



Official Report
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Health, Care and Sport Committee

**Comataidh na
Slàinte, Cùram agus Spòrs**

Wednesday 30 September 2026

Session 7



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HEALTH, CARE AND SPORT COMMITTEE

6th Meeting 2026, Session 7

CONVENER

*Helen McDade (Mid Scotland and Fife) (Reform)

DEPUTY CONVENER

*Jack Middleton (Aberdeen Central) (SNP)

COMMITTEE MEMBERS

*Heather Anderson (Dundee City West) (SNP)
*Adam Harley (Strathkelvin and Bearsden) (LD)
*Kayleigh Kinross-O'Neill (Edinburgh and Lothians East) (Green)
*Joe Long (Mid Scotland and Fife) (Lab)
*Paul McLennan (East Lothian Coast and Lammermuirs) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Amy Dalrymple (Marie Curie)
Mark Hazelwood (Scottish Partnership for Palliative Care)
Helen Malo (Hospice UK)
Rami Okasha (Children's Hospices Across Scotland)

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health, Care and Sport Committee

Wednesday 30 September 2026

[The Convener opened the meeting at 09:30]

Palliative Care

The Convener (Helen McDade): Good morning, and welcome to the sixth meeting in 2026 of the Health, Care and Sport Committee. We have received no apologies.

This is the first time that the committee has had the opportunity to focus on palliative care. Under the first agenda item, we will run an evidence session as a round-table meeting, which I hope will allow more discussion. There is no need for anyone to touch their microphones as the broadcasting team will manage them for us. We have up to 90 minutes for the session, and I think that we can get through a good deal in that time. I thank the witnesses for submitting useful background information to us. We appreciate that, particularly when submissions are nice and concise, as they were.

We plan to focus on four themes in turn: what good palliative care looks like; unmet need and demand; funding service models and inequalities; and Government policy, legislation and strategies for improved provision. Some of that will come up in each of the areas, though, so it is not prescriptive.

I am pleased to welcome our witnesses: Mark Hazelwood, chief executive of the Scottish Partnership for Palliative Care; Amy Dalrymple, associate director of policy and public affairs in Scotland for Marie Curie; Rami Okasha, chief executive of Children's Hospices Across Scotland; and Helen Malo, senior policy and public affairs manager in Scotland for Hospice UK. Thank you all for coming. We are not looking for introductory statements, as such. I will start with the general question of what good palliative care looks like, and I will start on my right with Mark Hazelwood.

Mark Hazelwood (Scottish Partnership for Palliative Care): Thank you for asking us along to a session to talk about this subject.

When somebody is diagnosed or receives the news that their health condition is a life-shortening condition, they need a range of things and supports at that stage and on their journey through to the end of life. Support is also needed for their family. People look for information about their condition and want to understand what the future might hold and what opportunities there might be

to talk about options for care, support and treatment down the line as their situation evolves. They want open and honest discussions and an opportunity for any preferences that they might have at that stage to be documented and shared across the many services and supports that they are likely to be involved with, we would hope, as their condition progresses. There might be practical things that they want to consider, and, sometimes, there are very practical things that they will need for their life circumstances. One such practical thing that is in the programme for government is support for fuel costs.

To be a bit more philosophical, before other witnesses come in to add to what I have said, I think that people are looking for dignity, respect and support to help them to make the most of the time that they have left, however long that might be. Palliative care can be important from the time of diagnosis right through until the end of life. Some people think that palliative care is just about the care of somebody who is dying, but it is about support for people to make the best of their life for however long they might have. That might be years or months or, if it is a late diagnosis, it might, sadly, be a shorter period than that.

As I said, people want support to make the most of their life and to live their life in the way that they would wish, and they want dignity and respect. They also want the clinical things that we sometimes think about; they want advice and support on managing symptoms, which might be difficult. It is important to remember that palliative care is about support for their family, if they have family, and it has a role in providing bereavement support for the family, too.

I will stop at that point because I am sure that other witnesses will have things to add.

The Convener: Thank you, Mark. That was great. Amy—sorry, I should have asked whether people mind if I use first names. Is that okay?

Amy Dalrymple (Marie Curie): I do not mind if you do not, Helen—yes, that is fine.

We concur with all of what Mark has said. I expect that you will find a lot of agreement between us all this morning. Marie Curie starts from a rights-based approach and the fact that the right to palliative care is part of the right to health as defined by the World Health Organization. That is about people being able to access the care that they need when and where they need it, no matter who they are, what their background is, what their diagnosis is and how old they are. Such equity of access is part of what would define good palliative care at system level in Scotland.

At individual level, good palliative care is about a person having their needs met, preferably

according to their plan and their choices, having had discussions with their health professionals and their needs having been identified by their general practitioner or whichever health professional is working with them. There is a big problem with access to pain medication for people who are in care homes, for example, so it is about addressing such issues. Needs should be met as close to home as possible, where appropriate, but people should be able to access appropriate hospital care or in-patient hospice care when they need it.

People's needs include their social care needs. Social care plays a huge role in delivering good palliative care, not just in care homes but through care at home. It includes people's mental health needs, too, which might change at the end of life. System navigation is a big issue, and addressing that would help to achieve good palliative care.

Alongside clinical, system and service provisions, good palliative care is about care that is delivered with compassion and humanity and that sees the person for who they are and not as a set of medical, clinical and social care needs. They are not a budget or somebody using a resource in a service. It is about seeing a person.

There is only one chance to get palliative care right for the person and their family, so it is important that good palliative care is available to everybody who needs it. If it is not provided, we do not get a chance to address it and do it again.

Helen Malo (Hospice UK): I agree with what colleagues have already said, and I will not repeat the good points that they have made. I will focus on people for a moment, and consider what good palliative care looks and feels like for the person.

I speak to a lot of people receiving palliative care, and their family members, as well as those who have missed out on care. There is such a stark difference in how people speak when they talk about their experiences. When a family member talks about a loved one who has had a good death, they talk about care and support that almost wraps around them and about feeling properly supported. They talk about dignity and compassion. They talk about the almost physical sensation of a weight having been lifted, and about feeling that they can breathe because support is there, services feel joined up and people are coming together and have focused in on what matters to the person as an individual. They talk about feeling empowered. They say that it is a powerful feeling, even though it is a difficult and distressing time. People can take a lot of comfort if it is done well, and the lasting effect that that has on people—and what it means at a human level—is massive.

We can contrast that with how people who have missed out on that care talk. They are frightened, distressed, anxious and sometimes angry that they have not been able to access the care and support that they need. Carers often feel that the weight of responsibility is left to them. I have spoken to people who, years after the event, still carry a sense of guilt and regret. That is a hard thing to hear, because it is the system that has failed them, but they take that on as a personal feeling.

When I talk to people who have had a good experience, they often use the word "lucky". They say, "We were lucky the district nurse came out," or, "We were lucky we got into a hospice." However, luck should not have anything to do with it. To go back to what Amy Dalrymple said about equity, good care is equitable care across Scotland. It is about the different parts of the system coming together. With palliative care, that means hospice care, general practitioners, social care, district nurses, community nurses and hospitals all coming together. It is about the different parts of the system working together to do what is best for people and achieve the best outcomes for them.

If you do that well, that also has big positive impacts on the wider system. Supporting more people at home and in the community will ease the pressure that our national health service and hospitals face. Therefore, that is important for people and for the wider system.

Rami Okasha (Children's Hospices Across Scotland): I agree with what has been said, and I will reflect on some of the more distinctive features of palliative care for children and young people. Palliative care is an often misunderstood term, because it is not the same as end-of-life care. End-of-life care is part of palliative care but, for children and young people, palliative care begins early, at the point of diagnosis or recognition of illness, which can be years or decades before a young person dies. At CHAS, we work with young people up to the age of 21, and some of the people we work with have transitioned from our services into adulthood, because they have lived longer than anyone might have thought. That is, of course, a wonderful thing, but they need a lot of care for a lot of time.

In the work that we do at CHAS, we often refer to the definition of children's palliative care from a young man called Mattie Stepanek, who was a 13-year-old boy in America who died a number of years ago. He was the fourth of four siblings to die in his family. He said:

"Palliative care no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently."

That is a beautiful description of what we try to do. We try to help families to live well and die well.

Good-quality palliative care for children and families means healthcare specialists who are treating the underlying condition working closely with palliative care specialists, who bring their expertise, and with family support experts who help families to go through the hardest thing imaginable. It is also about working with the social care systems that help children to live well.

On the convener's question about what good looks like, there are two elements. First, it is critically important that services are joined up, because it is multidisciplinary care and it has to be multi-agency care. In practice, that means doctors, nurses, social workers, care staff, play specialists, physiotherapists and a range of other professionals from various organisations working together around the child and the family. The point that Helen Malo makes about equity of access is hugely important. That sort of care has to be available everywhere in Scotland. In many ways, in Scotland, we have an advantage that is not found elsewhere in the UK. There are no organisations similar to CHAS in England that provide that service right across the country and can deliver care where it is needed.

The second thing that we look at is quality. What is the quality of care that is being provided? That has to start early, at diagnosis or recognition, and that does not happen often enough. The care has to be there to help families to live well, whether that is for days, months or weeks and, too often, that does not happen. When it comes to care around dying for children and young people, there should be a genuine choice about being at home or in the hospice or hospital.

Right now, too many children die in hospital when there is no clinical need for them to be in hospital, but we are beginning to see some positive shifts in that regard. CHAS is working closely with NHS colleagues to put in place interventions that are turning the dial on that, but we need to accelerate those.

Of course, bereavement support is a hugely important part of palliative care. After a child has died, the parents and siblings need to carry on, but they need support in order to do so, and very specialist interventions are needed to deliver that.

09:45

The Convener: Thank you. That gives us a lot to think about.

I have a follow-up question specifically on the children, although it applies to adults as well. At what point do you decide that someone qualifies for palliative care? Let us take the example of a

child who has had cancer and been treated, with an 80 per cent chance of survival. The child recovers and goes home but, some years later, comes back, obviously still hoping for a positive outcome. Those people need a lot of support, but there might be a great outcome where they walk out and never die of whatever the condition is; I am specifically using cancer because everybody thinks of cancer. Those people need a lot of support, but who do they get it from before somebody decides that it is time to talk about palliative care?

Rami Okasha: It is a really good question, and it is a difficult conversation to have with a parent, when we have to say that we are going to involve palliative care or refer them to the hospice. That is a huge barrier, and many parents would be very worried about that. There is a real skill in introducing palliative care early, because in the examples that you provide, there are undoubtedly things that CHAS, through our palliative care services, would do to support those families, because it is about helping families to live well as well as die well, and not all the children we work with die. Some survive, which is wonderful and great, and, as medicine advances, the numbers of such cases will continue to increase.

We always recommend early involvement of palliative care. We envisage two graphs, where there is a gradual decline of curative treatment, if it is not going to work, and a gradual increase of palliative care involvement. It is absolutely about involving palliative care early. CHAS has worked with NHS colleagues to have our staff embedded within hospitals to begin those early conversations and make it easier, so that rather than there being a referral to CHAS, it is simply that CHAS is there and is part of the team supporting children.

The Convener: Thank you; that is really interesting.

Amy, did you want to come in?

Amy Dalrymple: Your question is very relevant to adults as well, and maybe one of the important points to get over this morning is that palliative care and curative care are not mutually exclusive. You do not have to do one and then the other. My clinical colleagues talk about parallel planning—hope for the best, plan for the worst—but, for many conditions, palliative care and curative care can happen alongside each other. It is not a linear trajectory, especially for people who are living longer and have multiple conditions, none of which is designated as a terminal illness from which they will definitely die. I am talking about people over the age of 85, who are the fastest-growing proportion of our dying population in Scotland. Palliative care is about making their quality of life as good as it can be and making them as

comfortable as possible, and it is important that that happens alongside curative interventions, particularly when people have multiple conditions for which they are receiving support.

The Convener: Thank you.

Heather Anderson (Dundee City West) (SNP): This is a really important area to understand better. Where is the threshold at which social care becomes palliative care? I thought that Helen spoke very strongly. One of the big things about end-of-life care and palliative care is who is left behind—it is about the damage to the families. You talked about how bereaved people feel. Palliative care has a very strong role in supporting the whole family who are left standing at the end of the event.

I want to probe more deeply into what, in your head, triggers palliative care. Is it the level of medical intervention? Is it the level of specialist support? When does it stop being a social care or care in the community type of support environment and become one that involves the different type of support that we are talking about here?

Rami Okasha: I am happy to respond. It is important to recognise that there is not a set of clinical indicators that say that now is the time for palliative care. The decision is based around diagnosis and understanding what support a family needs.

The criteria that we use in CHAS include consideration of children who might die before the age of 18. That is the cohort of children that we work with. Most of that cohort will die before they are 18, although some will not, so we need to get in as early as possible.

For example, if a baby is diagnosed with a congenital condition early and might be expected to live for a number of years, we would want to be involved at an early stage in supporting that family holistically. That might involve helping a family to come out of the neonatal unit a little bit faster and to come and stay in Rachel house or Robin house for a couple of weeks; it might involve providing a bit of nursing care in that family's home to help the parents to adjust to caring for their child; it might involve arranging social work support to ensure that the family can access the benefits to which they are entitled; or it might involve providing support to help children to come to terms with the fact that they now have a disabled sibling. Those kinds of things happen really early.

That is why I make a very clear distinction between palliative care and end-of-life care. Palliative care should begin at the moment that it is recognised that someone is seriously ill and might die young. End-of-life care comes further down the line. We should be thinking about how

we help families to live well as well as how we help families to die well. Those are two sides of one coin.

Heather Anderson: I very much liked your definition about living well and dying gently. That was very powerful.

I think that Amy wanted to say something.

Amy Dalrymple: Yes, and Mark and Helen might wish to come in as well.

The support is dependent on the person—it is very personalised, as the committee will know, as you have recently been looking at community health and so on. That is one of the reasons why continuity of care is important, particularly as somebody gets more ill. The identification of the point at which somebody will need palliative care might be very different depending on the diagnosis or set of diagnoses that people have. For example, someone might live with dementia for a very long time—that is similar to the situation with children that Rami Okasha talked about in relation to younger people—whereas, for somebody with an illness that has a more predictable trajectory and moves faster, support might be required for a shorter, more defined period of time. What is important is that those conversations are had with the person in a supportive way as early as possible, and that the health professionals are not worried about what is going to happen, and are not overtreating the person.

We set our health service up to make people better and to fix them, and that is the mark of success for people who operate in our health service. Improving palliative care is about recognising when that is not necessarily going to be possible and making sure that quality care is delivered in contexts in which it is impossible to fix a person. There is a workforce piece in there, and there is something that needs to be done around the incentives that exist in the system and the way that the system is structured in order to make sure that people can get the care that they need, not just the care that the system has been set up to provide them with.

Mark Hazelwood: It is a difficult question to answer, and it is an issue that the field has struggled with a bit. In our work to come up with an answer to the problem, we have noted that one of the distinctive things about palliative care, as opposed to good care generally, is that mortality starts to impact people's thinking and decision making in those circumstances—when I say people, I mean the person themselves, their family or the clinical team. We need to think more practically about how to take account of that in operational terms.

I am thinking about the supportive and palliative care indicators tool—known as SPICT—which is a screening tool that is used in general practice that helps GPs to think about which of the people on their list might have palliative care needs or in relation to whom a palliative care approach might start to become relevant. I can follow up with more detail on that; all that I would say is that, if it were easy to know when somebody was going to die, you could work back from that, but we are all working in a situation of uncertainty in which that sort of thing is generally not known until much closer to the time.

The SPICT looks at the conditions that a person has and whether, for example, they have a growing need for support to carry out the daily activities of life. Do they have declining levels of energy that are contributing to their situation? Are they experiencing an increase in the frequency of emergency hospital admissions—which is actually quite a good predictor of somebody with palliative care needs? Therefore, the tool is not really to do with prognosis. Instead, it provides a framework that prompts GPs, and other healthcare professionals, to think about whether a person has palliative care needs.

We might also want to change our approach a little bit, because, as others have often said, the default approach in healthcare is to try to fix problems. Often, we focus on a specific part of the body or the immediately presenting clinical problem, for which there are often good fixes, but the SPICT and palliative care approaches encourage us to think broadly and to consider a person's trajectory instead. They might have growing palliative care needs, and mortality might be starting to become an issue—it is on the horizon, even if it is not immediate—so what does that mean for that individual? Do they need to have a conversation? Perhaps they are worried about what the future may bring. The tool provides a prompt to open up those conversations, and perhaps to do a bit of thinking about and planning for what they might want as their condition progresses.

The Convener: Thanks. Helen, did you want to add something?

Helen Malo: I will be brief, but this is a really important question, and early identification is, as Mark has just explained, very important from a hospice care perspective. Hospices do a lot of work with GPs and other parts of the system to support them in identifying people early on and helping to manage their symptoms.

There might be some misconceptions about what hospice care actually is. It is not just a building where you go to die; indeed, the majority of hospice care happens out in the community.

Hospice staff also do an awful lot to support the capacity of members of the wider workforce, through training and working in partnership with them. There is really good evidence that, if people are identified early, the involvement of specialist palliative care improves their quality of life, and it also saves the wider system a significant amount of money. Those who have been identified can come to the hospice and participate in some wellbeing activities, say, or the full range of hospice care services, and then, when their symptoms escalate, they can get more support from hospice care and other partners to manage those symptoms and stabilise their condition. They will be okay for a little while, and then they can come back again.

People's trajectories vary, so we need to have a flexible, responsive system. Such a system is really helpful if the people have been identified and you know who they are, and it also helps further down the line, because they will have started to have those conversations and to perhaps feel more comfortable with the hospice staff and what they can offer. I have heard some hospice staff say that some of those wellbeing services are like the welcome mat for hospices; they help to build relationships, and they help people to know that the support is there and who to turn to. As a result, further down the line, when their symptoms and needs escalate, they might feel more comfortable about having that support and get what they need.

10:00

The Convener: Thank you, Helen. I think that Jack Middleton wants to move us on to the next theme.

Jack Middleton (Aberdeen Central) (SNP): Actually, this broadly builds on your first question, convener, about what good palliative care looks like. It is clear that there is a lot of agreement and overlap with what you said, but it strikes me that there is not really a set of specific metrics for measuring what good palliative care looks like.

We will get into Government policy later in the discussion, but I wonder whether you agree with that. What would be the two or three key metrics or guidelines that would help us to assess whether an organisation is providing good palliative care and whether palliative care is improving across Scotland? What would they look like?

Amy Dalrymple: I must come in here—I hope that my colleagues do not mind. Marie Curie has been talking about the need for standards around palliative care in Scotland for a good number of years. Currently, there is no national standard for palliative care. When we discuss that, we are talking about a set of standards for people, so that they know what they can expect. It is important to

emphasise that this is about not only setting a floor for what people can expect, but aiding understanding so that everyone recognises that not many people who need palliative care require hospice care. Those who need it ought to be able to access it, but people should also have confidence that they can receive good palliative care from their district nurse, their GP, their community psychiatric nurse or their care home, whichever is most relevant to their condition.

We need to have a set of standards that operates across the health and care system, because palliative care happens across both systems. Those standards need to be accessible to the individual and their families. However, there must be a resourcing and accountability framework around that, because none of us wants to set up those GPs, district nurses, CPNs or care homes to be responsible and accountable for delivering care that they are not resourced to provide.

A set of standards can help to guide decision making on strategy, resourcing, workforce planning and workforce education. However, the most important aspect is that it helps to improve understanding and openness among clinicians and the people who need palliative care about what that is, what they can expect, when they can expect it and where they can expect it.

I hope that that was helpful.

The Convener: I think that Mark wants to say something about that.

Mark Hazelwood: Yes. A range of what I would describe as proxy indicators have been used. The most famous, or prominent, one is place of death. Other measures have been used to provide an indication, but they are all proxies. We could perhaps come back to that.

On what the metrics should be, I would suggest that it is vital to ask people and their families about their experiences. We have never done that systematically in Scotland. We have the health and care experience survey, which is carried out annually. It asks about people's experiences across the health and care system, but it excludes the experiences of people who are receiving palliative care and families who have been bereaved.

A practical step would be to ensure that the survey flags up people who have a life-shortening condition or who are receiving palliative care, as well as people who have been bereaved. That would mean that, when we look at the information that is gathered through the survey, we would be able to examine a subset of people living with a life-shortening condition or to perhaps gather information from family members who have looked

after them. In that way, we could hear directly about their experiences. That is eminently feasible and would represent a step change in the data that we have at a national level, given that we currently lack such experience data.

The Convener: That is a very valuable point, which I am sure that we will come back to. Helen, did you want to say something?

Helen Malo: Building on what Amy and Mark said, it is so important to have standards of care, to have a way of knowing what people's experiences are and to be able to track whether we are making improvements, because that will help us to plan services around meeting people's needs, to address where there are inequities and to plan around population demands. That would give us the basis that we need to be able to plan ahead for the future. We are looking at a really stark picture of rising population need for palliative care and very stark inequities in who accesses care and their experiences of care at the moment, and we need to shift that balance of care more towards the community. The system that we have is not working for people at the end of life. Too many people are ending up in hospital when they do not need to be there and they do not want to be there.

The balance of where we are spending money is very heavily weighted to hospital care. Research from Marie Curie has established that, of the £1.3 billion that we spend on healthcare in the last year of life, £1.1 billion of that is spent in hospitals. We need to move away from the system that we have at the moment. We need to move from crisis to prevention, from hospital to the community, and from being reactive to planning around population need and having some of the things that Amy and Mark said would help to provide the basis for that.

Paul McLennan (East Lothian Coast and Lammermuirs) (SNP): On that point, two years ago, a mapping exercise was carried out that showed that there was significant variation in palliative care services across Scotland. A key point for me is how we address such variation. That becomes really relevant in relation to health board reform, which we are discussing. It is about how we make sure that palliative care becomes a really important part of that process, and how we embed it nationally, given the variations across Scotland.

I think you are right in what you said about the shift, Helen. We have talked about various figures, but there is going to be a huge increase in the number of people wanting to die at home, so we have to build palliative care into our discussions about health board reform to make sure that it is an integral part of that, and not an afterthought. This is a really important point for me. Following

discussions on the Assisted Dying for Terminally Ill Adults (Scotland) Bill, everybody said that this needed to be looked at. We now have the opportunity to look at it; we cannot miss the opportunity to do so properly.

It is about how we make sure that palliative care is embedded in health service reform so that, regardless of where you live in Scotland, you get the service that you require.

Rami Okasha: There are two live issues there. To go back to the first point around metrics, it is a difficult area to measure because we are measuring people's experiences. There is not a set of interventions that you can tick and say, "Done," or "Not done".

To pick up on Mark's point, people are the experts in their own needs and wishes, so listening to what they say is hugely important. The question is, are people getting the care that they need and want? We work with between 500 and 600 families across Scotland, and 69 per cent of them say that there are gaps in their care. That does not mean that they are not getting care, but they are not getting enough care. Often, those are families that are living in the most deprived communities in Scotland with a lot of social complexity and they need a lot of support.

Paul McLennan's point is absolutely critical to answering this. If all that public service reform does is change the number of health boards, it will not change people's experiences. It might make the system more efficient, and there is a very good argument for doing that, but what will change people's experiences is the public sector and the voluntary sector, and local government and NHS services, working together differently.

At the moment, there is a risk that we focus on how many boards to have and what their boundaries should be, rather than on how the public sector and the voluntary sector can work together to say, "These are the things we are going to go after, we are going to do it really well, and we are going to change people's experiences". I encourage the committee to focus on that issue as much as on the structures and boundaries.

Helen Malo: That is a great question, Paul, which addresses something that we have been spending a lot of time talking about. Palliative care cannot be viewed as a marginal issue; it is absolutely central to everything that the committee will be discussing, including pressure on the NHS, delayed discharge from hospitals and shifting the balance of care. Can we use palliative care as a lens to look at whether we can get public service reform right for this cohort of people, their families and the wider system?

As Rami Okasha said, there is a real opportunity here with public service reform. Regarding hospice and palliative care, there is already great evidence on where we are already delivering what public service reform is trying to deliver. In achieving the shift towards a more preventative, community-based approach—providing joined-up care, supporting families and carers and empowering communities—can we use hospice and palliative care as a lead case for public service reform? We can demonstrate that, with the right partnership approach and the right conditions in place, including funding and sustainability, so much can be done in this important area for those people and for the system. That could bring a lot of wider benefits.

Kayleigh Kinross-O'Neill (Edinburgh and Lothians East) (Green): My question is a bit different; this is a segue. I want to talk about workforce planning in a bit more detail. We have already touched on health board changes, what is needed nationally and how this conversation can, hopefully, have some impact.

Dementia-specific palliative care stuck out for me in the briefing from our colleagues at the Scottish Parliament information centre. Could you give us more information on what that actually looks like? Do you need specialised environments or does the workforce need extra training? How will the fact that more people are dying with dementia affect workforce planning? How does that affect the conversations on unmet need or upcoming service provision? After we have discussed that, we can perhaps chat a bit more generally about workforce planning.

The Convener: That moves us on to unmet need and demand. It is fine that we have segued into that, though.

Amy Dalrymple: I can respond with some brief points on all three of those things. First, the experience of palliative care is how we measure unmet need for it. There was a new definition in research that Marie Curie commissioned at the beginning of this year. We have discussed that with the Scottish Government analytics division to ensure that it is acceptable. That figure that we quote of nearly one in three people missing out on the care that they need is the conservative estimate that we were given; it covers both people who have unaddressed symptoms and needs and those who are failing to access the primary care services that they need when they have those symptoms. It is a combination of those two measures. It is a relatively conservative estimate of unmet need, but it speaks to both Paul McLennan's and Kayleigh Kinross-O'Neill's questions.

On health board reform, it is not about what structures we end up with but what it does and what it delivers, and what people and families experience in every area of Scotland—in the rural far north, on an island, in Glasgow, in Edinburgh, in the Borders or down in Stranraer. Do people experience an improvement in accessing the care that they need as a result of the reform of the structures? As with any change, if you are not able to identify what it is going to improve in a given experience, the question needs to be asked as to whether it is really worth spending our time and resource on.

10:15

That leads me on to Kayleigh Kinross-O'Neill's question about workforce planning. Workforce education and workforce confidence are important to people getting the good palliative care that they need. We have done some work in care homes. It is not the kind of research that would be published in a journal, but we have found from talking to care home staff that there is a bit of a gap between their competence and their confidence. They can sometimes be competent to deliver the care that people need while being not sure—not being confident—about that. We must look at the workforce as a whole.

Dementia is a big part of that. I recognise the point about the increasing prevalence of dementia, particularly in cause of death statistics in the past 10 to 15 years. To go back to a point in Heather Anderson's earlier question, recognition of the dying phase of dementia is trickier and more difficult. That is where joining up different parts of the system is important. Someone receiving care in a care home and/or from their GP must be able to access more specialist services, which for dementia might be psychiatry, neurology or geriatric treatment. There must be integration in the system so that those who provide care can access the specialist input that they need to be able to determine what will most help or support a person with complex needs, which might be caused by dementia or by a set of more complex conditions.

The Convener: I will follow up on a couple of things that you said, one of which was about care homes, dementia and statistics. There is clearly an increase in dementia, but they put that on my mother's death certificate when she died and I do not think that that was an at-all-accurate reflection of what she died of. If someone is over a certain age and has been in a care home for a while, it is now quite likely that dementia will be given as a cause of death. I am interested in that from a medical perspective, although that is beyond the scope of this discussion. When did dementia become a cause of death as opposed to being

something that people died with? I am cautious about those statistics.

That takes me to a second area. You made a point about competence and about people having the confidence to do something. If someone is being cared for at home, is it a problem that people may be concerned about using drugs that would be used only at the end of life? I am thinking about pain relief drugs, and the level of relief. Are care-at-home teams or staff in care homes being left to get on with it, whereas staff in hospitals could turn round and ask someone higher up the clinical tree, "Is it okay to do this?". Does anyone see that as a problem, or am I wrong? Who would like to answer that?

Rami Okasha: I am happy to give an example that relates to children. The workforce in children's palliative care is much smaller. Only a small number of specialist doctors in Scotland are trained in paediatric palliative medicine and they are all employed, or funded, by CHAS, which gives the opportunity to work in partnership with the NHS.

You asked about supporting people at home. Over the past couple of years, in partnership with NHS colleagues, we have developed a clinical advisory service that means that a specialist consultant is available on call 24/7 to support clinicians anywhere in Scotland who are caring for a child at the end of life. We did that precisely to address the issues that you have described regarding the good use of drugs, appropriate escalation of drug treatment and so on. That model is a really important part of public service reform because it is about the voluntary and public sectors working together to expand access to specialist experience.

That relies on, and requires, a confident and skilled workforce on the ground. Community children's nurses play a key role, but there is currently no training pathway in Scotland for those nurses, which means that nurses who want to train in that area currently have to travel to England.

It is important to think about not just how we expand the specialist workforce, but how the wider health and social care workforce can gain the skills and confidence to be able to support care at home.

On the flipside of the clinical advisory service that we have developed, we are now testing in the west of Scotland—in a partnership between CHAS, the six health and social care partnerships and NHS Greater Glasgow and Clyde—a model of end-of-life nursing care for children, which is about delivering a fail-safe road to support children's end-of-life experience at home. That requires the nurses to be on call, so we are working in partnership to make sure that the skills, expertise and resource that we have are deployed into

supporting those families at home. It is a very new service, which has been running for only about six to eight months. In the first six months, it supported 244 nights of care at home for children who would probably otherwise have been in hospital.

Again, that involves the public sector and the voluntary sector working differently. So, when we ask ourselves what we mean by public service reform, I would say that it is as much about reforming those ways of working as it is about the big picture of how many authorities we have around the place.

The Convener: That is useful and interesting. Would you say, therefore, that we should be training those specialist nurses in Scotland? Is that something that we could be discussing with further education colleges, if that is the appropriate place, or somewhere else?

Rami Okasha: Universities would be the appropriate place. I know that there are universities in Scotland that are able and willing to deliver that specialist training, but I would imagine that it might be an area that the committee might want to examine further, and I could provide further information if that is helpful.

The Convener: Do you have any more detail on what you have been doing so far?

Rami Okasha: I would be happy to provide written information, if that would be helpful, or I can say more about the services that we provide. I can follow up with information about community children's nurses.

The Convener: Yes, I think that that would be useful.

Joe Long wants to come in.

Joe Long (Mid Scotland and Fife) (Lab): On the question of training, knowledge and skills, we have heard about the need for the wider workforce to understand end-of-life and palliative care, and you talked about the need for confidence and competence on the part of the wider workforce. I would like to unpack all of that a bit.

Mark Hazelwood, your submission talks about end-of-life literacy. What does that look like? What sort of knowledge and skills would that require the wider workforce to have? What would be on the syllabus if we were doing training in that regard?

Mark Hazelwood: We have started talking about end-of-life literacy as a way of framing some of the societal change that I think underpins a lot of what we would like to deliver more consistently and reliably in order to improve people's experiences.

We talk about end-of-life literacy for individuals and communities. All of us will face the issues that

we are discussing—we are all mortals, unless you are Dr Who. We will face them at the end of our own lives, but we will also face them in relation to our family members, our neighbours and our colleagues. For example, many of us will have had the experience of a colleague who has had a bereavement returning to work, and we will have wondered what to say, and how we can avoid making things worse for them—that is a big fear that people often have.

Although we have talked a lot about the services that people need, statistics show that, most of the time, people spend their last year of life at home, and we all know from personal experience that, during that time, people rely on friends, families, neighbours and colleagues for informal support, conversation and practical help. That informal community capacity is critically important. There are things that we can do to nurture and build that informal capacity, which I can perhaps talk about later.

On what end-of-life literacy means for health and social care practitioners, we can start with the basics around what palliative care is. Some of the questions that you have asked are not questions that everyone in the health and social care system can answer, because they involve tricky considerations, such as whether a person needs palliative care. If you are sitting there with an understanding that palliative care is about caring for somebody who is dying, you may take the view that the person you are dealing with should not be referred for palliative care or that you should not bring a palliative care approach to your own practice, and that person will then be one of the nearly one in three people who do not get the care that they need. There is an issue around health and social care practitioners' basic conceptual understanding of what palliative care is, and their responsibilities to ensure that the person gets the care that they need. That is the kind of fundamental shift that is required.

NHS Education for Scotland, which is now part of Public Services Delivery Scotland, has produced a very good framework that sets out a range of bands across the health and social care workforce and describes the sorts of knowledge and competencies that each person ought to have in conducting those roles. As you will have heard, people with palliative care needs are everywhere in our health and social care system, so care-at-home workers, for example, need to know some basic things about palliative care, as they will have a lot more face-to-face contact with people with palliative care needs than, for example, people in more senior clinical roles. Those people have a really important role to play.

We have a good framework that is critical to achieving change, because it is about

understanding the need for change, as well as delivering it. The framework has recently been refreshed and updated as part of the new strategy. That is one good thing that has happened in the first year of the strategy. We need to think more about how to operationalise the framework, because although it is a good framework, it must be used.

The Convener: Exactly. Thank you.

Joe Long: What is in the framework? What are the basic things that people need to know?

Mark Hazelwood: It depends on the person's level. Someone at a higher level will need to know the things that a palliative medicine consultant needs to know, which include all sorts of complicated things that require not only medical training but extra, specialist training. Someone at the bottom end will need to know the things that I have talked about, which are to do with understanding what palliative care is. That might include having basic conversation skills and listening skills. Those are the sorts of things that I am talking about. There is a broad spread.

The Convener: Would you be able to submit further information on that?

Mark Hazelwood: Absolutely.

The Convener: Thank you.

Helen Malo: I would like to provide an example that touches on both questions.

Obviously, hospice care includes the provision of specialist palliative care, but a really big role of hospice care is the support that it provides to the wider health and social care workforce. That includes the provision of training, education and clinical expertise, as well as information on systems and strategic leadership in the context of palliative and end-of-life care. In relation to what that can look like in care homes, I will give an example from Highland, where there is a 24/7 palliative care helpline that is run by Highland Hospice. Patients and carers can ring that helpline directly, but it is also for staff. Staff such as care home staff and ambulance staff can ring that helpline to get advice.

Because palliative care is delivered by so many different staff and partners, it involves interaction between generalists and specialists, so it is important for members of staff to be able to get specialist advice quickly when they need it. I know from early evaluations of the helpline in Highland that care home staff found it extremely helpful, to the extent that it stopped them phoning an ambulance. That goes back to what Amy said about confidence. When a member of staff is not sure about something and wants to check with someone, it is much easier to be able to phone that

helpline and get the advice and reassurance that they need. That can help to keep people where they are and to prevent unnecessary admissions to hospital.

How the different parts of the system work together is crucial, but what Joe said about the workforce element is right. It is so important that members of the workforce feel supported and have the skills that they need to support people at the end of life.

The Convener: You have given us a concrete point to consider in relation to what staff are available to provide such advice. The Government has mentioned that, in the new system, it envisages higher-level staff being available to give advice. That is an example of good practice that would help in many places.

I will bring in Amy, although I am conscious that we have several other subjects to get through in half an hour.

10:30

Amy Dalrymple: I was going to come on to talk about the 24/7 support line and advocate that it needs to be available across Scotland. That addresses your point about access to help and support for people who are at home or in the community, which means that they do not have to be in hospital to get the help that they need. That needs to be backed up by the services being available, whether that is pharmacy or nursing staff or whatever.

Often, what people—whether they are family carers or more general health or social care staff—need is advice, reassurance and support. As Rami described, the very successful clinical advisory service that CHAS has established provides that. Scotland can use the asset that it has in its specialist palliative care voluntary sector—Marie Curie and the other independent hospices—to support that. That is a good example of where that partnership makes sense.

Mark Hazelwood: I will pick up briefly on what I said about public education, because the issue of comfort and confidence is really important. We are working on something called end-of-life aid skills for everyone. First aid is a well-understood concept; it is a body of knowledge that is useful for pretty much anyone to have to deal with circumstances that may arise. At the beginning of life, for example, you have antenatal classes.

End-of-life aid skills for everyone is a course for the public. It is delivered by community members within communities, and it aims to give people comfort and confidence, and a basic level of practical knowledge of things that they may find useful. That can include how to listen to somebody

who has got concerns and worries, how to sit with somebody who perhaps is dying, navigating the health and social care system, planning ahead and looking after yourself as a carer. We would like to make it accessible to everyone in Scotland, because those are things that we all have to face, and we think that it would be useful if we can do a little bit to help prepare people.

We have moved on a bit from the public now, and we have thought about comfort and confidence and what level of end-of-life literacy policy and decision makers need. We are developing an hour-long taster module. It is a bit of experiential learning and reflection to equip policy makers to think about what it means to be end-of-life literate as a policy maker: what do I need to understand, and how can I use my influence to make a difference as a policy maker? It is something that we all have a responsibility for.

We are very happy to offer that taster session to the committee if you could find an hour at some point.

The Convener: Is that something that we do online, or would we come in and do it?

Mark Hazelwood: We have an online version, but the face-to-face version is the best version.

The Convener: We will take note of that. Thanks.

I recognise that we still have many questions. We could extend the evidence session a bit if the committee members wished and the witnesses could stay a bit beyond 11. We could continue for a bit longer if that is desired.

Okay. Heather, do you want to come in?

Heather Anderson: It sounds as if you have many checklists, frameworks and training tools there and ready. We know that there is a disparity of access to care across Scotland, and we now have this very short period of consultation while we move to two health boards, so I would like to get your views about how we best embed that training.

Mark Hazelwood, when you were talking about GPs, I did not know whether every GP had access to that checklist, and whether you had any evidence on whether they were using it. If all those tools are available, how do we use the opportunity with the transition to the two new health boards to ensure that they are being used? Presumably, they could help change the distribution of care across the country.

Mark Hazelwood: There is a wider implementation issue. We have lots of great tools and resources, and lots of good education in place, but the question is how we ensure that there is an impetus behind implementation and delivery, so that the tools are more widely used and

embedded. As you have heard, we know a lot about what good palliative care looks like, and we know a lot about some of the things that need to happen to deliver such change. For me, the gap is around implementation.

I was looking at my calendar, and I saw that 11 years and one day ago, I was here giving evidence to the Health and Sport Committee for the previous inquiry into palliative care. I looked back at some of the things that the report from that inquiry came up with.

The Convener: Can you put them in a briefing for us?

Mark Hazelwood: Yes. It included things that are also in our briefing this time. We know where we want to be. We know many of the steps that will help us get there. We need to reflect on what we have learned over the past 10 years, where we went, what worked with integration and what did not. I say this not in any spirit of blame attribution but in a spirit of learning: in order to actually effect change this time, we need to understand what will be different in terms of the institutional landscape and the cultures that will make a difference.

Heather Anderson: On that, the difference 10 years on is that palliative care is top of the agenda, and the previous Administration discussed it at length. We are about to restructure the health boards, so now is the time to ensure that we get it right. I suggest that the agenda is far more in people's minds in the light of the huge assisted dying debate.

Your sector is quite fragmented. Understandably, it evolved to meet a gap in NHS provision. Historically, it has grown up by moving through different routes, and we need to get a better sense of how your sector gets organised in order to take advantage of this opportunity.

Amy, you raised the issue that everybody gets trained in palliative care, so how do you protect the specialist provision that your sector provides?

Amy Dalrymple: That is an interesting point. To answer your original question and touch on the professional education framework that Mark Hazelwood described, I have two points to make.

First, we must ensure that palliative care is part of education and part of the curriculum for all health and care professionals—for medics, nursing staff, allied health professionals and those who work in social care—so that the qualifications that the Scottish Social Services Council requires for registration apply to whatever the successor body is in this restructuring environment that we are in.

Secondly, to go back to my point about the need for standards and the introduction of new health

board structures, the issue comes back to the question of what they are responsible for delivering. The reason that the committee is spending so much time on palliative care this morning is that—I think that we all agree with this—it has to be an explicit part of what health boards are responsible for providing on an equitable basis and to a quality standard.

To answer your question about specialisms, Heather, I do not think that any of us are here to protect ourselves or our organisations. Marie Curie, CHAS, the other Hospice UK members and the specialists in the NHS that are part of SPPC will always have a role, because there will always be people with more complex needs who need specialist intervention. Palliative care is already provided by GPs, nurses in the community and social care professionals.

A requirement of quality palliative care and equity of access is that when specialist intervention is required, that needs to be identified. People need to have confidence and comfort that if they do not have specialist intervention and do not get a hospice bed, it is because they do not need those things, as they will be able to get the care that they need from services in the community. They will not feel the need for a hospice bed because it is the only place that they can be confident that they will have the end-of-life experience that they want for themselves and their families. A lot of it is about making the system work as well as ensuring that it is understood, which is why we need explicit standards to be part of what the new structures in Scotland's health system will be charged to provide.

Heather Anderson: That is really helpful. You are keeping the specialism, but you are not relying on it to fill the gap.

The Convener: Rami Okasha wants to come in. I will then move us on to more difficult aspects.

Rami Okasha: I am interested in Heather Anderson's question, but I will frame it differently, if I may. I am not sure that hospices developed to fill a gap in the NHS; they developed to fill a gap in service provision for people and because there was a desire to improve outcomes. The solution to improving palliative care will not lie in moving from five or six health boards to one health board in the east of Scotland; that will not change people's experience.

First, we have to look at the issue through a wider lens than the NHS. Palliative care is not simply provided by health boards and hospices, but is provided by a wide range of partners in health and social care partnerships, GPs, and local authorities. We have to think about ongoing local authority reform and the consequential changes to health and social care partnerships. In respect of

children and families, we also have to think about the community authorities that the Scottish Government is proposing and which would be responsible for whole family support.

More fundamentally, the understanding of the relationship between the public sector and the voluntary sector has to change. There is an opportunity to move away from a perceived or dominant model of thinking that the voluntary sector is a subcontractor for the NHS or that it is a delivery agent for public bodies, towards recognising that the public and voluntary sectors need to work together as equal partners in strategic alliances to deliver improved outcomes for people. I say that because I think that we are at a moment in time with the reform process; if we see reform only on the basis of boundaries and structures in organisations and do not think about how all the people who have an impact on people's lives will work together, people will not see changes.

Heather Anderson: I do not think that you should assume that I see it that way.

Rami Okasha: I am sorry.

Heather Anderson: Many of us in the committee have made the case about the medicalisation of care and the need to ensure that it is seen as independent and as having parity of esteem.

Rami Okasha: Absolutely. I might have said "you", but I meant "we". There is a challenge for society, the Scottish Government, the public sector and the voluntary sector to think and work differently. It is on us all.

The Convener: I have a question to fit in before we move on to funding. We have spoken a lot about the fact that most people receive care at home and about the role of carers as well as that of professionals. I have a bit of a concern, which has already been mentioned, about inequalities for people in poorer areas and so on. However, this applies across the board: pressure is being put on carers to continue to care for people at home even when they do not feel that they can, or when it might not be the best thing for the patient. Although the patient may have said three weeks ago that they wanted to stay at home, they could be in a lot of pain by now.

The case for what is needed and what would be best has been set out clearly, so you do not need to convince us of that. However, I am really concerned about how people get to make a choice, not just the person who is dying but their carer, too. How do we respond to a carer, who might have mental or physical health issues or might be finding that life is just too much?

10:45

Helen Malo: It is a really good point, and I was just reflecting on what I have been told by people to whom I have spoken as part of my role. For example, a carer who had been supporting someone at home said:

“We need to get this right. It’s too important to rely on the good will of the limited resources available. The impact on families is catastrophic.”

We know that we need more support in the community. At the moment, the system is skewed; too many people are ending up in crisis and distress, and they are ending up in hospital when they do not need to be there, which is costing the system more money. We know that we have to shift the balance of care. Indeed, there are really good examples of how hospice care is helping to support that shift.

We cannot just leave this to families, and it is important that we think about the impact on them, too. It is also an important reason for having these services in the community—we need to support not just the individual but the wider family. After all, when we talk about those who are experiencing crisis, we might mean the individual with the life-limiting condition, or we might mean their families and loved ones who just cannot support them any more. They need to be reassured that services are available.

I have heard a lot about the weight of responsibility falling on families, in particular in rural communities, because we do not have the community capacity that we need in palliative care at the moment. Why are we spending more money on crisis care when it would be much better for people, for families and for the system to shift resources into preventative community-based care? That sort of care is for people and for their families.

The Convener: That moves us nicely on to the issue of funding. Does anyone have views on that? We know that much of the funding for the services that you represent comes from public sources, and that getting it is a struggle. Do any of you have an answer to the issue that is likely to be taken up?

Helen, I see you waving your hand—great.

Helen Malo: It is a topic that I have talked lots about.

I can share where we are with hospice funding and give you some background in that respect. The majority of our funding, as independent charities, comes from fundraising in local communities, and statutory funding makes up about 40 per cent of what the hospice sector receives. That is too low. Moreover, when I go out to different hospices, I see that the level of statutory funding that they receive varies widely

across Scotland, and that creates inequity for patients and families.

Recently, we have made good progress on funding pay parity. Obviously, staffing is one of the biggest costs, and it is very hard for hospices to match NHS pay; therefore, we welcome the Scottish Government’s recent commitments to provide funding to help hospices do so. What needs to happen now—and I am getting positive indications from commitments in the programme for government that this is starting to happen—is that that is embedded as routine, so that we are not negotiating year after year. We need a structural process that ensures that the funding to support hospices in matching NHS staff pay comes through automatically and as part of discussions and decisions around pay more widely.

Pay parity is a really important part of this, but it is not the only part, and it will not on its own provide sustainable hospice care services. What we really need is a national funding framework for hospice care. Such a framework is long overdue; various things have been in place over the past few years, but we do not have anything at the moment. It was something that the Scottish Government committed to bringing in back in 2023, but we have not had any progress on it.

It is important to help hospices have the stability to plan for future need—to have that greater consistency across Scotland to improve equity in access to hospice and palliative care and support us to work with wider partners to plan for future need. Looking to the future, the population’s need for palliative care is quickly going up: 10,000 more people will need palliative care by 2048. We need to address the inequities that we talked about and shift that balance of care. Let hospices come to the table; be part of what we are trying to achieve in Scotland. We as a sector could do so much more to help to shift that balance of care to achieve the wider reform agenda that we are talking about, and have that partnership that Rami Okasha was talking about, across the voluntary sector and public services. In order to do that, we need the stability and sustainability that a new funding framework would allow the sector.

The Convener: Lots of people want to come in.

Rami Okasha: I echo what Helen Malo has said. For example, the services that CHAS provides across the country are in hospice, home, and hospital. Last year, we spent about £29 million on providing services, of which the recurring element from the Scottish Government was £7 million. There was some non-recurring funding and some additional top-up funding for matching NHS salary increases. That is not a sustainable level. However, the Scottish Government

recognises that, and a process is in place for finding a more sustainable funding arrangement—because, ultimately, hospice care is a partnership between the Scottish people and the Scottish state. Right now, the Scottish people are stepping up, and we need to make sure that the Scottish state steps up, too.

I echo what Helen Malo said about its being preventative spend. Some years ago, we commissioned the University of York to produce an economic analysis of our work, which showed that, for every pound of Government money that CHAS receives, we can generate £6.24 of public value and save the NHS £1.85. That involves faster discharges, reduced admissions and pharmacy optimisation—all the community preventative spend that Helen has described.

There is no better financial bet in healthcare than providing hospices with sustainable funding, because they are charitable organisations that are solely interested in delivering good services, and the way that they deliver care in the community reduces demand in the acute sector, which, for many people, is the right thing to happen, and, financially, is advantageous to the system. Hospices have a key role in the future of the delivery of care.

Amy Dalrymple: I concur with all that Helen Malo and Rami Okasha have said. Marie Curie provides services across Scotland. We have two hospices—in Edinburgh and Glasgow. Each of those receives a different proportion of its funding from its health board. The services that we provide in people's homes across a number of different IJB areas in Scotland receive different levels of funding. It varies hugely by not just the type of service or the hours provided but the level of intervention, if you like, and the level of charitable contribution that is expected in order to get those services delivered. We have similar stats to Rami's when it comes to the return on investment that that provides.

However, I re-emphasise the research that Marie Curie commissioned from the Nuffield Trust and health economics unit not quite a couple of years ago—about a year and a half ago—which we published, and which found that Scotland spends £1.3 billion on healthcare for people in the last year of life, £1.1 billion of which is spent on hospital care. Although what Helen and Rami have described is a crucial and fundamental element of providing people in Scotland with the palliative care that they need, it is also about investing in the wider discussion that you are having on shifting the balance of care to the community.

It is more expensive to provide unscheduled care than scheduled care. It is more expensive to provide care in a hospital than in a community—

even inpatient care in a community. A system driver is sucking increasing amounts of resource into hospitals, no matter the best efforts and the initiatives over the years. Many of us have been part of those. We remember shifting the balance of care and all the other initiatives and short-term funding.

Lastly on the funding, I would say that that cannot just come from an initiative or programme. Hospices have had welcome injections of funding through one-off budget allocations, but there has to be more planning. Planned care is better-value care for the person and for the system. That is what the funding framework that Helen Malo has talked about can help to deliver. Even if there is not more funding, if we know what the agreement is several years in advance, we can plan the very expensive specialist services better and deliver them at better value.

Similarly, if the new structures that emerge through public service reform mean that partners in the public and voluntary sectors can plan more, that will help with workforce planning and workforce education. It will also mean that you can ensure that people get the services that they need in future, as well as more immediately, and will help to deliver better value for everyone.

Mark Hazelwood: I support everything that has been said on hospice funding. It has been encouraging to see the progress that has been made, but there is more to do.

I want to broaden out the issue of funding, because—this will come as no surprise—there are funding issues in statutory services as well. In Scotland, 41 per cent of adult specialist palliative care services are NHS services. That figure comes from background work that has been done in preparation for the Government's strategy. Those services are the specialist palliative care units, which are, broadly speaking, the NHS equivalent of a hospice, as well as the hospital palliative care teams across Scotland. Those NHS services have funding issues, too. I was talking to somebody who works in an NHS specialist palliative care unit, and they have had a budget that has flatlined for 10 years, despite a growth in demand. It will be no surprise to the committee that there are funding pressures in the system.

We have talked a lot about how palliative care is embedded in general practice, district nursing and social care. I am sure that you have heard or will hear evidence generally about the pressures on those services, and it would be good to think about what that means for palliative care. It might mean that GPs are struggling for time to have the complex conversations with people who are living with a life-shortening condition. It might be that there is a scarcity of district nursing, which means

that there will be a struggle to provide the rapid response in the community when somebody is at home. How long will it take for a district nurse to be available to support the administration of medication for somebody who is having a breakthrough pain episode?

Part of the challenge and one of the complexities in our sector is that we have the specialist and distinct service, which is visible, but we also need to think about the bulk of palliative care, which is embedded in other services and therefore can be forgotten or missed. The big headline challenges in the major policy frameworks are things such as unscheduled care, emergency admissions, acute hospital capacity, delayed discharge and shifting the balance of care closer to home. What you have heard from us is that, at the heart of those issues—very often and at scale—are people with palliative care needs and their families. However, you will not see those people referenced in the policy frameworks, and they have often been absent in the data analyses. That is part of what we mean about bringing an end-of-life or last-year-of-life lens to these things.

That is important, because it allows us to understand what is happening and to develop policy responses that are right and effective and that improve the experiences of people and their families. That would also increase the chances of delivering the higher-level headline priorities that I have talked about on unscheduled care and delayed discharge, as well as the aspects of public service reform around preventative spend.

The Convener: That gave us a lot to think about, and some encouraging points to try to get across, perhaps.

11:00

Paul McLennan: We are coming to the end of the session, but I will tell you about a few takeaways. One is about equity of access and the other is joined-up services; they are both important.

Rami Okasha touched on the need for parity between the public sector and the voluntary sector. At the end of the previous session of Parliament, we said that we have to do more about palliative care, and this committee has now had to take a step back and ask, “Okay, how do we achieve that?”.

My main takeaway is that we have to get a statutory funding model in place, because it helps with planning, recruitment and training. We therefore need to ensure that the Scottish Government gets to that as soon as possible.

Pay parity is also important. I remember having discussions with Helen Malo and others about pay

parity in health boards. IJBs top-slice the funding that comes in. Money might come in through the pay parity funding, but IJBs will top-slice the funding that goes to the hospices, which is an issue.

Fundamentally, if we truly believe in a palliative care system that works for Scotland, we need to ensure that we have a statutory funding model in place as soon as possible. I know that that is not simple, as Mark Hazelwood touched upon, but we need to recognise that and push the Government to ensure that that is in place soon as possible.

The Convener: Mark, did you want to say something?

Mark Hazelwood: No.

The Convener: Helen, did you wave at me?

Helen Malo: No.

The Convener: Adam, you have been very quiet, because I forgot you earlier, so say whatever you would like to now.

Adam Harley (Strathkelvin and Bearsden) (LD): My question quite helpfully moves us on a little bit, to legislation. It is mainly for Amy Dalrymple. There has been a lot of discussion about needing to routinely embed funding, the right to palliative care and to make standards explicit. Where does legislation play a part in that?

Amy Dalrymple, along with others from Marie Curie, worked quite closely with Miles Briggs during the previous parliamentary session on a members’ bill that did not progress in the end. What role do you think legislation could play during session 7? We have also talked about public service reform. Is that a better vehicle than a members’ bill? I would like to hear anyone’s thoughts on that, but Amy’s, specifically.

Amy Dalrymple: Yes, we worked with Miles Briggs on that proposal. He also explored combining his proposal with other legislation that did not progress either, including the National Care Service (Scotland) Bill and the human rights bill.

We have been talking about moving that forward again. We have done the consultation, so the premise remains. There is also the option to implement what would be in a bill on delivering the right to palliative care through standards and an accountability framework as part of other Government legislation. Those options are open, but while there is no proposal on the table, a members’ bill remains the best vehicle to deliver that.

We have had several Government strategies, statements, chief executive’s letters and commissioning guidance on palliative care in Scotland since the first strategy—“Living and

Dying Well”—and Mark Hazelwood referred to the inquiry that took place 11 years ago, which stated that there should be a right to palliative care.

However, there is still too much unwarranted variation and too many people are not getting the care and support that they need. You all accept and understand that, and the First Minister accepts and understands it, too. Legislation could be a driver for that.

To go back to the questions on the structural reform of health boards and wider public service reform, it would be great if we could embed palliative care explicitly in that reform. If we cannot do that, or if it is not accepted by the Government, it remains open to the Parliament to decide that doing so is important and to progress it.

Adam Harley: Has Marie Curie had any discussions with the Government or with the Cabinet Secretary for Health and Care about including that in legislation?

Amy Dalrymple: We have met the new Minister for Community Care. She came to visit the Marie Curie hospice in Glasgow, and I am aware that she has met a number of other palliative care organisations, in the independent sector and beyond. She is considering how the Government will take that forward. We have not yet had explicit discussions about legislation.

Adam Harley: Maybe the committee could explicitly ask the minister what the plan is when she is before us.

Amy Dalrymple: I would be delighted if you were to do that. I would love to hear her answer.

Adam Harley: Okay, great. We will do that.

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

Heather Anderson: Sorry, convener, but I have a question for Mark Hazelwood. You made the point that there is third sector funding, but a huge amount of palliative care is provided through the mainstream NHS as well. When we are considering funding and trying to channel money towards palliative care, what pointers would you give us about ring fencing that money to ensure that it does not all go into just one part of the sector?

It would be helpful to me if you could map out—not right now but at some point in the future—how funding is distributed across the whole sector. We need to ensure that we do not lose it all to the NHS.

Mark Hazelwood: I can certainly come back with something on that, but that will be a challenge. The issue with data on palliative care funding is that the visible part is specialist palliative care. What is probably most visible is the significant and

important funding that goes to the voluntary hospices, and some funding will be identifiable in relation to NHS specialist palliative care units and hospital teams.

I suspect that there will be some difficulty in tracking that funding right through because some of it is situated in the NHS, while the legal responsibility sits with the integration joint boards. Then there are the complexities of arrangements whereby, for example, you might have a hospital team but also have people working in a voluntary hospice who deliver sessions collaboratively in a hospital setting.

We can certainly have a look at that. The really difficult part is identifiable funding in relation to social care or general practice. There will be little that is explicitly identifiable in those areas, particularly in social care.

There has, for some years, although I am not entirely up to date on its current status, been some identified funding in general practice. There is a palliative care directed enhanced service that supports GPs to identify people with palliative care needs, have early planning conversations and create an electronic record so that those conversations can be shared across the system.

There may be opportunities for more embedded palliative care initiatives like that. Where there are specific issues, there could be opportunities to tag some funding for specific activities that require support. Those might include the kind of directed enhanced service that I have mentioned. It could also involve support for education and training among social care workers, or initiatives within care homes, which are important settings.

It is possible, but I do not think it will be easy to pick out and tell you what is happening currently.

The Convener: Okay—I will wrap up. I will have the last word and say that perhaps an easier way to do this would be to have single unitary authorities in charge of both social care and health, and then they would not be protecting their own budgets. That might be a bit too radical, although it is going to be done in the islands, so it will be interesting to see that. There is always a problem with moving people from one thing to another, and that needs looked at as we go forward with radical reform.

I will allow each witness two sentences to say anything that we have not covered. We have had an extensive discussion, and I appreciate that you have stayed on and given us more time.

Amy Dalrymple: The last question put into my mind the fact that, in a lot of the research that we have referred to, when we have done it as four-nation research rather than UK-wide research, a lot of the publicly available statistics, including

those about funding, have been easier to find for England and Wales than for Scotland. The work on palliative care data is important, and it relates to what I have been talking about in relation to standards and how we measure delivery, because we do not ask the right questions. We ask about where people die and about their cause of death, but we do not know as much about their care as we do in other parts of the UK, so we know that it can be done. Standards and measurement are necessary in order to make sure that we are delivering people's right to palliative care. Thank you very much for having us here.

The Convener: That is an interesting point to end on, and we can continue to consider that.

Helen Malo: As Scotland, we know what good palliative care looks like. What we need is a credible plan for how we fund and deliver it consistently—it is about how we meet rising need, tackle inequity and shift that balance for care. You have heard today that hospice and palliative care can show what successful public service reform looks like. The committee has such an important role, and I am buoyed by what Heather Anderson said about palliative care being a priority. We welcome the fact that you have asked us in and that we are having this early scrutiny of palliative care.

What comes next for the committee might be something around the context of public service reform and rising demands. How will Scotland deliver equitable access to palliative care? How will we get that shift—to the balance of where care is being delivered—from hospitals to communities? How can we make sure that the accountability, implementation, resourcing and delivery structures that we need are there to make that change happen for people in Scotland?

The Convener: Thank you, Helen.

Rami Okasha: The point about rising demand is hugely significant. The number of children in Scotland who are living with a life-shortening condition is up by about 40 per cent in a decade. That is not more children dying every year—it is more children living longer, and more babies being born with very complex needs, and surviving childbirth. We have to make sure that the systems of support for those families are in place going forward, and it will require everyone to work together to do that.

In the context of rising demand, public service reform and how local authorities, the NHS and the voluntary sector work together in different ways, the most important area for the committee to think about is how we make sure that everyone has access to equitable palliative care, and that the services that people need are there where and when they need them, and that they are high

quality. In many cases, that will involve a shift into the community to support more children over a longer period to live well at home, and then when it comes to the end of life, to give real choice to families about whether a child dies at home, in a hospice or in hospital, and that they have the best possible care in every setting. That is the key task, and CHAS is up for being part of that solution.

The Convener: Thank you very much, Rami.

Mark Hazelwood: I will use my first sentence to concur with my three other colleagues, who have all said things that I might have said. To give the committee something to think about, I hope that what will be different this time is the role of high-profile political leadership and senior sponsorship within the system, which has a lot of other pressures and is thinking about other things. Those two things are critical factors for enabling change.

The Convener: Thank you. That is food for thought. Something that you and Helen Malo said reminded me that, several decades ago, I stood for election and had a line in my speech about the fact that, by 2000, we would have an ageing population of whatever number, and I asked what plans we were making for that. We are now 26 years on, and I hope that we will not be here in another 10 years asking what plans we made and where they went.

Thank you very much to the witnesses; it has been a very useful and thought-provoking session for us. I appreciate your coming in and also giving us extra time. No doubt we will meet again, but if there is something that we have missed or something that we have asked for, if you could send it in a nice short briefing, I would be grateful and more likely to make sure that I read it all.

We will now take a break before we come back for the next part of the public session.

11:15

Meeting suspended.

11:25

On resuming—

Subordinate Legislation

**Tobacco and Vapes Act 2026
(Consequential, Transitional and Saving
Provisions) (Scotland) Regulations 2026
(SSI 2026/213)**

**Personal Injuries (NHS Charges)
(Amounts) (Scotland) Amendment
Regulations 2026 (SSI 2026/245)**

**Sports Grounds and Sporting Events
(Designation) (Scotland) Amendment
Order 2026 (SSI 2026/247)**

The Convener: This is the first time that the committee has considered secondary legislation. We have three negative Scottish statutory instruments to consider. We will take each in turn, starting with the Tobacco and Vapes Act 2026 regulations, which I do not think I need to read out, as we know what they are. The regulations are subject to the negative procedure, and I have had no notice of anyone on the committee wishing to lodge a motion to annul. Are members content that the SSI comes into force?

Members indicated agreement.

The Convener: The Personal Injuries (NHS Charges) (Amounts) (Scotland) Amendment Regulations 2026 are also subject to the negative procedure, and I have had no notice of anyone on the committee wishing to lodge a motion to annul. Are members content that the SSI comes into force?

Members indicated agreement.

The Convener: The Sports Grounds and Sporting Events (Designation) (Scotland) Amendment Order 2026 is another instrument that is subject to the negative procedure, and I have had no notice of anyone wishing to lodge a motion to annul. Are members content that the SSI comes into force?

Members indicated agreement.

The Convener: That concludes the meeting in public.

11:27

Meeting continued in private until 12:38.

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