

**End of Life Care Programme Launch  
31<sup>st</sup> June 2008**

**Sheila Hancock OBE**

Thank you very much. This is a wonderful initiative and I'm really glad to be here at the launch of it. It is so desperately needed, as I know myself.

When my mother was diagnosed with terminal cancer I was offered absolutely no support at all. Now this is some time ago, but the reason we're all here is because we know that this still happens now.

I was absolutely terrified, I had no idea. I had never met death even, I'd never seen a dead person. And I nursed her ineptly and badly, and as a result she died badly, and that fact has haunted me for the rest of my life.

Not long after that, my first husband, Alec Ross was diagnosed with oesophageal cancer. And I remember he was going to have that very big operation, which is now a matter of course, but was new then.

And I phoned up the specialist to find out how it had gone, having waited for hours at home with no news at all. And he was very, very cross, and he, and the words, I can remember that he used was riddled, riddled with cancer, it's hopeless, there's nothing we can do.

Nothing we can do. So Alec came home, he was in absolute agony, he couldn't swallow, so he couldn't feed himself properly, and I was given the news that he probably had about a month to live.

And then thank god, somebody told me about St Christopher's, because by this time I was exhausted with looking after my mother as well as facing the prospect of my first husband dying.

I went down to St Christopher's thinking I'm not gonna like this a terminal home, I'm not having my husband come here.

And I walked through the doors of this beautiful, you say it wasn't building based Jane, but that building was very important to me.

This beautiful airy building, lovely paintings all over that were done most, mostly by Sicily's partner. And I was welcomed by the man on the desk.

And then I went into Sicily's room and she held my hand, held my hand? And she said we're going to take care of you.

And by that she meant not just my husband but she meant me, and by god she did. Within a few days my husband's pain was under control.

She organised that he had a stent put in, so that he could eat, and he lived for another nine months, and he died at home, with me and one of the nurses from St Christopher's by my side.

Now one of the things that I got out of that was that there was an attitude in the medical profession that if you can't cure people you've failed, there is nothing more you can do.

I do think that has shifted a bit, but I don't think it's shifted completely, and I think it's something that this thing has to tackle, because they are the first line of communication.

And communication is what I want to talk about. Communication is the most vital thing, between departments and things like that obviously, but between people.

And the fact of the matter was that this specialist that I spoke to and many other doctors that I met at that period were bad at communication.

And their argument would be that they had to remain cool in order to operate, blah di, blah di, blah. But I think it's part of your job to be able to communicate. And I actually think you can be trained to communicate.

There are certain things, like not sitting behind a desk if you have to impart bad news. Touch. Maybe you can't bring yourself to, you can actually learn a script of which 'there is nothing we can do' is never a part of it.

Excuse me I have a sore throat so I'm having to keep take a swallow of water. Having, having. The attitude to old people, in this country, I, and I'm old, so I have a right to say this. I am old, it's condescending, it's patronising and it's disrespectful.

If I give you a tiny example, when you get to a certain age, women particularly, you do become totally invisible.

And I had breast cancer a few years ago, and I have to go for a regular check-up, you know. And I have to have those ghastly momographies.

And the last time, not the last time, the time before last I went, I was sitting there with my breast squashed into that agonising machine, it's not a present experience, as the ladies know.

And the two operators were having a conversation across me about the restaurant that they'd been to the night before, I kid you not, that happened in modern day medicine.

Why on earth had they not been trained to treat people better when they were doing that operation?

I have a dear friend, who died recently, a girl with an amazing brain, a woman called Claire Venebles, one of the most intelligent bright women that I know.

And I got a telephone call from her saying that she'd just been told that she had a terminal illness. And I rushed down to the hospital and she was in a general ward, and she'd been given the information, with a flimsy curtain tied round, and all this chaos going in the ward, and I went, and we were behind this ghastly flimsy curtain, and I was trying to say well what are we gonna do now, we've got to get you out of here, blah di blah.

And in came a perky little nurse and said hello my darling, here's some medicine for you, now drink it up like a good girl, there we are, thank you.

And Claire went piss off. Actually she said something much worse than that. But by god I agreed with her.

And that's what I mean, that we have to accept that people are individuals. I remember doing a ward round with, with um Sicily, many years ago, when I was very involved with St Christopher's. And eh there was in one of the side wards a man who was making a hellava noise, he was really angry, and really, and I got very upset, and said to Sicily can't we help him, can't we give him something, can't we let him make a basket or give him a drug or something like that?

And she said Sheila it is his right to be angry. If that's how he chooses to die, raging at the dying of the light, then that's what he must be allowed to do.

But similarly I remember there was a dear woman who'd obviously lead a very downtrodden life, and she was sitting on the ward, and it was her birthday.

And always at St Christopher's, I know I have people from St Christopher's here, but birthdays are made a great fuss of.

And the staff organised a party for this lady, and in came her four galumphing sons, who probably hardly ever spoke to her actually, and they all had little presents, which I suspect the staff had bought.

but anyway, they handed over these presents to this lady. In came the cake and they rather awkwardly sang happy birthday to you.

Anyway it was an awkward but lovely occasion. And afterwards I went to talk to her, I sat on her bed and she said, I can hardly bear to say this, she said, that was the happiest day of my life. And that's what can happen at the end of your life, you can make amends, you can say sorry, you can say you're angry, but those days and weeks, years, are valuable.

Now you're asking for opinions about how end care. I'm old, I'm gonna give you my opinion, I'm gonna give you my penny's worth.

I think as long as possible you should be allowed to stay at home, with support.

When I wanted a commode and a wheelchair for my mother I should have known where to phone and I should have been able to get one, but I didn't.

So you need a certain key worker whom you can actually have a really good relationship with.

Then if you go into a care home, oh and incidentally, if any of you are from care homes please will you get rid of those bloody awful armchairs.

Do you know the one's I mean with the wooden sides that are grouped round a television, what can be more depressing when you have to leave your home and the first thing you see is a group of old people sitting on these ghastly stained chairs, looking at a television, get 'em out.

The last years and months and weeks of your life can be so productive and so important, and that's where my business can come in.

It's a time when you can feed your soul. You can use drama therapy to look at people's pasts, dance, and I don't mean sedate ballroom dancing, I mean a bit of tango, a bit of Salsa, a bit of life.

I um, I have on my wall at home, or exercise, I do think exercise is vitally important, physiotherapy, even if you can only make the muscles of the leg work sufficiently to get up one step, that can be a major importance to old people.

I have at my home a beautiful picture, which I treasure, it's a little masterpiece, it honestly is, and this was painted by a young person who died in St Christopher's who'd never held a paintbrush in his life, until he was there.

And he did this beautiful piece of work, and he was so thrilled, it was probably the best thing he'd achieved in his life.

And he was particularly thrilled when I bought it for a great deal of money.

And if I can tell you of another experience, a friend of mine, who is a writer, he goes into hospices and she collect people's stories and publishes them in little books, a girl called Chrissie Gitten (?). And she phone me and told me about a particular man in Rochdale.

He had heckled a very high powered Tory Sir Anthony Nutting at, at a meeting in Rochdale. And obviously he was awfully troublesome, and Sir Anthony Nutting said well look I'll talk to you afterwards.

And they talked afterwards and they formed a life long friendship. And an extraordinary thing that he said was that during the Suez, crises, which all of you are too young to remember, but it was a major political event.

Sir Anthony Nutting phoned up Bill and said, what am I gonna do, this is awful, what am I gonna do? And he said you should resign, and he did, he resigned.

Anyway, Chrissie and I got this story together and we made a radio play out of it, and again this guy, his life suddenly became as important, as it was but he didn't realise that it was.

The other thing that I think is important, that if you go into a care home, I think you should be able to stay there until you die.

I think one of the most disconcerting things is when you have dementia or something like that, you have to be removed.

Now I know that's difficult, but I'm gonna give you an example of good practice, which I think you should all visit.

We have a wonderful home called the Denville Hall, which is for actors, and it's a fabulous place.

The central thing of the whole home is the bar. Everybody meets in the bar, and then most of the time fairly sort of you know going on.

And lots of entertainment obviously, because they're actors, lots of jokes, lots of fun.

They have now got a wing on the side, which is for people who develop dementia and can no longer, they are so disruptive that they can no longer stay in the main section.

Now this amazing new wing is built in a circle, so people can roam, they don't have to be locked away, there are no locked doors, they can actually go off on their own. And in the middle of the centre is a beautiful garden, with smells and colour, and they can wander in the garden.

The matron, I talked to the matron just recently. She said one of the worst things about dementia is when you are restrained, that's when people get aggressive, when they're not allowed to go.

And she was telling me that the other day, a little old lady, very, very old lady got very distressed and said I've got to go and pick up the children from school, I've got to pick up the children from school.

And the matron said alright, go on. And she disappeared off round the circle. And of course her mind went onto something else and by the time she came round she was calm again.

So I think that is a lesson to be learnt. And they, and they've got a bar, they've got a bar in the dementia wing, which I think is, why not? Why not for god's sake.

And they use very few drugs there. I mean well probably a few of those sort of drugs, knowing the actors but, a bit of cocaine but nothing else.

Another place that I want to use as an example, which is a Quaker foundation, which is near to my heart, because I'm a Quaker, and it's a place called the Retreat, in York.

And they have a dementia section where. I, I just one of the facts about taking drugs is did any of you hear that programme which said that three hundred and fifty five GPs were interviewed recently and all, more than half were actually still prescribing two drugs that they had, had an urgent warning from the CSM, should no longer be given to people with dementia, because it cause stroke. And that's about two weeks ago.

I mean how shocking is that?

And the Retreat, the man at the Retreat, that I spoke to, said no drugs for us really don't work. But they have a wonderful thing, which I've been in called the Snoozelum, which is a fabulous room, in which you go and there are all sorts of coloured lights, changing, all around you, and they can programme in any kind of sound.

So you can go in there, and if you've lived by the seaside, and they say that going back into your past is very important, when you have Alzheimer's, and you can here the sound of the waves and the seagull, or if you prefer you can hear motor cars, if you've lived in the city.

I went in and it is so calming, and they say this is such a fabulous thing, so I advise you to look at this amazing thing called the snoozelum.

Now obviously all of you are thinking oh that's all very well, but what about the ratio of staff in these places, and of course the ratio of staff to patient is huge.

But do we not care about our old people to do that?

They need people to talk to. Another shocking statistic is that in some of the care homes they only have two minutes chat every six hours, with a member of staff, because the staff are so high pressured and have no time to talk.

What about bringing in more ha, part time people, what about people who've retired, what about students?

I'm chancellor of Port Sutton university and thanks to all the fees and things they have to do part time work.

And I think it would be wonderful for old people in care homes to be in contact with young people. And in fact there is a scheme where young offenders are going into the various care homes and teaching the old people how to use computers.

I mean how great is that, both for the young people and for the old people.

I had a conversation with, with the um executive of St Christopher's just before we went, Barbara Monroe. And she said to me, cause I, I was complaining about. I remember in the old days it used to be quite difficult to get, get people to come to the programmes, at St Christopher's, nurses, doctors, care workers, people like that.

And she said that is changing, and just recently there is this amazing surge of change.

She said, her words were, it's a brave new dawn.

I do hope, I do hope that is true. We have to change our attitudes to the old, and we have to change our attitudes to death.

But we're not going to do that while the end is so fearful for so many people.

I personally, and I'm old as I said, I am not afraid of dying, but I honest, I, I don't want to die cause I like life.

But I'm not afraid of dying. And I know that is because I've wormed my way into Denville Hall, and the Retreat at York I've practically booked a room there.

So I know that when I become old, and when I met, reach the end of my life I'm still gonna be having fun, music and a drink.