HYACINTH SHAND, DEPUTY CARE MANAGER, THE ELMS RESIDENTIAL HOME IN EAST DULWICH, SOUTH EAST LONDON

I agree with Sheila, when you enter into a home, if you should be there for life, then home we call it, the Home for Life. We do care for people with dementia, Alzheimer's, cancer patients, and things like that.

We are a charity home and constantly have to apply for funding when you need training, most of the training is based in hospital, so we have to pay for most of our training. Access to exercises and Art and craft is another important area, but most of the time you have to pay for these things. It's not cheap. I think it's an area that needs to be looked at.

The other thing I noticed this morning is most older people get a Freedom Pass, but the Freedom Pass does not start until 9.30. Hospital appointments start at 9 o'clock. I think it's an area that you all need to look into. The bus driver refused to move the bus this morning because the lady didn't have a two pound, and I think it's very sad.

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE

Thank you, that was very well said and I think there is really valuable learning for us here.

In terms of your very important comment around training, and what access there is to training and the cost of training within care homes, that's something very much that we want to look at. More partnership working with the NHS sector and care homes because it's only together that we are going to be able to improve the system, and there are financial constraints all round, but I'm sure there is much more that we can do together. So please get involved in the programme and we'll see what we can do together.

SANDRA LAWMAN, SECRETARY TO THE CHARITABLE TRUSTEES OF SOUTH LONDON AND MAUDSLEY NHS FOUNDATION TRUST

I'm very happy to be part of this initiative. I'm concerned about what's called, the culture of elderly people in homes, because they're often given neuroleptic medication which is quite inappropriate. This is being raised in parliament at the moment but what can be done?

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE

I think part of what has been very important to me, is staff training so that people feel more comfortable with managing some of those disruptive behaviours. If there are not enough staff, or staff

aren't well equipped, then they may turn to medical intervention to try and reduce that behaviour. But as Sheila said, having space whereby people are safe yet not restrained can help. There are some models we need to go and look at and explore and I'll take the details from Sheila. It's an issue that's very important and I think staff training is going to be one of the keys to that.

SHEILA HANCOCK, OBE
But it is very worrying, isn't it, that GPs are continuing to prescribe drugs that they have already been given an urgent warning should not be used. I think it's a desperation thing, isn't it. People become agitated and difficult, and it's give them anything, you know. And I think it's shameful because there are other ways. But they are time-consuming and they require skill.

COUNCILLOR MARCIA CAMERON, LAMBETH COUNCIL
Councillor Cameron from Lambeth Council. I'd like to ask the Panel, what advances have you made in regards to cultural and religious observances.

TED BASSEY
My own experience is that with my brother Arthur, and you saw the clip on the screen. As far as the religious aspect is concerned, he was able, with help, to attend his local church, the church he went to. The vicar came to see him regularly and that meant a lot to him. When he visited the hospice once a week, to the care centre, one of the things that they did, was to encourage the patients to try and do something that they wanted to do. They talked it through and as far as my brother was concerned, they discovered that he'd been in the army during the war, and he was encouraged to write with their help a little book on his experiences in the war, and a copy of that book was deposited at the Imperial War Museum. And that was a great achievement to him. Having had that encouragement to do that meant so much to him.

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE
The diversity that we have in Lambeth and Southwark with over 150 languages spoken and the different cultures and religions provides a wonderful mix that makes life in these two boroughs so unique. We really have to look very carefully at how the care can be individualised at important times like End of Life Care. I recently heard an example, I think from Dr Hopper from Guy's and Thomas'. He was talking about a particular issue for a family that was very important in terms of a patient being discharged from a hospital to a care home, when they were reaching the end of their life. Somebody very much wanted the patient to stay within the hospital, because culturally to go to a care home was unacceptable for that particular culture for that family. What made the transfer possible, because the acute hospital wasn't the right place to be, was the close links between the consultant of the hospital

and the care home where the person was discharged to, which made it then culturally acceptable. So I think there's lots of very important things that we're going to need to explore through this project.

BARBARA MONROE, CHIEF EXECUTIVE, ST CHRISTOPHER'S HOSPICE

I was very, very affected by what Ted said, and I'm just wondering Ted if there are one or two things that you think are really important that should be transferred from your brother's very good experience into this new programme. What are the things that you think that we should really hold onto.

TED BASSEY

One of the things that impressed him greatly in his particular case was that you started with the expertise of the hospital, which was exceptional, and then beyond that you've got his GP, who was very much in touch and was always available, you had the District Nurse service, and the District Nurse came in once a week or twice a week to give injections and that sort of thing when required, you had the hospice movement, and beyond that you had the vicar from his local church. But also you had the people in his community. He was fortunate in as much that he had wonderful neighbours around him and friends and relatives, so he was able to carry on his life as far as possible, to meet his friends, to go out, go to his church, go to his Darby and Joan club. So it's a whole group of things that come together, including the ordinary private sector - people with no expertise in medical care but to have someone available to come to see them, to visit them, it means so much to them.

JONATHON HOPE, CHAIR OF THE KIDNEY MODERNISATION INITIATIVE PROGRAMME

I have a question also for Ted. As Jayne highlighted really crucially in her introduction, patient carer involvement is key. Ted, can I ask you, why did you get up on film? What motivated you to get up on film and to talk about your experience?

TED BASSEY

I was recruited. [Laughter]

I was asked...I was...I was asked if I was willing to give help and I didn't know quite what was involved, and I said oh yes, of course I will...I would. And it went from there in fact, yes, and I'm glad to have done it and I'm glad to be here today.

SIMON HUGHES, MP FOR SOUTHWARK

Thank you very much. Really valuable. Just two reflections in a way following on from Sheila's absolutely admirable contribution. The first is, and I've been through looking after quite a lot of older people as they've been dying over the years, a comparison between the care of an aunt who died in the Westminster about 15 years ago and my mother who died last year in Birmingham, was hugely impressive, the better service.

But quite often there's not one person who is responsible. I'm not talking about hospices, which are wonderful in every experience I've had. But there's not one person who can be your continuing point of contact all the time. Its really important, that if they have a holiday are or off they delegate to somebody else, but you have to have one person who knows the whole history, knows the family, knows who they are, knows what the issues are, and you can trust in as things get nearer to the end. And the other thing I so share Sheila's view about, some care homes, even some of the best, the televisions should normally be off, the windows should normally be open, not closed, the heat should be normally be turned down, not up, people should be taken out. I remember when my aunt was dying, another aunt, she was in a home, and I said look I'm going to take you out in the wheelchair. It'll be far better that you die falling out of the wheelchair by the brook than you die complaining about all the other old people sitting round the television. And she agreed. And she didn't die falling out of the chair in the brook, but the risk was worth taking.
But the last thing, the other partner, Geoffrey, that I haven't seen mentioned in the list of people, are schools. And if we can get schools in and out of the care homes, in and out of the geriatric wards, I know there are infection issues but two things will happen: you keep the people younger and more alert, and youngsters are wonderfully unembarrassed by a lot of these things, but also I think you will help bring respect for older people in our younger generation, who nowadays don't have the experiences of yesteryear, of being with the grandmother who's dying and the grandfather who's dying, who've almost always separated from that.
So please add schools to the partners, and bring them in all the time so that they are part of the improvement of the process too.

SHEILA HANCOCK, OBE
I agree with the point he's making about letting students work part-time in care homes because they do all sorts of jobs and it would be much more productive. And I agree totally about children. One of the lovely things about St Christopher's which I think has gone now, that there used to be a nursery in the middle of the place for the children of the nurses, and it was so wonderful to go there and hear baby voices amongst all these old people.
And you know when you get old, and I'm old and I much prefer being with young people. I really do. I get so bored talking about hip replacements. [Laughter].

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE
What I would say is St Christopher's currently have some really important work and are bringing children from schools in to meet patients so I think that's a model that we would want to share that learning much wider with the other partners we're working with. It's just having some phenomenal results and I think that's really important.

And I would say on a personal note, when I was back at school I was terrible at art which is why I ended up doing science and have the background I have. I used to skip my art lessons to go and volunteer in a home for older people. It was very inspirational and was what led me into nursing. So I think opportunities like that, we do need to work with our partners with the schools and we certainly will add them to our list. That's a point we'll make. Thank you.

GEOFFREY SHEPHERD, CHIEF EXECUTIVE, GUY'S AND ST THOMAS' CHARITY
I just wanted to add a word on this myself, because I think one of the advantages of a programme like this is that we have the opportunity of looking not just nationally but internationally at good practice. And that was a key part of the modernisation initiatives for stroke, sexual health, and kidney disease. I know that some years ago I went to the Scandinavian countries to look at care for older people there and I was enormously struck, Simon, by the point you're making, is that the care homes in Holland and in Denmark and Norway and so on, they are part of the community, and there are cafes within them. People come into those cafes from the streets and chat away with the older people. And I think, it's your point as well, Sheila, that they have to be vibrant. At their worst they're ghastly, these homes. So I do hope very much that this programme will enable people to go and look at best examples of practice, both nationally and internationally because I do think we have a lot to learn culturally about the way in which we care for older people.

SHERA CHOK, MEDICAL DIRECTOR AT LAMBETH PCT
I think Simon, that's a brilliant idea. I think we might have to end up doing CRB checks on everyone in a palliative care home as a side effect. But just to pick up on what Sheila said about GPs and prescribing practices. I think it illustrates that End of Life is a very complex area, and it's really important to get it right, getting communication between different professionals right from the beginning, because it's a shared responsibility. It's not just the GP but it's the palliative care team, it's the hospital consultants, it's the district nurses and so on. So building those links and communication from the beginning is absolutely crucial for End of Life care.

TED BASSEY
Just take up on that, and on the point that was made here about contact. One of the most important things, I think, is to have the ability to contact someone if you're concerned, if you're caring for someone. And in my particular instance, my particular case, the fact that you could telephone a particular person at the hospital, or at the hospice, to ask for advice or what you could do, that gave a great deal of comfort, because you felt you had someone behind you and I think that's one of the most important things really.

BRENDA BOND, CHIEF EXECUTIVE, AGE CONCERN LEWISHAM AND SOUTHWARK

Sheila you asked whether we care enough to spread the cost really, of home care and at care homes and so on. Sadly, no we don't in this country, and we know that. Governments and political parties, almost seem to have to not say that they're going to spend more on health and social care in order to get power and be able to do something about it.

We've seen huge investment over the last 10 years really in the health service and very, very little and, now a diminishing amount in London, in social care. One of the things the gentleman mentioned was about contact with friends and family. Lots of older people dying at home or in care homes do not have friends and family, or maybe have one friend or family, who can visit and who can maintain that sort of contact, one person or maybe nobody, who can make that phone call to say, what do I do now.

We provide a very small quite specialist palliative home care service. It falls into social care although it is purchased mainly by health. We're now told in Southwark that we need to reduce our cost. I rest my case.

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE

I think with the End of Life Care strategy and the NHS Next Steps Review coming out, hopefully there'll be a major political, and national drive to scrutinising End of Life Care which will include both social care as well as health costs. In the Action for London report, what was very clear in there was a message for Health to look at how they are commissioning with social care partners, so maybe that's things like pooled budgets and the no-go areas that we need to talk about. But we need to talk about those things and we need to be very frank about it. That's one of the things we'll be wanting to do with our partners.

DOMINIC STANTON, INTERIM ASSISTANT DIRECTOR (ADULT SOCIAL CARE) LONDON BOROUGH OF LAMBETH

I would just like to make one observation, and then ask Sheila a question. I'm involved in the Marie Curie scoping work which is invaluable, and this is a wonderful opportunity for all of us to make a difference. My concern from a social care point of view, is that a number of people we see who are isolated, who have nobody, and so I'd just like to put a marker down about not only the opportunity for people do die at home, but people who die alone.

And Sheila, I would also like to ask you how you would feel about, as an alternative to prescribing allopathic drugs for older people, what you would think about prescribing alcohol instead.

SHEILA HANCOCK, OBE

I'd be right behind it, particularly if it's me. [Laughter]

May I make a quick point that I do think we need respite places, and I think we need day centres that are fun, not chairs sitting round a television. The people who are in their own at home can go and visit other people. I think that is vital.

DELORES WILLIAMS, MODERN MATRON, SOUTH LONDON AND MAUDSLEY NHS FOUNDATION TRUST

Now within our organisation we do have specialist care homes for patients that have advanced dementia and perhaps can't be cared for with relatives. I suppose this is more a plea or reflection, where the patient's settle and it's obvious that the patient has come to the end of life, and the carers want to take the patient out of our organisation's home, they are supported to do so. I don't, currently think that they're supported enough.

I can certainly think of one case history where we jumped hoops and hurdles to get social services to support a husband caring for his wife at home. It happened but it was really, you know, really jumping through lots of hoops and it doesn't seem fair, and I'm sure there are other people who have had that experience, or would like to care for their relatives at home but the support isn't there at the moment. It's a plea.

JAYNE CHIDGEY-CLARK, PROGRAMME DIRECTOR, END OF LIFE CARE - MODERNISATION INITIATIVE

A plea... and very important thank you.

Please if I can use this opportunity to ask you to look at your packs, fill out the forms in there about how you'd like to get involved, talk to the team, identify yourselves, because your ideas and your priorities are what we're going to be working on. We're here to work with and for you, so thank you.