, at the moment, there is no force in law under the 1978 act, or a modification of that act, to say that we must do A, B and C with cancer.

Jenny Henderson: We are in grave danger of excluding people with dementia from palliative care. We struggle to get end of life care for people with dementia, and the problem could well be that there is no defining point at which we can say whether something is palliative care.

The Convener: Rhoda Grant has a supplementary question on the same issue.

Ross Finnie (West of Scotland) (LD): Can we hear from the other witnesses, convener?

The Convener: I have asked them to self-nominate. If they want to speak, they can indicate that to me, but nobody had indicated that. If you want to come in, Mr McNiven, just let me know.

David McNiven: I would just like to say that we would not like to see services withdrawn from any other category of patients as a consequence of legislation associated with palliative care.

Rhoda Grant (Highlands and Islands) (Lab): My question is on the same subject that Ian McKee and Richard Simpson have addressed, about who qualifies for palliative care. One of the issues is that people do not always know whether their condition is terminal. Someone might be asked to pioneer a new treatment or be offered a treatment that has only a 50:50 chance of success and have to decide whether to go ahead with that treatment. At what point should the palliative care come in? People may know that there is not a huge chance of their treatment working and altering the progression of the disease; however, there may be a small chance that it will. It is a difficult time for people as it is, but they would be being asked to choose between a treatment that carried no guarantee but gave them a chance and palliative care, which might make them more comfortable. Would it be wrong to force people into making that choice, or could the bill be amended to allow people to access both?

Dr Richard Scheffer (Dignity in Dying): It is important not to draw a distinction between palliative care and other treatment, as though they were mutually exclusive. From the papers that I have read, I understand that palliative care needs to be embedded in the whole of health care delivery and not be seen as an either/or.

That seems to be one of the benefits of legislation such as the bill, although I appreciate that this is not the only way in which to deliver universal palliative care. Palliative care must be received by all those who need it. What we welcome particularly in the bill is the education and training that will necessarily go alongside the provision of the care, which will ensure that people learn what patients will be eligible. However, we must recognise that that will not be absolute and that some patients will receive palliative care principally while they are also receiving chemotherapy or treatment for MS or Alzheimer’s.

David McNiven: There is absolutely no cure for MS. A number of disease-modifying therapies are currently used, such as beta interferon, and some other new therapies will be launched next year—probably oral therapies. However, there comes a stage at which those therapies will have no real impact on individuals and, at that stage, we expect the patients that we represent to be able to access good-quality, high-standard palliative care.

Jenny Henderson: We concur with that. An increasing problem is the fact that the public’s perception of palliative care is that it is about dying and people are afraid of the term “palliative care”. It recently took me four weeks to see somebody who was living at home purely because I was introduced as someone who knew about palliative care and worked with people with Alzheimer’s. It was very distressing, as during that time that lady remained at home with bowel impaction, screaming for 22 out of 24 hours. Health professionals were involved, but they were seeing all her symptoms in terms of her dementia and not her physical needs. There are a lot of problems with getting the public to accept that palliative care is a hopeful form of looking after people; it is not just all doom and gloom.

Mary Scanlon: That is helpful. I want to talk about the proposed new schedule 9A of the 1978 act, on reporting and indicators. The basis for reporting is, for example,

> "the average time it has taken for persons with a life-limiting condition whose palliative care needs have been assessed to receive palliative care".

Alzheimer Scotland says that

> "Indicators one to four do not allow for the identification of the number of people with dementia."

The reporting that would be required is a substantial part of the bill. If it does not fit dementia, will you comment on that? Also, is David McNiven equally concerned about the reporting requirements around identifying the life-limiting condition of MS, given what you have said to the committee? How easy or difficult would it be for patients who have MS or Alzheimers to be identified as part of the reporting process?

David McNiven: Data collection would be problematic, partly because of the definition and understanding of palliative care, but it is important. Most of the indicators as listed probably require some considered revision, review, or further discussion.

The Convener: Can you give an example? What would you suggest?

David McNiven: It comes down to the definition and understanding of palliative care. The dataset and how the data are collected at the moment are very much national health service driven. If there is confusion about what palliative care is, even among clinicians, it probably needs those individuals who are delivering the care and those in the Information Services Division, or whoever collects the data, to clarify what would be useful data to collect on that particular population. Some of my colleagues who work in hospices, which we do not provide, are seriously concerned about data collection and how it is out of sync with the traditional datasets that are currently in place in the NHS.

Jenny Henderson: From the point of view of mental health and the dementia strategy, although dementia is embedded in the palliative care strategy, the psychiatric model of dementia does not fully take into account palliative care. There will be a big need for education and I concur with everyone else that perhaps one of the most important parts of the bill is the education side.

The Convener: I will take the committee's guidance, of course, but really the bill has only two parts. There is the definition, which we have dealt with to some extent, and the recording system. I am putting all members' questions on the A list from now on, although some of them will sound like supplementaries.

Ian McKee: One of the World Health Organization's descriptors for palliative care is that it

> "intends neither to hasten or postpone death".

However, there is nothing in those descriptors about the patient's views of what is happening. Proposed new section 48A(1) of the 1978 act refers to provision

> "according to the reasonable needs of such person or persons."

Who decides those reasonable needs? Is that done by a doctor, the Government or the person involved? In what circumstances should a person's definition of his needs be overruled?

Jenny Henderson: The difficulty with people who have Alzheimer's relates to the point at which they lose capacity. The point at which they might have to make an advance decision or statement comes early in the illness. The illness lasts a long time, and people have a considerable period in which they cannot make decisions for themselves. They might have a proxy decision maker in the form of an attorney or guardian, but people in those roles are not well supported. As time goes by, research is beginning to show that such people have considerable difficulties in isolating their own emotional needs from the needs of the person for whom they care. The role is onerous.

We are in danger of creating a situation that cannot be predicted. That is the difficulty. The unpredictability makes the whole situation difficult for people with dementia. On autonomy, Alzheimer's Scotland is pro the person's views and wishes being heard, but making that a reality is difficult.

Dr Scheffer: The question raises one of my organisation's concerns about the issues of definition, which relate to the indicators, too. To answer the question, we would like the emphasis to be laid on patient choices and patients' identification of their needs and wishes. We recognise that some patients find it hard to face up to end of life issues or even to the fact that they face a life-limiting or life-threatening illness. The answer to Ian McKee's question is not one or the other—it is a combination of the patient in particular, their carers and the primary care team, which one hopes would know the patient best. I am happy to leave it there and to return to the definitions issue later.

David McNiven: I reiterate Richard Scheffer's comments. If we are progressing into a society in which patients are expected to have choice and to participate in treatments at the end of life, we expect patients, their care staff and their family to support the decisions that are made on palliative care and at the end of life. That fits comfortably with the living and dying well strategy.

Ian McKee: Would it help if the bill incorporated a requirement to take the patient's needs into account, rather than referring to "reasonable needs"?

David McNiven: That would be a useful amendment.

Jenny Henderson: Alzheimer Scotland's view is that such an amendment would help because it would raise awareness of the need.

Ross Finnie: The need to improve the range, quality and other aspects of palliative care services is not disputed. The Government's response to critical reports on the delivery of those services—particularly, but not exclusively, Audit Scotland's report—was to publish "Living and Dying Well: A national action plan for palliative and end of life care in Scotland".

I am interested to hear to what extent you believe that that plan is deficient, inadequate or whatever word you care to ascribe to it, and whether it would be better for the plan to be replaced by the bill. I ask that question because it has been put to us by Government officials that, in considering how they wished to or thought it best to address the deficiencies of the delivery of palliative care, they did not think of introducing legislation, nor did they think that the bill would make any material difference to the living and dying well programme.

10:45

Jenny Henderson: Alzheimer Scotland's position on the living and dying well plan is that it is an excellent plan that has brought to the fore the needs of people with dementia and made them much more mainstream. The plan is far more inclusive. I am not convinced that the bill would make a great deal of difference. Far more important for people with dementia are the dementia strategy and the emphasis that is being placed on dementia in other areas. People who are progressing through the illness obviously have needs, but I think it is more important to incorporate that into the strategy.

Dr Scheffer: The question is a good one. We found "Living and Dying Well" a very good document. However, we need to ensure that the aspirations in the plan are applied throughout the country and we must monitor that to ensure that patients have equal access to high-quality palliative care when they need it. As I said earlier, one way of doing that is through such a bill, but we must ensure that it has clear definitions and easily measurable outcomes. Clearly, there are other ways of working jointly to deliver on aspirational documents such as "Living and Dying Well".

David McNiven: I cannot add much to those comments. It is a complex question to be asked. I would just say that it is interesting to note that colleagues in Government are concerned that the bill would make no material difference.

Ross Finnie: Sorry—could you repeat that?

David McNiven: You stated that there would be no material difference.

Ross Finnie: That was put to us, but it is open to you to disagree with that.

David McNiven: I do not think that having legislation will make a material difference, from the society's perspective.

Rhoda Grant: On the general aims of the bill, we are all aware that palliative care tends to be available for cancer patients through the hospice movement, because it tends to focus on those people. We have representatives here of people with other conditions, and there are further ones such as heart disease. Is the same care available across illnesses? If not, would legislation change that situation and give people that equity? I feel that provision is quite unbalanced at present.

David McNiven: It is interesting to note that only 11 per cent of patients who gain access to services in some hospices in Scotland are non-cancer patients with, perhaps, cardiac or neurological diseases. There is a significant inequity in service delivery for those people.

Dr Scheffer: Inherent in the question is the point that we were trying to make earlier, which is that palliative care needs to be embedded in health care generally. The total care of people throughout their illness is important. It should not just be about end of life care; it should be about living with that illness and with all the complexities of a diagnosis throughout the illness.

One of the issues for me is the definition of how palliative care is delivered. The point has been made in some of the papers that the vast majority of palliative care is delivered by generalists—by primary care teams. I would argue that there is inequity. I have never worked in Scotland, but if I assume that what happens in England happens in Scotland, there will be inequity. That is why it is so important that we identify what is available and have an education and training programme to support it, to ensure that the standards are reached by all the generalists who are delivering it.

Specialists all deliver excellent care, but we need an education and training programme there, too.

Jenny Henderson: Many people with dementia are cared for in social care settings rather than under direct health care. That is another reason why the bill may not pick up a lot of people with dementia. There is a great need for training on people's palliative care needs in that setting as well.

David McNiven: The Multiple Sclerosis Society is concerned about what may happen in the health budget over the next wee while. Our population needs a working partnership with local authorities. If serious pressure on local authorities' budgets means that there is pressure on the services that they currently provide, that may impact on our population.

The Convener: I do not know whether Richard Simpson wants to ask a question or whether he is just smiling at me.

Dr Simpson: Proposed new section 48A(2) of the National Health Service (Scotland) Act 1978 says:

> "Nothing in subsection (1) shall require the Scottish Ministers to provide any treatment, help or support which is the duty of any other person to provide."

My understanding is that that refers to local authorities. It means that not only would the proposed legislation not lead to the provision of holistic palliative care, but, despite its references to spiritual and other types of support, it would preclude the minister from directing or dealing with the generalist aspects of care that were extremely important to me when I was a general practitioner. If I did not get the support of other providers, it was a major difficulty. I think that another dividing line is being created, but I would like to hear your comments. Is that a danger? Should we amend the bill in some way?

Jenny Henderson: I think that that is a danger. There are still a large number of people with undiagnosed dementias in the social care setting and in care homes. We do not have a good grasp on the issue. About 30 per cent of people with dementia have been formally diagnosed. Many of the people who have not been diagnosed are in care homes. I think that you are right—it will be another divide. I concur with what has been said about the problems that will be caused by the financial constraints on local authorities. As it is, there is no money within the care home sector for training and so on. It is a difficult situation.

Helen Eadie (Dunfermline East) (Lab): My question is on the financial aspects of the bill, especially in relation to the voluntary sector, which is referred to in evidence to the committee.

We know that the bill does not place any duties on the voluntary sector and that the financial memorandum considers that there will be no additional resource implications for the voluntary sector. That tends to fly in the face of some of the replies that we have received from members of the public and, in particular, from the voluntary sector.

Jenny Henderson and David McNiven have alluded to the fact that your organisations provide services in partnership with the statutory sector. There appear to be concerns about the financial implications of the bill, especially in the context of the national economic situation. Can you expand on your concerns about the impact on the voluntary sector of increased staffing, training, education and carer support costs as a consequence of the bill? You said that generalist services are integrated, but you indicated that there may be particular problems for specialist services.

Jenny Henderson: The Government has been generous to Alzheimer Scotland, which has been able to provide a free programme of education in palliative care and dementia for care home staff and some health care staff. That has enabled us to provide an excellent resource. However, in these difficult economic times, it is becoming far more difficult to drive that work forward, because we now have to charge care homes and the health service to access courses, and far fewer people are coming forward to do them. We have succeeded in creating a number of dementia palliative care champions, but we have reached only about 100 of the 960 care homes. It will be extremely difficult for us to reach out to all care home and health care settings.

David McNiven: One of the exciting things about being in the voluntary sector is that, generally, we are quite small and fleet of foot. We can influence and work in partnership quite well with many organisations, which is an exciting situation. Equally, we are under significant economic pressures. Our fundraising capability is dropping noticeably in this economic climate.

I refer the committee to a recent care issue in which I have been involved; although it does not involve palliative care, some people around the table may be aware of it. The costs of staff and care delivery to meet the requirements of caring for people with long-term neurological disease and to provide the quality of care that the Scottish Commission for the Regulation of Care demands are significantly at variance with what social services or social work are able to fund. There is a significant gap in relation to the staffing skill sets and so on that we are required to provide. The commissioners of services—local authorities—do not seem to have the funds to provide such care. The economic climate is impinging on us, even though we are a relatively small, fleet-of-foot group of organisations.

Dr Scheffer: For 20 years, I worked for a voluntary care organisation in England as a consultant in palliative medicine. I am sure that making palliative care available universally will involve increasing demand on services. Although some savings—from reducing hospital admissions and so on—have been identified, unfortunately the services to care for people, especially at the end of their lives, are staff intensive and cost money. Inevitably, there will be pressure on the delivery of current specialist palliative care services. Although not everyone will need them, there will be an increase in the number of people who need them. That money will have to be found somewhere.

11:00

I reiterate David McNiven's point that voluntary care organisations are good at delivering their service and finding ways around problems, but there are inevitable limitations to that. We should not ignore the pressures to which generalists who deliver palliative care would be subject. Even collection of the data that the bill requires would require time and technology. Apart from anything else, that would have financial implications.

One of the worrying things that my experience in England suggests is that, unless money is clearly identified for palliative care, it is easily lost in the system. Because of the pressures and priorities that they face when delivering services, health boards do not always give palliative care the same priority that palliative care deliverers give to it. The only way that we have found of ensuring that the money gets to palliative care is to ring fence that in some way.

The Convener: That would make the bill a good thing, as it would ensure that palliative care was given priority. Is that what you are saying?

Dr Scheffer: There are advantages and disadvantages to the bill. It would be an advantage if money were ring fenced in some way. Given the current climate, one wonders whether the money is there to be ring fenced.

Helen Eadie: I am grateful to members of the panel for their answers, especially the point that Dr Scheffer has just made. One difficulty, which is mentioned in our papers, is the underestimate of the cost of collecting data. That is a big worry for all of us, because we do not always know whether estimates are correct.

Given that the bill raises expectations of rights among your membership, do you think that additional costs might follow from the potential for legal challenge? Some respondents to our call for evidence raised that issue. Do you perceive it as a problem?

David McNiven: I represent a membership of about 40,000 across the United Kingdom and 10,500 to 11,000 in Scotland. Rightly and properly, the bill would raise expectations. I am not in a position to comment on whether it would lead to the additional costs to which you allude.

Jenny Henderson: It would give people some hope.

Dr Scheffer: I do not represent an organisation that has a membership in the way that my colleagues' organisations have, but I argue that the bill would inevitably raise expectations. That takes us back to the definitions in the bill and the indicators. We must be absolutely sure that they make clear what would be delivered.

The Convener: Thank you for your evidence. I suspend the meeting for a couple of minutes while we get in the next set of witnesses.

11:03

Meeting suspended.

11:08

On resuming—

The Convener: Our second panel of witnesses represents the hospice sector. I welcome Dr David Oxenham, medical director of Marie Curie hospice Edinburgh; Irene McKie, hospice director at Strathcarron hospice; Dr Colin Barrett, associate medical director at St Margaret of Scotland hospice; and Jacquie Lindsay, nurse lecturer at St Margaret of Scotland hospice. Good morning. Your microphones will come on automatically when you speak. If you want to answer a question from a committee member that is not specifically directed at you, let me know and I will come to you.

Helen Eadie and Mary Scanlon have indicated that they have questions—the women are quick. This time I will start with Helen.

Helen Eadie: I will start with some of the financial questions that I put during the previous evidence session. My first question is directed at Strathcarron hospice. I was interested to read in its submission that the hospice believes that

"There is no evidence to support the assertion"

in the financial memorandum that the bill will have no financial implications for the voluntary sector, and that it is concerned about the future funding of hospices. It would be helpful if Irene McKie could clarify the hospice's position on that assertion.

Irene McKie (Strathcarron Hospice): I am concerned about the future funding of hospices.

For example, according to an HDL, hospices are entitled to 50 per cent of agreed costs and—

The Convener: Just to clarify, I point out that HDL stands for health department letter.

Irene McKie: That is correct. The HDL itemises the costs that we are entitled to 50 per cent of; those, such as drugs costs, that we are entitled to 100 per cent of; and those that we have no entitlement to. There is a proposal to withdraw that HDL and replace it with a much more general chief executive letter that talks about working with health boards to achieve 50 per cent funding. We do not know what that means. At the moment, for example, all hospices receive 100 per cent funding for drugs, but the new CEL does not specifically say that that money will be protected. I do not think that there is any short-term intention to remove that funding but, as health services try to tighten their budgets, that is a risk.

I feel that the funding of hospices is vulnerable. Indeed, because of general slippage, we get only 42 per cent of agreed costs instead of 50 per cent. On the provision of palliative care, which is what the bill is proposing, I have at the moment 10 community nurse specialists who visit people in their homes. The 10th nurse was appointed because we had a 2 per cent increase in referrals, but I have not received any funding for that post from the health service because it cannot afford it.

Helen Eadie: Are you suggesting, therefore, that the proposals in the bill will have new cost implications or that there are certain cost implications associated with palliative care homes in general? I get the impression that it is the latter rather than the former.

Irene McKie: The bill itself raises a number of specific issues. For example, if we were providing community support in all homes but were not entitled to the full costs involved and there happened to be, say, an increase in referrals, presumably the bill would require us to provide the service unfunded.

One of our concerns about the bill is that there will be a cost in collecting the information. As we have very small administrative staffing teams, we are simply not geared up to collect some of the data that the bill proposes should be collected, and the process will take time that we do not have at the moment.

Helen Eadie: One criticism is that the costings in the bill are vague; indeed, some respondents to our consultation have suggested that they have been underestimated. Do you agree with comments made by our earlier witnesses and other respondents that there are issues about the costs of staffing, training, education and carer support? Would such costs arising from the bill impact on your organisation?

Irene McKie: The biggest impact would be on education. We provide a lot of education to the wider NHS and to care homes and are finding more and more that those organisations cannot afford to release people for courses, because they would have back-fill, and that staff are finding it very difficult to attend.

The Convener: Does anyone else wish to comment on costs?

Dr David Oxenham (Marie Curie Hospice Edinburgh): Previous evidence has suggested that the costs of the bill would be included in funding ascribed to living and dying well, but it is difficult to see how that might be the case. After all, the bill would engender an expectation of additional resource and therefore additional costs. Some costs would be a result of existing services seeing themselves do something different, but there would certainly be an expectation of additional resources and I do not know where, at present, they would be delivered from.

Helen Eadie: Might such expectations arise because, as I suggested to the previous panel of witnesses, when more rights are enshrined in law, people are more likely to take challenges to the courts, which only adds to cost burdens? Do you think that, as a result of the bill, certain unanticipated and unestimated costs might enter the scenario?

11:15

Dr Oxenham: When their mothers, their husbands or whoever feel poorly and are not going to get any better, people start to have strong feelings about issues such as palliative care. Indeed, I have patients at the moment who ask about their rights, and I would be surprised if what you have suggested was not taken forward by someone in distress who felt that things should have been different.

Jacquie Lindsay (St Margaret of Scotland Hospice): Although I support the comments made by Ms McKie and Dr Oxenham about costs, I should perhaps turn the issue on its head. I believe that in many respects the bill will bring a huge shift in thinking. As palliative care practitioners, we work in that environment and have experienced people’s passionate feelings about end of life situations and the effect on family members of the diagnosis of a life-limiting illness. I understand Ms McKie’s point about the funding not being concrete at the moment and hope that the bill will resolve the issue in some way by ensuring that funding is secured.

An earlier witness suggested that in a crisis palliative care could go under or indeed off the radar of many Government and health care strategies, and I am not sure that, in an environment in which so many people are living with very complex illnesses, we can afford for that to happen. The cost of providing palliative care will be far outweighed by the cost of not providing it. In the lead-up to the meeting I looked at NHS complaints and found that the cost of trying to manage end of life care complaints is immense. I am not saying that the bill will resolve all that but we hope that, given the philosophy and approach behind palliative care and if people are well educated and patients and families are well cared for, the number of those complaints will fall. Given that the complaints fall between staffing and the general environment, embedding palliative care in clinical practice will immediately remedy some—though not all—complaints. After all, not all complaints are related to palliative care.

The fact is that end of life care for patients in the current NHS structures, in the community, in care homes and possibly in some hospices needs to be looked at. Given that we are already heavily regulated, I am not sure that the cost of further regulation should concern us hugely. It would be wonderful if all of this could be tied together to ensure that we are not continually reproducing figures but producing meaningful information that makes a difference when it is sent to Government.

Dr Colin Barrett (St Margaret of Scotland Hospice): I agree that different hospices receive different levels of funding for different functions. However, community palliative care also receives different levels of funding. The bill will undoubtedly have cost implications, but given that part of its intention is to ensure equity of access across Scotland, it should at least bring up the level of funding in different parts of the country.

Helen Eadie: I thank the panel for those responses. I do not disagree with your comments about the cost implications, but it is important to be well informed about the issue.

The Convener: Ian McKee and Rhoda Grant have supplementary questions on the cost implications.

Ian McKee: Right at the beginning, the bill states:

> “The Scottish Ministers shall provide, or secure the provision of, palliative care”.

I gather that the hospice movement in general is not funded wholly by the NHS and in fact receives quite a lot of its income from charitable donations and so on. To my mind, it is possible that in times of financial difficulty such donations could diminish. After all, if they have less disposable income, people might give less to charity.

There might also be a risk that when the public know that a bill has gone through that makes it the duty of the Scottish ministers to

> “provide, or secure the provision of, palliative care”,

they might ask, “Why should we be giving to St Columba’s hospice or Strathcarron hospice if it is the duty of the Government to provide care in the national health service?” Is that a concern? Is there a possibility that the Scottish Government might have to increase its expenditure on palliative care to meet any potential diminution in charitable donations?

Irene McKie: We do not just get a contribution from charitable sources; 62 per cent of our income comes from charitable sources. We have seen a reduction in some sources of income during the recession. General donations have reduced and trust funding has reduced dramatically, so it has been difficult. My hospice runs with a deficit. I suspect that because we already run with a deficit there is no reason to suppose that the NHS would make it up. That is the first risk.

We already have a problem in that many of the people whom we support think that the NHS is fully funding the service. People think that their donations pay for the extras, but, in fact, their donations pay the phone bill, the electricity bill and the staff wages.

Dr Barrett: I agree with Irene McKie. There is undoubtedly downward pressure on donations and funding, which will continue for the next few years, as there is a depression on. It is important for everyone to know that hospices take seriously ill patients from the acute sector and put them into the right care setting for them. It is only right that the health service should fund that to the best of its ability. Undoubtedly there will be downward pressure from the health boards because of current financial constraints. It is a very difficult situation that will get worse over the next few months or couple of years.

Jacquie Lindsay: I do not think that the public would give less. When the public receive a good service, they could not give more. I agree with Irene McKie that the public already believe that the NHS fully funds hospices. People are quite shocked when they find out that they are not and wonder why not. I do not think that the public would give less just because there might be a possibility that the Government would give more.

Ian McKee: It is interesting that Ms McKie says that she has seen contributions diminish. It occurs to me that if the bill became law, the Government would be responsible for ensuring provision of palliative care. If your contributions were suddenly halved, or something dramatic occurred, the Scottish Government would have to pick up the tab; otherwise you would stop providing that service. Is that right, or have I misunderstood the situation?

Dr Oxenham: I think that that is probably for the Scottish Government to decide, rather than for us to say, but that would seem the logical conclusion.

Dr Barrett: Even if funding were to dry up, the need and requirement for palliative care will continue. In fact, given our ageing population and a host of epidemiological factors, the need for palliative care will be on the increase—it will not go away.

Irene McKie: We have different staffing levels and different types of staff in different numbers from the NHS. In the debate that we would have with the NHS, I think that it would simply require us to reduce the service that we offered. I do not think that it would let us close beds or stop visiting patients—it would instead expect us to reduce the frequency of visits and the number and range of staff on shifts and just not provide what we would consider to be a specialist palliative care service.

Rhoda Grant: I want to explore that a little further. Ian McKee is right that if the bill were passed the duty would fall on the NHS to provide palliative care. One assumes that it would then have a duty, where that situation occurred, to step in and do something. Perhaps it would help if you explained the situation to us a bit more. You have talked about referrals from the NHS and receiving 50 per cent of funding from it. If the bill were passed and there was a duty on the NHS, it could just up its referrals to you. Does any money follow referrals? If you suddenly had double the referrals, would you get double the money from the NHS? How does it work? How would that have to change, in light of the bill?

Irene McKie: It does not work that way. When there was a 22 per cent increase in referrals to home care, we did not get any funding for an additional home care nurse, although we felt that we had to put one in place. We work on the basis of block grants. At one point, they were worth 50 per cent. Each year, they are uplifted by a particular percentage. For example, this year my hospice paid the same pay increase that the NHS did, which was 2.25 per cent. The increase in our budget from the NHS was 2.15 per cent. On top of the actual pay award, staff get increments. Overall, hospice costs went up by about 4 per cent, although the increase in our budget from the NHS was 2.15 per cent. That meant that the percentage of funding from it reduced slightly.

Dr Oxenham: It works differently in different places. I represent Marie Curie, which includes the Marie Curie nursing service. We deliver nursing care to patients in their own homes, particularly at the point, during the last few days of life, when they are dying and wish to stay at home. That is funded differently, on an hour-by-hour basis. If more people need that service than is agreed with the particular health board, we go back and speak to the health board about how exactly we will deal with it. We work with the various health boards in Scotland to explore how best to deliver as much care as possible to patients so that they can stay at home and be cared for properly. That applies particularly to the nursing service when people are dying.

Our health board has been very generous to us, and we have worked together closely in Edinburgh. NHS Lothian has increased the funding to the Marie Curie hospice in Edinburgh, as we have an agreed vision of how we will deliver palliative care to people in Lothian in a better way. That is based on “Living and Dying Well”, which provides us with a coherent framework for improving palliative care.

One of the indicators in the bill is the number of people who receive palliative care, and it is just about the only indicator that is easily gathered at the moment. That is done through a general practice direct enhanced service—it is not fixed in law forever. Between 2008 and 2009, the number of people who were registered as being in a recognisable palliative care phase of their illness increased from 950 to 1,750 in Lothian. The living and dying well action plan has been delivering benefits, through collaboration across a range of services. It feels to me like a better way forward.

The Convener: Your helpful response contained something of a suggestion that there is a postcode lottery. You said that some boards are helpful and are funding you well, for instance, and that you are in discussions with them and so on. One argument for the bill is the desire to eradicate the patchy delivery of palliative care. Would that be the case? Would the bill assist in that regard? First, is it the case that there is a bit of a postcode lottery or NHS board lottery?

Dr Oxenham: There are variations. There is a discussion about centralisation and decentralisation. We cannot have both absolute equity on every measure across the whole of every health board and decentralised local decision making. The Audit Scotland report identified variations in the rates of dying at home in various parts of Scotland. However, those variations are complex. For example, it is difficult to compare rural Lanarkshire with inner-city Glasgow. The nature of the services that are needed to deliver the same palliative care is very different in each place. I am not clear that the indicators that are set out in the bill will enable you to say that you are delivering equitable palliative care.

11:30

The Convener: That is helpful, thank you.

Dr Barrett: I think that it is a matter of public record that in Glasgow we have, on a number of occasions, been at loggerheads with the health board about finances. David Oxenham is right that Audit Scotland identified quite marked inequities across hospices in different parts of Scotland—I presume that we will come back to that.

It is important to bear in mind the fact that when hospices take patients from the acute sector, we save the acute sector a significant amount of money. Beds in hospices are funded at only 50 per cent of NHS costs, whereas the health service funds 100 per cent of the costs of patients in general medical beds or acute intensive care beds. Hospices take patients and unload costs from the health service.

Mary Scanlon: I will briefly quote from the submissions from Marie Curie Cancer Care and Strathcarron hospice. Dr Oxenham referred to the living and dying well strategy. The Marie Curie submission states:

> "We are very much engaged in and fully supportive of the implementation of Living and Dying Well and welcome measures to monitor and further progress".

Ms McKie, in the submission from Strathcarron hospice you state:

> "We wonder whether it is necessary to have a Palliative Care Bill as well."

Can I take it from your submissions that you feel that sufficient progress is being made through the living and dying well strategy and action plan? You mention that further progress is being made. I do not want to put words into your mouth, but do you think that enough is happening and that the bill will not add much to that? Is there any point in having the bill? Ms McKie states that she wonders why it is necessary.

Dr Oxenham: It would be difficult for a palliative care clinician to sit here and say that they do not want a statutory duty to provide palliative care. That would seem like turkeys voting for Christmas. The principle of the bill—to ensure that everyone in Scotland accesses palliative care when they need it—is fundamental.

My challenge and Marie Curie's challenge with the bill is that we are making good progress with the living and dying well action plan. There is a huge amount of support from professionals throughout Scotland. We have a national "Do Not Attempt Cardiopulmonary Resuscitation" policy. If you go to other countries, you will not find such a cohesive policy across the whole nation. Electronic palliative care summaries are also a special development that we are just trying to get our heads around and work with.

I therefore cannot answer either of your questions. I do not know whether enough is being done, but we are certainly making progress and we have a focus. I guess that we feel that the bill may distract from that focus, so although it may not be the wrong bill in principle, it may not be the right time for it, because it may take us away from what we are doing. The discussion about definitions with the first panel of witnesses was fascinating, but if there were 10 palliative care clinicians in this room, they could discuss definitions for hours.

The Convener: Not if I was chairing the meeting.

Dr Oxenham: In order to get the bill right, you would have to have those discussions, so at this point the bill might be a distraction. However, if the living and dying well action plan does not deliver enough, we might come back and say, "No, this is the right thing to do."

Mary Scanlon: You mentioned the statutory duty to provide palliative care in section 1 of the bill. From my knowledge of the living and dying well action plan, is there not a duty or an obligation to address people's palliative care needs? It might not be a legal duty, but are you not already working towards each person having access while being assessed and reviewed?

Dr Oxenham: Absolutely. I fundamentally feel that every person in Scotland who is going to die at some point, whether it is in a few weeks or a year or two, should be identified so that, jointly with that patient and their family, we can decide what we will do to support them.

Mary Scanlon: That—

The Convener: Can I let the other witnesses answer your first question, Mary?

Mary Scanlon: No, I am sorry, but this is important. Dr Oxenham, that is in "Living and Dying Well"—that is the point.

Dr Oxenham: It is there; it is not a statutory duty.

The Convener: I want to go back to the first question, in which you named Ms McKie, Mary. I think that she is itching to get in.

Irene McKie: I think that we are making good progress with the living and dying well action plan. Health systems are working closely together. They are involving their hospices, community staff and acute staff, and they are working on action plans. The developments that David Oxenham has named have been really helpful—they have let the whole system identify the basic building blocks that need to be in place to improve palliative care.

I do not think that as an organisation we ever sit down to ask whether the plan is technically a legal requirement. We see the living and dying well action plan as something that we have to work towards implementing as much as we can. The fact that the action plan is not a bill does not give it any less substance. As was said, the bill is a distraction. I think that enough progress is being made under the living and dying well action plan.

Dr Barrett: I agree that the living and dying well action plan is a great step forward. Great steps have been made throughout Scotland, which I hope will continue. Apart from taxes nowadays, the only two certainties in life are that we were born and that we will die, and I can understand the disquiet felt by any professional clinician that one part of a service would have legislation but another would not. Palliative care has been a Cinderella service for years, even more so now. It has always been seen as outwith mainstream surgery or medicine, but as we move into the economic downturn it seems more important, with greater ageing populations, that we ensure equity of access and funding for such services.

If the living and dying well action plan were fully implemented and it were a legally binding document, there would be no need for an act. Its parameters are first rate, but there is no obligation on health boards to implement anything beyond the funding that they have available. That is the difference that an act of Parliament would make.

The Convener: Ms Lindsay, do you want to come in on that?

Jacquie Lindsay: Yes. I support what everyone has said, and I want to pick up on a point about a postcode lottery that David Oxenham and perhaps you, convener, made earlier.

The bill supports the living and dying well action plan, and it is important to note that the bill was created before the action plan. That is why some of the indicators are far off what is contained in the living and dying well action plan. Some work needs to be done with the professionals whom David spoke about to bring the indicators into line with the living and dying well action plan. We must report on what is measurable with continuity; we cannot have something that is completely separate.

The bill would take the living and dying action plan a step further and endorse its work. If the indicators were identified and people felt that it were possible, there would be a national access and national quality framework. Capturing numbers and attributing quality would be difficult, but in the first instance, when we have no idea what general palliative care costs, step 1 should be to elicit what we are spending on looking after people who are diagnosed with a life-limiting illness and moving towards end of life care, and to identify at what point that care shifts and the finance moves into the specialist realms. Not every patient who has a life-limiting illness requires specialist palliative care.

On cost, we need to find out how much we are spending and, as David Oxenham said, how many people require palliative care. We then need to take the actions in the living and dying well plan to ensure that they continue far beyond what has been committed by NHS structures. In achieving an implementation programme, we need a measurable outcome.

Dr Oxenham: The bill includes important elements that are in place under the living and dying well action plan, but there is no law that says that they will exist forever. That is the strongest argument for taking forward elements of the bill.

Ross Finnie: The bill raises an important principle. At the moment, under the National Health Service (Scotland) Act 1978, the minister has a general duty to promote

"a comprehensive and integrated health service".

At present, that tends to operate through the minister issuing either directions, guidance or strategies. In the case of palliative care, that happened following quite severe criticisms, particularly in the Audit Scotland report, of the failure of delivery across the country. Everyone has referred in reasonable terms to the living and dying well action plan, which is important in that regard.

The important matter of principle that I want to press you on concerns whether you believe that it would be an improvement to commit every major issue—cancer, coronary disease, palliative care and so on—to separate legislation, which would shift the whole way in which we operate. That is the principle that the bill opens up. Do you believe, on balance, that that direction of travel is in the best interests of health care delivery?

Irene McKie: No, I do not. If you have a bill for one specific part of care, other specialties will want legislation to be introduced for them as well.

Dr Oxenham: I think that palliative care is different, because everybody dies. I ask medical students what they think the mortality rate was in the 1700s, and they look blank when I tell them it was 100 per cent. I then ask them what it was in the 1900s, and many still look blank. Some do not even get it after the third time. The mortality rate remains at 100 per cent.

Unless someone is knocked down by a bus or undergoes some other sudden event, there will be an identifiable palliative phase to their life, aside from any illness. At the moment, we do not easily recognise that. It is difficult to do so. The members of the previous panel alluded to the difficulties in relation to diseases other than cancer. The reason why there are cancer hospices is that you can spot the palliative phase in relation to cancer. If you cannot spot that phase, you cannot deliver that care. However, we are getting better at that.

Palliative care is different, and having a duty to provide palliative care does not open up a duty to provide effective ingrowing toenail treatment.

Ross Finnie: But it already does. I am sorry, but that is the case, unless I have misunderstood things. Are you saying that the provision in the 1978 act that imposes a general duty to provide

"a comprehensive and integrated health service"

excludes ingrowing toenails?

Dr Oxenham: No, it encompasses all of that, but it is helpful to send the message that, over the next 10 to 20 years, attention to palliative care will become increasingly important as we get to the stage where someone's illness will not be addressed simply by throwing more potentially curative treatment at them.

Ross Finnie: And the living and dying well action plan does not do that.

Dr Oxenham: The living and dying well action plan does do that. We should work with that strategy and introduce a bill at some point in the future if we find that we have not made sufficient progress. I reserve the right to come back to you at some point and tell you that we need a duty—and, furthermore, that that duty is different from a duty that might exist in relation to cardiology.

11:45

Dr Barrett: You make a very reasoned case. The bill could open the door to other specialties coming along, but it would be within the remit of the Parliament to assess that. The essential difference is that, for 99.9 per cent of patients, the health service is about diagnosing and treating conditions to the best of its ability. Once someone becomes a palliative care patient, we have moved beyond that in that we have recognised a life-limiting condition—whether the person has weeks, months or whatever—and it is about ensuring access to those services that, in fairness, the health service is not as well geared up to provide in terms of diagnosis and acute treatments or planned treatments for on-going illnesses. That is right at the other end of the spectrum.

Jacquie Lindsay: I agree with David Oxenham that everyone who is diagnosed with a life-limiting illness requires palliative care to ensure that they can live life as fully as possible and die in a way that they regard as right and fitting for themselves, having been negotiated with professionals. I have no doubt that, if I were to present at an accident and emergency unit with chest pain and the beginnings of a cardiac incident, I would be seen by a cardiologist. However, I am not convinced that, if I were to turn up with a life-limiting illness, I would immediately see someone who was equipped in palliative care. I would possibly be admitted to a medical ward and I could become hidden.

David Oxenham makes the important point that it requires someone to know about palliative care and spot when it is needed. Will the bill make a difference in the first instance if we do not push forward a national education strategy to establish the building blocks that Irene McKie spoke about? Possibly not. However, five to 10 years down the line we could gather enough evidence to change the way in which nurses and doctors are educated to ensure that palliative care education is embedded from day one when someone enters university. We must ensure that the people who are required to spot those who have palliative needs have the right education, skills, knowledge, confidence and support. At the moment, even with the improvements that have been made through the living and dying well strategy, I am not sure that that has been achieved.

There is already disgruntlement among NHS boards about whether anticipatory care plan training will be undertaken. I am not sure that that is in the best interests of the public. Palliative care must take a person-centred approach—it is about what the patient requires. Yes, we have to provide that within a very tight structure and sometimes do that, after great discussion, in partnership with other groups. However, I am not sure that the living and dying well strategy will achieve all of that without having some reportable, measurable outcome.

Ross Finnie: Is that not a damning indictment of the very narrow view that those who run the health boards take and of their equally narrow view of their current statutory duty under section 1 of the 1978 act to provide and promote

"a comprehensive and integrated health service"?

Dr Oxenham: It is about timing, is it not? The bill was produced before we could sit here and tell you that the health department is taking the matter seriously. It was produced before we had an action plan for palliative care and end of life care. If you had asked me at that point whether we should have a bill—with the health department having no strategy and nothing else in place—I would have said, "Well, we had better have something." We are now working on something that is working very effectively. Although we may need to come back to it, our focus should now be on delivering really effective improvements in care for patients and their families.

The Convener: I want us to move on, as time is pressing and we have a lot to do today.

Michael Matheson (Falkirk West) (SNP): I want to pick up on the concept of palliative care taking a person-centred approach. I fully agree with that. However, our witnesses will recognise that a lot of palliative care is not provided by hospices or other specialist organisations that work in that particular field.

There is a very good hospice in Strathcarron in my constituency that is led by Irene McKie. The complaints that I receive from constituents are often not about the palliative care that they receive in hospices and specialist facilities but about the care that they receive as part of the general health care provision, whether that is at primary care or acute level.

I hear what you say about the living and dying well action plan, and I understand your experience with it given the specialist field in which you operate, but I wonder whether we are achieving enough in terms of embedding the provision of palliative care much more effectively in the wider NHS, among those who are working in that general field. Is there one aspect of the bill that could assist in ensuring that that takes place more effectively, and that everyone has a responsibility to provide palliative care?

Dr Oxenham: The living and dying well action plan is predominantly about generalist palliative care. If the bill placed a duty on ministers to put far more funding into palliative care provision and education, palliative care would improve more quickly. However, I am not convinced that the intention of the bill is to ensure additional funding for palliative care.

In the absence of that, we need to focus on generalist systems that help everyone. We need to help everyone to understand the anticipatory care planning to which Jacquie Lindsay referred. The do not attempt resuscitation policy helps people to communicate. We are now doing the same things, so it is not just me who discusses with the family the fact that we will not resuscitate their dad because it will not work. We are not giving the family a choice about it; we are just saying, “Look, we just need to share with you the information that resuscitation will not work for your dad, so we feel we should do everything that we can to avoid it.”

Those things are all happening in generalist settings. I cannot put information into the electronic palliative care summary; only GPs can do that. People like us now have structures within which we all work, and we can all help the generalist approach in our own geographical areas so that we understand it and work towards ensuring that we have consistent educational messages and systems. That is the main driving force behind the benefits of the living and dying well action plan.

Dr Barrett: A significantly large majority of palliative care undoubtedly takes place in the community, but there are differences in funding throughout Scotland. Currently, no statute dictates what health boards must put into community palliative care budgets. On occasion, the funding is simply what is left over or what a board can afford in comparison with other services. There must be some statutory obligation to ensure that palliative care is adequately funded on an equitable basis across Scotland, whether it is being provided in Glasgow, Edinburgh or the Highlands. Audit Scotland highlighted the disparity in funding as being partly accountable for the current situation.

Irene McKie: A number of initiatives, such as the gold standards framework in general practice and the electronic palliative care summary, have helped. There has been a huge shift in the NHS and its understanding of the benefits of palliative care. The risk at the moment relates to what is affordable. For example, when we consider how we implement some of the changes in the local health system, we sit in a palliative care strategy group and wonder how the NHS can afford to release staff to get the training that they need.

Unless the bill will improve funding, it will not make a difference. However, the will is out there in the health service to embed general palliative care across the service.

Michael Matheson: David Oxenham has suggested that the timing of the bill might be wrong, in that the living and dying well action plan is now in place and we must give it time to prove itself. What should the timescale be for us to wait and see whether the living and dying well strategy delivers what it is meant to?

Dr Oxenham: That is a good question.

The Convener: You are blushing.

Dr Oxenham: I had not really considered that question. I hope that I am not blushing.

I would say that we should come back to it in five years. If the living and dying well strategy does what it is supposed to do, there will be measurable improvements in palliative care in the next five years. We need to keep the palliative care direct enhanced service for GPs for that time so that we can have some of the indicators that are necessary to measure improvements. We are still learning things about palliative care and there are a number of other interesting developments, for example on how to deliver palliative care for patients in care homes. Professor Murray, to whom you will speak in the next panel, has been working closely on that. There will be good things in the next five years.

I would come back in five years and consider whether we have made sufficient progress. Ross Finnie is right that the duty is there—it is supposed to be an integrated health service and that is supposed to include palliative care. If we have not got there in five years, I would come back and say, "Let's do it." However, that would have costs attached.

Dr Barrett: I agree that, all things being equal, if the bill had not started its process when it did, it might not have come to fruition in the first place. However, we are where we are. It is very unlikely that such a bill will ever come back for consideration again. I accept that the living and dying well strategy could prove its worth in five years but, conversely, it could be disastrously bad because of the funding situations in the current financial climate. There is an opportunity, whether rightly or wrongly, for palliative care services. We are here now and we should grasp that opportunity.

The Convener: I am going to move us on, because time presses. We have another panel and we have a draft report to consider. I am just warning members.

Dr Simpson: I should declare an interest in that I am a member and previous chair of Strathcarron Hospice Association.

I have two questions, one of which is quick. It is a paradox that all the witnesses from whom we have heard say that things are advancing fairly well and that the living and dying well action plan has been a further impetus in the development of palliative care, yet the whole-time medical staff count reduced from 76 in 2007 to 63 in 2009. That does not square with what you are telling us. I would like a comment on that.

Dr Oxenham: Clearly, the generalists have got better, so we do not need so many specialist doctors.

Dr Simpson: So that is an appropriate reduction.

Dr Oxenham: There are difficulties with the counting. Manpower planning is difficult because there is NHS counting and charitable hospice counting. I have not seen those figures, and I would have to consider them more closely before I could answer that.

Dr Simpson: It would be good if you could come back to us with a comment. That is an ISD figure.

The Convener: If Dr Oxenham wants to write to me with supplementary evidence, I will distribute it.

Dr Oxenham: I am happy to do that, because I know that there are sometimes data capture problems associated with ISD figures.

Irene McKie: I cannot comment on the ISD figures, but I know that at Strathcarron hospice we have increased our medical staff by two whole-time equivalents, at consultant and middle-grade level, in the past four years.

Dr Simpson: It would be good if you could get back to us because, if the figures are wrong, that is an illustration of one of the problems. We need to think of palliative care as a whole and as an integrated sector rather than as just the NHS and the voluntary sector.

I turn to my second question. The traditional view of palliative care was that, when curative treatment was finished, people moved to palliative care—it was a vertical line, as it were. However, the new concept is that, as soon as someone is diagnosed with an illness that could be terminal, the two things run in parallel.

Is there a danger that, by having a specific bill that proposes an approach that is different from the one that is taken to all the other conditions that we treat, we could narrow that definition? We tried to enhance community care, but what actually happened is that local authorities are funding only the most severely problematic cases—the boundary has shifted in the opposite direction from the way in which we wanted it to shift. Do you foresee such a danger with this bill, particularly given the current economic climate?

12:00

Dr Oxenham: There is a risk of that, but it will not necessarily happen. We already have a register in general practice that identifies patients in a palliative phase, so we are already doing that. The delivery of palliative care is not a specific service in the sense that one service is removed and replaced by the delivery of palliative care. As I understand the bill, it is asking for a recognition of that palliative care and a change of emphasis of care, which might well be delivered by the same general practitioner, district nurse or consultant but which is definably a palliative care approach rather than one that ignores the change of decision making that is needed because someone is ultimately going to die.

Dr Barrett: I am a GP by background, as well. It is much easier for GPs to move from a diagnostic and treatment phase into the palliative care phase for their patients. The biggest change has to come in the acute sector and involves not only consultants but middle-grade and junior staff recognising that patients have moved to the end of definitive treatments and that they are now in the phase at which the generous specialist palliative care that is available should be given to them. That is important, as it prevents patients from being given treatments that are of no benefit to them.

Irene McKie: The way in which people move to palliative care, which has just been described, makes it extremely difficult to meet some of the reporting indicators defining when someone has had their first assessment and their first treatment, because such treatments run in parallel with others and there is no obvious distinction.

Jacquie Lindsay: The shift that we are discussing can occur only if we allow it to happen. I do not think that the living and dying well strategy would ever allow the defining line from curative treatment to treatment that is given to those who are dying to occur. Most professionals are now able to see the benefits of delivering palliative care from the moment of diagnosis. That is a palliative care approach that is very much in the specialist realm rather than simply involving someone being transferred or referred instantly to the hospice.

In response to Mr Matheson’s point, I would pick up on a point that David Oxenham made. The bill has been created for those who have, at a particular time, felt that they have been served inappropriately and deserve better care. Together, the living and dying well strategy and the bill will enhance awareness not only of palliative care and the need to deliver good care but of the need to report on that.

The Convener: We have heard a range of views, and I thank our witnesses for their evidence.

We will have a two-minute suspension. Members must not leave the room.

12:04

Meeting suspended.

12:07

On resuming—

The Convener: The final panel of witnesses is from the health care sector; I thank them for waiting. I welcome Sandra Campbell, who is a member of the Royal College of Nursing Scotland; Katrina McNamara-Goodger, who is head of policy and practice at ACT, the Association for Children’s Palliative Care; Professor Scott Murray, who is St Columba’s professor of primary palliative care, Association for Palliative Medicine; and Dr Euan Paterson of the Royal College of General Practitioners.

I invite questions. I know that the witnesses were present for the previous part of the meeting, so they know how it works.

Dr Simpson: I will come in first this time.

The Convener: Yes, you have to race to beat Mary Scanlon.

Dr Simpson: I thought that I would try.

We have concentrated on definitions so far, but I would like to ask about the indicator side of things. My question is about data collection. It seems to me that, as one of the witnesses on the previous panel said, we have problems in that regard. Some of the submissions mention data that we already collect, such as Scottish morbidity records, death certificates and quality and outcomes framework data. There is also the stuff that is associated with the direct enhanced service for generalist care. Do you think that the indicators that are laid out in the bill are appropriate and practical, and that they will help to develop palliative care in the way that we all want? Alternatively, could we achieve that end through some relatively simple measures? I am talking about developments such as e-health, which could provide fairly definitive data that would measure the progress of the living and dying well programme in a way that we would want. That would be far simpler than what the bill proposes.

Professor Scott Murray (Association for Palliative Medicine): Thank you for the opportunity to come to the meeting.

Euan Paterson and I both work as general practitioners, and it would be to primary care that we would look for indicators. I think that the indicators in the bill are hopelessly complicated, which is why the Association for Palliative Medicine, which I am representing, is not very keen on the bill. Speaking as a GP, I can think of a very straightforward indicator, which I suggested in my submission on behalf of the University of Edinburgh. I have 5,000 people in my practice up the road. Around 50 of them die a day—I am sorry; 50 of them die a year.

The Convener: I was going to ask for the name of your practice, because we would not have wanted to join it.

Professor Murray: I apologise. The figure is 50 a year.

Ross Finnie: I can see why you are in the palliative care profession.

Professor Murray: Around 45 of those people will have died during periods in which they might well have benefited from palliative care. One indicator could be the number of patients who died last year. For my practice, the answer to that question would be straightforward: 50. The next question could be how many of those who died had had a prior palliative care need assessment. The answer to that question is fewer than a third; a year ago, the answer would have been around a sixth. That is why David Oxenham said that the figures have increased. However, the answer to the question is still few. A third were assessed before they died. It should be remembered that assessments should start earlier in the illness course, so that is not the full story, but a simple indicator could be the number of deaths there were and the percentage of people who had had a prior palliative care need assessment. That percentage could be a UK QOF indicator. Currently, the percentage is less than 30 per cent, and it should be much higher. Therefore, there are simple indicators.

The problem with palliative care is not that there is a postcode lottery; rather, there is a disease lottery. If someone gets the wrong diagnosis or does not have cancer, they are, for various prognostic and funding reasons, much less likely to get care. Cancer charities like certain things. Fewer than 10 per cent of non-cancer patients are currently being identified and assessed. A simple, main indicator that we could have could be access to identification.

Dr Simpson: Could we—

The Convener: Just a minute. Does Dr Paterson want to come in on that point?

Dr Euan Paterson (Royal College of General Practitioners Scotland): I am thinking about the figures. We know that around 8,000 to 10,000 people went through the palliative care DES last year. The palliative care DES would fund up to around 33,000 patients, so there is quite a significant gap.

We have considered the matter in our practice in Govan, in inner-city Glasgow. We have a practice list of 4,000 patients. The incidence of death is around 1 per cent—around 40 people on our list die per year. However, the prevalence of palliative care—I am talking about how long people with needs might live for—is immense. We tried to apply the prognostic indicator guidance that came with the palliative care DES, and we finished up with a figure of more than 150 people in our practice, which, as I say, covers 4,000 people. If we extrapolate from that figure, we will find that 187,000 people in Scotland have palliative care needs—I am not talking about 8,000 on a register or funding for 26,000. As I sat at the back of the room, I thought that a weird reality check was needed. Do we genuinely believe that we are in a financial position to provide high-level end of life palliative care for 187,000 people in this country? I dare to suggest that we are not.

Dr Simpson: That is very helpful.

We are going to consider the Certification of Death (Scotland) Bill.

The Convener: We have a cheery pathway on this committee.

Dr Simpson: We are having a real time of it this year. We are going from end of life through palliative care to death certification.

I am not asking you to give evidence on the Certification of Death (Scotland) Bill, but would it be helpful to ask people when a death has been certified whether the individual had received palliative care? Would it be helpful to include that measure in that bill? We could link that to conditions of death and see which conditions receive palliative care—it is clear that those with cancer predominantly receive it at the moment—and which do not. We could then see what to focus on.

Dr Paterson: That takes us back to definitions. One of the concerns of the Royal College of General Practitioners Scotland has been the huge difficulty in accurately defining in a legislative sense whom the bill is for and what they are supposed to get. As a generalist, I see my duty primarily as being to advocate furiously on behalf of every single one of my patients. I do not care whether they are dying or not: if they are not, they still deserve my advocacy. That is terribly important.

I am a huge fan of palliative care. I worked in a hospice for 10 years and was a Macmillan GP facilitator for 11 years. I am the clinical lead for the NHS Greater Glasgow and Clyde palliative care managed clinical network. I represent the college. My own dad died with cancer—malignant spinal cord compression. I have an interest in palliative care, but I still do not think that it should take precedence over everything else that I care for and every other condition from which my patients suffer. Therefore, I have huge concerns about the increased inequity that such a bill would create.

12:15

In addition to that, I am worried that the bill represents a slight politicising of health care and that that may influence what policies are pushed forward because politicising may lead constituents to have a more favourable view. That is a worry, especially because it would then become a sort of political shroud waving.

My final point is on the postcode lottery. If you want to do something about that, you must go back 35 or 40 years and look at Julian Tudor Hart's inverse care law. If that is not addressed, the postcode lottery will continue. In NHS Greater Glasgow and Clyde, we have just undertaken an extensive and powerful health needs assessment for palliative care. Our most affluent area is East Renfrewshire and our least affluent is the east end of Glasgow. The east end needs 196 per cent more palliative care than East Renfrewshire. That is nearly three times as much.

We have an absolutely flat distribution of health care staff but, if we have such a distribution, we cannot address the inverse care law. Therefore, addressing the postcode lottery is dead in the water unless there are some major political and policy changes.

Katrina McNamara-Goodger (Association for Children's Palliative Care): I request that you remember the relatively small numbers of children with palliative care needs. Although their numbers may be small, they may have great needs. When we talk about 187,000 people with palliative care needs versus probably 2,000 children, there is a potential that we will overlook the children in whatever data collection is done if we take a complete-population approach.

I simply remind the committee that there are children with palliative care needs. In their career, most GPs might see one such child, so we are talking about very small numbers. Even with death certification data, it may not be possible to recognise that the child may have had a need, so it may be difficult to gather accurate data on that.

Sandra Campbell (Royal College of Nursing Scotland): It is a very complex task to define when someone does or does not have a palliative care need. People do not just become unwell with a long-term condition, deteriorate and then die. As was described earlier, some people suffer for many years of their lives. People can be well, then become unwell. They may be dying and then not dying. It is complex to diagnose dying. There may be times throughout someone's journey—which may be complex, depending on what illness they have—when we think that they are going to die and that they require palliative care but then they may recover and live fairly well with a long-term condition for many years.

The complexity of palliative care needs makes it difficult to define what palliative care is and makes it difficult to legislate for.

Professor Murray: That takes us back to how important it is to identify someone so that we can start to address their need. If I am a GP with 20 people, four or five of them per year will die with cancer. More die with organ failure and an even larger number are frail elderly people and people with dementia. They take longer in the final phase. Therefore, today, I may have only two out of 20 with active cancer and most of the case load will be frail older people.

The living and dying well action plan is good and is starting to identify more people, but that emphasis must continue. We must give care not according to age, diagnosis or even prognosis but according to the need that the person has at the time. We will not call it a palliative need, but it is an overall need for health care.

Ian McKee: As an ex-GP, I recognise Sandra Campbell's description of the complexity of the situation. When a bill is introduced and enacted, people start poring over the meaning of every word rather than the general drift. In the bill, the "life-limiting condition" for which palliative care must be given

> "means a condition, illness or disease ... the progress of which cannot be reversed by treatment".

Is it an impediment to providing palliative care if you have to say firmly that whatever disease is being considered cannot be reversed by treatment? For heart disease, for example, there are treatments that can reverse progress at least temporarily.

Sandra Campbell: I am sorry—would you please repeat the question?

The Convener: Is the description an impediment?

Ian McKee: Should the bill say firmly that the life-limiting conditions for which palliative care should be given must be those whose progress cannot be reversed by treatment? The description that you gave implied that palliative care could be given for a spell and taken away and that that was the best way forward.

Sandra Campbell: Absolutely—palliative care is more of an approach. The problem is that society does not understand clearly how the palliative care world works. In most cases, the generalist delivers palliative care at various stages throughout the journey—it depends on the person's needs. It is not all about specialist palliative care—most care is delivered in primary care, acute settings and nursing homes. The bill would complicate how we define and deliver palliative care.

Mary Scanlon: My first question will be brief. The British Medical Association supports the bill's general principles, the definitions and the provisions on data collection. However, the Royal College of General Practitioners says:

> "we do not agree with the general principles of the Bill."

Does that illustrate a wide range of opinion among GPs? In general, the BMA and the royal college agree, so the difference is unusual.

Dr Paterson: The position stems from what I said in a previous answer. The vast majority of GPs see good-quality end of life care simply as a core duty—it is just part of what they do. Our concern about the principle relates not to the advocacy of high-quality end of life care, which is a given, but to separating it from everything else. As a generalist, I struggle with that—it does not feel right.

Perhaps I should use the phrase "end of life care", because I struggle with the term "palliative care". I guess that much of what I do for many patients whom I try to help and serve could be defined as palliative, apart from the fact that they are not quite dying. Much of what we do involves symptom management. Our concern is about the separation rather than the quality of end of life care.

Mary Scanlon: Your submission says that

> "creating a statutory duty to provide one area of clinical care"

would be likely to

> "set a precedent for further clinical areas (diabetes care, asthma care, antenatal care)".

Is that a serious concern? Does palliative care stand on its own? Do you really think that passing the bill would create a queue of people who said, "Oh well—you've got a duty for that; we now want a duty for diabetes and asthma"? Do you truly think that that would be likely to happen?

Dr Paterson: There is a risk of that happening. Much of that can be driven increasingly by the shift of focus of a fair number of charitable bodies, which have become far more interested in patient advocacy and political lobbying. They can exert not inconsiderable pressure. The concern is genuine.

I return to the definitions. People are happy with us talking about the palliative care approach. I struggle with that, but why do we not talk about the antenatal care approach? When could an holistic approach that is conscious of the whole person, family and society be wanted more than when a child is born? I return to the fact that my father died of cancer and had a pretty hard time, so I have a personal belief in such care, but it is just about good care for people who happen to be dying. Let us just talk about having good care for everybody, rather than making one lot special.

Mary Scanlon: My next question is for Professor Murray. You say that you

> "cannot see any rationale for an additional legal requirement to be placed on NHS Boards to provide palliative care"

and that you

> "cannot see how this could be implemented or monitored effectively."

You are not exactly in favour of the bill, either. Has the living and dying well strategy addressed sufficiently the needs of people who require palliative care? It seems from your two submissions that you see no need for the bill. Is that a fair comment?

Professor Murray: I represent hundreds of palliative medicine specialists who are reasonably concerned that they might have to do an awful lot of reporting. We have discussed it, but it might not be a real concern for them because the reporting might fall instead on general practice. That was one of their concerns, but it could be addressed. The main issue for them is that the reporting is far too complicated.

Mary Scanlon: You are also against the additional legal requirement. Dr Paterson pointed out that, as there is no legal recourse, there is no need for legal requirement. If you are against the collection of data, all that is left is the legal duty, which you say that you are against. Do you support the bill? Will it improve things?

Professor Murray: If we went back to our members and told them that the requirement would be much simpler, as I outlined earlier, they might consider it to be a real possibility. Everyone, including GPs and the BMA, knows that end of life care, or palliative care, is the Cinderella area. It is the worst area in the health service. If any area should be highlighted, palliative care is the one.

Mary Scanlon: Is it even worse than mental health?

Professor Murray: Yes.

Mary Scanlon: Really?

Professor Murray: Last year, in a poll in the *British Medical Journal* to which all readers were invited to respond, end of life care was the area that came up. It is definitely the worst area, so if any area should be highlighted, it should be that one. The real issue on which the committee has to decide is whether to do that.

Mary Scanlon: The second part of my question was about the living and dying well plan. Has sufficient progress been made on that? Your submission suggests that the bill does not add much.

Professor Murray: The living and dying well plan has a tremendous vision, the Government has it, and specialists and generalists are starting to get it. However, we are only a year down the track and most people are still not being identified.

There are a number of ways of doing it. GPs are being encouraged in a slightly more innovative way to look at a patient with heart failure, for example, and ask themselves whether they would be surprised if that patient died in the next year. If the GP would not be surprised, then perhaps that patient could benefit from the strategy. The GP does not have to expect their patient to die within the next few months.

There are different ways of thinking, and people do not have to be written off before they are put on the register. Converting the register into a supportive and palliative care register, rather than just calling it a palliative care register, would enable GPs to feel much more comfortable about putting patients on it. The register should be for people to receive supportive or generalist care.

The Convener: You seem to be saying that it is preferable to making them feel as if they are sitting on death row and have been written off completely.

Mary Scanlon: I think that Dr Paterson has a point.

Dr Paterson: Yes, that is fine, but we should not lose sight of the numbers that we are talking about. A wee practice such as ours would have 150-plus people on such a register, and we discuss those patients every week. How long is that discussion going to take if we have to talk about more than 150 people? Palliative care is just one part of a huge generalist job.

Again, I am not knocking palliative care, but it is not the only thing that we do in primary care.

The Convener: We have two former GPs on the committee and they are nodding away.

Dr Paterson: They will be very conscious of that.

The Convener: I have managed to separate them; they were joined at the hip for a while.

Rhoda, did you want to ask a supplementary?

Rhoda Grant: I would not say that I am confused by what I have heard. However, it is clear that the bill has been introduced because palliative care was a Cinderella service and people did not receive that care, and Dr Paterson has said that good care should be given, so there is obviously a gap; how do we address that gap? If you are all saying that we do not need the bill, how do we make sure that people get the right care? It is a very difficult stage in their life for them and for their families. The witnesses have talked about how more resources would be needed if we were to give that care properly. People are also saying that if the living and dying well strategy was properly resourced, it would cover the requirements of the bill. It is almost as if people are taking contradictory positions and saying that something needs to be done, that palliative care should be affordable and that money should be put into the living and dying well strategy but that the bill is not a good idea.

12:30

Dr Paterson: I am not saying that the money is there to implement this bill; in fact, I do not believe that the money is there at all. I simply do not think that it is possible to do what the bill proposes in the current climate.

When distilled, what the college's patient group, which is part of the end of life care group that I am a member of, really want is more time with the same people. One of our concerns about the bill is that so much health care has become a transactional task-orientated interaction when it needs to be a relational interaction with people. That kind of interaction is in danger of being lost and it is even more in danger with legislation. The bill will not address the need to spend a continuum of time with our dying patients if we want to offer them proper support. Although I would love that to happen in primary care, it would require working out how to increase the number of primary care practitioners or deciding what primary care should no longer cover. Right now, there is certainly no slack in the system, which is why I am a bit dubious about introducing a bill that I genuinely believe is not deliverable.

The Convener: I do not know how the gesture that you just made will be reported in the *Official Report,* but if you were caught on camera, people will get the flavour of it.

Sandra Campbell: As a nurse consultant for cancer and palliative care, I live and breathe palliative care on a daily basis. Living and dying well is an excellent strategy that should be implemented in all health boards over the next few years—it certainly cannot happen overnight, because these things take time. In that respect, there are things that can be measured. For example, in 2005, only two boards in Scotland used the Liverpool care pathway, which is an end of life care pathway. I believe that most if not all boards are using either that pathway or some other end of life care pathway for patients in the last few days of life.

As for how people become aware of these things, the seventh short-life working group from the living and dying well action plan focused on raising awareness in the general public. We need to raise awareness of death and dying not only among medical and social care staff but among the general public, to take away the taboo around the issue. If we can communicate better, it will go a long way towards improving our conversations with people and the care that we deliver.

Katrina McNamara-Goodger: I remind members that, despite ministers' public statements that the living and dying well action plan is a population approach covering all age groups, many health boards have chosen to address the larger numbers of adults. I hope that documents that are due at any time now will focus on the needs of children and young people. Maybe then we can have confidence that the living and dying well action plan will bring about the necessary changes but, in any case, I am not convinced that the bill will do so. As was mentioned earlier, it looks only at health provision, and the fact is that much of palliative care falls outwith the health remit and into the area of social care and, for children, education.

The Convener: That is an important point to remember.

Professor Murray: A huge group of older people, especially those with dementia and such illnesses, require palliative care and certain small things that are being done need to be replicated elsewhere. For example, a nurse in the Marie Curie hospice has been visiting care homes in Midlothian to ensure that people admitted to care homes have care plans and Liverpool care pathways for the end of their lives. Because of that, people are able to die in care homes and admissions to hospitals have decreased by 50 per cent. Pilots and other initiatives are going on, but they need support, which might mean funding. It is important for the Parliament to support such measures, whether through legislation or simply ensuring that they go forward.

The Convener: I think that Ross Finnie has the final question.

Ross Finnie: I am not going to bother, convener. The panel has more than adequately answered our questions on the bill’s general principles.

The Convener: I thank the witnesses for their evidence and for waiting to give it. We will now move into private.

12:34

Meeting continued in private until 12:46.

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