I will speak about new clause 12. We have heard a lot about the lottery of catastrophic care costs, but there is one thing that is no lottery at all, and that is the absolute certainty that everyone in this room and everybody following this debate will come to the end of their life, and more importantly to most people—that somebody they love will come to the end of their life. We know that most people want to be at home when they die and to die in dignity, but unfortunately less than a third of us have the opportunity to do that. The new clause would ensure that terminally ill persons were separately recognised in the Bill. I want to set out why that matters and to address two of the most important barriers to people having a good, dignified death, at home and surrounded by the people they love.

From my personal experience of 18 years of general practice, I know that one of the main reasons why people who were desperately keen to stay at home ended up being admitted to hospital is simply the sheer stress and physical difficulty of providing personal care needs for someone at the end of life at home. Very often, of course, the families affected have not adjusted over a period of time to becoming carers but are thrown into that situation, at a time of quite extraordinary personal stress, when they are having to face the prospect of losing the person they love. When all the factors come together—not just providing 24/7 care, but the intimate and demanding physical nature of that care—it becomes too much. With the best will in the world, the elastic can only stretch so far, particularly for someone who is a single carer, and that is the point at which, sadly, people have to be admitted to hospital.

That admission can sometimes feel to families like an admission of defeat. There is a sense of failure that carries on into their bereavement. It is important that we address that, because often it is not a failure on the family’s part: it is a failure on the part of health care and social care to work together at the critical point that is the end of life. It does not have to be that way.

Of course, there are continuing care assessments, but 97% of health care professionals and of the families affected agree that those assessments are inadequate, because of the bureaucracy and delay that are involved. Anybody who has been involved in the process will know that continuing care assessments do not work effectively at the very important point that is the end of life, when often rapid decisions need to be made.

As my right hon. Friend the Member for Sutton and Cheam pointed out, 40% of people in hospital at the end of their lives do not need to be there, so social care is critical. We cannot address the urgent need for people to be able to die at home without addressing the need for free and rapid access to social care at the end of life. As the shadow Minister has pointed out, despite the welcome rise in the eligibility threshold, a number of people will still miss out under the Bill; and those people will be at a time in their lives when there is great financial uncertainty. A carer might have to leave their job to provide end-of-life care. They
might be asset rich but they are very likely to be cash-flow poor at what is a critical time in their lives.

That is why we must address the urgent need for free social care at the end of life. The period of time involved is short—although I understand that the definition of the time period for terminal care is six months, for most people it is much shorter. Of course, we need to address the issue of funding, but let us be clear: when people are admitted to a busy general hospital ward, in effect the taxpayer is paying more for worse care. We all recognise that the join-up between health and social care is the problem. The incentives are in the wrong place. There is a great incentive for hospitals to admit people and there is no financial incentive for local authorities to fund. Overall, we are all paying for worse care in the wrong place.

I welcome the palliative care funding formula, which is due to be revised by 2015, but the Minister will know that there are concerns that the timetable for revision could be slipping. We know that a choice review was due to start in 2013. I hope that the Minister can offer some clarity on that, because we need more certainty about the remit, who will be running it, what it will cover and, critically, what the proposed start date now is.

There is a danger, in a sense, because there are four reviews going on. Sometimes we risk losing the ability to see the wood for the trees. Whatever the reviews and pilots show, the one thing we are clear about is the fact that we are paying more for worse care, so I hope that we will have a definite commitment to introduce free rapid access to social care at the end of life for persons who are terminally ill. That needs a separate category because, although I accept that clause 14 could be argued to be an enabling clause, I do not think that it goes far enough. It sets out that certain conditions can be specified, but end of life covers every condition. It is possible that it will not be as enabling as the Minister feels it could be.

There are provisions under section 6 of the National Health Service Act 2006 that could also perhaps be interpreted as enabling, but they apply to health care, not to social care. That is why I hope the Minister will accept that it is right that we have a separate clause to cover such an extremely important issue. New clause 12 would still enable the Minister, rightly, to take account of the pilots, but it would also set out a clear intent to deal with the issue. I feel strongly that that is the right thing to do.

The second issue that the new clause covers is forward planning. My right hon. Friend the Member for Sutton and Cheam has already referred to electronic palliative care coordination systems, but we know that a lack of forward planning is also one of the main factors leading to people dying not in the place of their choosing. We have worrying data from GP surveys that show that GPs themselves are sadly still hesitant about initiating discussions on the issue—often, as they say themselves, they lack confidence. Such discussions must happen; it is no good having professionals shying away from them. Once they recognise that someone is dying, it is critical that, across health and social care, a preference for a place of death is recorded.

There must also be better information sharing, because often the issue is that a locum doctor, perhaps, sees someone who is unsure about what their wishes are, or perhaps is not in a position to express their wishes clearly at that point. Having good, clear information shared across health and social care with the patient's consent in advance, of course would make a real difference.

Previously in Committee, the Minister has stated that just because something is in a Bill
does not mean that it will be put in place, but there is no doubt that it helps to drive change if an issue is clearly expressed in legislation as important. As I have said, the new clause would be an enabling measure. It does not seek to set out in stone, in detail, how things should be done; it would simply enable the Minister to ensure that arrangements are in place. That is critical.

I look forward to hearing the Minister’s response and hope that he will accept new clause 12. If he cannot, will he at least give a clear commitment that the Government will fund free social care at the end of life? Do the Government recognise the importance of that and the need to have systems in place for advanced planning? That would be an extraordinary step forward and make a real difference to everyone following this debate.

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Hansard

Norman Lamb: Ultimately, we all know where we want to get to. In the meantime, until we get there, we want to ensure that we apply the rules equitably.

Let me continue to make the argument. As I said, it would not be appropriate for there to be a duty to meet all needs at end of life urgently, as there are many instances where it would be appropriate first to carry out financial assessment and eligibility determination in the normal way. I want to change the rules, as does my right hon. Friend. It is important that there is clarity until then about how the existing system operates.

Turning to amendment 54, we do not consider it to be necessary. When a carer’s needs for support are deemed urgent it is usually as a result of the adult’s needs being urgent, and so usually that would be best remedied by providing care to the adult urgently, for which there is already provision in clause 19. Where it is clear that local authorities need to put in place support for a carer quickly, they should obviously do so. We would expect provisions in the Bill to be applied proportionately, so that there need not be a delay in providing the support carers need, especially in urgent circumstances. However, we do not think that an additional express provision in the Bill is necessary to ensure that. I understand the concern my right hon. Friend the Member for Sutton and Cheam expresses and I would want to avoid inadvertent neglect of the carer. I will reflect genuinely on what he has said and report back to him in due course. Turning to new clause 12, tabled by my hon. Friend the Member for Totnes, the Government are committed to moving towards choice for all on how to have a decent and dignified death and where that should be. I am determined that we achieve that. A review this year will determine when such an offer of choice in end-of-life care can feasibly be introduced. I can provide guidance on the choice review which I think my hon. Friend raised. It will happen this year. A workshop in early February will scope the whole issue and it will involve the full range of experts and stakeholders. They will continue to be involved as the review progresses. But it will happen and be completed this year.

As I say, I am determined that we achieve the breakthrough and achieve what we are all after here in delivering choice at the end of life. Any offer will be introduced using existing legislative powers, namely the standing rules. One of the recommendations of the independent palliative care funding review was about free social care at the end of life. The Government have funded eight pilot sites to gather the information needed to develop a new system and to test the review’s recommendations, including its recommendation to provide free social care at the end of life. Other hon. Members have made the point that it
feels clear, and indeed, work has been undertaken to demonstrate that it should be cost neutral. There is a cost attached to the fact that so many people are dying in hospital and we are not delivering what those people want.

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Sarah Wollaston (Totnes, Conservative)

I thank the Minister for his words—I am pleased to hear that he is so committed. However, may I ask him for some clarification? When he says that he is determined to do this, does he mean the choice review? I think the words we would all like to hear are: implementing free social care at the end of life. I accept that the pilots have to guide the mechanisms for that, and no one expects him to set that out without seeing the evidence, but a firm commitment to introducing free social care at the end of life would really reassure everyone on the Committee.

Norman Lamb (The Minister of State, Department of Health; North Norfolk, Liberal Democrat)

I have given my hon. Friend my personal assurance that I want us to do this. I am not in a position to commit the Government, but, as the responsible Minister—indeed, I have some degree of influence over the decision making—I am determined that we achieve that objective.

Just to be clear, it seems that the issues of choice and free care are inextricably linked. It is the financial incentives that currently mess around with and undermine proper choice at the end of life, and that is what has to be resolved. The choice review can achieve that important objective, but getting the mechanism right is inextricably linked to the outcome of the pilots. It is my clear objective, however, that we achieve this ambition.

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Hansard

Sarah Wollaston (Totnes, Conservative)

I thank the Minister for his response, and I would like to ask him a few questions. I accept that he feels that these matters are dealt with elsewhere, and that regulations can be introduced, but I want to take him back to the wording. It says "in specific cases" in the regulations. Can he reassure me that "specific cases" could include the broader category of terminally ill persons?

Norman Lamb (The Minister of State, Department of Health; North Norfolk, Liberal Democrat)

I can reassure the hon. Lady about that.

Sarah Wollaston (Totnes, Conservative)

I thank the Minister; that is very reassuring. On his second point, he gave us reassuring
news about the progress of EPACs. However, may I point out that the figure is up to 80%, but it is not 80% across the board? We must not be distracted. That 80% figure could risk people thinking that we are going to deal with it all through EPACs and that therefore other measures are unnecessary. That is an important clarification on those data.

Norman Lamb (The Minister of State, Department of Health; North Norfolk, Liberal Democrat)

I am grateful to my hon. Friend for her clarification and I accept her point. I did say that I was not arguing that the figure undermined the case for reform.

Sarah Wollaston (Totnes, Conservative)

I accept that, but I thought it was an important clarification to put on the record.

There is also the fact that we have four reviews ongoing in this area—or one about to start. The Minister will know that one of those reviews was set to be completed last year. I am grateful for his categorical assurance that it will start this year, that it will be completed by the end of this year, and that the terms of reference will involve stakeholders. That is reassuring.

Most of all, I am absolutely delighted with the Minister’s assurance that he is determined to introduce the policy and that it refers to the issue of free social care at the end of life. Based on that reassurance, I look forward to seeing the progress of the policy, and I am happy not to press the new clause to a Division.

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Hansard