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Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Wednesday 10 November 2010

Session 3

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HEALTH AND SPORT COMMITTEE

33rd 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 GAVE EVIDENCE:

Gil Paterson (West of Scotland) (SNP)
Nicola Sturgeon (Deputy First Minister and Cabinet Secretary for Health and Wellbeing)

CLERK TO THE COMMITTEE

Douglas Wands

LOCATION

Committee Room 6

Scottish Parliament

Health and Sport Committee

Wednesday 10 November 2010

[The Convener *opened the meeting at 10:01*]

Subordinate Legislation

Foodstuffs Suitable for People Intolerant to Gluten (Scotland) Regulations 2010 (SSI 2010/355)

Mental Welfare Commission for Scotland (Qualifications, Training and Experience of Medical Visitors) Regulations 2010 (SSI 2010/356)

National Health Service (Charges for Drugs and Appliances) (Scotland) Amendment (No 2) Regulations 2010 (SSI 2010/366)

The Convener (Christine Grahame): Good morning and welcome to the 33rd meeting in 2010 of the Health and Sport Committee. I remind everyone to switch off mobile phones and other electronic equipment. No apologies have been received and I welcome to the meeting Gil Paterson MSP, who is attending the meeting for the oral evidence taking on his Palliative Care (Scotland) Bill.

The first item of business is consideration of three negative Scottish statutory instruments relating to food labelling regulations, regulations under mental health legislation and changes to national health service charges for drugs and appliances. Members have received a cover note from the clerk summarising the purpose of each instrument and, as you will see, the Subordinate Legislation Committee has made no substantive points on any of them.

I do not propose to go through the instruments one by one. If members have no comments, are we content to make no recommendations on them?

Members *indicated agreement.*

Palliative Care (Scotland) Bill: Stage 1

10:03

The Convener: Under item 2 we will take evidence first from the Scottish Government and then from the member in charge of the bill. I welcome back to the committee Nicola Sturgeon, Deputy First Minister and Cabinet Secretary for Health and Wellbeing; Colin Brown, deputy director, patients and quality, Scottish Government health directorates; and Mark Aggleton, health quality development manager, also from the Scottish Government health directorates.

Before we move to questions, I invite the cabinet secretary to make a brief opening statement.

The Deputy First Minister and Cabinet Secretary for Health and Wellbeing (Nicola Sturgeon): Thank you, convener. I thank the committee for this opportunity to reflect on palliative care in Scotland. Members will be aware that reports by the Scottish Partnership for Palliative Care and Audit Scotland set out a number of recommendations that provided strong evidence of a need for change and galvanised the palliative care community into action. Since the publication of those reports, the Government has, with the support of those in palliative care, worked very hard to provide a clear and planned approach to improving palliative and end of life care.

Since the publication of “Living and Dying Well: A national action plan for palliative and end of life care in Scotland” just over two years ago in October 2008, significant progress has been made in implementing its actions and undertaking the further development work required to achieve the full range of its aims. “Living and Dying Well” put in place a robust structure for implementing actions to improve palliative and end of life care, and work to date has been characterised by involvement and engagement across not only the palliative care community, but more widely. That has been backed up by very clear systems of governance and leadership from the national clinical and executive leads in NHS boards. A clear focus on delivery, not only for the national initiative but locally—within NHS boards, for example—has been demonstrated in the development of delivery plans to take forward all the actions in “Living and Dying Well” and those arrangements will continue through the next phase of work.

“Living and Dying Well: Building on Progress”, which has been circulated for comments to boards and other stakeholders, records progress since 2008 and sets out the next phase of actions that, in our judgment, are required to continue implementation and secure further improvement. A strong commitment to all this work has been shown by the Scottish Partnership for Palliative Care, the umbrella organisation representing the palliative care community; by NHS Education for Scotland in supporting the education and training requirements of staff; and by NHS Quality Improvement Scotland, which will provide improvement support to support the aims of the living and dying well action plan.

As I have already noted, "Building on Progress" is being considered by boards and stakeholders and our intention is that, in the short term, NHS boards will review the living and dying well delivery plans to incorporate the new actions in "Building on Progress". Although a number of priorities have been identified, I still expect a real focus on and momentum in implementing all the living and dying well actions. The clear intention is that, through a continuous improvement process, boards and stakeholders will develop measures that reflect the necessary improvement and will be supported through the process by a number of different means. In addition, a quality outcome measure that is being developed as part of the health care quality strategy will use existing data sources.

Although I have no difficulty in recognising that a lot of work still has to be done, I point out that the Government, NHS boards, stakeholders and individual practitioners in all sectors have done a great deal of work and remain committed to furthering the process. In the short term, the living and dying well national advisory group and executive leads will ensure that progress continues and, in the longer term, clinical leadership and quality assurance from NHS QIS will ensure that that integrated cycle of improvement will provide a sustainable and integrated approach to improving palliative and end of life care.

I thank the committee for its constructive consideration of what we all understand to be a sensitive and complex area. Moreover, although I do not support his bill, I thank Gil Paterson and acknowledge his sincerity in introducing it. I know that he is motivated, as we all are, by a real desire for continued improvements in this very important area of care.

The Convener: Thank you for those comments, cabinet secretary, and for providing us with the draft update on the living and dying well action plan. We will find that extremely useful. I seek questions from members.

Mary Scanlon (Highlands and Islands) (Con): I can certainly say that our stage 1 scrutiny of the bill has at least given me an insight into palliative care.

I believe that the bill was instigated prior to the publication of the living and dying well strategy in August 2008. I have not discussed this with my group but, from where I stand, most of our witnesses seemed generally content with progress in implementing the strategy, although I note your comment with regard to "Building on Progress" that there is still some way to go before the full aims of the living and dying well action plan reach fruition.

I am content that considerable progress is being made in a very integrated and co-ordinated way, but I was concerned by the view expressed by one or two witnesses that passing the bill might well hamper or divert the excellent progress that is being made under the palliative care strategy. Is there anything in the bill that you might wish to implement as part of the living and dying well strategy?

Nicola Sturgeon: Perhaps I should preface my answer to what is a very good question by repeating my point that, as I know from my discussions with Gil Paterson, the bill is not intended to divert attention from the living and dying well action plan. That does not mean that it would not have an unintended effect. One concern that I have about the bill is that its indicators are not aligned with the living and dying well strategy. Although the indicators would measure many things, I am not convinced that they would allow us to measure quality or equity of care throughout the country.

I know that other witnesses have expressed concerns that the bill seems to view palliative care as the end point in a linear journey of care—it starts when other treatment finishes—when in practice one often finds palliative and more substantive treatments running in parallel.

We will, of course, consider what the bill is trying to do to ensure that where we can learn from it and incorporate it into the living and dying well approach, we do so. It is right that the bill focuses on how we gather data that allow us to demonstrate the improvements that I have been talking about, which we want to continue.

Some of the material that is available to the committee runs through some of the data that have already been gathered around that area, but the work that we are doing under the living and dying well strategy, through the direct enhanced service and the electronic palliative care summary, will allow us to gather more information and data in future. That will enable us to demonstrate, rather than just think about, the scale of the improvements that we have made. Although I do not entirely agree with how the bill seeks to gather data, it is an approach that I endorse.

Mary Scanlon: I will focus on two of the most controversial issues in the bill. The first concerns the duty to provide palliative care according to "reasonable needs". Is that included in the living and dying well strategy?

The second issue concerns how we determine what constitutes a "life-limiting condition". As we have been considering the Palliative Care (Scotland) Bill rather than examining "Living and Dying Well", can you give us an idea of how the terms "reasonable needs" and "life-limiting condition" are defined in "Living and Dying Well"?

Nicola Sturgeon: The living and dying well strategy seeks to take an individualised approach to the provision of palliative and end of life care. Rather than attempting to give a generic definition of "reasonable needs", it takes the view that palliative and end of life care and services should be available to people based on their individual circumstances and what is appropriate for them in those circumstances. A very important principle of the living and dying well action plan, which sounds obvious when we say it, but which has not always characterised our approach to palliative care, is that palliative care should be applied regardless of diagnosis.

Many people who work—or observe work—in that area would accept that over the years we have been reasonably good at providing palliative care for people with a cancer diagnosis, but not for those with other terminal diagnoses. The living and dying well strategy attempts to take an individualised approach and to be diagnosis-blind in that respect.

On life-limiting conditions, I must be honest: I think that that is one of the difficulties in how the bill is drafted. I know that the committee has heard from witnesses representing dementia patients or patients with multiple sclerosis who have expressed similar concerns about that definition. I will not rehearse those concerns, because I cannot do that as well as the experts in the field, but for people with those conditions it is never as black and white as reaching a point at which treatment absolutely and definitively cannot help.

As I said earlier, one of my concerns about the bill is that it seems to cast end of life care in a linear process, when people may in fact go on and off treatment, but would benefit throughout that whole period from palliative care services.

Helen Eadie (Dunfermline East) (Lab): Good morning, cabinet secretary. The financial memorandum argues that much of the data that the bill requires are already being collected by NHS boards, but we have heard in written and oral evidence so far—in the NHS National Services Scotland submission, for example—that there seem to be some difficulties in gathering that data. Could some issues be taken from the bill—issues that you might, without the need for legislation, be able to make progress with, using lessons learned from this exercise? It will be for the Parliament to decide whether Gil Paterson's bill goes through, but good work has been done and I wondered whether you had identified issues that you want to take up.

10:15

Nicola Sturgeon: I am spending a lot of time on issues that I consider problematic in the bill; however, I take my hat off to Gil Paterson and to others who support the bill and are pushing for its adoption. The bill helps as part of the process. "Living and Dying Well" sought to raise the profile of palliative and end of life care issues, and we must ensure that we focus on continuing that momentum.

Helen Eadie is right to say that it will be for the Parliament—and firstly this committee—to decide on the bill; however, regardless of that outcome, the process of considering the bill will have been useful in ensuring that we are all focused on the work to be done.

As for the question of specific issues that can be taken from the bill, I go back to the answer that I gave to Mary Scanlon. There is a paper from the Scottish Parliament information centre on data sources, and we already gather data in a range of different areas. For example, there is the Scottish morbidity record; the part of the general practitioner contract to do with the quality and outcomes framework; the General Register Office for Scotland; and Scottish patients at risk of readmission and admission data. However, we acknowledge that we need to do more—first to identify people who have palliative and end of life care needs, and then to ensure that they receive the services that they need. The directed enhanced service supports GPs in primary care in identifying, registering and assessing patients in such circumstances. There is also the electronic palliative summary, which allows us to record and track what happens to patients. Those things will put us in a stronger position.

The bill puts an emphasis on gathering data, and that is a lesson that we will continue to reflect on.

Helen Eadie: The financial memorandum to the bill presses for a national database for precise data that would lead to an annual report, which MSPs would be able to scrutinise in the Parliament to see what is and is not working.

Nicola Sturgeon: I will be happy to consider how we can usefully present more data to allow the Parliament to assess the success and effectiveness of the living and dying well strategy.

We have no specific plans in that regard beyond those that I have mentioned already, but I acknowledge that the bill is right to stress the way in which we can measure our success.

Other witnesses have made the point, and I agree with it, that we should not divert resources into gathering data for data's sake. What we gather must tell us about the numbers but also—crucially—about quality and equity of provision. We will continue to give further consideration to such points, in the context of making progress with the living and dying well strategy.

Rhoda Grant (Highlands and Islands) (Lab): My questions are along the same lines. I have looked through the draft update of "Living and Dying Well", and trawled many of the appendices online, but it is very difficult to track what services are available, where they are, what standard they are, and who is accessing them. I do not see how we can measure progress: we do not know what is happening, so how can we measure improvement? One thing that the bill does is make an improvement. We have heard that the delivery of palliative care is patchy throughout the country, and that it is probably one of the least well served areas of health care. We need to know where we are before we can measure progress and hold health boards to account to ensure that they are providing care.

Nicola Sturgeon: I have a fair degree of sympathy with that question. Your difficulties will not be unique to information on palliative and end of life care services. A lot of the data that are collected in and about services delivered by the health service are provided for the use and benefit of the commissioners and providers of services, rather than in a format that would allow parliamentarians, through the parliamentary process, to track improvements and changes. There are some exceptions to that with waiting times data and so on. To go back to my answer to Helen Eadie, I am happy to give further thought to how we provide information over a period that allows the Parliament to assess the improvements that we are making here.

The only other point that I would make is that while statistics and data are important—I am not suggesting that they are not—they are not the only way of assessing whether we are heading in the right direction with any particular area of care. I have been struck—probably more than by any other issue that I have been involved in in three-and-a-half years in this job—by how much unanimity and consensus there is about what the living and dying well action plan is trying to do and about the acceptance of the progress that has been made in the two years since it was published. That comes from people who know what they are talking about, such as practitioners, deliverers of care and those representing individual patient groups. Without dismissing the importance of good quality data on an on-going basis, I suggest that the committee, and the Parliament as a whole, should take a lot of comfort from that and draw the conclusion that we have made considerable progress and that we are going in the right direction. Of course, we must continue to maintain that.

Rhoda Grant: I welcome that and I am pleased with the progress that has been made. My concerns are also about the general practitioner, who is in the front line of delivering palliative care. We are very much dependent on whether GPs are recording the data and what other services they are bringing in. I have great difficulty in understanding how we can monitor that and ensure that there is an equity of service, without robust information gathering.

Nicola Sturgeon: I will give you one statistic that is particularly pertinent to that point. Before I do so, I should say that you are absolutely right. Much of what we have done, not just on the policy in "Living and Dying Well" but in the investment that we have put in to back up the action plan, was about improving the generalist component of palliative care. For many people, that is what will determine the quality of the service that they get—not specialist services, to which only a smaller number will ever be referred on.

The Audit Scotland report in 2008 said that 5,000 patients were included on the GP palliative care register. In the two years since we introduced the direct enhanced service, that number has gone up by 40 per cent. That is still not enough, though, if we consider the number of people who die every year and the proportion that Audit Scotland estimates would benefit from some form of palliative and end of life care. We still have a distance to go. However, through the palliative care register we will be able to track and measure, in a very obvious way, the success of GPs in identifying people, which is the first step in ensuring that they get the services that they need. A 40 per cent increase in two years is a significant improvement, and definite evidence that we are going in the right direction.

Rhoda Grant: Does that help you to identify which GPs are doing a good job of identifying patients in need of palliative care and to flag up GPs who are not doing such a good job? Obviously, you are looking at average numbers and the like, and you can make some estimation that way.

Nicola Sturgeon: That was not an average number that I gave you; it was the total number throughout the country, and of course—

Rhoda Grant: I mean that the data come from individual GPs, so you can see that one GP has not registered any patients while another has registered 200. You can see where there is a gap because a GP is not picking up as they should be.

Nicola Sturgeon: I take your point. Yes, you can tell whether there are gaps in the register—my officials are providing assurance that that is the case. You can see whether there is a particular practice or part of the country where no or relatively few people are registered. That could be tracked from the palliative care register data. Data of that nature are important in not only allowing us reactively to assess, but proactively to ensure that the quality of services is improving.

On its own, the register will not do that, but if we link it to the electronic palliative care summary, which allows clinicians in different settings to look at the needs of patients and to identify and assess whether those needs have been met, we will see a system that gives us not just global numbers, but also tells us whether the quality and the equity of service are improving.

In summary, I am not suggesting that there is not more still to do; in fact, I am saying otherwise. I and the Government must give further consideration to the form of some of that information so that it can be used by parliamentarians as part of the scrutiny process. I am satisfied that the progress that we have made over the past two years is significant, and I think that that is backed up by the views that you have heard expressed by people who work in the field.

Ross Finnie (West of Scotland) (LD): In your opening remarks, you properly and helpfully set out the aims and objectives of “Living and Dying Well”. In answers to questions, you have gone on to expand on the progress that is being made and have drawn our attention to the draft of the updated document, “Living and Dying Well: Building on Progress,” a copy of which, as the convener pointed out, you have kindly supplied us with. I accept the facts that it presents.

Towards the end of your remarks, you indicated that you would not be supporting the bill. In response to questions from Mary Scanlon, you expanded slightly on that. For the record, I think that it would be helpful if you could be more explicit about some of the reasons for your being unable to support the bill. I take it as a given that you are pleased with the progress of your own policy, but it would be helpful if you could identify more specific reasons for your position, given that we have to deal with the bill that has been presented to us for consideration.

Nicola Sturgeon: I am happy to do that. I was probably trying not to be too full in my explanation because I do not like disagreeing with my respected colleague Gil Paterson, but as the committee has asked me to, it would be reasonable to lay out more of the Government’s thinking.

I will briefly enunciate the key reasons for my not being able to support the bill. First, I do not believe that it is necessary, because the evidence of the past two years suggests that we can make the progress that the bill wants us to make without legislating. An extension of that is that I do not believe that the bill is timely. Even if the argument could be made that primary legislation could assist, I believe that we have reached a stage in the living and dying well process at which it will pay more dividends to allow that process to continue.

Secondly, and perhaps more fundamentally, I worry that a bill of this nature would set a bad precedent. In the context of another bill, we have had discussions about patients’ rights. I made the point that that bill was about putting in primary legislation rights to do with the relationship between patients and the health service, and that it avoided dealing with specific treatments or services that patients would get, depending on what condition they had.

If we were to legislate for patients who required one form of treatment, my worry would be—and I do not mean this disrespectfully—that lobby groups on behalf of patients with other conditions who required other forms of treatment would seek similar primary legislation. That would inevitably restrict and perhaps skew the difficult decisions that all NHS boards have to make on the use of resources. We could find ourselves in a position in which patients who have rare conditions or conditions that affect only a small number of patients and which do not have powerful, effective and influential lobby groups arguing for the sufferers of those conditions end up being deprioritised. That would be a dangerous road to go down.

I have covered much of my third reason already. Although I think that the indicators in the bill send a strong message about the need to have good-quality data, which I take on board, the way in which they are framed is problematic. They do not align with what is set out in “Living and Dying Well”. They would allow us to look at global numbers, but they would not give us information to assess the quality or the equity of provision. I have spoken about how the bill defines palliative care and life-limiting conditions, which could inadvertently exclude patients with some conditions and could result in palliative care being viewed as the end point of a straight-line journey, when it is much more complex than that.

I hope that that sets out some more of our reasoning for not supporting the bill. However, I stress that I know that the bill is well intentioned and well motivated. If it does nothing else, it will help us in the process that we are engaged in of improving palliative care services.

Ross Finnie: That was clear and helpful. I have no further questions.

The Convener: As there are no more questions, I thank the cabinet secretary for her evidence.

10:30

Meeting suspended.

10:33

On resuming—

The Convener: We move on to the second panel. I welcome Gil Paterson MSP, the member in charge of the bill; Claire Menzies-Smith, from the Scottish Parliament's non-Executive bills unit; and Kay McCorquodale, from the office of the solicitor to the Scottish Parliament. To be even-handed from the chair, and as I did with the cabinet secretary, I invite Gil Paterson to make a brief opening statement before we move to questions.

Gil Paterson (West of Scotland) (SNP): Convener and committee, I am grateful to be invited to give evidence on my Palliative Care (Scotland) Bill. I am particularly grateful that I have the opportunity to say a few words in an opening statement. That is useful.

The committee is tasked with considering the general principles of the bill. As I see it, there are two principles for consideration. The first is whether there should be a specific statutory duty to provide palliative care, and the second is whether there should be some accountability and a mechanism for monitoring and measuring the delivery of palliative care.

I will first deal with the specific statutory duty. The committee has heard evidence that the provision of palliative care remains variable. In the oral evidence that the committee has heard, everyone, including GPs and the British Medical Association, referred to palliative care as the Cinderella area. Much has been made of the precedent that my bill will set. However, Parliament clearly thought that mothers and children required special provision, yet there has not been a raft of legislation or even requests following that special provision. Therefore, I do not believe that there would be a flood of legislation if special provision were made for those with palliative care needs.

If anything, the case on palliative care is equally strong. Everyone is born and everyone dies. Surely, the true precedent that is set by section 38 of the National Health Service (Scotland) Act 1978 is that medical and dental care of expectant and nursing mothers and of young children is now embedded firmly in the health service. That is what my bill aims to do for those with palliative care needs.

Excuse me while I blow my nose. I never get a cold, but I would have to have one today.

Ian McKee (Lothians) (SNP): Is it terminal?

The Convener: We will have no jokes about that. This is a serious matter. Go for it, Gil.

Gil Paterson: True.

There has been evidence to suggest that the living and dying well strategy should be allowed to bed in. Like others, I contend that it is effective only to the point at which there is financial and political buy-in. We have heard about difficulties in Glasgow, and no doubt there are difficulties in other areas. Those will become even more of an issue as resources come under pressure in future. Living and dying well is a strategy, an intention and a target—it is founded on good will. We accept the intent, so why not have a statutory duty, to ensure compliance?

The second principle relates to performance indicators. The mechanism of indicators that is set out in my bill provides a response to the question why we should legislate now and not wait to see whether the Government's strategy solves the problem of patchy provision of palliative care: how will we know whether that has been successful? We will not, because no system of measurement is in place. The indicators in the bill might need refining, but there is undoubtedly a need to collect consistent information to improve the planning and delivery of palliative care.

To show that, I need only point to the difficulties in costing the bill and the large margin of uncertainty in the costs. That is because no specific information is collected. Audit Scotland has made recommendations on that and my bill provides the opportunity to meet those points. It would allow providers to demonstrate what they are delivering. I find it difficult to accept that health boards do not know what they are delivering in palliative care. The bill would answer those questions.

The Convener: I am going to mix the pack a little, so we will have questions from Ross Finnie, then Helen Eadie and then Mary Scanlon.

Ross Finnie: As you heard the cabinet secretary say, we understand perfectly the motives and intent of the bill. No member would disagree with that. However, from listening to the evidence, I have two problems and therefore two questions that flow from that. The first takes us back to the point that you touched on in your opening remarks, which is the question about the need for a bill. You say that, without statutory backing, nothing happens. I want to put that to you in a different way, which is that the provisions of the 1978 act mean that there is statutory backing and that nothing happens unless a Government produces a decent strategy. Therefore, the reason why we are making progress on palliative care at present is that, for the first time in a very long time, we have a palliative care strategy. As the cabinet secretary indicated, the Government does not believe that the bill would add to that process. My first question is to ask you to respond to that.

Secondly, as you pointed out, we have had some interesting evidence on the variability of the provision of palliative care. You are quite right that that has been the evidence. Nevertheless, the more uniform aspect of the evidence has been that the professionals and those who are engaged in palliative care who have been before us have not supported you on the need for a bill. How do you respond to that?

Gil Paterson: With regard to the statutory element, I have often wondered over the past year whether Gil Paterson or the cabinet secretary is the biggest supporter of the living and dying well strategy because, everywhere I have been, I have mentioned it and how it is making progress. I firmly believe in the strategy—I hate saying, “Trust me,” or “Believe me,” because when politicians say that it usually means that they are telling a lie, so I will not say it now. I have spoken about the strategy face to face with so many people right across the board—it must be getting to about 500 people—such as patients, nurses, doctors, family members and professors. I have been to hospitals, hospices and care homes—not quite the length and breadth of the country, as the furthest north I went was Inverness and the furthest south was Greenock. This might seem strange, but I suggest that the living and dying well strategy is making good progress. However, if anyone were to ask me how I know that, I could not tell them. I gathered that impression from the people I met at the coal face, people affected by the strategy, such as those who currently benefit from palliative care.

I am coming to your question, but another aspect that I picked up from evidence is that palliative care provision is extremely patchy. There are areas in Scotland where the service is extremely good but, only a few miles away, it is extremely poor. Therefore, the only way to get to a situation where we can say that we are serious about providing good-quality palliative care is to legislate for it. We need to open up the whole of Scotland to it and ensure that our direction is consistent. The only way to do that is through statute.

Ross Finnie: I accept that proposition, but will you elaborate slightly? When you say that the only way to do that is through statute, what is it about statute that you think will make it happen? After all, you and I both understand that statutory provisions are matters of law.

Gil Paterson: In simple terms, statute would give the living and dying well strategy force.

Ross Finnie: So it has force. How do we give effect to that force?

Gil Paterson: It stands to reason that by using statute we put the onus on Government and health boards. We would use reasonable methods—the word “reasonable” is used throughout my bill—to introduce palliative care no matter where someone lives or what illness or life-limiting condition they have. The mere fact of putting palliative care in statute means that health boards must pay attention to it, which they do not do at present because it is just a strategy. Although it is an excellent strategy, there is no mechanism for making health boards provide that care. When we put it in statute, I believe that palliative care will happen. Legislation will assist the living and dying well strategy and bring faster outcomes. The main aim of the bill is to open up the dark areas, which can be geographical. By that, I do not mean in any shape or form the difference between rural and urban areas; such dark areas might well be in a single health board area. The only way to open up those dark areas is to take a statutory approach.

Ross Finnie: I have a final question. Although this could be a difficult leap of imagination, try to imagine for a moment that I am an NHS manager and I have before me “Living and Dying Well”, which was sent to me by the cabinet secretary, and I also have an act of Parliament that was sent to me by this Parliament. I decide to ignore both. What happens to me?

Gil Paterson: I have no idea—you will need to ask the Government that question. I am not sufficiently qualified to tell you what happens in that situation.

10:45

Ross Finnie: I say with respect that you have put it to me that an act would make provision more effective. I am simply trying to be clear about the sanctions, penalties, effects or whatever in the act and in the document that I have from the cabinet secretary that will make me more concerned about palliative care.

Gil Paterson: A complaints mechanism is in place—that is the number 1 aspect. The fact that the duty was statutory would mean that health boards would put into play what the Parliament and the Government desired. That is a straightforward political situation that applies to any statute. We expect what the Parliament says to happen through reasonable methods.

Ross Finnie: If I switch round, that is no different from you making the general presumption that I would act on the requirements that sections 1 and 2 of the 1978 act place on me to provide general care. That provision is in place and has been since 1978.

Gil Paterson: I agree entirely that that is in place, but it is not working for palliative care. Palliative care is new—it came into play in a meaningful way only in the 1980s, through the voluntary sector. Since then, it has picked up momentum in the health service. No matter when any acts came into force, we have heard evidence—not just today, but at other committee evidence sessions—that suggests that the legislation is not working, so we need to consider other ways to operate.

There is no choice to be made between my bill and “Living and Dying Well”, because the bill is “Living and Dying Well”, with the three differences that I have no doubt that the committee will ask about. The bill is all about delivering “Living and Dying Well”.

Helen Eadie: I hope that you will not misinterpret my questions as hostile, because my position is quite the reverse—I am sympathetic to your aims and objectives and to what you are trying to achieve. The cabinet secretary said that, if the bill was implemented, money would be removed from other services. What is your response to her statement?

We have seen the erosion of dental services over the years. Patients now pay a colossal amount of money for dental services that they would not have paid in the past. Would such an experience—although not necessarily paying for services—happen in other areas? Would money be moved from other areas to be put into palliative care?

Gil Paterson: The argument is powerful, but I do not accept it. The last thing that I would want to be involved in is redirecting resources from one part of the health service to another.

The Government has allocated moneys to “Living and Dying Well”—that is a fact. That money is making progress. My bill is the same as “Living and Dying Well”; it contains nothing—not even one comma—that differs from “Living and Dying Well”. The bill is “Living and Dying Well”; apart from the indicators and the reporting, there is no difference. I put it to the committee that the bill in itself does not bring any additional cost. If you are suggesting that “Living and Dying Well” will bring additional cost, you will need to ask the Government about that. This is about the delivery of “Living and Dying Well”.

I say in my financial memorandum that there is a need to collate the information. I have suggested a figure of £50,000. I also point out that it could cost closer to £400,000 to set up the system. The reason why I have gone for the figure of £50,000 is that we modelled it on a database that was set up. We have taken the costs and brought them into the bill. There is then the £10,000 per annum running cost. That is the only cost, other than what “Living and Dying Well” is about, that can be put on to the bill.

Helen Eadie: We have received evidence from the City of Edinburgh Council, Glasgow City Council and Dundee City Council, which have all told committee members that, although the bill does not place any duties on local authorities, they believe that there would be costs for the collation and publication of the figures.

More important in my eyes, Dundee City Council social work department believes that there could be inequality between someone who received palliative care in hospital, which would be free to them, and someone who received care at home from social work, which is a chargeable service. In Fife once upon a time, we paid £4 a week for our care, but now, with our new administration, our services are £11 an hour.

The Convener: I knew that we would get Fife in.

Helen Eadie: The reality is that we will see an inequality right across Scotland with regard to hospital palliative care versus home care palliative care. What would you say in response to that?

Gil Paterson: I heard the evidence that you took and I wanted to speak out at the time but, as I said to the committee, I was under a self-denying ordinance. People should have the right to bring to the committee unfettered evidence without me, as sponsor of the bill, interrupting it.

The bill will not place any additional responsibilities on to local authorities. That is a fact.

Helen Eadie: Although the bill will not put any additional responsibilities on to local authorities, Glasgow City Council says in its evidence that it could lead to an increase in the number of social care assessments that were demanded at a time when there was significant pressure on the system. It also noted possible resource implications of introducing the Liverpool care pathway in nursing homes, which could result in additional costs having to be borne by the local authority. It is alleging that there will be costs. So, too, did the voluntary sector. The Strathcarron hospice and Marie Curie Cancer Care said that they already have pressure on their funding and that they think that the bill will put more pressure on it. How would you allay members' fears about that?

Gil Paterson: I do not think that the bill will do that. The original bill was sponsored by Roseanna Cunningham, but she could not continue with it when she was elevated to government. The bill predated "Living and Dying Well". Since I have taken it over, having looked at the benefits of "Living and Dying Well", I do not think that I can add anything to it other than what I am suggesting in the bill. My answer is that what is in the bill is what is in "Living and Dying Well". The bill contains nothing that is additional to what is in "Living and Dying Well", other than the provisions on the collation of information, most of which is already collected. I acknowledge that that will require additional resources, but I have made provision for that.

The Convener: I want to move on because I think that we have—

Helen Eadie: I have one more question on a different subject.

The Convener: Okay.

Helen Eadie: I am quite content with the answers that Gil Paterson has given me.

To go back to the gathering of information and data, I notice that the paper that the Scottish Government presented to the Public Audit Committee on progress with the implementation of the living and dying well strategy described a number of possible sources of information for the development of services. However, I gather that you are saying that that information would not be published annually. If I have understood you correctly, you are saying that, because it comes from such a plethora of sources, it would be difficult to collate it and co-ordination would be a problem. Is that what you are saying?

Gil Paterson: I am not precious about the indicators, but I will come back to that.

What is the purpose of gathering the information? It would not be gathered just for the sake of it. It would be gathered so that we could see what best practice was. It would enable us to see who and what conditions were being treated to best effect and where that was happening. We could transpose that to areas where those benefits were not being felt. That is why we should collate the information, which should be consistent. Different information should not be gathered in different places.

I will pre-empt the question that I have no doubt the committee would have asked me about the indicators. In the consultation that Roseanna Cunningham undertook, some people said that there were not enough indicators and some people said that there were too many. The stock political answer, as we all know, is to say, "We have got it just right." I do not think that I have got it just right. Since the publication of the bill, comments have been made and the committee has taken evidence. What I want and what the bill wants is the best usable information. Neither I nor the bill wants the gathering of that information to be an onus on GPs or anyone else. I want information to be gathered that will benefit those people who, at present, are not benefiting from palliative care.

Helen Eadie: My final question—

The Convener: Before we move on, you say that you are not precious about the indicators. Are there any that you would be prepared to discard?

Gil Paterson: I am reviewing the indicators. As this is stage 1, I am still listening to the evidence and taking it extremely seriously. I cannot give you a commitment one way or the other, but stage 1 is about getting the best possible indicators. I am giving the indicators in the bill serious consideration, but I repeat that I am not precious about them—I want the best information possible.

Helen Eadie: My final question is about NHS QIS, which I note has agreed that palliative and end of life care will be included in one of the work programmes of the quality strategy. That will require joint working between NHS QIS and a range of bodies including NHS Education for Scotland, the SPPC and NHS boards. Given that one of the recommendations that has been made could lead to the formation of data concerning the development of new clinical standards for palliative care, do you think that that would that be an alternative way of achieving much of what you seek to achieve?

11:00

Gil Paterson: I do not, because of what I have already said. The information that we are gathering has to be Scotland-wide and consistent, for the very reasons that I gave earlier: so that we can identify whether a particular condition is not being dealt with properly or whether there are problems in a particular location. In my view, the only way that we can do that is to have good-quality, solid information that we can act on.

Mary Scanlon: I listened carefully when Ross Finnie asked you why the measures in the bill should be in legislation. I have looked over the draft progress report on "Living and Dying Well". You seem adamant that the measures have to be in legislation, but you also said that "Living and Dying Well" was a strategy. To me, it is more than a strategy; it is an action plan. Annex A of the progress report sets out 25 actions and states:

> "Monitoring of progress will be undertaken by the Scottish Government Health directorates through the Living and Dying Well National Advisory Group."

The cabinet secretary tells us constantly—and rightly so—that if a health board is not adhering to action plans, that will be brought up at the annual review and the board will basically be told, "What you're doing isn't good enough and you have to do better."

Action 13 in annex A is on the electronic palliative care summary, the implementation date of which is 31 March next year. That is the date to which all health boards must adhere.

Actions 16 and 17 are on the development of the care home agenda. Under those action points, the palliative care approach will become a care standard, which will be regulated by the Scottish Commission for the Regulation of Care. We all know that if a care home does not provide care to the required standards, ultimately it can be closed down. Although the actions are not legislation, there are fairly robust checks and balances in "Living and Dying Well". I am still not convinced of the need to put the measures into statute, given what we have in front of us today.

Gil Paterson: I have listened to people giving evidence and there is obviously a difference of opinion as to whether it would be more beneficial if all this was in statute. I believe that it would be. We have heard evidence that that would bring "Living and Dying Well" into areas that it is not reaching at present—that is the best way that I can describe what I heard in evidence in this committee. Therefore, I still contend that if the duty to provide palliative care is in statute, it will happen. The minister or anyone else is a free agent to lodge amendments on the indicators to ensure that the bill is not flawed, if the information gathered would be useless or the requirements would be only a burden. I want the information and the actions on it to serve a purpose that will help people the length and breadth of Scotland who, at present, do not benefit from palliative care.

Mary Scanlon: If neither the health board annual reviews, a date on an action plan, the care commission's regulation of care standards and all its power, nor the Scottish Government's health directorates' monitoring through the living and dying well national advisory group is robust, we have serious problems not only in palliative care, but elsewhere. Do you know what I am saying?

Gil Paterson: I understand.

Mary Scanlon: If legislation is justified by what has been described, we are saying that we do not have robust enough monitoring actions and strategies for an awful lot more in the health service. Legislation would be justified for an awful lot more.

I do not want you to think that I am unsympathetic. The bill has not only allowed us to hear evidence but benefited the whole palliative care movement. Given my questions to the cabinet secretary, I hope that she will include elements from the bill in the future implementation of "Living and Dying Well". However, when I read the actions in the progress report, I question whether the bill is necessary. Are the four actions that I have mentioned not sufficient to monitor the implementation of "Living and Dying Well"?

Gil Paterson: Thank you for your comments. I confess that I was comforted by what the cabinet secretary said—it would be remiss of me not to acknowledge that. For a cabinet secretary to say that she is listening and paying attention to elements of the bill is good and encourages me. However, that does not mean that I will take my foot off the gas pedal, because I do not have the answers that I have sought on the whys and wherefores.

The driving force behind the bill is the aim to improve palliative care. The bill is not—strangely enough—aimed at specialists, although I have heard people say that that is its aim. Palliative care is a generalist area. We need education across the board that brings about a change of attitudes or ethos—whatever name people want to use. We must monitor, measure, report and act. I am probably the best supporter of "Living and Dying Well" but, to make it go the extra mile, we need the elements in my bill.

I understand the argument that it is a big step to introduce legislation to effect palliative care, as if the subject is special, but it is special. The bill would not discriminate against anyone, because everyone will die. In contrast, a bill on hip replacements would discriminate, because it would affect only those whose hips would be replaced. The bill is about everyone—it is about you, me and our families. The approach is for everyone. For that reason, I will not take a step back. I heard what the cabinet secretary said but, even if "Living and Dying Well" does not need my bill, I still think that it needs something similar. That is the best answer that I can give.

Rhoda Grant: I have a fair amount of sympathy with what Gil Paterson is trying to achieve, but I am not totally convinced that the bill as it stands will deliver what he wishes it to, given the comments that the minister has made. I am also a little reluctant to legislate on things for which the patterns are changing. We have started from a poor base, and "Living and Dying Well" has improved things. Gaps remain, but sometimes if legislation sets things in stone, that legislation becomes a barrier that does not move when progress is made.

At stage 2, will you consider amendments to simplify, for example, the reporting issues? No one would argue that the long title of the bill makes very clear what the bill seeks to achieve, but the mechanisms in the bill may be difficult to implement and may cause problems. The long title puts a direct duty on ministers to implement palliative care. Would it be possible to amend the bill to allow ministers to introduce measurements and reporting functions and to monitor the situation? Could that be done via subordinate legislation that would be updated as progress was made? Have you given thought to that?

Gil Paterson: Thank you for your comments. Yes, I have given thought to everything I possibly could, and you can probably gather that I have been listening carefully to points that have been made about the indicators. I have said that I am not precious about the indicators as they are set out at present. I am willing to listen to anything that brings about changes in palliative care, and I am willing to assist. The only offer that I can make to Rhoda Grant is to listen to everything.

If they so wish, it will be up to members to lodge amendments if they believe that measures in the bill actually hold it back from its intentions. I have been willing to listen to any arguments. I am always in a listening mode.

Rhoda Grant: So there is no part of the bill that you would die in a ditch for, except the general principals.

Pardon my language—“die in a ditch” is perhaps not what I meant.

The Convener: That is gallows humour from the nature of all the legislation that we are considering.

Rhoda Grant: It was not the best choice of words—forgive me.

Gil Paterson: I did not quite hear you. Do you want to put it on the record again?

Rhoda Grant: No. In our efforts to get the bill to work, is there anything in it that you would insist should remain? I take your point that you are listening to comments and are willing to take issues on board, but I am trying to understand—

Gil Paterson: You want to know what is the bottom line.

Rhoda Grant: Yes—what is the bottom line?

Gil Paterson: There are two elements. There must be indicators; it is implicit in the bill that there must be a consistent system of reporting. If such a system does not exist, the bill, in effect, does not exist. I have already explained the reasons for that. We must not simply gather information for the sake of gathering information; we have to be able to transpose the information and use it to benefit people who require help.

I do not have any hard and fast evidence on this, but it is commonly said that 90 per cent of people with cancer will benefit from palliative care. Someone also told me that 90 per cent of people with other illnesses will not benefit from palliative care. The profile is changing, but we need to gather the information. “Living and Dying Well” needs that information to effect its progress.

That was the first element. The second element is this: from listening to evidence, and from what I have learned from visits I have made, I feel that there should not be a choice over this. The measures have to be in statute.

Those are the two elements on which I could not compromise.

11:15

Rhoda Grant: I suppose the statute could set out the way forward and place a duty on Government to ensure, as the long title of the bill spells out, that palliative care is available to people. The methods of measuring and reporting may change over time, depending on the situation. That would result in a much simpler bill. I agree that people coming into the world should be legislated for: we are all born, and we all die, so there are two distinct parts.

To that extent, I agree with your wish to legislate and the long title of the bill. My concern is what is in the bill. If there was a duty on Government to set measurable and transparent indicators, and there were targets for health boards to report on those to Parliament, would that satisfy the aims of the bill? Health boards have targets that they must meet, and they must answer to the cabinet secretary and others if they fail to do so.

Gil Paterson: It is a good question. The bill passes the power to vary the indicators to the minister, for the very reasons that you have raised. The indicators should not be set in stone: as the bill’s sponsor, I am still in listening mode on them. Ultimately, as matters progress, whoever is in government must have the power to make changes and to make the indicators relevant. I accept that the indicators must be relevant to what the bill is trying to achieve, which is to find out about best practice and transmit that to areas in which it will benefit individuals and families.

Michael Matheson (Falkirk West) (SNP): You have answered an element of my question. As a big fan of the Government’s policy in “Living and Dying Well”, what amendments would you seek to make to improve it further that would not necessarily require legislation?

The main thing that I have taken from your evidence so far is that you believe that the indicators are the significant element that could assist in delivering "Living and Dying Well". If the Government said that it was prepared to consider indicators that might give us a clearer and more transparent understanding of how "Living and Dying Well" is being delivered, would you be prepared to allow it the opportunity to do so, and to see what progress could be made without necessarily introducing legislation?

Gil Paterson: I would need to give that serious consideration. I was certainly encouraged by the minister's comments to the committee. It is a serious question that you ask, and I cannot answer it at this point; I would need to canvass opinion on that. Many people are relying on me to progress the bill, so it would be a major step for me to do what you suggest at this stage. I hear what you are saying, and I acknowledge what the minister said; it is no mean feat for her to come to the committee and spell out the things in the bill that it might be worth while to consider. Knowing the lady in question, I know that she means it. I cannot say any more, other than that I would certainly consider all options. However, I would need to seek counsel on whether to do what you suggest and drop the bill.

Michael Matheson: You will be aware that, in evidence to the committee, questions have been raised about the timing of the bill, given that the original concept of the bill came pre "Living and Dying Well". On policy and what it tries to achieve, "Living and Dying Well" is still in its infancy and still developing. It will probably take a good number of years to achieve its objectives in the end. I get the impression from the cabinet secretary's evidence that we are pushing at an open door with the Government in asking about what more can be done to improve palliative care within reason and without necessarily going down the legislative route. We might be able to get the Government to take on board measures that would make more incremental change in the way that you would like. Part of my thinking is that, rather than drop the bill, we need to hold back and see whether the progress that the Government expects to make and the additional changes that it intends to introduce will deliver. If that does not happen and the progress that we expect is not achieved, we have the threat of legislating.

Gil Paterson: I understand the question, and it is a good one. The suggestion is to keep the ammunition to be deployed another time. I listened to some of the evidence on that same line about "Living and Dying Well", which I acknowledge is new and which I understand is making good progress, although I have no way of quantifying that at this stage. However, I was concerned about one comment that was made, that it might take five years for us to determine whether "Living and Dying Well" is hitting the mark. I do not want to wait for that length of time. A year after the bill is passed, if it is passed, we will start measuring "Living and Dying Well" and find out whether it is making progress.

I do not want to wait for five years. Although we are making progress, we have waited too long in many instances. There is no blame here, but in my experience palliative care has been a soft touch for the health service. Although, broadly speaking, health boards across the country are making progress on "Living and Dying Well", they need the momentum that the bill would provide so that we get to the destination more swiftly.

The Convener: One of my great difficulties is with the term "palliative care", which is right at the heart of the bill. That is what the bill is about—I am talking not just about the reporting, but the actual definition. We all know palliative care when we see it, but there are difficulties when we try to define it in legislation. We can have all the good intentions in the world, but legislation must be crisp and have solid meaning and definition. However, when we try to define palliative care, we hit a road block. As we have heard in evidence and in questioning from members, other forms of treatment can be given in parallel with palliative care and people can come in and out of such care. A colleague of mine was diagnosed with four months to live two years ago, and I wonder when palliative care kicked in in that case.

As I think Rhoda Grant said, if we try to set a definition in stone, there could be unintended consequences. Having placed a duty, it might be difficult to know when that duty kicked in or moved out. Can you see the difficulty for me and, I suspect, other committee members with the definition and how it will operate? You must make it enforceable, and I cannot see when it would start to become enforceable. Some would say that it would kick in when a patient started palliative care, but I do not see how we can define that.

Gil Paterson: I understand your question. The bill uses the exact same definition as "Living and Dying Well". It is also based on the World Health Organization's definition. The difference is that the WHO uses "life-threatening" and the bill uses "life-limiting".

If there are questions, they are about palliative care in general, not about the bill. The bill neither changes, adds to nor subtracts from the definition in "Living and Dying Well". It is the same.

The Convener: The cabinet secretary made the point that "Living and Dying Well" is individual to individual circumstances, people, their families and professionals. However, the bill is generalist. It tries to encapsulate palliative care so that it can be transported to different, individual circumstances. For me, that is the problem. There is no flexibility, which is required in the circumstances, as I have already discussed.

When does palliative care kick in? In individual circumstances we will know what that point is, but it is a huge problem to try to put that into a bill, set it in stone and say what it means without being specific.

Gil Paterson: The bill is not intended to define in that manner. People can benefit from palliative care but come out of it and go back in again. When you go to the doctor, you do not sit in the palliative care seat; you sit in the same seat.

The Convener: Forgive me, but it does define palliative care. It sets it in stone. First of all, we hit “life-limiting condition”. Give examples of a “life-limiting condition”.

Gil Paterson: The use of a reasonableness test will be familiar to members from other legislation, including the Interests of Members of the Scottish Parliament Act 2006. The bill makes use of such a test in setting out the limits to the palliative care that can be required.

The Convener: I accept that. I think I will simply have to disagree with you on my difficulties with definitions. It is not that I think that the intention is not grand; it is just that legislation must be crisp and robust. Defining palliative care in a fashion that will be applied across the board may have the wrong effect, unlike the flexibility that exists under “Living and Dying Well” to address individual circumstances. People know palliative care when they see it, but we do not need to write it down like you have done, because that makes it difficult.

Rhoda Grant: I agree with Gil Paterson that palliative care is not defined in the bill; the bill defines who it is available to, because it says that palliative care will be provided to people with life-limiting conditions.

The Convener: No—proposed new section 48C of the 1978 act says:

> “‘palliative care’ means—
>
> (a) in relation to persons with a life-limiting condition”

and then it goes on. Immediately, “life-limiting condition” comes into play and there is a difficulty.

Rhoda Grant: Yes, of course. I apologise.

The Convener: We cannot have legislation that has the wrong effect. That is all that I am concerned about, Gil. I appreciate what you say about thinking about amending or perhaps dropping the bill. Speaking not as the convener but for myself, I do not think that it can be amended satisfactorily the way that you want with the phrase “palliative care” right at its heart. I appreciate that you have a completely different view.

Gil Paterson: If it would be in order, convener, I will write to you and give you a fuller answer for the committee to consider.

The Convener: That would be very helpful.

Gil Paterson: I think that I can give a definitive response to you in writing. It will be much fuller than I can give you just now.

The Convener: That ends our questions. The committee is entirely sympathetic to the bill’s purpose. We were testing you on the bill’s robustness, not its purpose.

Gil Paterson: I think that I can reassure you on that.

The Convener: That concludes the item. We now move into private as agreed previously.

11:30

Meeting continued in private until 12:07.

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