The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 29 September 2015

Session 4

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HEALTH AND SPORT COMMITTEE

26th Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Sandra Campbell (Royal College of Nursing Scotland)
Dr David Carroll (NHS Grampian)
David Formstone (East Dunbartonshire Council)
Professor Rob George (Association for Palliative Medicine of Great Britain and Ireland)
Dr Maggie Grundy (NHS Education for Scotland)
Beth Hall (Convention of Scottish Local Authorities)
Mark Hazelwood (Scottish Partnership for Palliative Care)
Jamie Hepburn (Minister for Sport, Health Improvement and Mental Health)
Ranald Mair (Scottish Care)
Dr Euan Paterson (Royal College of General Practitioners Scotland)
Nicola Paterson (Scottish Government)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 29 September 2015

[The Convener opened the meeting at 09:30]

Subordinate Legislation

Mental Health (Detention in Conditions of Excessive Security) (Scotland) Regulations 2015 [Draft]

The Convener (Duncan McNeil): Good morning and welcome to the 26th meeting in 2015 of the Health and Sport Committee. As I normally do at this point I ask everyone to switch off their mobile phones, as they can interfere with the sound system, although, as you will see, some members and clerks use tablet devices instead of hard copies of our papers.

Agenda item 1 is subordinate legislation and we have one affirmative instrument before us. As usual with affirmative instruments, we start with an evidence-taking session on the draft regulations with the minister and his officials. Once all our questions have been answered, we will have a formal debate, if necessary, on the regulations.

I welcome the Minister for Sport, Health Improvement and Mental Health, Jamie Hepburn, and his officials. Good morning, minister. He is joined by Nicola Paterson, unit head at the protection of rights unit in the Scottish Government's mental health and protection of rights division, and by Stephanie Virgo—[*Interruption*]—sorry, Virlogeux, who is a late witness, just to get me tongue-tied this morning. A special welcome to you.

I invite the minister to make a brief opening statement—I think that he has prepared for that.

The Minister for Sport, Health Improvement and Mental Health (Jamie Hepburn): Yes, convener. Thank you for the opportunity to introduce these draft regulations to be made under section 271A of the Mental Health (Care and Treatment) (Scotland) Act 2003. The draft regulations will deliver the Government's stated intention to ensure that the scheme that is provided for in the 2003 act can operate effectively in the present secure estate. They will fully deliver the Millan report's recommendation

> "that patients should have a right of appeal to be transferred from the State Hospital or a medium secure facility to conditions of lower security"

by extending the right that is already in force for patients in the state hospital to patients in the three medium-secure units in Scotland.

The Government's stated intention was set out in initial draft regulations that were provided to the committee on 24 April to assist in your consideration of the provisions in the Mental Health (Scotland) Bill, which is now an act of the Scottish Parliament, having received royal assent on 4 August. The draft regulations that the committee is considering today differ from those that were provided in April in only two respects. I shall deal with each regulation separately and will highlight where there has been an amendment.

The 2003 act introduced a requirement for applications to the Mental Health Tribunal for Scotland from patients in the state hospital and those in medium security to be accompanied by a supportive report prepared by a medical practitioner. Regulation 3 is an addition to the April draft regulations. It amends the 2003 act so that the medical practitioner must be an "approved medical practitioner", as defined in section 22(4) of the 2003 act.

As approved medical practitioners have been approved by a national health service board or by the State Hospitals Board for Scotland as having special experience in the diagnosis and treatment of mental disorder, they have the necessary expertise to assess and determine whether a patient requires to be detained under conditions of special security in the state hospital or whether the test in the regulations is met for patients in qualifying hospitals.

Regulation 4 remains unchanged and lists the three medium-secure units in Scotland. Patients in those "qualifying hospitals" will benefit from the regulations through the extension of the right of appeal against being detained in conditions of excessive security.

Regulations 5 and 6 set out the test that must be met for the Mental Health Tribunal for Scotland to grant an order declaring that the patient is being held in conditions of excessive security and requiring the relevant health board to identify a suitable hospital with the appropriate level of security. The test focuses on the key issue of the risks that the patient may pose to themselves and to others. After all, the purpose of security in psychiatric care is to provide a safe and secure environment for patients, staff and visitors that facilitates appropriate treatment for patients and appropriately protects the wider community. It is only when the level of security that the patient is subject to is greater than necessary to manage those risks that a lower level of security can be considered.

The draft regulations that were issued in April included reference to the risks to a patient’s safety that other persons may pose. That reference has been removed following consultation that highlighted concerns about patients being detained in conditions of excessive security due to the risks posed by others.

With that, I am happy to field any questions that the committee may have.

The Convener: Thank you, minister.

Rhoda Grant (Highlands and Islands) (Lab): Quite often, patients want to appeal their level of security after it has been changed, for example when someone has been moved to a place where there is increased security. One problem in such cases is that, even if the patient wins the appeal, the place that they previously occupied has been given to somebody else. They might win the appeal against increased security, but no bed is available for them anywhere else. Is there anything in the regulations that would keep their bed open for them until they have had a period of time to appeal?

Jamie Hepburn: I do not think that anything in the regulations specifically relates to that; I can ask Nicola Paterson to confirm that in a moment. The legislation is set out such that anyone who is successful in an appeal is transferred when a bed becomes available. That is no different from the approach that is taken now. Am I correct, Nicola?

Nicola Paterson (Scottish Government): You are correct.

Rhoda Grant: Are there any plans to change that? Somebody’s liberty could be at stake because the level of security is wrong but the bed that they had has been given up.

Jamie Hepburn: I am always willing to take on board suggestions to finesse and adapt the system that we have in place. We have just been through a very extensive bill process for the Mental Health (Scotland) Act 2015, and the committee was integral to that process. We have no plans to reassess it any time soon, but we are always willing to keep things under review.

Rhoda Grant: The issue was discussed during the bill process, and I think that it was put on the record a number of times that a place should be kept open with a time limit to allow someone to appeal, so that they would not be held in excessive security. I would be grateful if you would look at the issue again.

Why is the right of appeal restricted to key places rather than applying to any level of security? One imagines that anyone who is being kept under an enhanced level of security should have the right to appeal, right down to having no security at all.

Jamie Hepburn: As I set out in my opening remarks, in essence we are trying to fulfil what the 2003 act required us to legislate for. It has taken us a long time to get there—I concede that point willingly.

The 2003 act was pretty clear, as was the Millan report, that the right of appeal against excessive security was to relate to those who are held in the state hospital and in medium security. That is the requirement that we are fulfilling with the regulations.

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I share Rhoda Grant’s concern, but I accept that the issue was dealt with at stage 3 in the chamber.

I still have a quarrel with you, not just about what you said now but about what you say in your policy note about what the 2003 act required. There is no mention of medium security in the 2003 act. The Supreme Court case in 2012 that required you to bring the regulations would never have been taken up had medium security been mentioned in the 2003 act, because the man who went to the Supreme Court was in low-secure accommodation. I do not think that it is accurate to say that you are doing this because of what the 2003 act requires. You made a policy decision to have the right of appeal only in medium security.

Jamie Hepburn: I willingly concede that it is also a policy decision. However, I take up your point about the legal challenge. It is correct to say that the challenge was brought by someone who was held in a low-security environment. However, the court’s ruling related not to the security level but to the fact that we had failed, as a Parliament, to institute any form of legislation, based on what we had said we would do in 2003 when we passed the 2003 act. The fact that the individual was held in low-secure accommodation was not necessarily relevant to the specific regulations that we sought to bring forward.

Malcolm Chisholm: I accept that the judgment did not say anything about low security, but my point was that it would never have got to court in the first place if the legislation had referred to medium security, because the individual would have had no grounds for appeal if he was in low-secure accommodation and the legislation described only medium-secure accommodation. It is very annoying that you keep talking about this in your policy note.

The policy note also refers to the Mental Welfare Commission consultation forum and says:

> “There was some divergence of opinion among participants. While some consultees questioned the need to introduce regulations, the group as a whole recognised that this was not an option.”

However, it fails to say that the Mental Welfare Commission, the Scottish Association for Mental Health, the Scottish Human Rights Commission, the Law Society for Scotland, the Equality and Human Rights Commission and the Scottish Independent Advocacy Alliance all wanted it to be extended to low-secure provision.

Jamie Hepburn: But you already know that, Mr Chisholm. The Millan report was very clear that patients in medium-secure facilities should have the right of appeal. We are fulfilling the recommendations that were set out in that report. We should also remember that the issue is the level of security that a person is held at, rather than the specific circumstances under which a person might be detained. There are already means by which people who are held in low-security accommodation can appeal against certain circumstances of their detention. If they are in lower security they can ultimately appeal the fact that they are being held at all. There is already a mechanism in place for those who are held in the lowest form of secure accommodation.

Malcolm Chisholm: The key thing in the Millan report was that people should be held in

> “the least restrictive manner and environment compatible with the delivery of safe and effective care”;

that was the principle behind the amendments to the 2003 act.

On regulation 3—I realise that this is a minor point, but I am always worried when regulations amend primary legislation—I am curious as to how the situation came about. Was the change to the term “approved medical practitioner” omitted from the 2015 act, or was it just not caught? Is that the definition that is now used in section 329(1) of the 2003 act?

Jamie Hepburn: It is a bit of tidying up. Practitioners raised the point that that is the definition that should be used.

Malcolm Chisholm: The policy note refers to an

> “approved medical practitioner (as defined in section 329(1) of the 2003 Act)”.

Was that definition a result of the act that we debated in June 2015?

Jamie Hepburn: I think that it was from the 2003 act, rather than the one that we have just passed.

Nicola Paterson: The term “approved medical practitioner” is defined in the 2003 act. In introducing the amendment, we are just using the definition that already exists, following discussions with stakeholders. Rather than using the more general term “medical practitioner”, the 2003 act uses the specific term “approved medical practitioner”, which is defined.

Malcolm Chisholm: It is not a substantive point, but I am still a bit curious about it. If that term was used in the 2003 act, why was it not used in the particular sections of the act that regulation 3 amends? I accept that that is a technical point, but it is interesting because an important part of what you propose is that appeals will be possible only with the consent of an approved medical practitioner. That might be a restraint on how many people are able to exercise that particular appeal.

09:45

Jamie Hepburn: Of the first 100 state hospital patients to make an application, 91 per cent of those whose applications were unsuccessful did not have support for the application.

I suppose that we are trying to strike a balance between ensuring that we do not have speculative appeals that might be encouraged by someone other than the patient, which could be very disruptive for the patient’s treatment, and ultimately giving the patient a right to seek to appeal where they feel that the circumstances are merited and they can get an approved medical practitioner to provide evidence to back that up.

Malcolm Chisholm: Do you accept that you are restricting in that sense the intention of the 2003 act?

Jamie Hepburn: I would not say that we are restricting the intention of the 2003 act. We are trying to put in place a system that is designed to ensure that those individuals who are held in either the state hospital, or indeed the medium-secure accommodation, have that right of appeal but that it is taken forward in such a manner that it is not likely to be unnecessarily disruptive to the treatment of people who might be in very vulnerable circumstances.

Malcolm Chisholm: I hear what you are saying. However, I think you should accept that you have modified the intention, which was praised so profusely by the current Cabinet Secretary for Health, Wellbeing and Sport. She thought that it was the part of the 2003 act that she was most enthusiastic about.

Jamie Hepburn: I know that she is very happy with what we are doing here, too.

Malcolm Chisholm: I am glad to hear it.

Richard Lyle (Central Scotland) (SNP): Good morning, minister. You said that a number of patients will be able to apply to appeal. Do we have an idea of how many appeals there could be and what the total cost might be? I am all for people being able to appeal, but I would like a bit of background on what you believe the total cost will be.

Jamie Hepburn: We do not know how many patients might appeal, because clearly it is incumbent on the individuals to seek to make an appeal. The mental health in-patient bed census, which was published in June, shows that the number of patients as at 29 October 2014 who were in medium-secure units was 127, all of whom would be eligible to seek to appeal.

We have provided some detail on the costs that we think might arise out of this mechanism. That was set out in the business and regulatory impact assessment. Estimated costs for the public sector, health boards, the Mental Health Tribunal for Scotland and the Scottish Legal Aid Board are around £760,000 per annum.

Richard Lyle: How will we fund them? Will they be given extra money to deal with the regulations?

Jamie Hepburn: We always seek to fund anything that we deliver, Mr Lyle.

Richard Lyle: I am happy to hear that, minister. Thank you.

The Convener: Agenda item 2 is the formal debate on the affirmative SSI on which we have just taken evidence. I remind committee members and others of my previous remarks. We cannot put questions to the minister during the formal debate, and officials cannot take part in the debate. I invite the minister to move motion S4M-14389.

Motion moved,

That the Health and Sport Committee recommends that the Mental Health (Detention in Conditions of Excessive Security) (Scotland) Regulations 2015 [draft] be approved.—[*Jamie Hepburn.*]

The Convener: Do any members wish to contribute to the debate?

Malcolm Chisholm: Obviously, given my questioning, I am not happy with the regulations. Given that they are consistent with the primary legislation that was passed on 24 June, however, there are no grounds for voting against them.

The Convener: No other members wish to speak. I do not know whether the minister feels the need to sum up, but he is free to do so.

Jamie Hepburn: I think that that was a steer for me, convener. I do not feel the need to sum up. It is fine.

The Convener: The question is, that motion S4M-14389 be agreed to.

Motion agreed to.

09:49

Meeting suspended.

09:52

On resuming—

Palliative Care

The Convener: Agenda item 3 is our final evidence session for our inquiry into palliative care. Before we hear from our witnesses, Rhoda Grant and I will comment on the recent visits that we undertook to gather evidence from service users and carers at the Children's Hospice Association Scotland's Rachel house in Kinross and Ardgowan hospice in Greenock.

I ask Rhoda to put some of her reflections and observations on the record.

Rhoda Grant: Probably the most striking thing was that the care at Rachel house is different from what I had thought of as hospice care. We see hospice care as being very much at the end of life, whereas the care at Rachel house is pretty much lifelong. Young people who are born with conditions that need a lot of intervention get the support that they need—indeed, that applies not only to the young people, but to their families.

Hospices deal with the whole family, and I think that parents sometimes get as much out of Rachel house as the children. Looking after a child is continuous, and Rachel house enables parents to get a break. The staff are clear that they look after the child in the same way that the parent would look after them, so the care fits with what the parent wants. That is a lifeline for people who use the service, and they use it depending on need rather than anything else.

When I spoke to staff and parents, I was also struck by the differing levels of support outwith Rachel house. We met two parents who probably had similar caring responsibilities for their children but had totally different care packages at home. One family had no complaints whatsoever because they had a good care package with loads of support, but the other had very little support. We need to get to the bottom of that because it is unfair that parents should be required to give the same level of input but do not get not the same level of support.

Another point that was flagged up—I do not think that we have dealt with it—relates to advances in medicine and how young people who might not have been expected to live very long are now living a lot longer. Places such as Rachel house have an age limit, and people become quite dependent on the level of support that is given and see it as a lifeline. I therefore imagine that it is important to have some kind of transition between services for children and those for adults.

It was a good visit; we were made very welcome. The staff and parents were really open in speaking about their experiences, and I am grateful to them for that.

The Convener: Thank you.

Dennis Robertson, Malcolm Chisholm and I visited Ardgowan hospice. We had a good tour of the facilities and were able to engage with groups of male and female service users and some carers. Many issues came up. Bearing in mind that we are dealing with the specialist end of the service, it is, I think, highly valued.

People seemed to feel that the routes to referral to the hospice were not always obvious—they might have been pointed in the right direction by clinicians or a network or whatever. Many found themselves using wider services, which meant that they needed to access the volunteer transport system to leave the Inverclyde area, for example to attend the cancer services that the Beatson provides. That is a valuable support service.

We also heard that such services helped people to overcome their misconceptions about the hospice and its care. We heard some evidence that, before they experienced the services at the hospice, people felt that it was a place where people go to end their life. Of course, that was not the case for some patients, who had been going to the hospice for some time. The hospice provided them with a personalised service that allowed them to seek out peer support to deal with their fears and apprehension about their illness.

As I say, the service was highly valued by those who could access it. I do not know whether Malcolm Chisholm or Dennis Robertson wish to add anything to that quick summary of our engagement.

Malcolm Chisholm: I thought that the concept of inside-out delivery of palliative care was striking. The phrase is almost a soundbite. I am sure that lots of people are doing it by taking services out into the community, but I thought that that was quite an interesting way of capturing the concept.

I was also struck by the idea of training people in the community who might be able to assist in signposting potential service users to the hospice and its facilities. Hairdressers are one example, because of the extent to which people in the community use them and how they talk to their hairdresser. That was also an interesting idea.

The Convener: Anyone else?

Dennis Robertson (Aberdeenshire West) (SNP): I suppose that you are referring to me, convener. The only thing that I would add is about the positivity that was around Ardgowan hospice, not just from the patients and carers but from the staff. I certainly did not hear any negative comments. There might have been issues in some areas, but they were not seen as barriers—they were viewed as things that could be overcome. That was the message that I left with: regardless of what they were, issues could be addressed or overcome. There was a huge sense of positivity, on which the hospice should be congratulated.

10:00

Nanette Milne (North East Scotland) (Con): I was not able to go on the visit to Rachel house, but I was there getting on for 10 years ago, and I absolutely agree with everything that Rhoda Grant said about the care of the whole family, not just of the patients.

Rhoda said that she was struck by the fact that people with severe disabilities, such as muscular dystrophy, are now surviving into adult life. That was not the case when I went to Rachel house—the situation is different from what it was a decade ago, and things have moved on quite significantly.

The Convener: Thanks for that. We now move to the evidence session.

Thank you for your patience, folks. We welcome to the committee Mark Hazelwood, chief executive of the Scottish Partnership for Palliative Care; Dr David Carroll, strategic lead for palliative and end-of-life care at NHS Grampian; Ranald Mair, chief executive of Scottish Care; David Formstone, fieldwork manager at East Dunbartonshire Council social work services; and Beth Hall, policy manager in the health and social care team at the Convention of Scottish Local Authorities. Thank you all for your attendance this morning. We will go straight to questions.

Dennis Robertson: One of the things that strikes me from the evidence that we have heard and from a lot of the written submissions relates to definition. It is not necessarily a matter of confusion, but there are so many definitions, and I wonder whether the fact that there are different definitions presents a barrier or obstacle to the provision of palliative care. There is the World Health Organization definition, and there is the definition from the General Medical Council, and there are differences—although I accept that there should be a difference when it comes to the definition for children and young people. Is the definition issue a barrier? Is it causing the problems with the provision of palliative care?

Dr David Carroll (NHS Grampian): I have to agree with you. I was very interested to read the report by Professor David Clark for the Scottish Parliament that was published just the other day, in which he mentions the fact that there are a lot of definitions, which may

> “inhibit clarity of thought and action”,

as he put it.

I think that certain definitions are necessary for generalist palliative care and perhaps specialist palliative care. However, palliative illnesses are on-going illnesses. There is a continuum from the point of diagnosis ultimately through to death. There will be decline, and there will be fading timescales. What the person and their family require is appropriate care at specific points throughout the illness.

Identification and assessment of need are important. Sometimes need may be very appropriately and easily managed by generalists—in other words, by non-specialists in palliative care. At other times, situations or problems may be complicated, and we need the input of a specialist palliative care team.

The definition of "end of life" is not good. There was a very good paper in *The BMJ* in 2008, which stated clearly that we needed clarification of that definition, because people use such definitions very differently. I agree with you.

Ranald Mair (Scottish Care): I suppose that I take a slightly different view from that taken by Dr Carroll. I think that the previous iteration of policy in "Living and Dying Well" broadened out our approach to palliative care, from a fairly narrow focus on premature death linked primarily to cancers to saying that we have to consider end-of-life care for a range of groups and we have to get it right.

As members can imagine, from my perspective the inclusion of social care was hugely important. It is not just a medical and health issue; it is about broader social care provision. Over the past decades, there has been a slight danger of our medicalising death. It is no longer a natural process; it is now something akin to an illness. That seems to me to be a misfortune.

Let us simply look at the numbers. Tonight, there will be 33,000 people in care homes for older people, all of whom are approaching the end of life—indeed, a large number of them may have conditions that are in themselves life shortening—but they are not routinely included in definitions of people who need palliative care. Nonetheless, I—and, I imagine, members of the committee—want to ensure that there is a good death for each of those people, that the care that they receive is adequately resourced to deliver that and, indeed, that there is access to specialist support when that is needed. We do not want people to be routinely moved from care settings to hospitals in order to access that support.

It seems to me that the definition of palliative care matters hugely, so I agree entirely on that point. There needs to be a continued approach that is about specialist palliative care provision, but the thrust of policy has to be more encompassing of end-of-life care. It should not retreat into a narrow focus that looks simply at premature death.

Mark Hazelwood (Scottish Partnership for Palliative Care): There is sometimes a lack of distinction between general palliative care and specialist palliative care, and there can be slightly careless use of terms so that discussion takes place without people being clear about what they are talking about. That lack of clarity around terminology is a problem, which is compounded by a need to raise professional and public awareness of end-of-life issues more generally.

In our paper, we included the formal definitions that have been around for a long time but which have not solved the lack-of-clarity issue. We said that one way of thinking about palliative care is to think about providing good holistic care to people whose health is in irreversible decline, whose lives are coming to inevitable close, or who have received a diagnosis in which their mortality will impact on decisions that they may make about what their priorities are. If we try to frame our thinking in those terms, it is not a matter of specialist palliative care or general palliative care; it is a matter of thinking as a professional about the person who is in front of us, what their needs and circumstances are, and what matters to them.

Meeting those needs might involve something that can be offered and provided by a generalist service. However, if somebody has more complex needs, we may need to think about accessing all sorts of specialist services, which might involve specialist palliative care with particular expertise around communication, meeting social and psychological needs and symptom management.

Dennis Robertson: I should declare that Dr Carroll provided the end-of-life care—I know that he does not like that term much—for my mother back in 2006.

In your submission, Dr Carroll, you said that access to care

> "should be based on clinical need, not diagnosis."

Is that the holistic approach that Mark Hazelwood talked about?

Dr Carroll: Yes. One of the great strengths of "Living and Dying Well" was that it stated clearly that need, not diagnosis, was the prime mover for care. As Ranald Mair said, the vast majority of people with palliative illnesses are out in the community and, therefore, the vast amount of palliative need is there, too—not in hospitals or hospices. Therefore, the vast amount of palliative care is provided by generalists, largely in primary care teams. Irrespective of the diagnosis, the person and their family will have needs. Having been identified, those needs must be assessed and addressed appropriately and as promptly as possible.

If we do not get that right, there will be a large amount of unmet need in the community. I agree with Ranald Mair that, sometimes, that need will be physical and will involve symptom control; sometimes, it will be social, such as a lack of support for carers; and, sometimes, it will be emotional, just as in the World Health Organization definition of palliative care. Therefore, palliation is holistic.

David Formstone (East Dunbartonshire Council): The reports in 2008, the Audit Scotland report and the report on children in 2012 inevitably focused on clinical pathways and relationships between secondary care and primary care; there was perhaps not so much focus on the social and psychological aspects. We need to be much clearer about the pathways and about the fact that most people will be in the community for most of their end-of-life care. I hope that the creation of the new integration joint boards will help with the links, so that there are good pathways from the hospital into the community, and that voluntary agencies and a range of support agencies will be included.

The hope is that we minimise the number of readmissions to hospital and ensure good discharge planning. Not everybody will need a social worker, but social workers’ core skills focus on good assessment and good support planning, which we have talked about. Where possible, we need to help people put together flexible packages of support through measures such as self-directed support and direct payments, so that they retain control for as long as possible—right up to the end of life. We need to ensure that there is good multidisciplinary working between social workers, occupational therapists—many of whom work in local authorities—and a range of health practitioners.

The Convener: Is that your cue, Beth?

Beth Hall (Convention of Scottish Local Authorities): I do not have a great deal to add because the discussion has drawn out the points that I would have made. Back at the start of the discussion, Mark Hazelwood talked about a different definition and a different way of thinking about palliative care. I do not think that he said the word “outcomes”, but that was the meaning behind what he said. If we take an outcomes approach, it leads us to think about services differently and to move away from the clinical understanding of palliative care that tends to focus on acute provision towards the end of life.

I agree with Ranald Mair and David Carroll that there is a role for a much more person-centred approach. That presents some challenges for the way that we think about services and how we classify them into specialist palliative care and general palliative care, but it is the right way to go.

10:15

The Convener: Can we probe that a wee bit? In hospices, people get specialist 24-hour care. In my experience, there are lots of people around and people are given a range of intensive support, whether it is clinical care at the end or support with the emotional aspects of dying, as we heard from the people we met last week. There is lots of help for people who are in a stressful situation, with things such as relaxation techniques. How do we compare that with what happens in the community?

Ranald Mair: Members reported on their visits to hospices. It might also be important for you to touch base with people who provide care in care homes and homely settings and through care-at-home services, who also support people as they move towards the end of life. We need a consistent approach, which is partly about upskilling the workforce in such settings so that they are aware of the agendas around dying.

There has been a significant improvement over the past six years since “Living and Dying Well”. I think that there has been less traffic of people from care homes to hospitals at the end of life. There has been more investment by care organisations, and more support has been given by, for example, Macmillan and Marie Curie, to develop capacity to provide positive end-of-life care.

However, it is not surprising that there is an agenda to do with resourcing. Resourcing needs to be adequate. The average staff ratio in a care home for older people is one member of staff to five residents, which is woefully inadequate.

The Convener: What would it be in a hospice?

Ranald Mair: I do not have the figures, but maybe someone else knows.

The Convener: One of the other witnesses might know.

Dr Carroll: It is significantly better than one to five.

The Convener: Yes.

None of us mentioned that Ardgowan hospice provides care and support at home and in the community. We engaged with the wider partners who are delivering some of the social care, but I take Ranald Mair’s point that maybe we could have done more.

Ranald Mair: I know that this is not the arena in which to take forward the debate about resourcing, but if we want an even standard of provision of end-of-life care across different settings—people’s homes, care homes, hospices and hospitals—there has to be a more level playing field in the resourcing of services and the support that is available. I simply make that point.

David Formstone: It is inevitable that there is a resource issue. As Ranald Mair said, it is about training and upskilling ordinary carers and home workers, who are going to be the people who work with the majority of those who are approaching the end of life. We should recognise that, when it comes to overnight care or weekend and evening care, local authority home care purchasing services are not geared up to providing intense support over weeks and months, whether the care is provided by direct or commissioned services.

As well as the service aspect, there is a personal care funding aspect to the problem. As members know, personal care is free for people over 65 but not for people under 65, so people under 65 who need intensive support at home have to pay for it. Indeed, they will probably have to pay the maximum charge for care.

Members will also be aware of the virtual demise of continuing care. A circular came out a couple of months ago that in effect means that, unlike what happens in England, if someone can be cared for anywhere other than a hospital, that should happen and the NHS will not fund that care. That contrasts starkly with the United Kingdom Parliament Health Committee’s report in March, which said, first, that all social care funding should be free for everyone and secondly, that there should be much more promotion of continuing care for people, neither of which is the case in Scotland.

Dr Carroll: Let me use figures. In 2012 in NHS Grampian, 5,318 people died. Of those deaths, 3.7 per cent occurred in a hospice—a tiny minority. Of the people who died, 88 per cent were over 60 and 75 per cent were over 70. When we look at all the people who require care at the end of their lives, we are not looking at the cancer population. There is very much a changing spectrum of palliative care.

If we aim to enable more people to stay at home for as long as possible and ultimately die in their own homes, we need a workforce. It is important that the approach should be about not just having people at the coalface but having people with sufficient knowledge and skills to be able to identify and deal with the problems that people will face if they are to remain at home safely and comfortably.

The other thing that is likely to be required is some form of respite. Looking after someone at home in the last weeks of their life can be physically and emotionally exhausting. If family members are fit, they might be able to carry that burden, but given the ages of the people that we are talking about it is likely that the main carer will be old and will have medical problems of their own. The carer will therefore be unable to sustain such a level of care without help. Respite is important for patients and for carers. That brings us back to what Mr Chisholm said about inside-out care—people being in but out. Respite care could be given at home, or admission to a unit could be required.

Mark Hazelwood: The convener asked about the contrast between what happens in a hospice and what happens elsewhere. The point is that we need good care in all settings. As we know, more than half of all deaths in Scotland occur in hospital. There is an aspiration to reduce the percentage, but we know that, for a significant number of people, end-of-life care will be provided in a hospital setting.

Ranald Mair talked about the number of people who are in care homes for the elderly towards the end of their life. We have to get care right across all settings. I agree with the points that have been made about the need for resourcing if we are to do that. If we compare the complexity of the needs of people who are in care homes with the situation five or 10 years ago, we find that the population in care homes is very different; we need to think about the implications of that in relation to resources and education.

There are lots of great education resources out there, but there is no comprehensive and systematic framework that acknowledges that palliative and end-of-life care is one of the major core businesses of our health and social care system. For someone in that system, what are the core competencies that they should have to play their part in providing good care across all settings? We need to develop that sort of framework. It would perhaps be a bit like the framework for excellence that was put in place for dementia. We should think about that for palliative and end-of-life care. We need to embed palliative and end-of-life care education in undergraduate curriculums, too.

There is then a question about culture. Although there is some very good end-of-life care in hospitals, our hospitals largely come from a model of cure, and we need to try to make them places where it is possible for good holistic care to be provided in circumstances where cure is not possible. That is a challenge in busy acute hospitals. There are good examples of care, but we need a bit of a culture shift around that and to recognise that, as I said, a big part of what Scotland’s acute hospitals do is to provide care for people in their last year of life.

Beth Hall: I want to pick up on a couple of points that have been made. I agree wholeheartedly that we need to develop the workforce and use it more flexibly. As the discussion has indicated, a wide range of staff in many different settings play a role in palliative care and could potentially play a much greater role. However, as several people have highlighted, developing the skills and knowledge bases in the workforce requires investment. There are some real challenges there and some big political issues about an on-going desire to protect investment in the NHS, often at the expense of investment in local government. That is taking place against the backdrop of a situation in which we, as a society, do not value social care in the same way as we value NHS care. We are not willing to pay decent wages for social care, which causes problems with recruitment and retention in the workforce.

Against that backdrop, it is difficult to upskill staff and ask them to take on more responsibilities that may be outwith their traditional professional boundaries. If we are unable to provide an increase in benefits to staff for that, it does nothing to help to address recruitment and retention problems; in some cases, it makes those problems worse.

We started to touch on the role of carers. We recognise that people who provide unpaid care are absolutely key to our health and social care system. Without them, that system would collapse. However, in recent years, we have seen a dialogue that represents a very superficial approach to carers. The committee has been scrutinising the Carers (Scotland) Bill, which will introduce a universal entitlement to assessment for carers. However, that does not equate to an entitlement to support and will actually divert resources away from the support budget. We really need to take a step back and look at the bigger picture of what is going on in the system and why it is producing the outcomes, variation and issues that we are all talking about today.

Ranald Mair: David Carroll made some very positive points. There are parts of the country where we are unable to recruit the workforce. Although there are issues about resourcing and training, what we actually need to do is to promote careers in care. Parts of Grampian are particularly problematic at this point. In Aberdeenshire, it is very hard to recruit the people we need. We need a workforce to deliver the care.

We must ensure that we maintain the volume of care. Contrary to what we might expect given the demography, we are delivering home care to 10,000 fewer people now than we were 10 years ago. Ten years ago, we were delivering home care, including the traditional home help service, to 60,000 people. We are now delivering care at home to 50,000. A lot of people may be getting more intensive care packages and the hours of care being delivered have increased, but the number of people receiving care at home has decreased.

Similarly, we are seeing a reduction in respite services and people’s access to those services. If our goal is to support individuals and their families at end of life, we have to ensure that we are maintaining the volumes of care of different kinds that we require and that we are managing successfully to recruit people into working in those settings. That is proving hugely challenging.

10:30

David Formstone: Dr Carroll talked about training. Because of the focus on clinical matters, training for social care and social work has tended to lag behind. We could be more proactive than we have been.

A home carer who visits a patient three or four times a day knows that patient best. Home carers are no different from anyone else when it comes to their feelings about death and mortality. They, too, hope that somebody else will take on their care. There are some good examples of initiatives in Renfrewshire and North Ayrshire, where there have been partnerships between home care agencies and hospices. In Renfrewshire, community psychiatric nurses have, off their own bat, set up training programmes for home carers. If that could be replicated throughout the country, with electronic training and some funding, that would be good.

Something similar applies to the professional training that social workers receive. That is probably another topic to be added to the list of topics, as it is an area that needs to be promoted much more. As I said, most people will not need to come near a social worker—they will have good family support. Other people will be a lot more vulnerable and isolated and may lack mental capacity. There are a number of areas in which social workers can intervene, not only by delivering services and helping with practical aspects to do with housing and welfare benefits but by helping with advance planning and by doing bereavement work with families once the person has died. They can work with a person in their last stages of life, too.

We have talked about the psychological and emotional elements. Social workers can help people to come to terms with their situation and get them to talk about their feelings and concerns about dying. Patients can do things such as writing letters to people. Another example is the life story book, which helps people to take stock of their lives.

Beth Hall mentioned support to carers. A huge area of social work that is maybe not explicit is work with people with long-term conditions, dementia or cancer. That is an area for development.

Dr Carroll: As we discuss workforce, skill mix and education, we must always be mindful of the fact that 70 per cent of the week is now deemed out of hours, and therefore we also require a workforce out of hours that has the same qualities and skill mix as the in-hours workforce. Unfortunately, illness is not a respecter of Monday to Friday, 9 to 5. Problems—deteriorations and acute symptoms—are statistically more likely to happen out of hours than they are in hours.

We plan care and handovers to the out-of-hours service, we have the key information summary and we do our best. Unfortunately, though, all illnesses, particularly illnesses that require palliative care, have two components—there is a degree of predictability, but also a degree of unpredictability. That is the problem. We have to be prepared for the things that we cannot predict.

The Convener: I thank the witnesses for their engagement. It is almost a panel that we have got here this morning, so we have been taught a lesson to listen for a wee while.

Rhoda Grant: I want to turn to equity of service provision. We have talked briefly about how people with life-shortening conditions usually have more access to palliative care and about that option being open to people who are coming to the end of their lives. One of the things that has struck me—and which certainly struck me at Rachel house—is that different levels of palliative care are available in different areas, depending on the health board or the local authority. How can we get a minimum level of service that people can expect towards the end of their lives to ensure that we do not have a situation in which some people are getting exceptionally good care while others are not? We hear that exceptionally good care is available but we also hear that some people are pretty much left alone and, quite often, they are the ones who fall back on accident and emergency and so on when families are no longer able to cope. After all, nobody wants to die in hospital if they can die comfortably at home, so how can we ensure such provision?

Mark Hazelwood: We have heard about postcode lotteries in the health and social care system, and that the bulk of palliative care is provided in generalist settings. However, the sort of support and access that people get might be less to do with their postcode and much more about the microlevel with regard to the health and social care professionals that people encounter. We have some data about general practitioners' levels of comfort about initiating and conducting discussions on people's preferences for care towards the end of life, and we know that some GPs are more comfortable about doing that than others. The issue, therefore, might not be where someone lives but whether a particular general practitioner is more comfortable about taking forward discussions on end-of-life care.

When someone is admitted to hospital as a result of a sudden deterioration in their condition, the kind of palliative care that they get might come down to whether they are admitted to a ward where the staff have been able to access training and support and are comfortable about using their knowledge and skills to provide someone with that care. That is why I have emphasised the importance of comprehensive education and training; that is how we can start to address the slightly arbitrary nature of the general palliative care that people experience.

Ranald Mair: I want to echo in part what Mark Hazelwood has said and to add to it. Parallels with dementia care are quite useful to us with regard to palliative care. We have tried to make inroads into improving dementia care by setting comprehensive educational standards for specialist or general staff in the sector and certainly in social care. Furthermore, the Government has set a requirement for one-year post-diagnostic support for people with dementia, which is all about setting out what people who have been diagnosed with dementia can expect. Perhaps we need to move in a similar direction to ensure that people know what to expect with regard to standards for palliative care.

We are at the point of reviewing the national care standards, and we are looking for them to become more embedded in human rights. We are likely to have a new framework of national care standards within the next two years, and it is important for palliative and end-of-life care to be anchored or embedded in that framework going forward.

We can apply to palliative care mechanisms the things that have made a difference in dementia care—for example, the improvements that we have made to dementia care by introducing national standards for, say, tissue viability—and attempt to put in place a similar joined-up approach for palliative care. That has become more possible with local integration. Indeed, the regulatory bodies and the improvement services are becoming more aligned as well. Healthcare Improvement Scotland and the Care Inspectorate are working well together, and that could be a vehicle for putting in place a standard approach to palliative and end-of-life provision in health and social care settings.

Beth Hall: Perhaps I can highlight what I think are two of the biggest access issues. The first is the reach of specialist palliative care services and attempts to improve their reach beyond hospital settings and out into the community. I will not talk about the challenges in that respect—there are colleagues here who are better able to do that—but I recognise that there are resource issues to deal with, just as there are for local government. The second issue is about improving equity of access, which comes down to the upskilling and the greater use of generalist services that we have already talked about.

As we have already mentioned recruitment and retention difficulties, I will not dwell on the issue, but I think that we also need to look at improving the flexibility and availability of commissioned services. That will partly come down to the commissioning behaviour of the integrated joint boards. As they are in their shadow year, it is very much a case of watch this space. We also need to recognise that rural areas have real challenges not just around the recruitment and retention of staff but around the range of providers that operate in the area. Indeed, that is a real challenge for integrated joint boards as they develop their joint strategic commissioning strategies.

Those partnerships are looking at how we can support different and more innovative types of provision. Whether we are talking about the Moray area, where support for microproviders is being looked at, or other areas, the issue is finding out how we work with providers in an area in a much more integrated and open way, projecting the likely needs of the population and having an open discussion about the provision that will be needed now, next year and into the next 10 years.

David Formstone: On Ms Grant's question about equity, it is, as Mark Hazelwood says, partly about there being a certain amount of geographical inequity, depending on where the flagship projects happen to be. Obviously, the people who are dying are as diverse as the whole population. There will be hard-to-reach groups such as substance misusers and homeless people who do not engage with services, and there will be people in prison who need special attention.

A major group whom I want to emphasise is people with a learning disability. Increasingly, people with a learning disability are surviving well into adulthood and into old age, and many of them either are being cared for in supported accommodation units or are known to social work and have particular needs. Research suggests that, although they lack capacity, they can often express choices about where they would like to spend the rest of their lives.

We know that, for a number of reasons that I will not go into, people with a learning disability do not do well in hospital, but care homes might not be geared up to meet their needs. There are medical aspects such as the difficulty of assessing the pain that somebody with a learning disability is experiencing. They might also lack a sense of time so it is difficult to know the best time to try to engage with them and talk about end of life. They might immediately think that it is imminent. We need to develop more accessible tools for working with people with a learning disability, and it is a whole area that I acknowledge we need to be much better at.

Going back to the dreaded resources issue, I think that continuing to maintain people at home or in supported units has major staffing implications, because it is often about one-to-one or two-to-one support, which is hugely expensive. We are absolutely committed to that—after all, moving somebody who has a learning disability or autism at a point of change is certainly best avoided—but it is increasingly becoming challenging for us with regard to resources.

The Convener: Did you want to come in, Dr Carroll?

Dr Carroll: It is okay, convener. My points have been covered.

Rhoda Grant: I have another small question. The issues in rural areas have been highlighted, but sometimes the best care can be found in rural areas, because the whole team knows each other. The GP knows the community nurse; the community knows the care worker; and they all roll up their sleeves and get their heads together to make things work. There are really good examples of that. On Skye, for instance, Macmillan works with Boots and community nurses to make sure that drugs are available for people at the end of life.

10:45

Care seems to fall down where there are big teams in which everyone has demarked roles and nobody takes responsibility. We might need to consider having a named person for end-of-life care who can oversee things and ensure that care is being given and that teams are called into more urban areas, where people might not speak to each other every day, in order to discuss patient care.

Ranald Mair: Drawing a parallel with dementia, I note that the whole purpose of one-year post-diagnostic support was to have a co-ordinating worker, whose role was to help the family and the individual come to terms with the diagnosis and to co-ordinate the support around that person. There could be scope for something like that here. I know that a debate is going on about the use of the phrase "named person" in relation to children's legislation, but having a key worker—a co-ordinating presence—involved in somebody's care could well be a positive model to consider.

Dr Carroll: I agree with Rhoda Grant. Sometimes small is beautiful, and smaller rural communities have a continuity and a cohesiveness. I have certainly witnessed that in NHS Grampian. As an old and ageing general practitioner, I am very keen for someone to be in control of or to be organising a lot of the care. Palliative care in a community setting is becoming multistranded and we do not want the strands to be tangled up randomly; instead, we want them to be pulled together in a cohesive way in order to maximise the quality of care that an individual patient gets.

Nanette Milne: I think that my question fits in at this point. Inevitably, there has been a lot of talk about the workforce and about resource. It might be impossible to answer this question, but has any work been done on the financial implications of a comprehensive and good palliative care system across Scotland? It would be interesting to know just how far short we are falling financially.

Ranald Mair: I do not have a definitive answer, but we can compare the cost of having somebody in hospital and the cost of supporting them in the community, even making the case for additional investment that we are making. This ought to be a win-win policy area where there is a gain to the public purse as well as improved outcomes for the individuals and their families.

I do not see this as an area where there has to be an overall explosion of or a major increase in resource; it is all about spending and distributing the pot of money that is there to best advantage. The cost of having somebody in a general hospital ward can be £1,400 or upwards a week; if they are in an acute hospital bed, the cost is between £3,000 to £4,000 a week. We could do a lot with that money in the community. That is a lot of hours of home care, several places in a care home or a whole lot of respite care.

Of course, it is not as simple as that, because there is no straight reallocation of resource if we keep somebody out of hospital. We understand that. We have been saying that politicians love to defend the NHS and hospitals, but this committee in particular has to be a defender of health and social care and of making the best use of resources to achieve the end results. Some redistribution of the existing resource pot might be an important move before we start coming to the Government and saying that there will have to be a major increase in the resource allocation.

Beth Hall: Like Ranald Mair, I do not have a figure for how much would be required. It would depend partly on where you wanted to set the bar for the kind of service that you wanted. Some of the points that we have been discussing relate to the need for a wide range of different services and staffing groups to play a greater role, especially in generalist palliative care, which makes it difficult to pull out figures. We know that particular areas of work would contribute to that vision. For example, COSLA is having discussions with the Scottish Government on investment to lift wage levels in the care-at-home sector to the level of the living wage.

As we have heard from those round the table today, we all want to do more. For example, we want to look at the core training that takes place at college and university and at how we put a focus on that. As Ranald Mair has said, simply raising wages in the care sector to the level of the living wage will not solve the workforce issues, and he made it quite clear that there needs to be a career pathway so that people see social care as a good career. You would be able to cost those elements, but as far as I am aware, no such exercise has been done.

Bob Doris (Glasgow) (SNP): I have a couple of little questions, but I will hold off on the second one because I know that Richard Lyle wants to come in.

As I have mentioned in the chamber, the career pathway in social care is, in my view, a major issue that stands out. I have family members who are cared for in residential units, and I have seen the amazing and outstanding job that care workers do under huge pressure. Some of them will stay for 20 or 30 years doing the job, but others see it as a pathway to something else.

Often, however, the job is a filler in a pathway that might not necessarily stay within health and social care. We need to look at how we ensure that we retain people on the health and social care pathway. For example, is there scope for accreditation towards a social work or nursing degree if someone does a year or two years in a care home? Is it possible—heaven forfend—that some of our medics who go on to senior posts in the NHS could do a turn in a care home for a year and see what good-quality social care looks like at the coalface, rather than simply making clinical decisions on care?

Do we have to be more cute in thinking about how we address the issues, so that we are looking not just at building the status of social care—I am not looking to provide an exit strategy from palliative social care; it should be seen as a high-status job in its own right—but at other ways of recruiting and retaining a broader range of people to the career pathways in social care?

That was one of my two questions, convener; I thought that it was an appropriate point to raise that issue.

The Convener: Does Mark Hazelwood want to come in at this point? I think that I cut him off the last time.

Mark Hazelwood: I want to pick up on Nanette Milne's question. I am not aware of any work that has been done in the area that she highlighted. As we have said, a lot of care is provided in generalist settings, so it is difficult to pick one area out and attach a particular price tag to it.

With regard to improving things, there are one or two big-ticket items that are not specific to palliative care. We have talked a lot about the need to ensure that we have an adequate social care workforce. We have also mentioned capacity in general practice; there is a lot of work going on around that at present. There is a lot that can be done.

The "Grasping the nettle" report that we have provided to members asks what can be done to improve palliative and end-of-life care. We have set out 37 specific actions. Some of those are big-ticket items, but an awful lot can be done that will not necessarily be terribly expensive.

What struck us in engaging with our 50-plus member organisations was the degree of consensus on actions that will move the field forward. As a field, we often struggle—as the committee has done—to come up with clear definitions. However, when we ask people what needs to be done to improve the experience of the population who are living with advanced disease to support them to make the most of their time and to die well, and to improve support in bereavement, we discovered that there is quite a lot of consensus.

One example—it is a small-ticket item—is the suggestion that a huge amount could be done if we promote public awareness and understanding of the importance and value to people of learning about the decisions and choices that may be available towards the end of life. For example, people might think about whether they want to make a plan or have a discussion with their GP about what they might like if their health should deteriorate.

We have only just started to explore the potential of working collaboratively with the Scottish public. If we can do that by promoting a more open culture of discussion, there is huge scope for improvement. There are many barriers—which I know the committee has explored extensively—around whose job it is to start the conversation and when. If we, as professionals, and the public are able to be a bit more open about such things, and it becomes a bit more normal to discuss them and to do a bit of thinking and planning ahead, those barriers and difficulties will start to move away.

That sort of public awareness work would require some investment, but not a vast amount. There is, as you know, good work happening through the good life, good death, good grief initiative and similar programmes.

Ranald Mair: I want to pick up on Bob Doris's point. There is on-going work to articulate qualifications more clearly so that people can put the credits from SVQs for working in a care home or a care-at-home setting towards a social work qualification. Similarly, there has been consideration of nursing pathways.

However, that approach tends to reinforce the sense that people should move on to something better, whereas I want us to value the people who provide front-line care. I visited children's homes in Sweden some years back. The staff who work in those homes are among Sweden's highest status, most qualified and best remunerated people. They have to do a social work qualification and then a qualification and training in residential care. In other words, Sweden has turned the system upside down. People there cannot understand why we see people who work in residential settings or in social care as being at the lower level of the workforce.

My only reservation, therefore, is that we might continue to reinforce the sense that social care is something that people want to get out of in order to move on to something better, when what we actually need to do is reward and value social care roles more strongly.

David Formstone: On Bob Doris's point about internal gradings in home care, I am sure that there is work in progress, but we must, without turning home carers into specialist palliative care workers, recognise the new world of integration and the fact that health and social care are coming together. Key areas include the administration of medication, which home carers cannot undertake at present. If they were properly trained and graded, and there was an agreement with trade unions, that would free up nurses. We should certainly look at that so that those workers could, rather than just prompting people, actually administer medication.

The Convener: The issue is not just the wage rates or the status of care workers, is it? It is an adversarial system, as the private sector and the third sector are involved in social care and care in the community. Someone in the health service would not be told, "You've got only 15 minutes with that person." The 15-minute visit, with the "ding" of the microwave, means that carers' time with the people for whom they are caring is limited. In addition, continuity of care is an issue when people have 15, 20 or 25 different carers. That type of adversarial system would not be tolerated in the health service. We are not talking about simply valuing some individuals at the bottom. There are two systems operating: one is heavily regulated, and the other is less regulated and is ignored.

Ranald Mair: I do not think that it is a question of the care sector being less regulated. It all comes down to commissioning. It is not that the providers are choosing to provide 15 minutes of care; most of them are fundamentally opposed to that.

11:00

It is a source of real sadness, particularly around older people's care, that because of the higher volumes that we have compared with the learning disability and childcare groups, we want to offer each older person less and we want to provide it for less money. It is about making stretched budgets go further. How do we do that? We reduce the amount of time that is spent with people.

The problem could be solved if there was a will to have home-care workers spend more time with people. That is about what the commissioner, which is usually the public body, says it wants workers to deliver. If any of the independent organisations that are delivering home care exceed their hours, they get penalised. If they stay with Mrs Smith and do not make it to Mrs Jones in time for the next 15-minute visit they are penalised.

I am not quite sure what you mean by an "adversarial system", but it is certainly a needs-based system, in which the constraints are to do with the available funding for care. As I said, that disadvantages older people in comparison with every other group of service users.

Beth Hall: Ranald Mair has clearly laid out the issues behind 15-minute visits. It is not helpful to characterise this as a problem that is present in one part of the system and not in others. The point is the amount of time that is required to deliver the outcomes that we want. We are trying to move towards outcome-based commissioning. That said, it must take place within a resource envelope that is becoming ever tighter. The pressure that social work budgets have been under for a number of years is simply not sustainable. Several times in this meeting we have talked about the need for a wider debate around that—it is the elephant in the room. We are starting to see the impact of budgetary pressure.

At the risk of repeating myself and coming off the topic of palliative care, I have to agree with Mark Hazelwood's point about having a public debate, because greater willingness to talk about death and dying would be a cost-effective route into addressing some of the issues. However, we would also need to ensure that the debate was focused on the fundamental question of how much we are willing to pay for care. The amount that we are willing to pay at the moment is producing the outcomes that we are concerned about today.

Richard Lyle: I have been sitting here fascinated by both Dr Carroll's and Ranald Mair's comments. Mark Hazelwood covered the question that I was going to ask. On Beth Hall's point, we will have to reassess what we do. We do a good job, but maybe we need to look at how we provide care. We have a lot of ex-nurses out there who could maybe do social care jobs. They might have families, but they could come back into the care setting, as Dr Carroll mentioned. I had to say that, convener, so please accept my apologies.

I will move on to my question. On public awareness and information, which Mark Hazelwood covered slightly, none of us likes to talk about death or what will happen when we get older. I nearly laughed when Dr Carroll said that he is an ageing GP. I do not think that you are old—you have a long time yet. Please stay, because we need you as long as we can have you.

The basic situation is that a lot of people do not want to talk about death or what will happen to them if they have to move into palliative care. How do we raise public awareness? How do we inform people? How do we make a cultural shift in order to get people to talk about it? I made a will years ago, so my son and daughter know that I want to be cremated, how my funeral service should be and so on. When my mother-in-law and father-in-law were, unfortunately, getting near the end of their lives, they did not want to talk about or discuss the matter. How do we involve people? How do we set up a campaign? How do we ensure that people get the palliative care that they are due and know where to go to get it?

David Formstone: As well as having the public awareness campaigns that Mark Hazelwood talked about, we need to recognise the massive isolation that everybody who faces terminal illness, even those with a huge amount of family support, must feel. Whether we are talking about social work or health practitioners, we need to get better at engaging with the community. I am thinking about the use of social media, for example. I have a relative who is terminally ill who is using the website of a charity called CaringBridge, which allows the individual to set up a blog so that they can communicate with friends and family and people on the internet. It gives them back some control over their situation.

In East Dunbartonshire, we are working with Macmillan Cancer Support on a community assets approach. We have set up a website and have got members of the public and service users to identify services or community facilities that are useful, which are all plotted on the website. People can customise their support plans. The aim is to work with people who are living with cancer or other long-term conditions, not just people at the end of life. If we can help people to build up networks at a much earlier stage through things such as peer support groups and champions, by the time they come to the end-of-life stage they will have a network of people who are going through similar experiences, and they will know where to go for advice and information.

Mark Hazelwood: In response to Richard Lyle's question, I suppose that when you made a will you had an understanding of why that would be a useful and beneficial thing to do for your family and your nearest and dearest, that you had information about how to start the process, and that you were able to overcome barriers that might have existed. Those are the things that we need to think about when it comes to raising public awareness and getting more engagement and discussion.

It is important to raise awareness of why it might be of benefit to people themselves, and to their nearest and dearest, to be a bit more open, to have some discussion and to do some thinking and planning ahead, whether that involves making a will, granting a power of attorney or having a discussion with a GP about what preferences they might have as regards medical stuff towards the end of life. People need to understand why that might be beneficial. They need more information about practical choices and the implications of choices: they need to have those discussions. Earlier, I made reference to the fact that some GPs are very good at initiating such conversations. That process becomes more difficult as people become sicker, so it is one that should be started upstream.

I want to give two practical examples from different ends of the life spectrum of how we can go about changing the culture in Scotland. We have linked up nearly 1,000 organisations and individuals in an alliance called good life, good death, good grief, which is about providing information and opportunities, shifting culture and normalising such discussions and planning processes. One of the organisations involved is Age Scotland, which has formed a really nice partnership with a consortium of legal practices called solicitors for older people Scotland. It got a lawyer along to do some presentations and to encourage discussion about legal planning ahead at some of its lunch clubs across the south of Scotland.

There might be an argument for having top-down public health campaigns, but it is also really important that local organisations take a grass-roots approach. They are more likely to know what is relevant and sensitive for their stakeholders. That is extremely important, because circumstances vary a great deal.

I also want to flag up some very good work that was done by Strathcarron Hospice but not in the hospice. It did some work on running workshops with primary school teachers and primary school kids in local schools. I will paraphrase the experience. To start with, the hospice staff found it quite difficult to get access to primary schools—the schools were wary and scared of a sensitive subject—but once they started to work collaboratively with schools, that attitude changed enormously and they were invited to work in other schools.

A really high percentage of pupils are likely to have suffered a bereavement of some sort, and not doing proactive work in schools to support children and staff to deal with issues of loss in order to avoid the harm of upsetting people is not the way to think about it. The issues of loss, bereavement and people nearing the end of life are impacting on students in our schools and, by implication, on our staff. Therefore, we need to ensure that the issues are addressed, that staff are supported and that the kids are encouraged and supported to talk about those things. Children and young people are often much better at talking about such things openly than are those of us who are towards the other end of the spectrum.

Ranald Mair: I am almost entirely with Mark Hazelwood on this. We need to encourage people to regain ownership of dying. When I was four or five, my Auntie Gertie came to stay in our front room for three or four months before she died. At the time, I did not know that that was the plan, but it meant that there was first-hand experience of someone dying within our family as a normal part of family life. We have somewhat distanced ourselves from that immediate ownership of dying. Of course, we need all the professionals—we represent the professional services, so we are not arguing against that—but we must allow people to take ownership and control of the experience. It is not something that has to happen somewhere else, in a hospital or care home; it is part of family life. Some public engagement must take place. Politicians have recently been pushed on whether they would open their houses to refugees. Maybe we should ask politicians whether they would have somebody die in their homes.

The Convener: That's an offer you can't refuse.

Richard Lyle: Is palliative care currently readily available to all those who require the service?

Dr Carroll: The first question that I was asked was about that horrible thing—the definition of palliative care. People think of palliative care as having arisen in the 1960s with the hospice movement and cancer care, but it did not. Before that, general practitioners had looked after people with incurable illnesses but it was not called palliative care because the word had not been invented. From the onset of the health service, general practitioners have looked after patients with incurable, life-threatening illnesses.

The answer to your question is that, yes, palliative care is readily accessible because everybody should be registered with a general practitioner and should, therefore, have access to a primary care team. That is the theoretical answer. However, I do not know about the quality of that care or the availability of the additional components that would support the person, which could vary across the country. The bigger question is about how available specialist palliative care is to those who do not have a cancer diagnosis.

11:15

Malcolm Chisholm: I thank the witnesses for their oral and written evidence. I will pick out, in particular, the “Grasping the nettle” report. I mean no disrespect to the other submissions, but that is obviously a long report, which I hope the Government will pay attention to. I will ask a couple of questions related to it.

Given that all the relevant players are represented at the meeting, my first question is about health and social care partnerships. There are quite a lot of interesting recommendations in the “Grasping the nettle” report. I do not have time to read them all out, but they include the recommendation that the partnerships should have

> “an identified lead for palliative and end of life care”

and that the partnerships should ensure that palliative care is included

> “within strategic and operational plans”.

The recommendations are at action points 8 to 13.

To what extent do you agree with the recommendations? More practically and more immediately, given that you are setting up the partnerships at this very moment and they will go live in a few months’ time, to what extent are those issues being discussed? Palliative care will clearly be one of the responsibilities of the health and social care partnerships.

Ranald Mair: There is active discussion at local level. There are continuing concerns that not all the new partnerships have fully engaged both the third sector and the independent sector. There is varied experience of the extent to which there is full inclusion of all social care provision in the work that is being done.

People continue to see palliative and end-of-life care as an area in which—in a sense, this is the wrong way for us to put it, given what we have been talking about—some gains can be made by shifting the balance of care. It is still seen as an area in which, if we can promote care in both the community and in homely settings such as care homes and hospices, there are gains to be made, as it could ease some of the pressure on the acute sector.

The harder part, because the mechanisms are not fully there—even when there are pooled budgets—is to get the corresponding shift in resource that is required. People might say in their strategic plan, “This is the direction that we would like to go in”, but to get the resource shift to happen at the same time is more problematic.

Beth Hall: Again, I agree with much of what Ranald Mair said. In a sense, the purpose of health and social care integration is to grasp the nettle of shifting the balance of care. Recognition of that means addressing a much broader range of things than we have focused on at the meeting, but palliative care and supporting people who wish to die at home or in a homely setting is very much part of the discussion that partnerships are having about shifting the balance of care.

Dr Carroll: In NHS Grampian, we had our original meeting a number of weeks ago with all the relevant parties. As a result of that meeting, we have identified priorities that we need to look at. There will be a series of subsequent meetings—again with representatives of health, social care and the third sector—to pull everything together so that we are ready for April.

Malcolm Chisholm: The recommendations in “Grasping the nettle” are interesting, and I have another brief question on the report.

It is interesting that Ranald Mair referred to rights-based approaches in the new care standards. Such approaches have been more widely talked about and, indeed, legislated for quite recently. However, “Grasping the nettle” states:

> “Rights-based approaches can be helpful in raising public awareness and understanding of what people can expect to receive. ... Framing policy in terms of people’s needs and the outcomes we want to see is an alternative way of providing clarity about what people should be able to expect.”

My question is really for Mark Hazelwood. What does the report have in mind? The comment might almost be seen as a criticism of rights-based approaches, but perhaps that is not what is intended.

Mark Hazelwood: When we pulled the report together, we were mindful that in many policy areas there is now an increased emphasis on rights-based approaches. We flag up in that paragraph that there are positive aspects of a rights-based approach, but I am conscious of discussions that we have been having about the need for a wider public dialogue about resourcing, particularly in relation to our social care services.

I think that it was Jeremy Bentham who said that rights were nonsense on stilts. I do not subscribe to that view, but it is quite easy to ascribe to people a right to excellent palliative and end-of-life care, and we have to be cautious about doing that without having the serious and important discussions about the economic resources that are required to deliver that.

Malcolm Chisholm: The "nonsense on stilts" quote is interesting. That might be circulating somewhere soon.

David Formstone: In the same way as we are moving from a medicalised approach to one that is much more reflective of the wider and holistic needs of people and the need to involve social work, social care and voluntary agencies, I suppose that the next stage is more about empowering the individual and putting the person at the centre.

Earlier, I mentioned the use of self-directed support, which is confined to social care at the moment but which could be considered within the health context, too. Helping people to self-manage is a big thrust for the larger voluntary agencies in this area. The issue is about allowing people to get control. I mentioned social media in that regard. The feeling that people have a say in the way in which their care and support requirements are met and about who comes in to see them and what they do to them is important.

Ranald Mair: I was at a meeting of the Scottish older people's assembly and I was challenged on the use of the term "outcomes". People noted that the term had come increasingly into use but felt that it was fundamentally vague. They felt that there is a lack of clarity about what is an entitlement and what is an aspiration, and that both elements are combined in that term.

It was felt that people should be clear at any point in time about what their entitlement is—what they have a right to expect—and what the aspirations for them are. Both are equally important, but we should not roll them both into a term that conveys a sense of vagueness about what is being committed to.

We should be clear about what people have a right to expect in terms of palliative and end-of-life care. Equally, we should be clear about what our aspirations are. Dying well combines elements of both of those things.

Dr Carroll: I am happy with the concept of self-care and self-management, but I go back to the figures that I quoted from NHS Grampian, which noted that 70 per cent of the population died when they were over 75. People's ability to self-manage their illness drops all the time. It becomes a nonsense to expect people to self-manage at a certain point. I get uncomfortable when I see the elements set out as a triangle with specialist services at the top and self-management at the bottom. Yes, self-management is important, but it is not going to continue all the way through an illness.

Bob Doris: I know that we are running out of time so I will try to be brief. I want to focus on the care home sector. However, before I do that, I want to read something from "Grasping the nettle". The executive summary says:

> "People receive health and social care which supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death. Each individual's care may look very different."

I wonder how that aspiration could be met in a social care setting.

I suspect that palliative care is already taking place in social care settings every day of the week, even though it might just be called "care". However, there are various competing needs that exist in the residential social care sector—I am talking about not nursing needs but the various needs relating to general care for older people in the residential sector. Do we document anywhere what is going on, because good work is being done in relation to palliative care, or do we tend to just say, "That's the last year of life; something will kick in" and take a tick-box approach to documenting what palliative care looks like? Are we missing a trick there?

There is a substantive point that I would like you to reflect on. Mr Mair mentioned aspirations in relation to palliative care. Irrespective of resource and staffing issues, is there a period of contemplation that residential care homes go through during which they ask, "If we could do more, what is it that we would like to do?" Such aspirations might involve hoisting someone into a bath twice a week rather than once a week, because that gives a therapeutic benefit to that individual, or having visits from allied health professionals who used to visit when the person was being cared for in their home but stopped visiting when they moved into residential care.

Are we documenting what we are actually doing well in the care home setting? Are we having those discussions about aspiration, or are we just a little bit scared about the resource issues?

Dr Carroll: Ranald Mair should answer the question, because I cannot, but before he does so I want to say something.

I am delighted that you have asked the question because, all the time that we have been here, we have essentially been speaking about illness, deterioration and dying. However, palliative care is also about living. Sometimes, we forget that people are actually living during their illness. From a social point of view but also from a medical point of view, part of the palliative care that we offer people must involve maximising people's quality of life. Let us hit as many items on people's bucket lists as we can.

I wanted to say that because that is the essence of what you have asked.

Ranald Mair: Likewise, I believe that you have asked a key question. On one hand, there has been a danger of the adoption of a one-size-fits-all approach to the care of older people in care homes. There has been insufficient diversification of styles and models of care. There must be more of that diversification, and there has to be a much greater emphasis on person-centredness. One individual's plan needs to look quite different from somebody else's.

We have the building blocks of that approach, but we have not gone all the way towards doing that. For example, the Government stopped short on self-directed support, saying that it did not fully apply to residential care. There are some pilots taking place at the moment to test out the extent to which self-directed support could fit with our model of residential care.

We have to be aspirational about how we move forward. We have to say that not all care homes should look the same, that there should not be a one-size-fits-all approach and that there should be extremely individualised care plans and pathways. All of that should include discussions with people on anticipatory care planning, not just on what they want the end to look like but on what they want the bit before the end to look like, because that is the more important bit—I agree with David Carroll on that point. A lot of people who go into care homes, some of whom have been told that they may only have a few weeks, actually recover to a degree and have more time. It is important that that time is not just spent waiting for the end but is used to add quality to their lives.

David Formstone: I want to pick up on Ranald Mair's point about keeping the person at the centre for as long as possible and Dr Carroll's point about the fact that people inevitably deteriorate and are less able to be actively involved. It is important that anticipatory care plans focus not just on medical aspects of treatment and the withdrawal of medical support but on people's social and psychological lives. Also important is the use of advocacy, with advocacy organisations continuing to speak for people even when they lose capacity.

We also spoke earlier about encouraging as many people as possible to take out power of attorney and become guardians of people who lose capacity. There are a number of ways in which we can retain the person at the centre beyond the point at which they have the ability to do that for themselves.

The Convener: Thank you for your attendance and participation and for answering all of our questions. You have given us lots of food for thought.

11:30

Meeting suspended.

11:36

On resuming—

The Convener: We will now take evidence from our second panel on what is the last day of evidence for our palliative care inquiry. I welcome to the meeting Sandra Campbell, a Macmillan nurse consultant for cancer and palliative care at the Royal College of Nursing; Dr Euan Paterson of the Royal College of General Practitioners Scotland; Maggie Grundy, associate director, nursing and midwifery, NHS Education for Scotland; and Professor Rob George, president of the Association for Palliative Medicine of Great Britain and Ireland and medical director of St Christopher's hospice.

In the interests of time, we will go directly to questions.

Malcolm Chisholm: I want to ask about recording systems, which is an issue that we did not really cover with the first panel and which I think you are all ideally suited to answering questions on.

The first issue, which I suppose is particularly for the Royal College of General Practitioners Scotland, is the palliative care register. We have heard from various people that there is a problem with identifying people, and there is a question about how well general practitioners record those who would benefit from palliative and end-of-life care.

Actually, as we are a bit short of time, I will roll all my questions up into one. The other recording systems that we have read about in the evidence are the emergency care summary, the electronic palliative care summary, the key information system and the anticipatory care plan. Obviously, there is a clarity issue around how all those systems relate to one another. Of course, things sometimes get even more confusing when the acronyms are used. Can you give us some clarity on the relationships between those systems and, without labouring the point, what improvements could be made to make those systems work better? That would be helpful.

I am sorry—I realise that there are rather a lot of issues in there. Can the witnesses—the Royal College of General Practitioners Scotland, in particular—say something about the registers and broaden the discussion out to the other recording systems?

Dr Euan Paterson (Royal College of General Practitioners Scotland): There are indeed lots of issues in there.

On the palliative care register, probably the biggest issue for me as a GP is the awkward issue of how to define that stage. I was in the room for the committee's previous discussion, and I think that deciding whether somebody should be on a palliative care register is an extremely awkward issue.

One of the problems is that we struggle to come up with a working definition of what palliative care is and who it is for, and it is difficult to work round the edges of that. To me, little separates good care from palliative care; palliative care is just good care for people who happen to be dying. I would argue that the dying side of that is when the individual's death becomes relevant to them. That is the crux of this, and it is a very personal matter for people. Some will embrace the idea that they are dying at a much earlier stage than others.

Recently, I looked after somebody with motor neurone disease who was incredibly reluctant to accept that death was inevitable. That was how he dealt with it. Sometimes, our role as health professionals is to try to explore with people the fact that we believe that they are now at a stage where they should be considering the imminence—however we define that—of their death. They might be reluctant to do that themselves.

It is a complex area, but if we can deal with that, it becomes easier to put people on the palliative care register. Historically, although we have been keeping registers for five or six years, they are still heavily weighted towards people with a cancer diagnosis. I would argue that that is because people with a cancer diagnosis are far more likely to be willing to be considered as palliative. That brings me to some of the points that Mark Hazelwood made about the good life, good death, good grief initiative. If there is one big hit here, it is to get the population on board with the fact that people are born, live and die. That is an uncomfortable reality, but we need to make the best of it.

I could talk about the palliative care register for 45 minutes, but I will move on. We have various different systems. The emergency care summary is just an upload of some key demographic stuff on drugs and allergies from GP systems. Fundamentally, all of these things have been lifted from general practice systems, so they contain only what we put in. It is our records that other people access, and we need to be mindful of that before we think that these things are more than they are. The ECS is for everybody, and everybody, more or less, has given informed consent—although I would put inverted commas around the word "informed", because I suspect that most people do not know that they have done it.

The electronic palliative care summary is probably lapsing; it has been taken over by the key information summary, so I will focus on that. Because it is attached to the ECS, it gets uploaded out of our records along with that, but it carries far more information. It has five separate subheadings, one of which is palliative care. I might argue that, if people are adding data to the palliative care section, they might be beginning to think that the person's mortality has become relevant, but we should not forget that the key information summary is used for far more than people who are dying. It can be used for anybody with any significant condition.

Again, the key information summary relies on information that we input as GPs, because we are, more or less, the only people who have write access to it. Lots of people have read access, but we are the only people who write into it.

Professor Rob George (Association for Palliative Medicine of Great Britain and Ireland): Just to come clean on what I think palliative care is, I will start by saying that I think that it is about looking after people rather than their pathologies, and engaging with uncertainty, suffering and complexity. As Euan Paterson has said, that thread runs through everybody's life, but there are certain points at which it comes in, and it becomes more pressing as death starts to come up on the horizon. That might happen intermittently, particularly where there are longer-term conditions, frailty or multiple comorbidities. It involves what I sometimes call "practising dying"—it is what my mother does about every six months and has done for the past five years. Those difficulties are very real, and the only way in which our complex healthcare and social care systems can keep on top of this is to ensure that the systems in which we record things talk to each other, which means that we need portals and all those kinds of things.

In London, we have engaged with the question whether we should have a palliative care register or whatever by putting in place what we have called the co-ordinate my care service, because the point at which it becomes relevant is when there is a need for co-ordination and for people to be able to manage the uncertainty when somebody suddenly comes into hospital or has a particular view about what they do or do not want to happen in their care. It is important that ambulance crews or whoever see it so that they do not do what the person does not want. In a sense, it is about specifying the limits and refusals that the person has on their radar. In the institution where I work at the moment, we are looking to join our hospice-based electronic system to the primary care system, which is the main one in south London. We are, in effect, doing what Euan Paterson has talked about by docking into the system that is used by the clinicians who are primarily responsible for patients' care—that is, the general practitioners.

11:45

To my mind, it all has to focus on the primary care record. We may or may not have write rights, but we should certainly have read rights, and the day will come, in the not-too-distant future, when people themselves will be able to determine who reads their records. A person's records belong to them, and we are looking at people having tablets with which they will be able to access and contribute to their own clinical records. At the moment, there is sufficiently rapid growth in the electronic world, particularly in the web platforms, that it is within our reach for people to have multiple access points and to be able to dock into portals and suck data down or put data up into various places. All the security issues and so on apply, but we do it with money, so why not do it with healthcare?

If there is one thing that we have to pay attention to, it is the ability to read what everybody else is doing in real time. When a call goes out, an ambulance crew should within three to five minutes be able to access, within the ambulance, a care record that says what the person is likely to be facing and, in particular, what they do or do not want to be done. That would make joint decision making and personalised care real.

Malcolm Chisholm: That is a useful recognition. Should that apply to the anticipatory care plan as well? It seems as though that would be relevant.

Professor George: It is implicit in that idea. Another definition of palliative care is that it is anticipatory planning in real time, because we spend our whole time revisiting people's priorities. Every time a clinical intervention or a task is met, another piece of anticipation has to apply. In a sense, therefore, palliative care is anticipatory planning in real time.

Malcolm Chisholm: I have a final question for Dr Paterson. Given that not all the needs of cancer patients are being met, is there a particular issue with those who have other conditions? Should GPs make more effort to ensure that their registers encompass the full range of people who might benefit from palliative and end-of-life care?

Dr Paterson: Yes. Should GPs be making more effort? I am sure that we should be making more effort on lots of things—competing priorities is another issue. The issue of resource has surfaced before, and we should be mindful of the fact that the supply of general practice resource is currently pretty short and getting shorter. There is an issue of workload and workforce that needs to be recognised; indeed, you will have read the paper from the RCGP.

If we are to start to identify other groups of people with long-term conditions or old-age frailty and decline—I am putting various conditions under that one subheading—we need societal buy-in to the fact that those are big issues. The thing that gets in the road is probably patients' lack of personal awareness of the enormity of what they are facing and their acceptance of that. If I diagnose somebody with cancer—it is usually a matter of confirming a diagnosis—they start right down at the bottom and, hopefully, come back up a bit as they realise that things can be done. However, if I tell somebody that their breathlessness is caused by heart failure, they are likely to say, "Goodness! I thought that it might be cancer. What a relief." I then have to unpick that. As Rob George said, the uncertainty that is inherent in long-term conditions, old-age frailty and decline and dementia makes the management of somebody with such conditions very difficult indeed. Almost in the blink of an eye, they can flit between feeling that they are in their last hours of life to feeling that they still have months, if not more, of life left.

We use the surprise question: "Would you be surprised if this person was to die in the next year?" I have a 94-year-old mother. Would I be surprised if she was to die in the next year? No, because 94-year-olds die. Would I be surprised if she did not die in the next year? No, I would not be, because the lady is still buying her sherry by the case; she is doing well. She would love to be on someone's supportive care register, but I would get a flea in my ear if I put her on a palliative care register.

Malcolm Chisholm: Thanks. That was very helpful.

The Convener: Going back to the definition, we discussed with the previous panel whether it triggers certain actions or elements of support. The definition will become important if it is described in the new palliative care strategy, because it can lead to a referral and additional support. In some cases, however, it might not. Given that the definition could become a gateway to access, it is important in a bureaucratic sense, but it does not take account of differences in human beings and how they face life-threatening or life-changing situations.

Dr Paterson: Yes, but I think that the people for whom we are caring—the people whom we are serving—face enormity all the time. It is not just a question whether they are dying; it is an enormously big deal. There is a tremendous amount of human suffering out there that we are trying to deal with and help with on a day-to-day basis.

For me, there are only two things that separate palliative care from good care. The first is the fact that it is an enormous deal, because you only do it once. I am not being at all flippant about that; we navigate our lives according to the important events, one of which is the death of loved ones. That is important, and it separates palliative care from the care of someone who is, say, anxious.

Other than that, the only thing that separates palliative care from good care—and the previous panel touched on this—is that, as one fails, the ceilings of what one is offered and what is considered appropriate begin to lower. One moves away from being a transplant candidate, a high-dependency unit admission candidate, a cardiopulmonary resuscitation candidate and so on. Finally, towards the end of life, one will move away from being an oral antibiotic candidate. I contend that, apart from the enormity of the end-of-life situation itself, the gradual lowering of the ceilings of treatment or intervention is the only thing that separates palliative care from good care.

The Convener: Some of the people whom we spoke to last week said that access to certain aspects of care was provided only when they reached a crisis point rather than earlier. They said that they wished that some of the support had been available earlier, but it was only when they had reached a crisis point that everything kicked in. At that point, all the interventions become available and cost does not matter. All the interventions are squeezed into the final couple of weeks or months.

Dr Paterson: Is that not because we are still encouraging people to separate care from palliative care? The result is that, until people reach that bridge, they do not get the care that they need. What we should be talking about is needs-based care, which Rob George was referring to.

The Convener: Some of the people whom we met said that they felt that they were just passed along. They had a lot of faith in their GP, then they were passed on to a consultant and when the day came when they were told, “We can’t do anything more for you,” they were passed on again. They had been through the process. Although they were cared for by their GP, the consultant and then the radiologist, they felt that they were just being passed along. Wider support to meet their wider needs was not made available until they found out, by word of mouth, about specialist hospice services.

Professor George: This is a really important point. From listening to the previous evidence and reading some of the other evidence, I think that it is clear that we are at a tipping point in society. Society must change the way that it sees care, the way that it sees mortality and the way that it sees the responsibilities that we have to one another.

Within that is the role of this peculiar thing that has come to be called “palliative care”. In a sense, it is an existential crisis: we have to define who we are in order to know who we are, and then it just becomes a problem. The fact is that I have certain areas of expertise that are useful and which might be applicable at various points in the clinical journey.

You might have heard about interesting recent studies of early referral to palliative care for people with lung cancer and a number of other diseases that found that patients not only had a better experience but lived longer. That was because they were getting choices, we were probably not poisoning them and they were living a life rather than dying a death. The idea of someone being passed along like a plate of cakes until there are just a few crumbs left, which means palliative care, has to end. We have to help people live complete lives until they die, with all the practicalities that go along with that.

As for electronic registers, let us say for the sake of argument that Euan Paterson has a problem with a patient and refers the person to me, as the clinician involved. I can see the data from the primary care record, and I can contribute to it. The issue stops being one in which people think, “Oh, they’re on the register”; instead, they start saying, “This person needs to be seen over here, and this is the body of electronic records for them setting out everything that has gone on.” We must start to break down barriers and have a much more fluid way of working across disciplines, between health and social care and within communities. That is the direction of travel that we need to take, and it is quite radical.

The Convener: I am conscious that we have not heard from Sandra Campbell and Maggie Grundy.

Sandra Campbell (Royal College of Nursing Scotland): At the core of what we are discussing is communication, not just with patients and families but between teams.

There is an important thing that we sometimes miss. The very sensitive conversation about what we think might happen to an individual and their family sometimes comes too late. We need to be able to have that conversation a bit earlier on the journey, to avoid people feeling that they are being passed from pillar to post. I accept that people have to go through certain stages and investigations, but we need honest communication with individuals along the way, and we need to introduce the concept of thinking ahead and anticipatory care planning perhaps a bit sooner than sometimes happens.

That is not the be-all and end-all but, if we have those conversations sooner, it helps teams to put support in place a bit sooner. We must remember that along with the dying there are the living. People in our society are having fewer children, so families are smaller and there tend to be fewer carers available to look after older family members who are on a declining trajectory. We need more time to enable people to plan in a safe and effective way, so that they get the best outcome.

It is important to discuss outcomes, because we want everyone to be able to live as well as possible for as long as possible and achieve what they want to achieve. If we do not have conversations early in the journey, when it is possible to do so, we deprive people and their families of the ability to achieve what they want to achieve in the time that they have.

A speaker on the previous panel talked about funding and direct payments. That is all very well when there is enough time to plan for self-directed support, but in many cases patients with life-limiting conditions and their families unfortunately do not have time to have such conversations. We need to strike a balance in providing support and the appropriate funding and resource for each case.

We need to get person-centred care on the map, rather than just the typical care package. Every individual has different needs, and we can ascertain what they are only by holistic assessment at appropriate stages on the journey by appropriately trained individuals, whether they are from health or social care.

I have waffled on a bit, so I will stop, but the key message is about communication.

12:00

Dr Maggie Grundy (NHS Education for Scotland): I agree with Sandra Campbell that it is all about communication. There is a wider systems issue to do with communication between professionals. Palliative care is not understood by everyone. People need different levels of palliative care throughout their illness and towards their death; they will need more or less support depending on where they are. We should focus on a holistic assessment of a person’s needs at a particular time, rather than get involved in thinking about who is on a register and whether that is the route in to palliative care. Rather than focus too much on one aspect, we need to help the system to join up so that people speak to each other.

Dr Paterson: I reiterate what my colleagues said. I struggle slightly with people’s perception of palliative care—David Carroll talked about this earlier—because actually it is just good care. People should be involved in decisions about their health whether or not they are dying. The care that I give to someone who is depressed or who has asthma is the same as the care that I give to someone who is dying. There might be a couple of things that the person who is dying might not be offered, such as CPR, but they should still be supported.

I am bouncing into one of my great concerns here. We are talking a lot about what we do to and for people, but there is a huge amount that we do simply by being with people when they are ill. A large chunk of my job, not just in palliative care, is about witnessing people’s suffering—a phrase that I have lifted from the work of Iona Heath, who is a GP in London—which is critically important when people are dying. We just need to be with the person—not doing anything to them or for them but just being with them.

I talked about my patient with MND who died—I have his family’s permission to use his story. As I was with him, I was helping him to smoke, because he could not do that for himself any more. That is being with someone at the end of their life. We should not ignore those things.

Rhoda Grant: Let us move on a bit. Both panels have talked about where palliative care takes place, and it is clear that it takes place in normal settings, at home and in the community. Sandra Campbell said that we need appropriately trained professionals, but a lot of people who care for people at home or in the community are not suitably trained, because they are not specialists but generalists. How do we ensure that they are properly equipped with the skills and knowledge that they need? Some people might be reluctant to raise issues because they are not sure how the patient will react. How can we enable people to feel confident about giving the support that people need?

Dr Grundy: That is an issue. Communication is not done well—that comes up all the time. We have had lots of communications skills training initiatives over the years. Communication skills are incorporated into undergraduate education for healthcare professionals, and in recent years a lot of effort has gone into improving the approach.

We perhaps do not do so well with people who are already working in the system. Some qualified professionals might not have had the input on communication skills at an early stage in their education that more recently qualified people have had. Often our reaction is to put everything into undergraduate pre-registration education but if, when people get into the system, they find that what they learned is not used in practice, they can quickly be socialised out of using it. A few years ago, we did a literature review on the barriers to using communication skills for people who had attended training, and one issue was people's inability to apply their skills when they started practising.

You asked about how we help people who are not specialists but generalists. That is about helping them to build confidence and competence and enabling them to use their skills in practice. The training for that would be intensive, but it can be done. The issue is how we facilitate it.

We have various tutor training courses for facilitators on communication that could be employed more widely. We have lots of pockets of good practice, but practice is not consistent across the country. Therefore, we perhaps need to think more creatively about how to make communication more applicable in practice and how to help people to use those skills.

Sandra Campbell: I support that. It is about having consistent levels of education and knowledge. Whether we are talking about health or social care, there will often be unqualified staff on the front line managing patients at the end of life who may be asked difficult questions and put in difficult circumstances. Staff may feel ill-equipped to deal with that. That is not good for the patient or the family, or for the staff member. How do we ensure that we have a consistent approach and a certain level of knowledge and training across health and social care for that group of staff, along with more advanced communication skills for the complex decisions, such as whether a patient should have a percutaneous endoscopic gastrostomy, or PEG?

I have given two examples of the different levels of skills that are needed. As Maggie Grundy said, boards adopt and use different models of education, but a consistent approach would be helpful and beneficial.

Dr Paterson: I will stick to general practice, because that is the only group that I am in any way vaguely qualified to talk for. I accept that part of the issue is about communication skills, but I am unconvinced that that is the answer. There probably will not be a GP under the age of 52 or 53 who has not undergone extensive communication skills training. When I used to do GP training, which was 10 years ago, I would, over a year, probably spend about two or three hours every fortnight with my trainee on communication skills. That is a lot of time.

Sadly, there will not be a single person in this room who has not had a bad encounter with a GP. Is everyone in that boat? No? If you have all had good encounters, that is fantastic, but I think that most audiences would be on my side. The issue is not that GPs lack communication skills; rather, it is that, for whatever reason, we are not using them. Why might that be? There are several reasons for that. One is purely attitudinal. I would love to think that the level of care that is afforded to the retired GP at 69 who is dying of metastatic breast cancer would be exactly the same as for the 45-year-old heroin addict who is dying of hepatocellular carcinoma and cirrhosis, but I suspect that it would not be.

Another issue relates to the systems in which we are expected to work. If people are put into a system where the environment is such that they are struggling to do the tasks that they have, compassion can leach out. There is all that stuff going on down south in England that we do not need to go into, but that is what can happen.

I love communication, I love working with my patients and I love trying to support people, but I know that I will enter every surgery and most consultations unable to meet the demands of the people who I am trying to serve because of time limitations. For me, it is not the microwave pinging, as the convener mentioned; it is the wee clock that goes round in front of me in surgery. I hasten to add that the patient cannot see the clock—it is in my field of view, not theirs—but I know that the time is limited. That affects the compassion of the care that we can deliver, which can sap the healthcare providers' morale. If they know that they are not doing the consultations as well as they can, that is not a good place to be.

Professor George: I support that. Our primary task is as witness, and what comes with that is a burden. The burden of witness is a significant morbidity in healthcare professionals, particularly in dealing with the difficult area of palliative care. If we do not take account of it, we develop compassion fatigue. If we are driven by outcomes that are not patient related and do not keep ourselves fit and healthy in our tasks, we start to malfunction. The first stage of burn-out is usually to disengage—you necessarily distance from individuals for no other reason than to protect yourself. There are no mechanisms in place to support that and provide the debriefing. Those of us who are in specialist practice have clinical supervision as a matter of course. That is really important.

It is the depth of time and not the length of time that matters. Someone very skilled can have a five or 10-minute interaction that will be more significant than an hour or two by somebody who is not skilled.

Skill is important, but actually it is about keeping fitness and health within the workforce in order to do the job well. We will do it more efficiently, effectively and probably more quickly, because we will not be frightened to engage the question rather than worrying about protecting ourselves in the process because we are so exhausted.

Rhoda Grant: I am not sure that I picked this up right but, from what I have heard, the training is there. All the generalists are trained, but what is missing is the time and space to have more difficult conversations with people.

Professor George: Also, a lot of the work that I do is debriefing with colleagues over difficult deaths or interventions, or helping with a complex family. I might be involved in facilitating a complex family interaction where there is a breakdown of relationship, for example in the healthcare or the social care set-up or within the family itself. We also have those types of role.

Dr Grundy: Education and training are available, but who takes the training and the impact of it all is not known. We are also unclear about how people use those skills in practice once they have had the training. That is the area that needs support. We need to support people to change the computer program, if you like, because we are all programmed to say certain things at certain times and if we want people to have real, in-depth and sensitive conversations, they need to know how to ask the right questions and have the right conversations at the right time. People need support to build up their confidence so that they can do that in practice. It is only with practice that people actually develop skills; perhaps that is where we need to focus now.

Sandra Campbell: There has been a lot of discussion about training and communication skills, but there is also a lack of access to general palliative care education. People in specialist centres will be highly trained, but the majority of palliative and end-of-life care is delivered in the community or hospital by staff who might not have had access to education. That is not a criticism; that is the reality and we need to put programmes in place that support existing staff to deliver excellent care.

Mike MacKenzie (Highlands and Islands) (SNP): I want to explore a point that Dr Paterson and Professor George have just touched on about the pressure that the medical professions generally are under. I wonder how much of that has been created by a false public expectation that we all are going to enjoy perfect health throughout the entirety of our lives and that we are a bit like cars, in that there is a perfect solution for every problem. That extends into palliative care. Somehow, there is a notion that palliative care is a gold standard and, if someone can get through the gate marked “palliative care”, they are still alive but they are actually pretty much in heaven.

When the committee undertook its inquiry into the Assisted Suicide (Scotland) Bill, I was so struck that palliative care and the whole near-death process was described in such glowing terms that I made the comment that I could hardly wait for it to happen to me. Therefore I just wonder how much of this is about real pressures on the interventions that we can make through better technology, better treatment and so on, and how much of it is about potentially unrealistic public perceptions that contribute to intensifying the problem rather than helping with it.

12:15

Dr Paterson: Public perception has a huge role. In turn, that is often pushed by the media, which can have a worrying influence on what people think. We need only think of the furore around the Liverpool care pathway to see the damage that the media can do, I contest. Healthcare professionals, particularly doctors—I can speak only for my own profession—are guilty of promulgating the myth that we can fix everything for ever. It is a dangerous myth and it is a game that we have been playing pretty successfully in healthcare for 60 or 70 years. However, we have probably reached the limit of what we can do on a lot of stuff.

My experience of patients who have had specialist palliative input in one of the local hospices, for example, is that it is truly tremendous. It is fantastic. That is partly because of the skill level, partly because of the surroundings and partly because of the staff numbers. My heart goes out to care home staff, whom Ranald Mair mentioned and who supply lots of palliative care. They do not even know that they are doing it and they often do it extremely well, unrecognised and with a skeleton staff. They might have one trained member of staff on at night for 24 residents, with somebody who is dying. That is really good-quality palliative care and they are not given credit for it.

We need to shift the focus away from heaven’s anteroom and think about the reality for far more people. Although specialist palliative care is very good, it is probably still more focused on cancer than the numbers suggest. I guess that the numbers are still roughly a third cancer, a third long-term conditions and a third frailty, old-age and dementia. It must be seven or eight years since we considered the matter in NHS Greater Glasgow and Clyde, where I work as a general practitioner, but at that point in time the number of people in, say, hospices who were dying from non-cancer illnesses was very small indeed. We need to broaden out palliative care, and St Christopher's hospice is at the forefront of that.

Professor George: Society and an awful lot of doctors think that patients die only when doctors stop treating them. Otherwise, those doctors would not abuse people with monstrous interventions that will clearly make no difference but that make those doctors feel better for having done it. A dance of denial is going on in certain social contracts that we have. That is a difficulty. It is a cultural question that we must consider.

In the early engagement of palliative care with lung cancer, which I mentioned—surprise, surprise—people live longer. That is because we promote their living rather than preoccupying ourselves with their dying and giving them treatments that are probably more harmful than beneficial. The harm benefit analysis—the finely balanced equation of whether an intervention will do anything—depends on a much more sophisticated answer to the question about what is a benefit and what is a harm. That changes as people start to die.

To answer the question about specialist palliative care, being human entails suffering. That is a fact and for us to pretend otherwise is ridiculous. However, suffering is also perception, in so far as I know many incredibly disabled people who live fulfilled lives. The debates that we have had on both sides of the border recently about assisted suicide have often turned on the question of what people perceive as suffering. As often as not, we are managing the least worst. It is helpful to free people from the proposition that there is a magical thing called a good death. It is important to consider a healthy death, which is one that makes sense to the person in their context. It has to have cultural appropriateness. However, some people need to struggle as they die, particularly young people with young families.

As a nurse, Sandra Campbell will probably know better than I do that, the more that we work with the suffering of people, particularly if we go into a care home, the more we see that the incredibly complex dialogue and interaction that are going on are a social phenomenon. People die from a life, not just from a disease. Engaging with the reality of dying helps people to bring meaning. That is important, as bringing meaning—I use that word rather than talking about spirituality or religion—into the situation makes a difference for folk.

We perhaps have a slight advantage in our specialty, in that we have the time, resource, motivation and training to engage with what are sometimes very painful things. The least worst option can, as often as not, turn out to be very much the best in enabling people to get through the gate of a really bad time. I do not know whether anyone has read "The Death of Ivan Ilyich" by Leo Tolstoy, but it is well worth an afternoon's read. It takes you into an understanding of the nature of suffering in a particular kind of way.

Mike MacKenzie: Thank you very much—I will make a point of reading that.

Bob Doris: I apologise for the fact that my questions are somewhat driven by process. I know that the overall issue is how we care for people, but since the start of today's evidence session we have heard about the emergency care summary, the electronic palliative care summary, the palliative care register, the care information system, SPICT—the supportive and palliative care indicators tool—and care action plans. Sandra Campbell spoke about overarching communication and how all those things interact with each other.

I am thinking about how that impacts on the way in which resources are allocated to help with people's care. We know that much of the issues come down to resources and time. No one wants to find themselves on the palliative care register, but their condition is their condition, and they may or may not be on the register. The issue is whether more time or resource is directed to someone if they are on the register. I am interested in finding out about that.

In addition, there are other ways in which someone might get on the palliative care register. For example, if an elderly person is in hospital for whatever reason and a discharge plan is put in place, does the drawing up of that plan include asking whether the person is nearing the end of their life for whatever reason? Is palliative care effectively taking place, whether it is called palliative care or not? Does it feed into a back channel, or should the person go on the palliative care register?

Likewise, how does anticipatory care planning and the drawing up of care reviews in care homes feed into the process? We know that the GP is the hub of the process but—to go back to what Dr Paterson said—we know that they cannot do everything, as they do not have the time.

If someone finds themselves on the palliative care register, does that drive resourcing? How do we work out whether people are missing out—that might be the wrong expression, I suppose—and are not on the register when they should be?

There is an opportunity there to place them on the register.

I am sorry that my question is so process driven, but I am trying to get my head round the question of how, in public policy terms, we can change the structures.

Dr Paterson: There are many issues in there. We sometimes get very good discharges from hospital, in which people are discharged home with the expectation that they are now facing death with some sort of immediacy that matters to everyone. Death might take hours, days, weeks, months or longer, but that sort of thing is extremely helpful. Nothing makes my life easier as a generalist, which is what I am, than when one of my more knowledgeable specialist colleagues in whatever discipline says, “That’s that.” I can then do my stuff, and everything is okay.

Does being on the register make a difference to what people get? I suppose the answer is yes. I am unlikely to refer somebody for specialist palliative care input if I do not think that they are dying. Should being on the register make much difference? If people buy into the model that I am suggesting, which involves the provision of good care for people who happen to be dying, I am not sure that it matters so much.

Where do the resources need to go? Lifting the structure from Maslow’s pyramid of human needs, I would start at the bottom. There are a few core things that people need; I am being dead serious in that respect. They need a bed, aids and appliances and things like that. One level above that, however, they need care. They need people who are there around them, whether it is their family—if that is possible and if they have family—or their social carers, before we even think about healthcare and nursing staff.

We are not in a situation—certainly where I work—in which we can guarantee care for somebody who is dying. My last patient died of MND; I have permission to use his details. We could not guarantee that he, as a single man whose nearest relations were two brothers, one in Skye and one in York, would have a night carer every night of the week. I am talking about somebody who was so paralysed that he could not move. Until we get that right, we will struggle with the rest of the stuff, because that is a pretty core need.

There are a lot of issues, which brings us back to what Ranald Mair said. The people who supply that sort of work, such as the staff of Cordia, who provided the care for the man with MND, are fantastic, and we need to celebrate what they do. However, we need a lot more of them, and that is a macroeconomic issue. I believe that they should be paid a lot more. They are working with the most vulnerable and needy people in society, and we pay them less than they would get if they were stacking shelves in Tesco. That does not work for me.

On top of paying those people a decent wage and giving them a decent career structure, we should look at their personal attributes. This is a dodgy area to go into, but we need to find people who are genuinely caring, compassionate and empathetic. There are big differences between people in that respect, and there is research on palliative care that looks at the variations in personality between those who work in palliative care and other people. They are very different.

I think that I am quite a caring and compassionate individual, but I would be a disastrous surgeon. I would be full of anxiety and worry, asking, “Should I cut that artery?” and stuff like that. It would be terrible. We need to look for the right people and give them a career and a way forward.

Sorry—I was sitting in the public gallery behind Ranald Mair earlier, and I would very much get behind what he said.

The Convener: You were cheering—it was noted.

Professor George: There are some data available on case complexity, but I am always cautious about looking at any calculus of how complicated cases are because of all the things that I mentioned earlier. It is the humanness that is often complicated. If we cannot provide a bed or somebody to care for a person, that is pretty bad, and it is a problem across our nations.

There are ways of measuring case complexity and ways of looking at the resource that goes with that, but that tends to apply in the higher areas of specialist practice rather than down at the level of the basics. If we get the basics right, an awful lot more—in a utilitarian sense—will be achieved.

Sandra Campbell: It is important to say that not everyone who is dying requires specialist palliative care. Yes, the surroundings and the environment in which hospices function are fantastic, but not everyone who is dying needs that type of care. It is important that we differentiate between those who need care and those who do not, so that those who really need it have access to it when they need it, regardless of diagnosis.

There was a lot of talk in the previous session about older people, but there is a bit of inequity in care for the under-65s. Although there are fewer people dying younger, which is fantastic, such situations can pose challenges for teams in planning care packages, and we must be mindful of that.

We need to be careful in looking at the funding for people who are younger and who are perhaps already facing difficult financial challenges. As I mentioned earlier, there is the living along with the dying. Family members still have to work and children still have to be picked up from school, and Granny still has to be taken care of while someone else might be dying. There is the whole issue of social complexity, and we need to be able to support families and carers rather than just the person who is dying.

Bob Doris: Again, I am sorry that my question is process driven but, unfortunately, that is the avenue that we are forced into when we look at structures. I am trying to tease out whether there is a way of prioritising resources via the palliative care register, and whether that happens.

We know that the issue is about care, and the degrees of care and resources that are available. However, it is worth noting that I have a number of constituents who work for Cordia and have had direct experience of the situation. They are going through a pretty tough time right now. I will not elaborate on that, because it would be inappropriate to do so in this committee, but they would think it odd if I did not mention the issue here.

I come back to the prioritisation of care needs. Ranald Mair is always passionate about his field. If there are a number of people in a care home and there is a staffing ratio, and there are 10 older people in a unit and three of them find themselves on the palliative care register, that could trigger a higher staffing complement. I am not saying that it should—I am just thinking about how we direct the prioritisation of resources.

I know that it should all be individualised, but I am trying to think how we can put systems in place to direct resources in the most appropriate way. For example, if a Cordia care worker has a dozen clients without palliative needs but another Cordia care worker has three or four clients with palliative needs, should the latter’s case load be smaller and should they have more time for visits? It is about how information is used to prioritise existing resources. I agree that it would be nice to have more resources and a better system, but I am interested in what system of prioritisation there is.

12:30

Professor George: That is precisely where the case complexity modelling is useful, certainly with case loads or service provision. We have four community teams that cover a population of about 1.5 million, and it is good clinical practice to pay attention to the case loads of nurses to equilibrate them and distribute the burden. If the funding structure reflects the complexity of practice, we will get a better and justifiable argument for how we are or are not using or claiming resource. There are process measures available, and some are validated and being developed. I can give you information on that, if it will help. They are to do with specialist practice as distinct from other things, but they would give you some markers.

Dr Paterson: I have several clinical examples from my work. For example, we supply medical care to a social care-run centre in the community that has several young people with severe needs because of learning disability and so on. They do not have palliative needs, but they have huge needs. I would hate to think that their needs were not met because we were looking after dying people.

We have about 25 people now in the care home that we supply care to, and the people there who probably need the most time are not the dying ones but a couple of people with advanced dementia who now have very challenging behaviours, which are difficult to cope with if staff levels are low. Would I be surprised if those people were to die this year? I would not be that surprised, nor would I be surprised if they did not. I would struggle to put them on a palliative care register, but they still need a high level of care.

We would need a model that does not look only at whether a person is on their final dying trajectory—whatever timescale that involves—and I do not think that that is to do with palliative care registers. We four witnesses here are interested in this issue, but we could probably discuss for three or four days who should go on a palliative care register and not come to a conclusion. Is that not so?

Sandra Campbell: Yes.

Dr Grundy: Yes.

Professor George: Yes.

Dr Paterson: If it is about diagnosis, does that mean that every person who is diagnosed with dementia, which is a life-limiting illness, goes on a palliative care register? Statistically, they may have 14 years left to live, but maybe not. Pancreatic cancer is a bad one. In my experience, it is one of the worst conditions to get. It means a death sentence, usually within a year. In my clinical practice, I would put someone with that condition on my palliative care register, but I would not put someone with dementia on it. Those are the gross examples, but in-between is a complexity of examples. I am not being flippant, but our patients refuse to do what is expected of them, because they get better when we think that they will get worse and they get worse when we think that they will get better, and then we have to replan, replan and replan.

I love the idea of having a process for a palliative care register, but the reality is too complex for that.

Sandra Campbell: SPICT is helpful in trying to identify those who may be expected to die within the next year. Someone referred earlier to the predictability of some illnesses, but a lot of illnesses are unpredictable. We have spoken about uncertainty, but it is not just about the uncertainty of a person's illness; it is about their families who live with that uncertainty and how we support them to do so. The vast majority of care is good care. People want to deliver good care, but it is about how we support them to do that.

Dr Paterson: We ran SPICT across our practice population; we have only 4,000 patients and we identified 140-odd people. We cannot consider 140 people from the point of view of dying. We do not have enough time to do that, because we also supply care to an awful lot of people who are not dying. SPICT is useful as a starter for 10, but it does not really help us to get right down into the group that we need to be concerned about, whose ceilings of treatment and intervention we need to visit and with whom we have to do more of the existential witnessing role, because their life is coming to an end and it is much better if they, and their family and loved ones, are prepared.

Maybe the hospital setting has been covered previously, but I have not heard it being mentioned. If the committee has already dealt with it, I will be quiet now. I feel for my colleagues in the acute setting. The situation is far more uncertain in the hospital setting than it is in the one in which I work, because in that setting they can do far more dramatic stuff to people, so their decision-making process is very different from mine.

The watershed for me as a GP is whether a patient goes into hospital. If they do not go into hospital, not a lot will happen in the way of dramatic life-saving interventions, because we do not do much of that in the community—at least not where I work in inner-city Glasgow, although the situation may be different in a more rural area where GPs are more involved in such interventions.

In the acute setting, there might be the ability to maintain somebody, to help them improve and not quite to resurrect them but to get them back out with a reasonable quality of life for another few months. However, it is very difficult. That is maybe why patients sometimes seem to be passed from pillar to post. Staff in the acute setting are trying hard to get the person with chronic obstructive pulmonary disease, who may be in with their eighth exacerbation in two years, to make a recovery and get home again for another three or four months. However, suddenly non-invasive ventilation is not possible for the patient and they are dying. When that decision is made, it is a sudden sea change for people. That is a hard place in which to work and we should be mindful of that environment.

The Convener: Does anyone else have a comment on the acute setting? Professor George has referred to some of the issues with regard to invasive treatments and people's choice at that stage.

Professor George: It is incredibly difficult. I could regale the committee with hundreds of stories, because I also work in the acute sector—I work in tertiary hospitals from time to time. The whole problem of managing patients between the acute sector and the community is an important issue. There must be rapid discharge planning. If somebody has what we might call an acute attack of death or acute chronic dying and they want to be at home, can we mobilise them and get them out of hospital in six to 12 hours, facing those possibilities? We have as many definitions of dying as Eskimos have of snow. I do not mean to be flippant when I say that—it is true, because there are so many variables.

One of the immensely difficult tasks in the acute sector is that it is built to deal with specific diagnostic problems. I have been quoted in the newspapers as saying that hospitals are like conveyer belts and processing plants. That is not necessarily a bad thing, because hospitals do that work most effectively.

Nevertheless, some people need to die in hospital. The COPD patient or the person with heart failure with very bad symptomatology is often someone who needs to die in a hospital setting, because of the levels of uncertainty that lead up to death. We do not know that they are going to die until 24 hours or 48 hours before they die. Furthermore, we only realise that after they have died. Prognostication is that difficult. One in 10 patients who we would say are in the last week of life turn out not to be, so it is difficult even for experts. That is why the issues around the LCP and so on were so difficult for us to manage in the acute setting. It is a very different environment and we have to recognise those difficulties.

In my opinion, we need to have mechanisms so that there are possibilities for individuals who need to be cared for in those settings. There are good examples of hospitals that have palliative care units that are either units for acute intervention and rapid turnaround for difficult symptoms or units where people can be looked after as they die over a few hours or a couple of days. There needs to be more flexibility in the system, because people die in hospital often because they need to. We must recognise that group of people and not deprive them of the care that they should receive because we are preoccupied with community settings and so forth. I am glad that Euan Paterson brought the issue up—thank you.

Dr Grundy: That is where the different levels of education and training come in. People who work in acute settings may or may not be working with dying people most of the time or some of the time, but we need to get at least the basic level of education to everybody in an acute setting if they are likely to be involved with people who are at the end of life and require palliative care.

Sandra Campbell: In September 2014, the RCN conducted a survey on end-of-life care in which we asked our members key questions about how they provide that care. Almost 8,000 nurses responded within a few days—it was the biggest response that we have ever had—which tells us that nurses are passionate about what they do and are concerned about the knowledge that they do not have. Almost 3,000 of those 8,000 nurses were hospital staff, and over a third of them dealt with dying people on a daily basis but had never had any formal education in it, and that troubled them. It is important that we run programmes and that staff are released to attend them or that we encourage reflective practice. There are ways in which we can educate people through learning on the ward or in the environment that we work in, and reflective practice is a model through which we can enhance the knowledge that exists.

The Convener: Time is getting on and I have one final question. Before that, does any other committee member want to come in?

Dennis Robertson: I will try to be brief, convener. Professor Clark believes that one way to ensure that we provide good-quality care in the future is to use the national bereavement survey as a tool to measure the outcomes. I find the terminology strange—it is called a satisfaction survey. It looks at what care was provided and what could have been provided. The survey is of carers and relatives, but we are hearing that we should perhaps find out what the professionals believe as well. Is a national bereavement survey, such as the views of informal carers—evaluation of services survey that is undertaken in England, the right way in which to collect the information?

Dr Grundy: The national bereavement survey provides one way of looking at people’s needs and what individuals want. Professionals also have a perspective on what people need, which may or may not be what individuals want. Professionals could bring in things that families and relatives might not recognise, and they might pick up on different aspects. There are two sides. The bereavement survey provides a good way of looking at how people would like things to have been, but there is also the professional side and what professionals feel could have been done better.

Professor George: Forgive me for getting on my soapbox about this. I think that the data is very valuable, but let us not forget that it comes from a group of people who have had the burden of witness, and it is worth noting the extent to which they are dealing with their own loss and suffering. However, that is not really what I wanted to say.

We as specialists care for two groups of people: the first group is people who are dying and their families, and the second group is our colleagues. I spend as much time supporting my colleagues in their decision making, helping them through difficult problems, debriefing them and so on. We need to develop measurement tools—experience measures—to find out whether we are delivering adequately for our colleagues. That is a task for specialists.

To go back to the hospital question, I think that all professionals should have access around the clock to advice from specialists. That advice could be provided in any form, but it should be available particularly in hospital settings where death often arrives in an unexpected and unpleasant way. It is the legacy of bad death that leads to difficulties in society.

I was the expert witness on the LCP inquiry that Lady Neuberger chaired, and the experiences that families related were dreadful. In a lot of cases, if there had been support for staff—it does not matter whether that is from peers or experts—and the opportunity to help staff, the experiences would have been a lot better for all concerned.

The morbidity among clinicians who have been involved in bad deaths is the tip of the iceberg as regards problems that we just do not know about. As a society, we will need to face that at some point.

12:45

Dr Paterson: For a long time, general practices have been doing significant event analysis. When something significant happens, we look at it. That can be a death or other things. Part of the GP contract is to encourage that analysis, which provides a very good way to learn. Looking at a death that went well and at a death that went badly is hugely instructive.

We do the same sort of thing with care homes. We can do post-death analysis at a fairly simple level or at a deeper level and encourage people to review what happened. I accept that that is centred on the healthcare professionals but, in conjunction with such things as the VOICES programme and other bits of work, that could work well.

The caveat is that that takes a lot of time. If I look at the death of one of my patients and we discuss that as a practice, we lose about 80-odd appointments. The unit of currency that I use is appointments because that is our unit of currency now. In general practice land, the metric that is used is the number of appointments that we offer per 1,000 patients per week.

We are trying to offer about 90 to 100 appointments per 1,000 patients per week to meet demand. My practice is looking at offering 400 appointments, so 80-odd appointments would be a fifth of our weekly total—for one review. If the five of us were all part-time and we were all involved, that would be a whole week gone just on a death, not on a misdiagnosis of cancer or the non-accidental injury of a child, which is terribly important, or postnatal depression—it could be catastrophic if we missed that.

The worry is that we are struggling to meet demand as it is. We have the tools, but we need more of us to do this properly. It is not that the tools are bad, but the system that we are working in is creaking.

The Convener: Professor George has mentioned a couple of times his important role in supporting professional colleagues who are dealing with bad deaths and so on. Ranald Mair spoke about home carers earlier. If we think about the hierarchy, someone might see a doctor once a week or once a fortnight and a nurse twice a week. Home carers go into homes daily and build up attachments. When a death eventually occurs, the home carer will often be at the funeral and they will be around the family. Is there any known support that is given to the carers—they are predominantly women—who provide that care? Perhaps Sandra Campbell or Maggie Grundy might know.

Does anybody know of any support mechanisms that those carers have? Maybe I should have asked the first panel that question. In my experience, I do not know of any support mechanisms that help carers at that level through the death of someone who is at home—the death of a young person or someone who has MND or cancer. There does not seem to be much consideration of how we support those home carers.

Dr Grundy: From a healthcare perspective, it is probably more of an informal arrangement than any sort of formal structure that is in place. I am not so sure about social care, which has a really good system of supervision for social care workers. I do not know whether that extends down to home carers, but it would be worth looking at that. From a healthcare perspective, there tends to be very ad hoc peer support.

The Convener: So the support from the healthcare perspective, which Professor George referred to, involves more of an informal process.

Dr Grundy: Yes. There are places that have put in some sort of system and there are pockets of good practice out there but, for the most part, the reliance is on peer support and individual teams.

Sandra Campbell: I agree. I do not think that there are any formal systems, and I imagine that practice varies across the country. In the hospital setting, spiritual care teams can more and more pick up the support for staff. Perhaps we would not have seen that five or 10 years ago. The spiritual care teams across the hospitals and the bereavement structure that is being set up in Scotland are certainly about how we support staff as well as patients.

Professor George: There are models of care, and hospices provide support, but that touches a small percentage of the population. I think that most of us as clinicians who work in the community would have identified high-risk people as part of our case load or would have taken notice of the paid carers who come in. We know who they are. There are informal mechanisms that feed back into the care agency, and debriefings can be provided.

I am aware of the disability groups, for example, and the homes that have individuals with disabilities, who live much longer than they used to and now die in early middle age or later. Such individuals often encounter dying for the first time in a family setting, in effect. There can be 10 to 20 residents in a home. Our palliative care services would provide specific support around the bereavement of that whole social unit, which includes the carers and the other residents, who might have known the individual for 10 or 15 years and will have the burdens of their intellectual frailty and so on to deal with at the same time. However, the approach is always informal.

Dr Paterson: I do not want in any way to counter the importance of all those things but, as a GP who has worked in the same area for almost 30 years, I am constantly humbled by the phenomenal resilience of the patients whom I work with. What they have put up with through their lives in ill health and through some of the inequities in our society is staggering, and their ability to cope is magnificent.

A lot of the social carers whom I encounter—particularly the carers of patients of mine—are from that area. They have been through it all; they have been there, done it and bought the T-shirt, and they are incredibly resilient. We have to recognise that and point that up to them. The danger is that we will start to make them think that they are not coping, whereas we are talking about something else that they are well able to cope with. Maybe they need acknowledgement that they have been suffering.

The carers and I had a couple of mutual teary encounters outside the house of my last MND man who died, because it was horrible. I think that we all got a lot out of that. We had a kind of bereavement meeting at his funeral, and that was good. I think that my wee letter of congratulation to them, their staff and their manager helped.

The approach is informal and family-like. We should not decry people's abilities.

The Convener: That concludes the evidence session. I thank the witnesses very much for their attendance, the oral evidence that they have given and, of course, all the written evidence that we have received.

As previously agreed, we will now go into private session.

12:53

Meeting continued in private until 13:00.

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