End of Life Care: Modernisation Initiative briefing

Lambeth Scrutiny Committee
Tuesday 23 February 2010

1. Purpose
The purpose of this paper is to inform the Lambeth Scrutiny Committee of the Modernisation Initiative End of Life Care programme work and how it interfaces with Lambeth health and social care commissioning and service provision.

2. Background
We all die, but we don’t all die well. Each year around 500,000 people die in England. We know that although some people receive excellent care at the end of life, many do not. The Modernisation Initiative End of Life Care Programme is committed to improving services in Lambeth and Southwark so more people have a ‘good death’. The programme is ambitious and far reaching. We look at every aspect of end of life care, to see which services are good, where the need to improve and how they can be exceptional. We are researching the cost of end of life care today, to understand how high quality services can be provided efficiently tomorrow.

The Modernisation Initiative End of Life Care Programme is funded by Guy’s and St Thomas’ Charity with support from the King’s College Hospital Charity and South London and Maudsley NHS Foundation Trust Charitable Funds. This three year programme commenced in April 2008. End of Life Care is the fourth Modernisation Initiative and previous programmes were used to transform the quality of sexual health, stroke and kidney services. A new programme launched in 2010 will focus on the prevention, detection and treatment of diabetes. ¹

2.1. What is end of life care?
End of life care is care for people with advanced, progressive, incurable conditions. It supports them to live as well as possible and to die with dignity. End of life care includes management of pain and other symptoms and considers a person’s psychological, social, spiritual and practical support. It also considers planning for death and bereavement.

We have identified essential areas for achieving exceptional end of life care. These are:

- Identifying people’s needs
- Carrying out advance planning
- Providing person-centred care
- Responding to changing needs
- Supporting patients, carers, relatives and staff
- Ensuring reliable information and communications

¹ For details visit [www.gsttcharity.org.uk/projects/eolc.html](http://www.gsttcharity.org.uk/projects/eolc.html)
To deliver this we are working to:

- Involve patients, carers and those close to them and local residents
- Support conversations about death and dying
- Ensure care is affordable and sustainable
- Support the development of staff skills, knowledge and attitudes
- Support the delivery of end of life care leadership
- Measure and monitor changes and their success

2.2. Partnership working

In 2008 the Department of Health published a national end of life care strategy. This was introduced as an important milestone for health and social care as it is the first comprehensive framework aimed at promoting high quality care across the country for all adults approaching the end of life. The national strategy has developed a standard end of life care pathway, a range of nationally recognised end of life care tools, launched core competencies for workforce, and published a set of quality markers for end of life care.

Lambeth health and social care have been responding to the framework to improve services in line with recommendations and the work of the Modernisation Initiative End of Life Care programme is complementary to this.

Patients, carers, bereaved relatives and local residents are ‘experts by experience’ and are working in partnership with us across health and social care, voluntary and independent sectors to deliver exceptional end of life care.

The Modernisation Initiative End of Life Care Programme and the Southwark and Lambeth End of Life Care Strategy Group is collaborating to develop new, innovative models of care and roll out proven models of care (Gold Standards Framework & Liverpool Care Pathway\(^2\)). There is an established Southwark and Lambeth End of Life Care Strategy which circulated its penultimate draft of its strategy at its last meeting on the 15\(^{th}\) January 2010.

2.3. Lambeth

Around 1,600 people die a year in Lambeth with around 60 per of people dying in hospital (Appendix 1). Although Lambeth has a younger population than others in Greater London, there are aspects of its demography that have potential impact on service delivery. Lambeth has a diverse population with over 60% of the population not of UK origin and over 150 languages spoken across the borough. Lambeth wards have a relatively high deprivation score and 16 out of 21 in Lambeth are amongst the most deprived wards (top 20%) in England. There are also high numbers of older adults with learning disability.

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\(^2\) The Gold Standards Framework and Liverpool Care Pathway are nationally recognised tools to support best practice in end of life care
3. Current challenges to providing excellent challenges

There are a number of challenges to providing cohesive, reliable person centred end of care in Lambeth. These are not unique to Lambeth and the challenges include:

- A societal reluctance to talk about death and dying
- Identifying people who have end of life care needs, the uncertainty around prognosis contributing to barriers in conversations taking place with patients to plan for end of care – in particular for frail / elderly / patients with dementia and patients with cardio-respiratory disease, adults with learning disability (AwLD).
- Ensuring staff have skills, confidence and attitude to have conversations to support advance care planning around end of life care and provide end of life care, including care of dying
- The complexity of community based services, with a number of providers and specialties providing elements of end of life care [Appendix 2]
- Ensuring there is coordination, clarity on leadership and roles and effective team working “around the patient” [see Appendix 3 for the model being developed through the Modernisation Initiative]
- Ensuring that there is good infrastructure to support virtual team working: this includes Gold Standards Framework (GSF) for GP practices and care homes; information and communication systems; clarity about roles and responsibilities.
- Clarity of roles and response required for out of hours and emergency services alongside effective communication channel
- Ability of services to respond to sudden changes in people’s need including the ability to enable rapid transfer of care from hospital, appropriate out of hours response (medical and nursing) and ambulance response
- Ensuring there is measurement and feedback loops, including clinical feedback to support continuous improvement
- Providing people and their carers with support and information to enable care to be received in preferred place of care
- Ensuring that care homes receive the medical support they require to provide good end of life care and implement GSF

In the current financial climate, there is a drive to reduce costs in health and social care, alongside improving quality, and through its work the Modernisation Initiative has identified a number of areas that can support efficiency improvements. However, in an area as complex as end of life care, it is possible that cost savings in one area can have the unintended consequence of driving up costs in another area. Consequently we are working very closely with health and social care commissioners to understand the implications of service innovations.
4. Existing and potential drivers for change
- Commissioning for quality and efficiency – acute and community (both health and social care)
- Senior clinical leadership
- Clear communication from hospitals around end of life care
- Patient and public involvement
- Royal College of General Practitioners End of life care strategy (2009)
- Southwark and Lambeth End of Life Care Strategy and Strategy Group
- End of life care register developments
- Clinical facilitation, training and education
- Education commissioning
- National end of life care strategy

5. End of life care: current progress
The following selection of end of life care projects will contribute to improving end of life care in Lambeth.

<table>
<thead>
<tr>
<th>Project</th>
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<tbody>
<tr>
<td><strong>Gold Standards Framework</strong></td>
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<tr>
<td>Development with GP practices to GSF level three / four and supporting training and development</td>
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<tr>
<td><strong>Identification:</strong> Meetings with pilot practices and linked staff are being held over the coming weeks to discuss the impact of the changes initiated to improve identification of people with end of life care needs.</td>
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<td><strong>Advance care planning</strong> South East London (SEL) sector are developing standards. The PEACE documentation (patients transferred from hospital to care home) pilot is expanding. Pilots and dementia pathway work is exploring processes and roles for advance care planning. Lambeth PCT is piloting advance care planning tool in conjunction with St Christopher's Hospice.</td>
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<td><strong>Reliable patient centred care:</strong> Liverpool Care Pathway training within Lambeth community providers starting February 2010</td>
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<td><strong>Communication and information sharing.</strong> New end of life care register and out of hours information system hosted in SELDOC (south east London out of hours cooperative) – business case and requirements (29.01.10) waiting approval with Lambeth, Southwark, Lewisham commissioners.</td>
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<tr>
<td><strong>Staff and patient information</strong> Patient information: planned distribution of “what to do after death” guidance for professionals working in the community in February 10</td>
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<tr>
<td>Three month pilot of information for patients who join the GSF register (Jan,</td>
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</table>
Model of care: “team around the patient” this is being developed through pilot practices and the community work stream. Work on the interface between specialists and generalists is progressing. This also includes work around the health and social care interface.

Work examining assessment and care planning processes, and information sharing between agencies

**Measurement and quality feedback loops** developing systems to ensure patterns / clinical related issues can be reviewed and feedback to the medical director

**Hospital:** developing and piloting a model of care that supports the routine identification of patients with around 1-2 months prognosis and provide them with best practice care alongside treatment and rapid transfer to preferred place of care.

Palliative care formulary and accessibility for medicines in the community. Ongoing development work in this area.

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### Summary

The complexity of end of life care across Lambeth and Southwark is reflected in this programme. Work areas cover many different aspects of the care pathways, and are clearly part of an overall emerging model of care. The end of life care programme is working closely with Lambeth health and social care commissioners to inform their commissioning intentions, to support the development of commissioning levers for development and delivery of high quality end of life care services.

By the end of the programme we are confident that Lambeth and Southwark will have recognition for the development of innovative and effective end of life care services. Appendix 4 details some of the current projects that will contribute towards gaining that recognition.

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**The Committee is asked:**

- To note the opportunity that this Modernisation Initiative End of Life Care programme, working in partnership with health and social care and local residents, patients and carers, has to improve end of life care in Lambeth
- To note the breadth of the work programme
- To note the collaborative working of the programme with health and social care commissioners (and service providers across health and social care, NHS and voluntary and private sector)
### Appendix 1:

<table>
<thead>
<tr>
<th>Place of death</th>
<th>Southwark</th>
<th></th>
<th>Lambeth</th>
<th></th>
<th>England</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
<td>%</td>
<td></td>
<td>%</td>
</tr>
<tr>
<td>Hospital</td>
<td>941</td>
<td>65%</td>
<td>960</td>
<td>60%</td>
<td>58%</td>
<td></td>
</tr>
<tr>
<td>Home</td>
<td>303</td>
<td>21%</td>
<td>336</td>
<td>21%</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>Hospice</td>
<td>97</td>
<td>7%</td>
<td>108</td>
<td>7%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Care Home</td>
<td>90</td>
<td>6%</td>
<td>160</td>
<td>10%</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>19</td>
<td>1%</td>
<td>40</td>
<td>3%</td>
<td>3%</td>
<td></td>
</tr>
</tbody>
</table>
## Appendix 2: End of life care service provision in Lambeth 2008/9

<table>
<thead>
<tr>
<th>Service</th>
<th>Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Specialist &amp; Generalist Care</td>
<td>Guy's and St Thomas’ Trust Medical Services</td>
</tr>
<tr>
<td></td>
<td>King's College Hospital Medical Services</td>
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<tr>
<td>Acute Specialist Palliative Care</td>
<td>Guy's and St Thomas’ Trust Palliative Care Team</td>
</tr>
<tr>
<td></td>
<td>King's College Hospital Medical Palliative Care Team</td>
</tr>
<tr>
<td>Community Specialist Palliative Care</td>
<td>Guy's and St Thomas’ Trust Palliative Care Team</td>
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<td></td>
<td>St. Christopher's Palliative Care Team</td>
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<tr>
<td></td>
<td>Marie Curie Palliative Care Service</td>
</tr>
<tr>
<td>Hospices</td>
<td>St. Christopher’s Trinity</td>
</tr>
<tr>
<td>Care Homes and Nursing Homes</td>
<td>FNC in 11 Lambeth Nursing Homes Category 1 Patients (mainly Collingwood House)</td>
</tr>
<tr>
<td>Continuing Care</td>
<td>Minnie Kid House</td>
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<tr>
<td></td>
<td>SLAM</td>
</tr>
<tr>
<td>Primary Care</td>
<td>53 Lambeth Practices</td>
</tr>
<tr>
<td></td>
<td>43 Lambeth Practices signed up to GSF LES</td>
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<tr>
<td></td>
<td>SELDOC</td>
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<tr>
<td>District Nursing Specialist Nursing</td>
<td>Lambeth District Nursing Team</td>
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<tr>
<td></td>
<td>Continence Nurse</td>
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<tr>
<td></td>
<td>Tissue Viability Nurse</td>
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<tr>
<td></td>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td></td>
<td>Heart Failure</td>
</tr>
<tr>
<td></td>
<td>Specialist Respiratory Nurses</td>
</tr>
<tr>
<td></td>
<td>Diabetes Nursing</td>
</tr>
<tr>
<td></td>
<td>Head &amp; Neck Cancer</td>
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<td></td>
<td>MSK</td>
</tr>
<tr>
<td></td>
<td>SLAM mental health older adults</td>
</tr>
<tr>
<td>Other Support Teams</td>
<td>Lambeth Therapists Team</td>
</tr>
<tr>
<td></td>
<td>Dietetics</td>
</tr>
<tr>
<td></td>
<td>Dieticians</td>
</tr>
<tr>
<td></td>
<td>Care Home Support Team</td>
</tr>
<tr>
<td>Domiciliary Care</td>
<td>Allied Healthcare, Keratome</td>
</tr>
<tr>
<td></td>
<td>Supportacare main providers for adults with physical and sensory impairment and older people, with other providers commissioned on a 'spot' basis to meet specialist need i.e. Dementia care, BME provision for adults and older people. Other arrangements in place for AwLD and people with mental ill health</td>
</tr>
</tbody>
</table>
Service | Provider
---|---
Social Care | LA Social Work Teams
Carers services- Carers Hub, respite provision
Day care provision
Community Meals
Social capital e.g. befriending services, Gateway network

Day Centres | St. Christopher's Day Centre
Trinity Day Centre
Social care provision as above

Non-Borough | Other non-borough Services

Appendix 3: Team around the patient model

Draft community model:
Team around the patient

Gold Standards Framework
- Identify patients with needs
- Green
- Amber
- Red
- Patient dies

Transfer
- Ambulance/Transport
- End of life care
- Support crisis
- Hospital: back-up for community
- Hospice

09.02.10

3 Note that this model is under development. Education and training underpin the model.
Appendix 4: Emerging areas of local and national significance

By the end of the programme we are confident that Lambeth and Southwark will have recognition for the development of innovative and effective end of life care services. The current projects that will contribute towards gaining that recognition include:

1. **Identification of patients with end of life care needs**

If people are not identified as dying their end of life care needs may not be assessed and addressed (Box 1).

<table>
<thead>
<tr>
<th>Box 1: case example</th>
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<tbody>
<tr>
<td>Joe’s widow Mary speaks of her dismay that nobody ever discussed with her that Joe was reaching the end of his life. “I knew that his chest and heart were bad – he was in and out of hospital about three times that last year. But they always patched him up and got him home. Then the last time he was in he looked so poorly but they were always so positive and then in the middle of the night I got a call to come in urgently. My son brought me in but he had already gone. It would have helped so much if they had prepared me, we could have said goodbye, we could even have maybe got him home so he could be with his dogs he loved so much.</td>
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</table>

This may seem obvious but in the current care system many people are not reliably identified as reaching the end of their lives, both in acute hospitals and in the community. Identification has to be the foundation of any model of end of life care. There is an inconsistent approach in community and hospitals have not been geared up to support identification in the community or early identification of end of life care needs in hospitals. Professional reluctance to label people as being “end of life” is a major contributory factor to poor recognition. We are currently testing tools in hospital and in GP practices that support more reliable recognition that someone has end of life care needs. These tools will be incorporated into standard clinical practice and available for dissemination to others.

2. **AMBER and the hospital model of care**

Locally and nationally there has been a focus on implementing a care pathway called the Liverpool Care Pathway for people in hospital who are imminently dying (in the last few days of life). This is a framework that supports high quality standardised care for people who are dying.

AMBER supports patients facing an uncertain prognosis by:

- Identifying people who may have end of life care needs – to allow “planning for the worst”
- Providing standardised high quality care to assess, plan and respond to their needs
- Supporting staff to start conversations about death and dying, giving patients, carers and others close to them time to prepare.
- Providing sustainable models of staff support, training and development
This model will enable rapid transfer, early planning, and providing quality of care when a patient’s outcome is uncertain (Box 2).

**Box 2: Case example**
Mohammad speaks of the death of his wife in a busy general hospital: “She had been getting worse for some time and didn’t seem to be responding to the new tablets. One morning when I visited the doctor and nurse came to speak to us, we knew it was serious. They explained that overnight she had become much more ill and that they could not reverse what was happening to her heart. They helped me understand that she was dying and explained that they would keep her comfortable. She died very peacefully the next day and was looked after very well. My only regret was that they hadn’t discussed her dying with us before she got so poorly. If they had prepared us that this might happen maybe we could have talked about her coming home, as I know she would have wanted that. Also, we could have talked about the treatments that she was having and maybe stopping them sooner as they made her feel so sick.

This system of high quality, reliable care that meets the needs of patients whose outcome is uncertain but who are not imminently dying is an important step change with wide implications and applicability for other acute hospitals.

3. Dementia care

**Peer support**
The peer support model the programme is developing for carers of people dying with or from dementia is unique. This means that carers who have previously experienced someone dying with or from dementia are trained and supported to support other carers who are going through a similar experience. It is anticipated that there will be national interest in the learning from this model of caring for carers, as a quality innovation, which is sustainable and will provide much needed support for carers (Box 3).

**Box 3: Case example**
David cared for his partner who died with dementia. He now wants to help other people who are caring for loved ones with dementia. He says "I didn’t have any idea what to expect in the last months and weeks. It would have really helped to talk to someone who had gone through the same experience. It might have helped me cope better and I might have managed to keep my partner at home at the end. It is not that the nurses and doctors were not helpful but they did not have the same experience as me living with it day in day out. Now I feel I can share my experience and support someone else who is going through that most difficult time".

**Advance care planning**
The programme is developing a groundbreaking project with Professor Sube Banerjee, the National Clinical Lead for Dementia, and Professor of Mental Health and Aging and Clinical Director for Mental Health for Older Adults at South London and Maudsley NHS Foundation Trust. This will develop and implement a training package to support teams in the newly developed early
memory clinics. This includes advance care planning conversations with people in the early stages of dementia (Box 4), which is part of the overall model of care for dementia, and will be of local and national significance.

**Box 4: Case example**
Jean’s husband died last year following a long decline with dementia. Jean told us how she wished someone had involved John in discussions about future care needs before he became too unwell to make decisions for himself. “It was so hard making the decision that I could no longer cope with his care and to agree to him moving to a care home. If only he could have been part of those discussions. Also, I had to make decisions about resuscitation orders and things that I should have asked him about. I never thought about it, and didn’t want to guess in the early days”.

4. Responsiveness of care
Current inefficiencies and delays in the system for transferring care between settings for people who are identified with end of life care needs are significant. This results in poor quality care for patients and families and potential increased costs for services (Box 5). We are developing a model to support much greater responsiveness to need. This work has already stimulated local interest and support. Once implemented and tested, it will be of much wider application.

**Box 5: Case example**
Ayesha’s father died at home. She is angry as she feels the system let her father down as he spent three weeks in hospital before getting home two days before he died. “We knew that he was dying and they had asked him where he wanted to be cared for. He wanted to be back at his home where he lived by himself. There was some problem in the system and he just deteriorated before our eyes in hospital. Not where he wanted to be. I have a disabled son and couldn't sort it out myself. They had some problem getting the care package sorted. I feel really let down by the system and that I let him down as well. OK he got home eventually but was too poorly to make anything of those last days. Who wants to sit around in hospital knowing that these are your last days?”

5. Economic modelling
This is fundamental to the success of the programme. There is a requirement to ensure that any changes to services improve efficiency and effectiveness. Learning from previous Modernisation Initiative programmes, particularly stroke, demonstrates that understanding the costs of current care, and then modelling the impact of service redesign and innovation is key in ensuring sustainability.

There are national predictions and estimates of the resource implications of increasing the proportion of people achieving a death at home (if that is what they wish). However, these estimates are not useful for local decision making.
This work area will provide a detailed model for local commissioning decision making and through this further understanding of the costs of end of life care. There has already been wide interest in the modelling as this is an area applicable to all health economies, in particular Healthcare for London are interested in our findings and methods.

6. End of life care leadership development in care homes
Developing leadership and education are key elements to improving quality of end of life care in care homes. We have just completed a pilot leadership programme, for 11 delegates from seven residential and nursing care homes and extra care facilities. It provided an opportunity for leaders in care to meet and explore the subject of leadership within the context of end of life care. Participants are being supported to apply practical learning within their care home (Box 6). The programme is being evaluated through self-appraisal and an evaluation of action plans. Following evaluation the programme will be offered to all Lambeth and Southwark homes with more than 25 beds, and all extra care facilities.

Box 6: Quotes from course participants October 2009:
The most important thing about end of life care I have learned:

“To feel comfortable discussing death and dying with residents and relatives”
“giving the care that is needed and person centred making the end of life as comfortable and respecting their wishes.”

“That one needs to give client time to understand what an end of life of care plan is and how to meet their needs and keeping their independence and dignity at all times.”

“I will be setting goals that are measurable, realistic and so achievable as well as goals that are short term rather than longer term.”