

**End of Life Care Programme Launch
31st June 2008**

Dr Jayne Chidgey-Clark, Programme Director

Thank you Geoffrey and good morning and thank you to you all for joining us for the launch of our End of Life Care programme.

A particular thanks to the Honourable Frank Field, MP, for hosting this launch in these lovely surroundings. Back in 2003 Frank, in a debate in the Houses of Commons, made a plea as “an ardent advocate of modernisation” and thus it is fitting that he supports this Modernisation Initiative. We know that Frank is a supporter of improving End of Life care as he supported a recent early day motion to call on the government to increase funding to enable end of life care to be provided at home. So thank you Frank for this support today.

As Director of this important programme, on behalf of my team , all the stakeholders across Lambeth and Southwark, and on behalf of people living and dying in Lambeth and Southwark I want to thank the Guy's and St Thomas' Charity for having the vision to invest in the Modernisation Initiative way of working. The outcomes of the three previous programmes (you can find out a little more about them in your packs) are testament to the success of this new type of investment for the Charity. Then I need to thank Guy's and St Thomas Charity, for recognising the importance of end of life care and investing in this particular programme and King's College Hospital Charity and South London and the Maudsley NHS Foundation Trust Charitable Funds for their additional funding.

In the few minutes I have to share with you I would like you to see what the End of Life Care programme is about, hear about how we intend to go about the work, have a greater feeling for why it is important and have an understanding of the Modernisation Initiative way of working.

We all die. How we die is of great importance to us and to our loved ones. I think it is difficult to exaggerate or overestimate the importance of getting care right at the end of our lives. I believe that the manner of our dying is a reflection of our care to the living.

Can I take a couple of moments to get you to stop and think about a couple of facts:

1. We all die.
2. We do not all die well.

I could give you facts and figures to support these statements but you will find those in our brochure and on the display stands. I could also give further personal examples. But I will not as time is limited –

and because we do know that there is room for improvement – otherwise we would not be here this morning if we thought we had it right.

There are many ways to die, but what is a good way for one person may not be for another. There is a concept of a “good death” but it is difficult to define. Let us just take a moment this morning and think what is important to us.....here is a list of statements that some people have said is important to them – if I were to ask you to prioritise your top three or add others there would be great variation across this room. What does this tell us – it tells us that if we do take the time to think about it we do have preferences about how we want things to be at the end of our lives and therefore that end of life care needs to be responsive to the needs of individuals.

So, what is this End of Life programme in Lambeth and Southwark about: Our vision is to work with our communities and partners to provide exceptional end of life care.

We know that people want and need choice at the end of life – where possible choosing to die where they want, but most importantly having the ability to choose the best quality of care possible. Currently across Lambeth and Southwark we know that we cannot say that all people dying have this.

We know that there are excellent services providing end of life care in Lambeth and Southwark. Some of you providing those services are here today. However, we know from local evidence that there are shortcomings and excellent quality care is not accessed or necessarily available to all. Both nationally and locally, particular unmet end of life care needs have been identified for people living with dementia.

This £4.5 million investment gives us the opportunity to take stock of strengths and weaknesses in the current health, social care and voluntary sector provision in end of life care – to look at where our commitment to outstanding services is not being met and to develop, pilot and implement approaches to address the gaps.

How are we going to do it

- The funding collaboration reflects the genuine partnership approach that we will be taking in this programme.
- We will be working with local communities, and all professions and partners that have a role in end of life care to drive service improvement.
- The MI approach
 - Places people who receive services at the centre
 - Empowers them to drive service improvement
 - Brings people together, giving new insights into other’s roles and perspectives
 - Builds on best practice and evidence, locally, nationally and internationally

- Ensure changes are sustainable and embedded into practice
 - We use change improvement methods and evaluate carefully changes and improvements to the system – we will be working closely with commissioners to ensure that the outcomes that we measure and are looking to improve are those that are important to them.
- Integral to the MI approach is placing people who receive services at the centre and harnessing their experiences, good and not so good, and their understanding of what is important to them. As part of the kidney programme in the previous MI, a DVD was made to help people facing kidney disease understand the treatment options available to them. Part of the DVD shows Ted Bassey, the brother of Arthur who died of kidney disease, discussing his brother's care, what was important to him, how he was looked after by different services. Arthur made a decision not to start dialysis, even knowing that it may shorten his life because other quality of life issues. It cannot have been an easy decision for Arthur or his family. We have a short clip, with Ted's permission, and thanks to Ted for being here today, which I would like to share with you.
 - Thank you Ted and Arthur. What do I want to bring out from this? First that this is a powerful example of how people can be involved in improving services – this particular section of the DVD has been requested by people from far afield as the power of having a patient and carer story shared can be more helpful than a professional alone when people are making difficult treatment options such as opting for conservative management which may affect their length of life but have benefits for their quality of life. But what is also so powerful here is the learning from their experience of excellent care. What made it excellent – Arthur was supported to make choices about treatment, quality of life and support for his decisions. “I know it was the right decision not to start to dialysis, I know it may shorten my life but it is about quality of life....” The referral to palliative care came at the right time. The transfer to palliative care was smooth, we could ask anything. The normal process is I will die one day but the support I have received means I no longer worry. It was not about the treatment received but the way it was given”...We need to work with people like Arthur and Ted to understand what it is that makes it right and then what it is that means that it is not right for all....and jointly find innovative solutions to make it right.....Ted has kindly agreed to sit on the Q & A panel at the end of these presentations and you may want to ask him for further comment about the importance of involving patients and carers in improving services.

Next steps:

We have been working closely to understand the local context of care, various needs assessments and scoping work have been undertaken including the work of the Marie Curie Delivering Choices

programme in South East London and to learn from their phase 1 scoping. We have been getting to know our key partners and their work across Lambeth and Southwark and establishing our systems for working and governance and reporting. Now we will be working closely in the next couple of months, to agree priorities for work across Lambeth and Southwark and to commence the relevant work groups, recruiting professional and user champions and starting the projects. We will of course be looking at the End of Life Care strategy that the Department of Health will be publishing in July alongside the NHS next stage review findings and ensuring that we work with you to look at the implications of these locally.

We, the team, and this Charitable funding will be here to work **with, for and alongside** you for the next three years – you will remain after we have gone to continue the work. We recognize and understand the importance of ensuring that we work with you to ensure the changes that we make are sustainable and really make a difference.

I hope you will have the opportunity to meet the team this morning....as local partners **you** are very much part of our extended team and vital to the success of this programme. We have put a form in your packs and a graffiti board in a prominent position as a starting way of harnessing your ideas for the programme and we will be having a sustained programme of involvement and feedback to ensure that we are working with you on the important areas.

I am quoted in our brochure as saying that “enthusiastic and committed, this team will share their skills and experience with those of local partners. This synergy is a great opportunity to make a difference”. I read recently that the Local Government Association has banned the word synergy (along with many others) believing that people may not understand it. Just in case I am not speaking in Plain English – synergy is the interaction of two or more agents or forces so that their combined effect is greater than the sum of their individual effect.

A key part of our work in this programme is to tackle the barriers that get in the way of giving people optimum end of life care. This includes tackling both public and professional reluctance to discuss issues related to death and dying. As individuals and as professionals we often do not wish to face our own mortality, let alone the detail of how our dying and death might be and let alone talk to others about theirs.

I have had the privilege and inspiration of working with Dame Cicely Saunders, founder of the modern hospice movement, at St Christopher’s Hospice as a young staff nurse. Yes she founded the modern hospice movement but it was never about buildings but about a philosophy of care that placed dying patients and their families at the centre. Her vision was that this philosophy of care should be available for all not just those receiving care in hospices. Dr Robert Twycross, in his writing about Dame Cicely, after her death says:

To honour Cicely, we too must not just talk the talk,

But like her we must walk the walk,

And stay the course, and continue the task of changing the world.

Fear of death is instinctive,

So the task in unending,

For each new generation, the same battles to fight and win”.

We want to help people be comfortable with the uncomfortable. And just as Cicely did our task in this team and on this programme, is to join with you our partners to continue the task of changing the world.....but I promise we will start with Lambeth and Southwark.

Thank you for listening to me and most importantly for sharing this launch this morning. My team and I are looking forward to working with you all to make a difference.

I would like to hand over now to Sheila Hancock – I do not suppose that Sheila needs much introduction to you, an acclaimed actress, an Olivier award winner, awarded an OBE for services to Drama, the first female artistic director at the Royal Shakespeare Company and recipient of the British Book Awards’ Author of the Year in 2005 for “The Two of Us”, her memoir of life with John Thaw. Thank you Sheila for your support and for taking the time to join us this morning Sheila.