

# A Good End to Life

Sutton and Merton

Strategy for End of Life Care

Progress and Refreshed Priorities

April 2011

## Foreword

End of Life Care is one of the most important aspects of providing and commissioning care, because as GPs we want to make sure that our patients have the best experience of services at the end of their lives. This refreshed strategy re-inforces our commitment to listening to patients, carers and families so that we can continually enhance the quality of our services.

Since our strategy was first published in 2007 we have made good progress in improving services locally, and this is seen in the fact that we have increased the number of people who choose to die at home from 12.3% to 16%. This means since our strategy was developed on average about 430 more people each year have been able to die where they wanted. The innovations that have enabled us to achieve this increase are described in this report and include implementing best practice models, new services to enable more people to die at home if this is their wish, and support services for carers.

We established the Sutton and Merton End of Life care network to oversee the implementation of our strategy and this partnership forum has played a crucial role in making sure we have joined-up end of life care services for local people. Partnership across health, social care and the third sector, will continue to be central to our approach going forward.

We are always looking to make improvements that embed and sustain best practice and help us, now that finances are constrained, to make sure services are excellent value for money. In our refreshed strategy we have set ourselves new aspirations, for example reducing the number of unnecessary emergency hospital admissions, and improving care for people with specific needs such as people with dementia or people with learning disabilities. We are looking forward to working with our partners and the new Local Authority Health and Well Being Boards in Merton and Sutton to achieve these further advances.

## Our commitment

In Sutton and Merton we want to make sure that there are the best quality end of life care services, so that people who are dying have a 'good death'. People will have a dignified, peaceful and controlled end to their life with good care and practical support in place. Families and friends will be supported through this time and afterwards. A key aspect of this means that people can express their preferences about where and how they are cared for, supported, and die, and as far as is possible health and social care services will respect this. However, irrespective of whether people have expressed their preferences, our aim is that there should be a 'good end to life' for all.

We will provide:

- Equitable access to services for all people needing end of life care.
- The best possible care for all people needing end of life support.
- A choice of place of care and death, where possible.
- Appropriate support services for both the dying person and their family and friends.
- Good communication between all professionals and with the patient and those closest to them.
- End of life services based on best practice models.
- Access to information and advice.
- Improved co-ordination of care across service providers.
- Support and training for staff.
- Adequate funding, making the most of existing resources.

Above all we will involve local people, patients and carers in the development and improvement of end of life care services.

We will work in the spirit of partnership with health and social care organisations, both statutory and voluntary.

We will ask you what you think about our end of life services and will review them regularly to ensure they keep up with best practice and respond to what you tell us you want.

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# 1. Introduction

## Re-refreshing the *Sutton and Merton End of Life Care Strategy*

The *Sutton and Merton End of Life Care Strategy* was first published in July 2007, following engagement events with local people, patients and professionals from both the statutory and non-statutory sectors. It was updated in 2008 to take account of the new national *End of Life Care Strategy – promoting high quality care for all adults at the end of life*, published by the Department of Health (DH). Since 2007 considerable progress has been made in implementing and realising the benefits of many of the service priorities first set out in 2007. It is timely to refresh the *Sutton and Merton End of Life Care* strategy in 2011 to mark this progress and in recognition that end of life care (EoLC) remains a priority in Sutton and Merton and nationally.

Locally, although much has been achieved, our commitment to ensuring people have a 'good death' is still paramount and in this strategy re-refresh we want to demonstrate this by setting ourselves new ambitions to continue to innovate and strengthen the quality and productivity of our services. Nationally, the importance of end of life care is spelt out in the new *NHS Outcomes Framework 2011/12*, which signals that there will be an 'improvement indicator' to measure the experience of care of people at the end of their lives. End of life care is one of twelve national priorities for the *Quality, Innovation, Productivity and Prevention (QIPP)* programme. Moreover, one of the first announcements by the coalition Government following election in 2010, was the instigation of an independent Palliative Care Funding Review, due to report in summer 2011.

In this strategy re-refresh we highlight achievements, and identify scope for further improvement, including productivity gains, as required in today's constrained financial climate. We also update the original strategy to reflect the new policy landscape post election; include up to date information from audits and reviews; and importantly, feature a new patient story to show what progress is like for our patients. Not every word or section in this strategy has been changed as we stand by the commitments and aspirations of the original report, many of which have enduring relevance. This re-refresh is intended to strengthen our original strategy.

## Our main achievements in summary

- **Increase in deaths at home** from 12.3% in 2004 to 16% in 2007-09. This means since our strategy was published on average about 430 more people per year have been able to die at home.
- **'Coordinate my Care'**, an electronic register, is active in 24 GP practices, which is just over 50%; St George's, Epsom and St Helier, The Royal Marsden and Croydon University Hospitals; St Raphael's Hospice; 8 district nursing clusters; the respiratory and cardiac specialist nursing teams and the night nursing service. It is estimated that all practices will be active in 2011. As a result of the implementation of the register we are achieving a 70% community place of death rate.
- **Hospice @ Home** has increased the level of care provided at home in the last few weeks of life to support patients and families to achieve their preferred place of care and death, with 93% of referrals to the service achieving this during the pilot phase (May –December 2009).
- End of Life Care **Nurse Consultant and Facilitator** appointments, to support implementing best practice and leading key programmes. 70% of care (nursing) homes have completed the **Gold Standards Framework** for Care (Nursing) Homes programme. Specialist nurses have also been trained in the Gold Standard Framework, e.g. heart failure, respiratory and diabetes and all community matrons. The **Liverpool Care Pathway** is being rolled out across community services.
- End of life care **telephone bereavement service** established.
- End of life care **fast track discharge home service** implemented at St George's Hospital, enabling 82% of people who were surveyed as part of the evaluation of the service and wanted to die at home to achieve this in 2009/10.

## 2. Our approach

### Your needs and hopes for End of Life Care

Most people when asked have a simple and common set of hopes for end of life care and death. They want a dignified, peaceful and controlled end to their life, with good care and practical support in place. Families and friends are important, and people who are dying want to know that those closest to them will be supported too, at the end and afterwards, in bereavement. A 'good death' is an individual concept, but in this strategy a key part of this means that people can express their preferences about where and how they are cared for, supported and die, and as far as is possible health and social care services will respect this. However, irrespective of whether people have expressed their preferences our aim is that there should be a 'good death' for all. Making sure that people have quality end of life care and a 'good death' should be the goal of everyone involved, as those last recollections of how someone is cared for and dies can often become the prevailing memory. The impact on care professionals should not be overlooked either, and they should be able to offer a quality service with access to training and education, best practice models and emotional support.

### Listening to you - our partnership approach and how it influenced the development of *Sutton and Merton's End of Life Care Strategy*

Involving everybody concerned with end of life care services, from patients and carers to NHS and social care staff and the local voluntary organisations, is crucial to how we developed our strategy and how we have implemented it. In April 2007, we held an event to involve representatives from all these groups to stimulate ideas about how to improve end of life care. Sutton and Merton Primary Health Care Trust (SMPCT) & Nelson Commissioning Group (NCG) facilitated the development of this local strategy in response. Health and social care commissioners and providers have and continue to work closely to ensure an integrated approach to care, clarity over resource issues, shared decision-making and planning that takes account of the different funding regimes between health and social care. Under the new NHS commissioning arrangements we are now working with Shadow Health & Well Being Boards for Merton and for Sutton to further align our strategies from a health and local borough perspective.

As part of that first 'listening' exercise we heard your experiences, and the stories of two local patients, Sally and Winston, inspired our vision. Those stories challenged us to work more effectively together across organisations to make sure we put the needs of patients, their carers and families at the centre of everything we do. One of the initiatives that then followed was '**hospice @ home**' involving St Raphael's Hospice, district nurses and the Marie Curie service. A new patient story, about John, is featured in this strategy re-refresh, showing how we designed services based on the improvements you asked for and how this has significantly improved the quality of care.

As well as the new patient story, which gives a perspective on how services have progressed in the last four years, we have continued to keep a focus on what you think of our services by taking a more robust approach to capturing patient feedback and ensuring this is reported to commissioners. We require all of our service providers, from hospitals to hospices, to have arrangements for recording patient feedback. Now these systems are in place, we next need to make sure that the feedback they capture is used in a systematic fashion by commissioners and providers to make continual improvements to services.

We also take an active interest in research projects about end of life care, looking to participate in studies, and implement findings of nationally recognised research quickly. For example, The Empowering Patients – Place

of Care (EPPOC) team at King's College London is investigating ways of improving the quality and the cost-effectiveness of end of life care for patients with cancer and their families. A postal survey has been undertaken with five hundred bereaved relatives in four London boroughs, looking at the care provided in the last three months before their relative died. The study is examining variations in the care, costs, preferences and outcomes associated with place of death in cancer. We have supported this study. In general the majority of people rated the care they received at home, in hospitals and hospices, and in care homes as 'very good' or 'excellent'. Home preferences were seen to prevail, with few relatives changing the patient's preference. However, about a third of the participants (37%) had concerns with some aspects of care. For those dying at home, the concerns show that there are variations in home care which need to be better understood, and for those dying in hospital access to medication, equipment and the lack of involvement of their GP seem to have been issues. In November 2010 the findings were presented to the project steering group, Department of Health and local NHS services to aid further service improvements. We are acting on this valuable patient and carer feedback.

**Your views will always be important to us and you can find details at the end of this strategy about how to contact us.**

## 3. Background

### A definition of end of life care services

'End of Life Care services support people with advanced, progressive and incurable illnesses to live as well as possible until they die. This enables the supportive and palliative care needs of both patient and carers to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and the provision of psychological, social, spiritual and practical support'. (*National Council of Palliative Care 2006 and adopted in the National End of Life Care Strategy, 2008, DH*).

### Sutton and Merton: the local context

In Sutton and Merton we set ourselves a target of increasing home deaths, where this is the person's preferred option, by 10% year on year. When we set this target the home death figure was 12.3% in Sutton and Merton, well behind the then national (22.4%) and London (17.8%) averages (2002-2004, National Centre for Health Outcomes Development, NCHOD). The figure for the most up to date information is 16% for Sutton and Merton (2007-2009, NCHOD). This means that since we developed our strategy on average about 430 more people have been able to die at home each year. We have made good progress here, but there is still some distance to go and we now wish to increase this to 30+% (including our patients' usual residence as the new national measurement).

Since we developed the strategy in 2007, the percentage of deaths at home from all causes in Sutton and Merton has increased as follows:

Percent deaths at homes from all causes (source: NCHOD)			
	2005-07	2006-08	2007-09
England	18.9	19.5	19.9
London	17.5	18	18.2
Merton	16.1	16.2	16.6
Sutton	14.8	14.6	15.5
NHS Sutton and Merton	15.4	15.4	16

(Deaths at home from all causes for 2007-2009, National Centre for Health Outcomes Development).

The following best practice end of life care services are now provided in Sutton and Merton following investment by Sutton and Merton PCT in this strategy:

- Hospice @ Home and inpatient service provided by St Raphael's Hospice.
- Fast-track discharge at St George's Hospital.
- 7 day palliative care nursing at St Helier Hospital.
- Gold Standards Framework (GSF) in care homes and primary care.
- Liverpool Care Pathway in community services (district nurses).
- Marie Curie nursing services.
- Social care services.
- Bereavement support.
- General practice services.



## End of Life Care Commissioning in Sutton and Merton

When we first developed our end of life care strategy it was set within the context of the Sutton and Merton PCT *Commissioning Strategy Plan 2008/12* and *The Commissioning Intentions 2008/09*. End of life care was one of the key priorities identified in these plans, and we have made good progress against the actions required at that time. We describe this progress in section 6.

Sutton and Merton PCT has recently renewed its *Strategic Plan 2010-2015, 'Faster, Safer, Fairer, Nearer'*. Its overarching aim is promoting choice in end of life care ensuring more people can die where they choose to, which will often be at home. A target has been set for 2011/12 of increasing the proportion of people who die at home as follows (N.B. this will now also include people who reside and die in care/nursing homes):

	2011/12				Total
	Q 1	Q 2	Q 3	Q 4	
Number of deaths in usual place of residence registered in the respective quarter	208	217	225	233	883
Number of total deaths (less exclusions) registered in the respective quarter	625	621	617	613	2476
Proportion of deaths in usual place of residence	33.3%	34.9%	36.5%	38.0%	35.7%

## South West London Cluster

The NHS South West London Cluster (SWLC) Plan 2011/12-2014/15 describes several major improvement areas including end of life care. The plan calls for more resources to be transferred from acute hospitals to the community to enable people to die in the place of their choice. Better coordination and cooperation is required across health and social care services. GP and community nursing out of hours resources should be focused on preventing avoidable admissions. The Royal Marsden 'Coordinate my Care' scheme is singled out as an example of innovation. (Clusters represent and bring together key functions a number of PCTs on a geographical basis. The SWLC covers the PCTs for Richmond, Kingston, Sutton and Merton, Croydon and Wandsworth. Clusters take the lead on acute service commissioning, financial and performance management and the development/transition planning for the move to GP led commissioning).

## The London context

In the past three years PCTs across London, including Sutton and Merton PCT, have worked with Commissioning Support for London (CSL) to develop tools to improve end of life care commissioning and provision. A useful *End of Life Care Good Practice Guide* to aid implementation of the national strategy has been produced, signposting many resources. Since the latter half of 2010 CSL has been working with PCT commissioners to put together an economic modelling tool, through which to understand the size of the acute end of life care population at least, and associated costs. Sutton and Merton PCT was pleased to be a pilot for the economic modelling tool. Work is needed, however, to refine this and make it more statistically robust. The outcome of similar economic modelling work from the National EoLC Programme team is expected during 2011.

## National policy and developments

The Department of Health (DH) published the first national strategy for end of life care in 2008. Since this time there have been a number of other key reports and developments. The national strategy and developments

between 2008-2010 still stand for the time-being, following the election of the coalition Government in May 2010. End of life care remains a priority and new commitments are outlined in the Government White Paper published in July 2010, *Equity and excellence: Liberating the NHS*. In addition, the Secretary of State for Health announced in July 2010 an independent review of Palliative Care Funding, due to report in summer 2011. This section will give an overview of these as background context for our local strategy:

➤ ***End of Life Care Strategy – promoting high quality care for all adults at the end of life, DH, 2008***

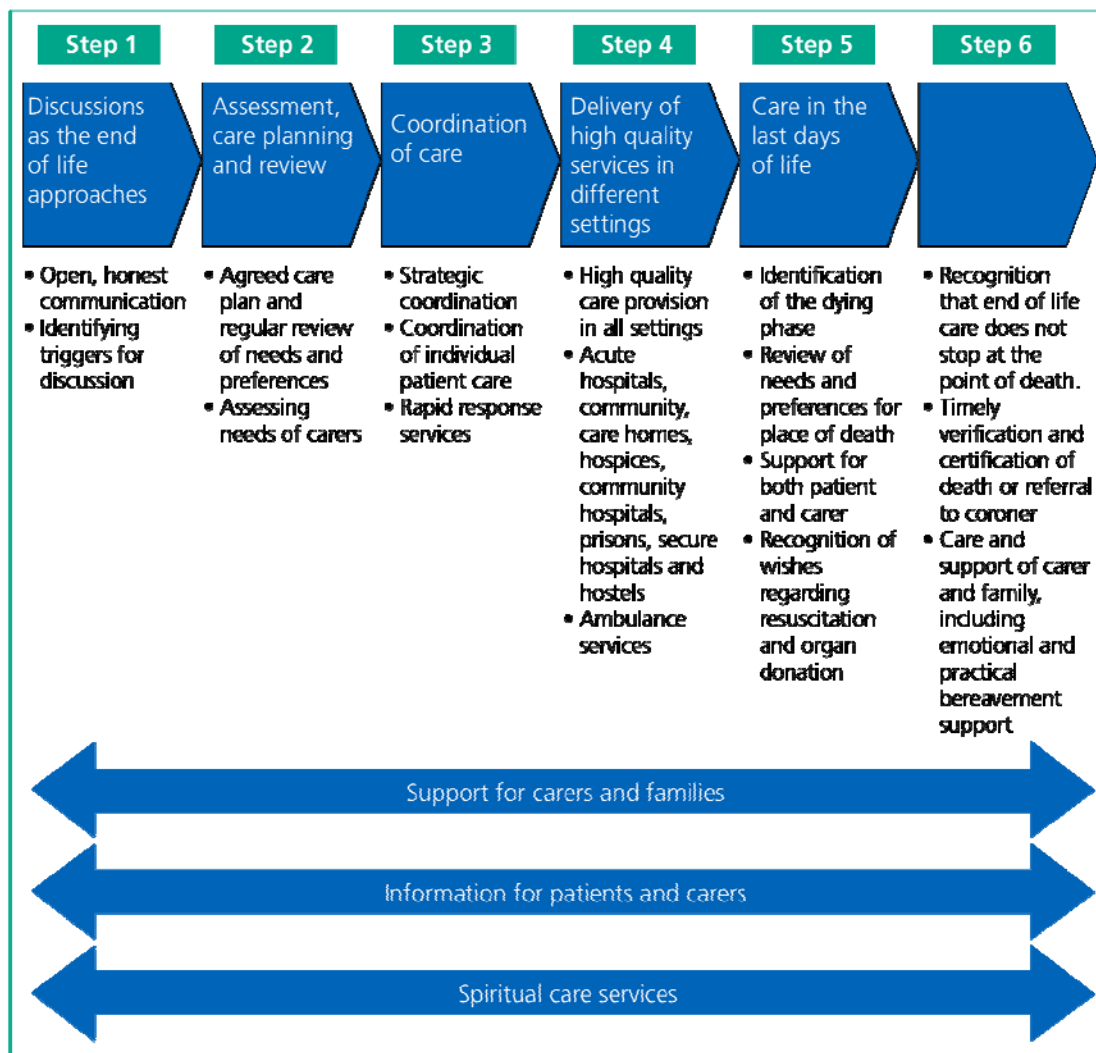
In the past the profile of end of life care within the NHS and social care services has been relatively low. Reflecting this, the quality of care delivered has been very variable. The aim of the national strategy is to bring about a step change in access to high quality care for all people approaching the end of life, whatever the setting, taking account of age, gender, ethnicity, religious belief and diagnosis. To achieve the broad aim of the strategy twelve key areas for improvement, with actions and recommendations are set out:

1. *Raising the profile of end of life care* and attitudes to death and dying through health services and Local Authorities engaging with local communities.
2. *Strategic commissioning*, taking an integrated approach led by health service commissioners and Local Authorities, involving providers.
3. *Identifying people approaching the end of life* – equipping staff to be able to do this by providing communications skills training programmes and competency based training.
4. *Care planning* – ensuring all people approaching the end of life have their needs assessed and their preferences discussed and recorded. Care plans should be reviewed by multi-disciplinary teams, patients and carers and should be available to all who have legitimate reason to access them (e.g. out of hours services).
5. *Co-ordination of care* – establishing a co-ordinated approach across all agencies, supported by locality-wide end of life care registers.
6. *Rapid access to care* by ensuring that medical, nursing, personal care and carers' support services are made available in the community 24/7, including care homes, sheltered and extra care housing.
7. *Delivery of high quality services in all locations* by adopting a care pathway approach and reviewing the availability and quality of end of life care in different settings including hospitals, in the community, in care homes, sheltered and extra care housing, hospices and ambulance services.
8. *Last days of life and care after death* by widespread use of the Liverpool Care Pathway tool (see section 6 of this document).
9. *Involving and supporting carers*, providing information about the likely progress of the person's condition and information about services. Practical and emotional support should be provided, before and after bereavement. Carers have a right to have their own needs assessed and reviewed and to have a carer's care plan.
10. *Education and training and continuing professional development* by designing core competencies for staff and ensuring end of life care is embedded as a topic into raining curricula, induction programmes, continuing professional development and in appraisal systems.


11. *Measurement and research* to encourage change and monitor progress. Organisations will be measured against quality standards. Patients and carers will be surveyed. End of Life Care Strategy Quality Markers and Measures for End of Life Care were issued by the DH in 2009.

12. *Funding* – commissioners to review local costs of end of life care and ensure better use of resources.

To support the implementation of these twelve key action areas the national strategy advocates a whole systems, care pathway approach to commissioning and provision of end of life care.



The Department of Health's national **End of Life Care National QIPP Programme** (Quality, Innovation, Productivity and Prevention) is working at a national, regional and local level to implement the national strategy, improving the quality of care while making efficiency savings. The End of Life Care Work Stream aims to enable a good death for an extra 20,000 people (slightly more than 5% of all hospital deaths) by April 2012, and also achieve a saving of 5%.

 *The Sutton and Merton End of Life Care Strategy* has been reviewed and refreshed to align with the wider strategies, commissioning and QIPP plans described in this section for Sutton and Merton, South West London, London and England.

## 4. The case for change

Although some people will receive excellent care at the end of life, delivered by both the statutory and voluntary sectors, there is a variation in service provision and some receive less than good care. This is true of end of life care in Sutton and Merton, as well as nationally.

Health and social care professionals may sometimes find approaching the issue of death and dying with patients and carers difficult. The result can be that preferences and needs for care are often not elicited or adequately assessed and care is not sufficiently planned or reviewed. As a result, there can be a mismatch between where people wish to die, their actual place of death, and how they are supported.

The 2008 national *End of Life Care Strategy* notes that in recent years detailed research and several large scale surveys of the public have been undertaken to understand people's preferences about end of life care, including where people want to die. People said that whenever possible they wanted to be cared for and to die in the comfort of their own homes. Most, but not all, would prefer not to die in a hospital, although this is where most people do die. Across England we know that 58% of people die in hospital, and just 18% at home and 17% in care homes (based on Office for National Statistics figures for 2004).

The National Council for Palliative Care (NCPC) has also demonstrated that there is significant inequity of access to palliative care due to diagnosis, geography, age and social disadvantage. It is important to note that 54% of complaints in acute hospitals relate to care of the dying/bereavement care (*Healthcare Commission 2007*).

*Healthcare for London, A Framework for Action, 2007* highlighted that less than a quarter of GP practices across London were at that time using best practice models for end of life care. *The End of Life Care Good Practice Guide* from Commissioning for London notes that nationally only 29% of doctors and 18% of nurses have pre-registration training in end of life care. Of more concern, only 5% of staff in care/nursing homes have staff qualified to NVO Level 3 with some end of life care component.

As well as a good clinical case for change, there are also pressing economic issues to consider. The National Audit Office (NAO) commissioned some economic modelling as part of an extensive review of end of life care: *The Potential Cost Savings of Greater Use of Home-And Hospice-Based End of Life Care in England*. The NAO's modelling estimated costs of providing care in the last year of life. Some key estimates are:

- For the nearly 127,000 patients who died from cancer, it costs approximately £1.8billion, corresponding to £14,236 per patient.
- For the nearly 30,000 with organ failure (heart and respiratory diseases combined) the cost of providing care is £553m, or £18,771 per patient.
- The simulation of different scenarios that examined decreases in the proportion of unplanned admissions for cancer patients (5-20%) and in the corresponding length of stay from 1-5 days (of those admissions) show expected reductions in expenditure ranging from £42 to £171m per annum.

Long-term projections by Gomes and Higginson indicate that if the trend in home death proportions observed in recent years continues, less than one in ten (9.6%) people will die at home by 2030. Institutional deaths would increase by over 20%, from around 440,000 to 530,000 per annum. People will die increasingly at older ages, with the percentage of deaths amongst those aged 85 and over rising from 32% in 2004 to 44% in 2030. This projection indicates the huge potential pressure on acute services in future years unless there is investment in adequate, alternative community options. (Gomes B, Higginson IJ. *Where people die (1974–2030): Past trends, future projections and implications for care*. *Palliative Medicine* 2008; 22: 33–41).

In addition to these issues, which are true of Sutton and Merton as much as anywhere else, we also identified our own local case for change back in 2007. We completed an End of Life Care baseline review for our two boroughs that highlighted differences in access to care, and that the Liverpool Care Pathway and Gold Standard Framework were not at that time being implemented systematically. Since then we have participated in the first ever national snapshot of end of life care in primary care, known as the After Death Audit (ADA). The audit took place in 2009 and examined the type and quality of end of life care provided locally, and what improvements might be identified to be effective, sustainable and value for money in the future (see Appendix B). Thirty-one of the practices submitted anonymised information relating to 160 people who died during February and March 2009. Analysis of data from NHS Sutton & Merton found key local achievements included:

- Regular discussions take place about the needs of people near the end of life at multidisciplinary team meetings.
- Tailored information is provided to the carers of those nearing the end of life.
- A key worker is identified for those nearing the end of life.

Key areas for development include:

- Improving the number of people identified as nearing the end of life, so they can be provided with supportive care and avoid unnecessary admissions.
- Setting up systems to ensure people die in their preferred place of care.
- Offering bereavement support to all carers.

Back in 2007 we also held the Sutton and Merton End of Life Event with a wide range of people, including carers and representatives from the statutory and non-statutory sectors. Our aim was to reach a shared vision for end of life care in Sutton and Merton from which we could build a local End of Life Care Strategy. At the meeting we set out a vision for enabling patients' choice in their place of death, highlighting our case for change through a story of an unacceptable experience and then a story of a 'good death'. It is the second story, Winston's, which became central to our vision for end of life care:

### This is Sally's story...

Sally lived with her elderly mother, June, and her 16 year-old daughter Gemma in the Sutton and Merton area. In 1998, Sally developed motor neurone disease. Over the years her condition slowly deteriorated but in 2004 her health got considerably worse. At the age of 48, she became bed bound, had to be fed through a special stomach tube (PEG) and lost her ability to communicate verbally. Gemma became her main carer. In February 2005, Sally's GP advised the family that he would like to make a referral to the local community palliative care team as it was clear to him that Sally was approaching the end stage of her disease. Sadly the family were unable to accept that there was no available active treatment and declined the referral. Over the next few months Sally experienced several emergency admissions to hospital and her family became more frustrated and stressed. Although the family found it hard coping with Sally's deteriorating health and recognised that she was very poorly, they were still not open to talking to anyone about what was happening and they continued to have expectations of active on-going treatment, rather than end of life care. Inevitably, this led to tensions between the family and the care professionals, who were trying to help them.

In October 2005, Sally's family finally accepted a referral to the palliative care team. The team were able to find out from June and Gemma what Sally's preferences were for her place of death. They said 'home'. At that point a range of care professionals became involved with Sally's care in the community. A specialist nurse from the community palliative care team visited to assess Sally's needs and that of her family. The nurse informed the family of the various support services available at the hospice and gave advice on symptom management. Thereafter she offered to visit Sally regularly to offer her support. District nurses visited to give personal care, to monitor Sally's condition and to provide equipment. The GP visited regularly. The palliative care Consultant undertook a home visit to discuss on-going symptom management. Out of hours services were made aware of Sally's situation so that they could be better able to support Sally if she needed help during the night or at the weekend.

However, the tensions that were caused by the mismatch of the family's expectations of active treatment and Sally's end stage diagnosis meant that the family were wary and unreceptive to support. They turned down resources and offers of support and often professionals found the family would not let them in to see Sally. Sadly, this impacted upon the level of care and support that professionals were able to give Sally and her family with the result that her care in her last months was not as good as it could have been. Despite the difficulties in providing Sally with optimum care, she did achieve her wish to die at home, **but could Sally's death be said to be 'a good death'?**

This next story shows how end of life care can and should be for everyone who needs it in Sutton and Merton.

### This is Winston's story...

Winston, aged 56, also lived in the Sutton and Merton area. He had been married to Rosa for 25 years and they had just celebrated their silver wedding anniversary together with their family. Winston and Rosa had three children, Grace, Joy and Samuel. Grace, her partner and their baby were living temporarily with Winston and Rosa whilst Samuel and Joy lived nearby with their young families. Rosa was the main carer for her aunt, Celeste, who had dementia and who was living nearby in a nursing home.

Winston was diagnosed with throat cancer in 2004. He underwent chemotherapy and radiotherapy and initially did quite well. Sadly, after a period of time, Winston was dismayed to find out his cancer had returned. He was told that his cancer was no longer curable but that every effort would be taken to ensure his comfort and quality of life. Winston was referred to the community palliative care team in March 2006 after he talked to his consultant at the specialist hospital he attended. His greatest fear was that, as he became less well he would not have enough support to stay at home. Winston said that he wanted to be cared for at home, where he could be near his family. Rosa and the children supported his decision whole-heartedly.

Winston met the clinical nurse specialist from the hospice community palliative care team and his district nurses who came in to assess his nursing needs, to organise his personal care, and to assess the equipment required to nurse him at home. His GP visited regularly and liaised with the medical staff at the hospital. As Winston's condition deteriorated the district nurses arranged for Marie Curie carers to come in a couple of nights a week to care for Winston and to give Rosa time to rest. Out of hours services (the doctors and the London Ambulance Service) were alerted to Winston's situation and to the fact that he wanted to stay at home to die. Emotional support was offered to all the family by the hospice and Rosa took this up. Good communication between all services was promoted via the monthly Gold Standards Framework meetings held at the GP practice.


Winston died peacefully at home, with his family around him. Following his death the district nurse visited to offer bereavement support and the specialist nurse organised bereavement follow up from the hospice. The feedback from the family was that they considered Winston to have had 'a very good death- all that he had wished for '.

Addressing the issues described here in both the national and local case for change has been central to the development and implementation of our strategy in Sutton and Merton.

## 5. Our Priorities in 2007 and progress to date

The two very different stories in section 4 told us that in order to provide quality end of life care services and a 'good death' for people who are dying, we must provide in Sutton and Merton:

- Equitable access to services for all people needing end of life care.
- The best possible care for all people needing end of life support.
- A choice of place of care and death, as far as possible.
- Appropriate support services for both the person dying and their loved ones.
- Good communication between all professionals and with the patient and those closest to them.
- End of life services based on best practice models.
- Access to information and advice.
- Improved co-ordination of care across service providers.
- Support and training for staff.
- Adequate funding, making the most of existing resources.

 Above all we must involve patients and carers in the development and improvement of end of life care services.

In 2007 five major priorities were identified to take forward the principles above in a real and practical way: patient and carer empowerment, access to care, continuity of care, quality of service provisions and communication. These key priority areas were complemented by a detailed action plan to take forward the aims of the Sutton and Merton PCT *Commissioning Strategy Plan 2008/12* and *The Commissioning Intentions 2008/09*. We have made significant progress for each of the five priorities and on the action plan (See Appendix A1 and A2 for an updated action plan, noting outcomes and progress). Progress was also measured against the national EOLC Quality Markers in August 2009 and we identified actions where further work was required, and this is underway.

The real mark of our progress in is the new patient story featured at the end of this section.

### Patient and carer empowerment

*We said we would:*

- Ensure all patients who wish to have their resuscitation preferences noted are able to do so, and staff are trained to discuss these issues.
- Establish a pilot to increase the use of preferred priorities of care (PPC).
- Clarify needs of carers.
- Improve bereavement support.



## *Progress:*

- Work is in progress at a pan London level to develop a protocol for Do Not Attempt Coronary Pulmonary Resuscitation. We are involved in this work. In the meantime The Resuscitation Council has produced **guidance on resuscitation** preferences and we are implementing these.
- Thirty-one GP practices participated in the first ever national snapshot of end of life care in primary care, known as the **After Death Audit (ADA)**. The practices submitted anonymised information relating to 160 people who died during February and March 2009. Analysis of the data found the following key local achievements:
  - Regularly discussing the needs of people near the end of life at multidisciplinary team meetings.
  - Providing tailored information to carers of those nearing the end of life.
  - Identifying a key worker for those nearing the end of life.
- In addition to the After Death Audit completed by the GP practices two audits of deaths are in progress by the EOLC team to review and improve care. One is an audit of deaths in nursing homes and the other is an audit of all deaths of patients known to community services. Both audits will take place throughout 2011/12.
- One of the ways we have responded to the After Death Audit and our previous baseline review has been to commission CRUSE to offer the NHS Sutton and Merton End of Life Care Telephone **Bereavement Support Service**. This is available to anyone who is registered with a GP in NHS Sutton and Merton and provides a range of services including:
  - Someone to talk to over the telephone.
  - Information about many aspects of bereavement and other sources of help and support.
  - Helpful leaflets.
  - The service is provided by trained, experienced volunteers, is confidential and free.
- **The Commissioning for Quality and Innovation (COQIN)** incentivising scheme for end of life care ensures improved support to carers, including a carers assessment.
- **Information resources for carers** are also being updated.
- The **Royal Marsden 'Coordinate my Care'**, an electronic communications register pilot has been implemented to support preferred priorities of care (PPC). For more detail see section on Communication below.

## **Access to care**

### *We said we would:*

- Review access to specialist palliative care team, including referral pathways and protocols.
- Increase access to end of life care services for patients who do not have cancer, but do need end of life care services. At present half the people who need end of life care services are people with conditions other than cancer, and often these people do not get equitable access to services.
- Increase GP awareness of pathways (Gold Standard Framework and Liverpool Care Pathway).
- Reduce inappropriate admissions to hospital by increasing access to alternative community based options.

### *Progress:*

- The **Liverpool Care Pathway** is being implemented in the community and is currently in use in eight district nursing clusters and associated GP practices.
- Specialist nurses have been trained in the **Gold Standard Framework**, e.g. heart failure, respiratory and diabetes and all community matrons.
- A facilitator was seconded to support the implementation of the **Gold Standard Framework in primary care**, although there is a need for more work here. See section 7.
- The **Hospice @ Home** service has increased access and equity for non-cancer patients, see section 6.
- An **End of Life Care Resource Pack** for GPs, district nurses, nursing and care homes, specialist nurses, hospital and community specialist palliative care teams has been developed.
- The **Commissioning for Quality and Innovation (CQUIN)** incentivising scheme for end of life care has successfully raised awareness in district nursing services and GP practices of the importance of multi-disciplinary Gold Standard Framework team meetings and working.

### **Continuity of care**

#### *We said we would:*

- Improve late night access to palliative care drugs.
- Ensure effective discharge planning, improving speed of and quality of discharge co-ordination.
- Make improvements to continuing care assessments to ensure fast track for patients where appropriate (including a review of current arrangements and piloting joint funding for fast track discharge).

#### *Progress:*

- To support end of life patients to die in their preferred place of death the palliative care team launched the **End of Life Discharge Home Service** from St George's Hospital (SGH) in June 2009. The main features/results of this fast track service at SGH are:
  - 24 hour, 7 day per week specialist palliative care advice available from St George's Hospital, (meeting the NICE requirements).
  - The Specialist Palliative Care Nurse from the palliative care team escorts the patient in the ambulance and hands over care to community staff in the patient's home.
  - The service is evaluated, including carers' views.
  - Of those patients referred to the service who stated a preference to die at home, the proportion achieving their wish increased from 39% in 2008/9 to 82% in 2009/10.
  - 34 SMPCT patients were fast tracked from April 09-March 10.
- Late night access to palliative care medication has been improved due to an overall Local Enhanced Services (LES) initiative to increase provision of out of hours pharmacy services in Sutton and Merton. There are now identified pharmacies that stock palliative care medication and these participate in the out of hours scheme. Medication during the night can be accessed via hospices

## Quality of service provision

*We said we would:*

- Review service funding to assess ways to fund sitting service and professional home carers.
- Ensure care (nursing) homes are included in Gold Standard Framework.
- Improve services for people with dementia and neurological conditions.
- Improve access and provision of training for staff.
- Make better use of specialist teams, with training for specialist nurses in respiratory, cardiac and dementia care.
- Agree a research programme, as part of service level agreements.

*Progress:*

- Since 2007, £600k has been invested in end of life care in Sutton and Merton.
- The national **Dementia Care Strategy** was published by the DH in 2009, and Sutton and Merton is implementing this strategy.
- 70% of nursing homes have completed or are in the process of completing the **Gold Standard Framework in Care (Nursing) Homes programme**. Key findings of an audit of GSF accredited Nursing Homes found:
  - The number of residents who died in their preferred place of care improved by 48%.
  - The Out of Hours form being sent and used increased by 146%.
  - The numbers of unplanned crisis admissions to hospital in the last six months reduced by 45%.
  - Hospital bed days reduced by 72%.
  - The number of residents where an Integrated Care Pathway (ICP) was used in their final days increased by 164%.
  - 618% increase in 'recognising dying' – i.e. patient was within final days of life at the time of their death.
- **Research studies** that have been undertaken/are in progress in Sutton and Merton (or wider studies that the PCT has participated in) include the audits of the Gold Standard Framework in Care (Nursing) Homes and the audit of deaths in care (nursing) homes and the community mentioned in the bullet point above, the After Death Audit (see section 4) and The Empowering Patients – Place of Care study (see section 2).
- An **education and training** strategy has been produced and a training programme rolled out.
- **End of Life Care for All (e-ELCA)** is an e-learning programme commissioned by the Department of Health to support the implementation of the national strategy. Its aim is to enhance the training and education of all health and social care staff who are involved in caring of people in the last year of life, with any disease, in any setting. It provides free access via computer to short interactive e-learning sessions. The format provides easy access to learning in four key areas: Advance Care Planning, Assessment, Communication Skills and Symptom Management. There is also a fifth module called 'Integrated Learning' which brings learning together in 'real-life' clinical scenarios. Importantly there are also sessions in each area that are accessible to the public and any other learner with an interest in end of life care, such as volunteers, care (nursing) home unregistered staff etc. These sessions can be found at [www.endoflifecareforall.com](http://www.endoflifecareforall.com). Dr Martine Meyer, Consultant in Palliative Medicine at St Helier's Hospital was the Module Editor for the largest module, Symptom Management and co-editor of a further Module containing clinical scenarios to integrate learning (50 sessions), is a resource for implementation and

teaching e-ELCA in SW London. At St Helier's Hospital GP trainees, hospital nurses and the medical education leads for junior doctors have attended workshops and training led by Dr Meyer. Workshops have also been held at Kingston Hospital and in the community.

## Communication

*We said we would:*

- Produce a service information directory that is suitable for patients and carers.
- Improve sharing of patient information between all services, including use of single assessment process.
- Provide communications skills training.

*Progress:*

- We are working with our providers to update the information they have available to patients and carers. Booklets on caring for someone dying at home and services available after a death have been updated. There is an information work stream, as part of the EoLC action group, which is leading work to make further improvements.
- The '**Hospice @ Home**' is an excellent example of improved communications and co-ordination between agencies (see section 6).
- **Advance Care Planning** is being implemented by the community nursing teams to support patients' choices and preferences, and to record discussions. This is also being promoted within GP practices.
- **The Royal Marsden 'Coordinate my Care'**, an electronic communications register pilot has been implemented. The national End of Life Care Strategy advocated that PCTs develop locality-wide electronic end of life care registers. This is also an EOLC quality marker. The Department of Health has awarded funding to eight pilot sites across the UK to develop, test and evaluate these registers. NHS Sutton & Merton, in collaboration with the Royal Marsden Hospital NHS Foundation Trust and the London Programme for Information Technology, is one pilot site. The register, using Adastra software, has been designed through extensive stakeholder engagement and closely resembles the current fax palliative handover form used throughout NHS Sutton & Merton. The register is now active in 24 GP practices; St George's, Epsom and St Helier, The Royal Marsden and Croydon University Hospitals; St Raphael's Hospice; eight district nursing clusters; the respiratory and cardiac specialist nursing teams and the night nursing service. It is estimated that all practices will be active in 2011. As a result of the implementation of the register we are achieving a 70% community place of death rate. This compares to a hospital death rate of 66% for London (2008, Office for National statistics mortality rates).
- We have undertaken an audit of the quality of palliative care handovers from GPs, care (nursing) home staff and palliative care team staff to the **London Ambulance Service**, and one of the key issues we have identified is how limited or poor information sharing impacts on the quality of services. Currently handover takes place via fax or secure e-mail. The audit took place between January to June 2010. 120 forms received were analysed, revealing 80% of the forms used in handover were out of date versions and less than a third of the forms were legible or complete. We will now develop a set of actions to address the issues raised, targeting staff training in use of the forms and use of 'Coordinate my Care'.

### **This is John's story...end of life care services today**

John and Helen had lived in the Sutton and Merton area for a number of years and were a popular couple, with a wide social circle locally. Sadly, John became unwell and was diagnosed with cancer and had to stop working almost immediately. John and Helen had a son working overseas and a student daughter who was abroad for a year as part of her degree course.

John's cancer was not curable and within a year he had deteriorated, and was experiencing symptoms, such as seizures, that meant he needed health support. Helen was his main carer. As his condition worsened, John and his family discussed and agreed with health staff that he would like to die at home. This was recorded in his care plan, and services worked together to make sure this could happen. He received support from a range of end of life care services from specialist oncology and palliative care from the hospital to the Marie Curie night sitting service and community nursing, who supported Helen in her role as his carer.

John received input from St Raphael's hospice, which helped with symptom control, in particular the new 'hospice @ home' service, which greatly assisted with his care. Two weeks before he died, John became bed-bound and the district nurses visited frequently during the day and there was support from the out of hours GP service. Medication was provided in John's home to prevent an unnecessary admission to hospital and enable him to know he was in control of his symptoms. All services were well co-ordinated and the handovers between them worked effectively. Throughout this time John and Helen were also in regular contact, by telephone and in person, with their GP and there were on-going discussions to make sure that his care plan reflected his needs as his illness progressed. It was recognised that he was dying and this meant there was time for the children to come home to be with their parents and say goodbye to John.

In the last 48 hours before he died the 'hospice @ home' service increased support so that Helen could be there as his wife, rather than carer as well. Helen was able to spend those precious last two days beside John in bed, holding his hand. It was important for John and Helen, for spiritual reasons, that their family and friends could be with them in these last hours, and with the support of 'hospice @ home' this was possible. After John passed away family and friends wanted to stay with his body, to honour him, until it was removed for the funeral service and all the services and staff were respectful of this time. Helen and the children were offered bereavement support, which they found a great comfort.

When John had first become ill he had been concerned that because of his symptoms and how they could worsen he would inevitably have to be supported in hospital and die there. Thanks to all the end of life care services and in particular the new 'hospice @ home' he was able to be in control to the end and with his family and friends. Afterwards Helen and his family thanked the services for helping John to die a 'good death' that respected his and his family's religious and emotional needs, as well as his physical ones and gave them a final comforting two days to remember well.

### **Increasing the death at home rate – the latest good news**

When we first developed our end of life strategy the percentage of people in Sutton and Merton who were able to die at home, if this was their choice, was just 12.3%. Four years on and our latest validated information show that between 2007-2009 this percentage had increased to 16% as an average for both boroughs (Merton at 16.6% and Sutton at 15.5%). We monitor these rates regularly and more recent, but as yet un-validated information, seems to indicate that this increase is continuing. Our strategy is making good, steady and sustainable progress.

## 6. Progress in implementing best practice

In taking forward our *End of Life Care Strategy* we committed to ensuring that we supported improvements to the local provision of end of life care by systematically adopting nationally recognised quality frameworks and best practice models. These are the models we identified in 2007 and have since made considerable progress in implementing. We appointed an end of life care nurse consultant, working clinically and strategically across the patch, to influence practice and support implementation of best practice tools. End of life care facilitators were also appointed, and this team together with primary care colleagues, has been rolling out the programmes and raising awareness.

### Gold Standard Framework (GSF)

GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last year of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. GSF can help coordinate better care provided by generalists across different settings.

*Progress:*

- A facilitator was seconded to support the implementation of the Gold Standard Framework in primary care.
- 70% of care (nursing) homes have completed or are in the process of completing the Gold Standard Framework in Care (Nursing) Homes programme. There have been improvements in reducing admissions, anticipatory care and appropriate identification of patients who are at the end of their lives.
- Kingston Hospital is a pilot for the Gold Standard Framework in acute care and St George's Hospital has also now signed up to this.

### Liverpool Care Pathway (LCP)

This has been developed to transfer the hospice model of care into other care settings.

*Progress:*

- The Liverpool Care Pathway is being implemented in all acute hospitals used by Sutton and Merton patients and the community services, and is currently in use in eight district nursing clusters and associated GP practices.

### Hospice @ Home

This service aims to enable patients with cancer or other advanced illness to be cared for at home, and to die at home if this is their preference. Care may be provided to prevent admission to an inpatient unit, for respite, or crisis management, or for longer periods of time (Source: National Forum for Hospice @ Home).

*Progress:*

The Hospice @ Home service became operational in May 2009, with the aim of providing quality end of life care and also increasing the percentage of people who want to die at home from 15% to the London average

of 18%, in the first instance. From April 2010–Nov 2010 the service has seen 143 referrals for patients with varying conditions, both cancer and non-cancer. Working collaboratively with the district nurses and Marie Curie service, Hospice @ Home has increased the level of care provided at home in the last few weeks of life, helping to support both patients and families to achieve their preferred place of care and death. Evaluation of the pilot service from May–December 2009 shows that sixty-eight patients were referred into the service, the preferred place of death was identified for fifty-nine patients and 93% achieved their preference. 22% of all referrals were for non-cancer patients. Importantly, this service has allowed those who live alone the opportunity to die at home in a supported way. The service has also supported care homes, avoiding inappropriate admissions. An evaluation of the first six months noted positive feedback from patients, carers and families. The service is cost effective and is enabling S&M PCT to make savings through more appropriate deployment of resources. The average cost of a Hospice @ Home visit (3 hours) is approximately £120.00 (daytime) and £173.00 (night time) compared to cost of an inpatient episode at £361 per day plus costs of £130 per contact for the hospital support team and £80 per contact for palliative medicine input; or a hospice inpatient episode at £550 per day (source: *Hospice @ Home End of Pilot Evaluation Report, May – December 2009*).

### Preferred Place of Care Plan (PPC)

The PPC is intended to be a patient-held record that will follow the patient through their path of care into the variety of differing health and social care settings.

*Progress:*

We are implementing **The Royal Marsden 'Coordinate my Care'**, an electronic communications register pilot, see section 5.

### Advance Care Planning

Advance Care Planning (ACP) is a process of discussion between an individual and their care provider irrespective of discipline. The difference between ACP and more general planning is that the process of ACP is to make clear a person's wishes and will usually take place in the context of an anticipated deterioration of the individual's condition. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed and communicated to key persons involved in their care.

*Progress:*

We have implemented Advance Care Planning, based on the St Christopher's Hospice model, across acute and community services in Sutton and Merton. It is being promoted within GP practices.

## 7. Priorities 2011 - 2013

We have made significant progress in implementing the strategy we first set out in 2007, however, there is still scope for improvement and increased productivity. As well as reporting on the progress we have made, we also take this opportunity to review and renew our priorities going forward to the next three years. We want to make sure we continue to set an agenda for innovation, drawing on feedback from patients, carers and families, staff ideas, best practice and audit results. In section 3 we highlighted the local and national strategic context and ambitions, and these are reflected in our revised priority actions. We set out our priorities using the framework of twelve key areas used in the national End of Life Care Strategy.

### **Raising the profile of end of life care**

We will seek to promote the profile of end of life care through our local Health and Well-Being Boards in Merton and Sutton, and working with all our partner organisations including social care and the third sector. We will also continue to work with our local communities to raise awareness, particularly spiritual care organisations and groups. We will promote choice in end of life care services, so that people are better informed about what services are available to them.

### **Strategic commissioning**

End of life care continues to be a key priority in the *Sutton and Merton Strategic Plan 2010-2015*. The Sutton and Merton EOLC Network, a strategic stakeholder group, will continue to ensure our plans are implemented and links made to relevant work streams. This group involves our key partners and will link to the SW London Cluster EoLC group. We will utilise the Marie Curie 'Delivering Choice' methodology/systems approach to ascertain end of life care gaps and unmet needs.

### **Identifying people approaching the end of life**

We will continue to implement, embed and sustain symptom assessment tools (i.e. GSF prognostic indicators) and knowledge and skills of symptom management, with all professionals working with patients in the last year of life in all clinical settings.

Sutton and Merton PCT has one of the highest proportions of adults with learning disabilities in residence (4.1 per 1,000 population). Many learning disabled young people who have life limiting illnesses, and are currently served by children's hospices, are now likely to live to an age where they will require adult end of life care services. The end of life care needs of adults with learning disabilities have until recently been little understood. The national End of Life Care programme has published a useful guide to improving end of life care for people with learning disabilities, *The route to success in end of life care - achieving quality for people with learning disabilities*, 2011. We will consider the implications of this guide and adopt best practice including identifying how well prepared our providers are to manage the end of life care needs of people with learning disabilities, appropriate pathways and policies, and ensuring staff are aware of the guide. The learning disability teams are members of the Sutton and Merton EOLC action group and play an active part.

### **Care planning**

We will implement, embed and sustain Advance Care Planning across community and acute settings.

### **Co-ordination of care**

We will continue to develop and roll out the 'Coordinate my Care' and ensure there is a visible register available in all settings. In addition we will look to develop a provider to co-ordinate end of life care services across Sutton and Merton.



### **Rapid access to care**

We will continue implementing preferred place of care, which will lead to reduced length of hospital stay, through extension of the 'Coordinate my Care' and 'Hospice @ Home' schemes to patients with a non-malignant diagnosis.

### **Delivery of high quality services in all locations**

We will ensure the remaining 30% of care (nursing) homes that have yet to undertake the Gold Standard Framework in Care (Nursing) Homes programme undertake this; and will sustain those care (nursing) homes that have completed the programme to maintain it. We will extend and implement the Gold Standard Framework and other best practice in primary care by seeking to employ a Macmillan GP and introducing a Local Enhanced Service (LES).

**We will promote the development of expertise in end of life dementia care.** The London Borough of Merton, NHS Sutton and Merton and the third sector, have published a *Joint Commissioning Strategy for Dementia for Merton 2010-2015*. The London Borough of Sutton with NHS Sutton and Merton have produced the *Sutton Joint Commissioning Strategy for Older People's Mental Health 2009-2014*. Both strategies include an action to develop a specific carers information pack covering end of life care: what to expect with advanced dementia conditions; the range of assistive treatments and services available to people with dementia who are in the final stages of life; and, where and how carers can get help and support after the person has died – i.e. putting affairs in order, probate, bereavement counselling etc. Expertise in dementia care and end of life care will also be promoted by encouraging nursing homes to participate in the Gold Standards Framework Programme for Care (Nursing) Homes.

### **Last days of life and care after death by widespread use of the Liverpool Care Pathway tool**

We will ensure that widespread use of the Liverpool Care Pathway continues through a focus on multi-disciplinary team meetings and working. We will review the bereavement support to look at both face-to-face support and telephone advice.

### **Involving and supporting carers**

We will seek feedback and undertake bereavement research, using the 'Voices' questionnaire.

### **Education and training and continuing professional development**

We will focus our training on communication skills, symptom control, psychological care/bereavement care, and spiritual care, ensuring this is in place for all professionals working with patients and clients in the last year of life.

We will continue to identify best practice locally and also implement any new national best practice, as it is published.

### **Measurement and research**

We will undertake research into symptom assessment and control, exploring the use of validated tools, such as the Palliative Care Outcome score and/or another tool called SPARC. In relation to pain assessment, our EOLC action group identified the need to progress the development of a pain diary, and, to ensure that psychological and spiritual dimensions of pain are incorporated into pain assessment. This work is in progress.

### **Funding**

We will utilise the Commissioning Support for London economic modelling tool (or similar), when ready, to understand the size of the acute end of life care population and associated costs.

## Commissioning for Quality and Innovation (CQUIN)

We are incentivising implementation of our end of life care priorities in 2011/12 with CQUIN schemes for acute and community services.

The **acute CQUIN scheme** aims to improve care for patients approaching the end-of life-in hospitals by increasing the number of patients being placed on end-of-life registers and having the opportunity to undergo discussions regarding preferred priorities for care. The specific actions that the acute hospitals will implement as part of this CQUIN are:

- Within the defined specialty or ward (to be agreed with each hospital) to establish a hospital-based end-of-life register (HBELR).
- To establish mechanisms for identifying patients (within the defined specialty / ward) who are suitable for inclusion on the HBELR (e.g. by use of prognostic indicators or the “surprise question”).
- Of those patients identified as being eligible to be included on a register, capable of having a discussion and in whom the primary consultant is in agreement: 60% should be offered a discussion regarding their preferred priorities of (PPC) (including if appropriate a discussion about preferred place of care and/or preferred place of death).
- 90% of those patients who are considered suitable for inclusion on the HBELR and who agree to a discussion of PPC should be entered onto the hospital based register.
- 90% of patients on the hospital-based register who agree to have the information shared with the primary care team, should have evidence that this information has been shared with primary and community teams.
- Regular (annual) audits will be undertaken to identify wards using the Liverpool Care Pathway (LCP) where <25% of expected deaths are managed using the LCP, and an implementation plan will be produced to target education on the wards where LCP use is below this benchmark
- Evidence of achievement of preferred place of care and preferred place of death using a sample of patients.

The **community services CQUIN** aims to improve end of life care for people with an increase in the number of people on an EOL care pathway dying in their preferred place\* and achieving the quality standards:

- 95% of patients identified as end of life should be offered an end of life care planning discussion.
- 80% of patients offered a discussion should have an advanced care plan.
- 98% of patients who have an advanced care plan should have a record of the decision to resuscitate stated clearly in the notes.
- 98% of patients should have evidence of sharing advanced care plans and decisions taken with primary, community and acute care clearly stated in the notes.
- 30% of patients who die in hospital should die on a Liverpool Care Pathway or equivalent pathway.
- Increase in % of deaths in preferred place of care.

NB: The community services use the term ‘advanced care plan’ to mean a care plan that contains information about end of life care services. This could be any care plan rather than the dedicated end of life care plan used in Advance Care Planning mentioned elsewhere in this report.

\*Preferred place to be identified within care plan produced as part of the Liverpool care pathway.

## Value for Money Scheme

We are developing a scheme to assess and ensure our end of life care services are value for money, and this will aim to improve quality whilst reducing the reliance on acute hospital beds.

## 8. Conclusion and Next Steps

Sutton and Merton PCT invested in implementing this strategy over the past four years and we have made significant progress in improving the experience of patients, carers and families of end of life care services. We have set out in section 7 our priorities for the coming three years, 2011-2014. In summary, we will continue to focus on the following key next steps:

- Continuing to deliver high quality end of life care services for people in Sutton and Merton by implementing best practice.
- Working in partnership with the London Boroughs of Sutton and Merton and our other key partners in the third sector to ensure good co-ordination in the delivery of the best quality information, services (community & care home based) and support to patients and their informal carers.
- Systemically acting on the feedback from patients, carers and families to continue to improve our end of life care services.
- Ensuring our end of life care services are productive and value for money.
- Exploring options for improving the co-ordination of services by commissioning a lead provider to organise the chain of services from different providers, so that the patient experiences seamless care.
- Implementing any outcomes and changes required as a result of the national review of palliative care funding, due to report in the summer of 2011.

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## Appendix A1 End of Life Care Commissioning Intentions 2008/09 Action Plan and Progress (short term)

Aim: Increased access to end of life care by patients and increased preferred priorities of care including place of death

	Service Change	Action Required	Measurement	Outcome	Lead Organisation
1.1	Increased use of GSF	Ensure all PHC teams implementing GSF <ul style="list-style-type: none"> <li>- GP/DN/specialist nurses inc. dementia training/awareness</li> <li>- LA training</li> <li>- Care homes trained</li> </ul>	<ul style="list-style-type: none"> <li>- No. of practices GSF registered</li> <li>- No. of non-cancer patients on GSF</li> <li>- No. of care homes registered for GSF</li> </ul>	<ul style="list-style-type: none"> <li>- 99.8% of GP practices claim QOF points for a palliative care register</li> <li>- 21% patients on register had a non-malignant diagnoses (ADA)</li> <li>- 70% of care homes registered</li> </ul>	Provider units and general practice
1.2	Increased use of LCP	Ensure all providers implementing LCP	<ul style="list-style-type: none"> <li>- Increased roll-out in secondary care</li> <li>- Pilot in primary care</li> </ul>	<ul style="list-style-type: none"> <li>- 50% in those GP practices (31) who undertook in ADA audit</li> <li>- All acute units using LCP</li> </ul>	Provider units and general practice Nelson/PCT
1.3	Increased use of PPC	Pilot to be established	Pilot in primary care	<ul style="list-style-type: none"> <li>- CmyC Comms Reg in 24 (50+%) practices</li> <li>- 70% community place of death rate</li> </ul>	General practices
2	Improved discharge co-ordination	Propose models of discharge co-ordination to include: resource, outcomes, identified resource transfer To include assessment of resources required for Marie Curie Home Care	Increased % of non-hospital end of life care & death	16+% (validated)  18% (unvalidated)  On average approx 430 more people dying at home each year since strategy developed	PCT
3	Bereavement support	Increased equity of access to bereavement support before and after death as per SMPCT baseline review, national strategy "Emerging themes" and London review. <ul style="list-style-type: none"> <li>- Agree benchmark as per specialist palliative care</li> <li>- Cost service for all EoLC care packages for patients</li> </ul>	Increased availability to patients and families in community setting in line with service offered in specialist palliative care.	Service established, provided by CRUSE	PCT Commissioning

	Service Change	Action Required	Measurement	Outcome	Lead Organisation
4	Better use of specialist teams in End of Life Care	GSF and LCP training of specialist teams in: – respiratory	Input to GSF register LCP utilisation by team	All staff trained	PCT provider arm
		– cardiac	Input to GSF register LCP utilisation by team	All staff trained	PCT provider arm
		– dementia	Input to GSF register LCP utilisation by team	All staff trained	South West London Mental Health Trust
5	Improvement of banding to ensure fast track for patients where appropriate	<ul style="list-style-type: none"> <li>Review of current arrangements for banding</li> <li>Pilot joint funding for fast track discharge</li> </ul> Link to Marie Curie work re cost etc.	Minimum 50% increase of patients able to die at home (based on StG study)	82% achieved at StG (Dec 2010)	PCT/Network
6	Co-ordinated training programme	Annual training programme developed across health and social care in Sutton & Merton	EOLC training programme in place in across community settings in 2009 and 2010 X% training by: 1 <sup>o</sup> care 2 <sup>o</sup> care Care homes PHC teams in agreed areas	The following courses have been provided and are available: - Communication skills - EOLC best practice including use of EOLC tools - Palliative care workshops programme These courses are available to all GP practices. They are available to all care (nursing) homes. Uptake from >70% Also VOED training and Mac pack training specifically for care homes in addition to the facilitation of GSF. Substantial programme in place for DN, specialist nurses, including communication skills, prognostic indication, ACP, LCP, DN team leader development programme, Foundations in palliative care, & palliative care workshops.	PCT & Network
7	Research programme	Agree programme as part of SLA	Identified programme with outcomes linked to service improvement/commissioning support	ADA completed Audit of all deaths in community and nursing homes running over 2011	PCT
8	Resource	Investment plan for 2009-12 Costed investment plan		2008-10 £600K	PCT

## Appendix A2 Commissioning Intentions: End of Life Care Milestones (long term)

Milestone	Measure	Due date
Establish End of Life Care Network	- Terms of reference agreed	Sept 07
Completion of SMPCT End of Life Baseline Review	- Baseline review submitted to NHS London	Nov 07
Development of SMPCT End of Life Strategy	- Strategy agreed	Dec 07
Revision of SMPCT End of Life Strategy in light of End of Life National Strategy, listening exercise	- Strategy amended as necessary	March 08
Agreement of action and implementation plan in line with SMPCT baseline review, SMPCT End of Life Strategy, EOLC national strategy: emerging themes.	- Action and implementation plan in place - Stakeholder event held	April 08
End of Life Care commissioned in line with agreed model	- Contracts agreed with providers - Initial cohort of outcome measures agreed	Feb 08
Assessment against outcome measures/ strategic implementation plan	- Review quality outcomes and - Local gap analysis completed	Sept 08
Assessment of financial/commissioning implications of agreed End of Life Care Model	- Commissioning Intentions 2009/10 fed into planning round	June 2008
Joint finance arrangement	- Joint finance arrangements to support fast-track discharge from hospital	March 2009
Implementation of Liverpool Care Pathway or Gold Standards Framework by all provider organisations	- 100% patients are assessed against LCP - LCP used appropriately by all clinicians - 100% practices using GSF - 100% care homes using GSF	July 2009
Improved access to preferred end of life care for all those requiring EoL care	- Increased percentage of patients achieving their preferred place of care - Increased % of patients to whom planned end of life care is delivered - More representative provision of end of life care across all specialities - End of Life Care Centre in place	March 2011

## Appendix B

### Summary: End of Life Care in Primary Care: 2009 Snapshot for NHS Sutton & Merton (ADA) Author: Eleanor Brown, Chief Executive, Nelson Commissioning Group

#### Introduction

In 2009 all general practices in Sutton & Merton were invited to take part in the first ever national snapshot of end of life care in primary care. Thirty-one of the practices submitted anonymised information about 160 people who died during February and March 2009 using an online After Death Analysis (ADA) tool. The Department of Health's End of Life Care Strategy encourages all health and social care services to provide high quality care in the final year of life using a pathway approach. The following sections based on the headings above examine how practices in Sutton & Merton are addressing each element of the pathway as follows:

#### *Identifying people*

A key step in providing high quality end of life care is to identify people who may be in the last 6-12 months of life. Key markers identified by the Department to measure this include:

- The proportion of people identified for the palliative care register
- How long people were on the register
- The proportion with a non-cancer diagnosis

For the above, Sutton & Merton results are as follows:

99.8% of practices across Sutton & Merton now claim QOF points for having a register. In February and March 2009, 32% of people dying (from participating practices in NHS Sutton & Merton) were on the palliative care register. In comparison, 27% of all deaths from participating practices nationally were on the register. We are therefore doing better than some areas. The best performing PCT was also at 32%.

In Sutton & Merton, practices thought that 46% of deaths in the Snapshot were sudden or unpredictable, but research from the National Audit Office suggests only around 8% of deaths are totally sudden or unpredictable. The main underlying diagnoses recorded as causing sudden death in NHS Sutton & Merton were infection, heart disease and heart failure.

Practices in NHS Sutton & Merton said that, on reflection, an additional 11% of deaths where people were not on the palliative care register could have been anticipated. The national overall Snapshot figure was 15%.

The percentage of people on the palliative care register over 6 months in Sutton & Merton was 35%. The Snapshot average was 27% and the best performing PCT was 36%.

Locally, we are trying to ensure that high quality end of life care is available for everyone, regardless of diagnosis. From 2008/09 this has been reflected in QOF whereby people in the final year of life of all ages and with all end-stage conditions, are to be listed on the palliative care register. We know that in the initial stages of having a palliative care register, those with cancer form the highest percentage of people on the end of life care register.

Our local End of Life Care Strategy is trying to address this and encouraging access to high quality end of life care for all those entering the end stage of their lives. Nationally, the snapshot found that 29% of those on the register had a non-malignant diagnosis, 21% had a non-malignant diagnosis in Sutton & Merton, and the best performing PCT in the snapshot had 43%. The Gold Standards Framework has worked with the Royal College of General Practitioners to produce the prognostic indicator guidance tool which helps to identify who might be in the final 6-12 months of life and should be included on the GSF register including non-malignancy. If you do not already have these widely circulated in your practice, please see the link for downloading ([www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk) [section 11 Non-cancer]).

### *Assess preferences*

The National End of Life Care Strategy suggests that everyone approaching the end of life should have their needs assessed, their wishes and preferences discussed, and an agreed set of actions reflecting the choices they make about their care recorded. In order to identify this, two areas were measured as follows:

- The proportion of people who are given an opportunity to discuss their preferences
- The proportion whose wishes are recorded.

The report found the following:

- In NHS Sutton & Merton, 25% of people who died during February and March 2009 were offered an advanced care planning discussion. The overall national snapshot figure was 20%. Looking only at people on the palliative care register whom primary care teams knew were nearing the end of life, in Sutton & Merton 63% were offered an advanced care planning discussion. The overall national snapshot figure was 58% and the best performing PCT 66%.
- Recording people's preferences: In NHS Sutton & Merton 37% of those on the palliative care register had their wishes and preferences recorded in an advanced care planning document compared to 43% in the national snapshot overall, and 58% in the best performing PCT.

We are currently looking at a revised advanced care planning document template for local use led by the End of Life Care Action Group, chaired by Ros Cook (End of Life Care Nurse Consultant) with representatives from all providers and primary care. The suggested format will be coming to the Sutton & Merton End



of Life Care Network in May. At the same time, the group is also looking at how to raise awareness of advanced care planning amongst patients and carers and ensuring availability of training opportunities for all professionals.

The community provider services co-ordinated by Ros Cook are looking at ensuring support for their teams to deliver the advanced care planning discussions and user group documentation.

In addition to this, Sutton & Merton is one of 8 national pilot sites looking at the End of Life Care Electronic Communication Register. The register will help us to record patients' preferences and wishes and ensure appropriate distribution to all members of the team: care home, hospital, out of hours services, and hospices, as appropriate. Further information about this is being disseminated via the PbC groups.

### *Planning*

The End of Life Care Strategy recommends that health communities should develop co-ordinated end of life care across sectors at all times of the day and night. The audit looked at some of the ways in which practice teams can seek to enhance co-ordination within the team and amongst close partners by looking at:

- The proportion of people that were discussed at a multidisciplinary practice team meeting in their final months
- The proportion of all deaths where the practice team reflected on the care given with a view to improving care for the future
- The proportion where a checklist or clear record was kept of all steps needed to ensure systematic approach to care
- The proportion who had a documented key worker responsible for co-ordinating care
- Whether an out of hours handover record was used to enhance co-ordination and communication

The following was reported from the audit:

**Team meetings:** In Sutton & Merton, findings from the snapshot suggested that 34% of all patients and 89% of those on the register were discussed at a multidisciplinary team meeting at least once in the final three months of life. The overall figures for the national snapshot were 29% and 78% respectively.

Almost all practices said they held multidisciplinary team meetings to discuss end of life care every 1-3 months

Sutton & Merton reported that the primary health care team discussed the patient's care following death in 45% of all cases, e.g. at a reflective practice session, or during significant event analysis. Among those on the palliative care register, this increased to 72% of all deaths. The overall figures for the national snapshot showed that 29% discussed the patient's care following death and those on the palliative care register 50%.

**Record of aspects considered:** The End of Life Care Strategy recommends that practices take a systematic approach to end of life care including developing a system to ensure that all aspects of care are considered for each person on the register. Practices in NHS Sutton & Merton said that 82% had documentation that all aspects of care were considered. This is compared to 80% in the snapshot locally, and 95% on the best performing PCT.

**Key workers:** The End of Life Care Strategy suggests that each person on the palliative care register should have one assigned contact person and the quality markers refer to a primary care key worker. In NHS Sutton & Merton, 80% of people on the register had a key worker documented as compared to 74% in the snapshot overall, and 87% in the best performing PCT.

**Out of hours:** Sharing information is important to ensure a smooth transition between services. A simple paper or electronic handover sheet is helpful for this and recommended with out of hours services and is already part of QOF. Practices reported that 61% of people on their palliative care register had handover information sent to out-of-hours teams compared to 46% nationally, and 64% in the best performing PCT.

Locally, the electronic communication register should encourage development of information sharing with other health professionals and may in time also enable better communications with social care professionals. In the meantime, please ensure information about patients on your GSF register is faxed (as appropriate) to the OOH team.

### *Delivering care*

The National Audit Office suggests that a lack of prompt access to services in the community leads people to be unnecessarily admitted to hospital towards the end of life. This section was particularly looking to help the PCT to consider any gaps in access to community services and covers service use towards the end of life.

The national snapshot looked at care from a primary care perspective, but also explored some of the hospital and community services that people use during their final six months of life. With the exception of three services (Marie Curie, Allied Health Professionals and Rapid Response), Sutton & Merton PCT used a higher percentage of services than the overall snapshot identified, apart from GPs, where the usage was the same (98%). Services we utilised more than other areas included district nurses, community specialist palliative care teams, out-of-hours GPs, night/out-of-hours nursing, hospice inpatients, social services, Hospice@Home, community matrons, intermediate care, hospice day therapy.

In relation to hospital services, the core principle of providing high quality end of life care is to support people to receive care where they choose and to avoid unnecessary hospital admissions.

In NHS Sutton & Merton the overall average number of emergency admissions in the final six months was 1, and the average number of days in hospital was 13. In the national snapshot, the average number of emergency admissions in the final 6 months was 1, and the average number of days in hospital was the same, 13.

## *Managing final days*

Supporting people in their final days is crucial and can significantly impact on the emotional and physical wellbeing of both the dying person and their family. In this section of the report the audit covered:

- The proportion of people on the register dying at home who were managed using a care protocol
- The proportion who died in their preferred place of care.

The following results were noted:

- Using integrated care pathways: In NHS Sutton & Merton, of those on the palliative care register who died at home, 50% were cared for using an integrated care pathway or protocol for the final days. The overall figure for the national snapshot was 60%.
- Preferred place of care: In NHS Sutton & Merton, 56% of people on the palliative care register had a preferred place of care recorded which is the same proportion as the overall national snapshot. The best performing PCT recorded PPC for 79% and for the reportedly died in their preferred place of care, for 51%.
- Practices said that 32% of people on a register died at their preferred place of care, compared with 42% in the overall snapshot. When people did not die in their preferred place of care, practices most commonly suggested this was due to not being able to access palliative care medicines, the person having complex clinical problems that could not be managed in the community, a breakdown in carer support, or the person dying in hospital before they could be discharged.

We will be exploring these issues within the EOLC Action Group. Taking part in the Department of Health pilot for the electronic communication register will help us to document preferred place of care and offer a process for sharing that information across organisational boundaries. In addition, the advanced communication skills course offers all clinicians an opportunity to review their current practice in discussing PPC and death with patients, and is available locally. Please contact Ros Cook ([Ros.Cook@smpct.nhs.uk](mailto:Ros.Cook@smpct.nhs.uk)) or Martine Meyer ([Martine.Meyer@esth.nhs.uk](mailto:Martine.Meyer@esth.nhs.uk)) for further details.

## *Providing support*

Providing information and support to those people nearing the end of life and their families is at the heart of good quality care. The areas audited included:

- The proportion of people who held information about their own care
- The proportion of people who were signposted to benefits
- The proportion of carers given tailored information
- The proportion of carers who had their needs assessed
- The proportion of carers offered bereavement support

**People holding information about their own care:** The snapshot looked at whether a nursing care plan, patient-held record or home pack were used and found these were used locally for 65% of people on a palliative care register. In 13% of cases practices said that a nurse care plan or patient-held record was not used and 22% did not know. Overall, 61% of those participating in the snapshot used a patient-held record or home pack, and 74% in the best performing PCT.

**Signposting to benefits:** The end of life can be an expensive time for people and their families. People who are stressed financially tend to suffer more symptoms. It may also restrict their lifestyle and be more isolated, and carers can feel stressed and unsupported. Among those on a register, 54% of people or carers had been signposted towards benefits or were receiving benefits. The overall snapshot figure was 46% and the best performing PCT was 61%.

**Providing information:** For those on a register, practices said tailored information was provided to carers in 69% of cases, compared to 69% of all participating in the national snapshot, and 83% in the best performing PCT.

**Assessing carers' needs:** 44% of those on a register were recorded as having their carer's needs assessed. 5% of those not on a register also had carers' needs documented. The national snapshot figures were 50% of those on the register and 8% not on the register. The best performing PCT was at 61%. Full implementation of GSF would improve this figure.

**Bereavement support:** In NHS Sutton & Merton only 33% of families were offered bereavement support. Practices reported offering bereavement support to family members for 52% of people on the register and 24% of people not on the register. For those in the overall snapshot nationally, 34% of families were offered bereavement support (52% of those on a register, and 27% of those not on a register). The best performing PCT was at 47%.

Sutton & Merton PCT have now commissioned an End of Life Care Bereavement Support Service. The service is being offered by CRUSE and began in March.

## Local Next Steps

This report tries to identify where we have already made changes as a result of the End of Life Care Strategy or the ADA audit. The audit indicates a high level of excellent care being provided to patients. We should celebrate this across primary care and community care. There are also a number of areas where we should look to improve on the care that we provide now. The report encourages:

- Each practice to look at developing an action plan based on their results for the individual practice (these have all been sent to you). We are also able to undertake the report with practice participation. This would help us to identify the progress we have made as a result of the individual action plans and the PCT plan.
- The National Gold Standards Framework Centre has developed a training programme online – e-ELCA. This is an e-learning facility and can be accessed at [www.e-elca.org.uk](http://www.e-elca.org.uk).
- The PCT Operating Plan identified the need for a local enhanced service for end of life care to support excellent EOLC for patients in a non-acute setting. This will be based on the Croydon model and details of this will be available from May.

Progress towards Department of Health Quality Markers (primary care section)

Quality marker	PCT status	PCT figures	Snapshot averages
<b>Quality marker 2.1: developing strategy and plans (not measured)</b>			
<b>Quality marker 2.2: mechanism to assess and document</b>			
% whose preferred place of care is recorded		56%	56% of those on the palliative care register
% who die in their preferred place of care		32%	42% of those on the palliative care register
<b>Quality marker 2.3: mechanism to assess and document carer needs</b>			
% carer's assessment / carers needs recorded		44% on register	50% of those on a register
<b>Quality marker 2.4: use of multidisciplinary team meetings quarterly</b>			
% dying discussed at a multidisciplinary team meeting in final year		89% on register	within 3 months: 78% on the register
<b>Quality marker 2.5: communication with out of hours</b>			
% on register with info given to out of hours		61%	46% of those on the palliative care register
<b>Quality marker 2.6: nominating a key worker</b>			
% with a key worker identified		80%	74% of those on the palliative care register
<b>Quality marker 2.7-9: awareness and action regarding training needs (not measured)</b>			
<b>Quality marker 2.10: adopting care management pathway when dying</b>			
% of those dying at home where the Liverpool Care Pathway or equivalent was used		50%	60% of those on the register who died at home
<b>Quality marker 2.11: collate information on quality of care for audit purposes</b>			
% who take part in audit		57%	60% of practices invited
% who die at home		26% on register	31% on the register; 20% of all deaths
% who die in their preferred place of care		32%	42% of those on the palliative care register
% of carers who receive bereavement support		33% all deaths; 52% on register	34% of all deaths; 52% on the register

Note: the 'PCT status' column indicates progress towards the Quality Marker in th PCT area. The 'PCT figures' column provides local data. The 'snapshot averages' column lists the overall results from 4487 records submitted throughout England for the national snapshot.

## References

### *Strategies and reports:*

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*Equity and excellence: Liberating the NHS*, Department of Health, July 2010.

*NHS Outcomes Framework 2011/12*, Department of Health, 2010.

*NHS Operating Framework 2007/08: PCT Baseline Review of Services for end of life care*, April 2007 (Gateway reference 8116).

*NHS Operating Framework 2011/12*, Department of Health, 2010.

*The Potential Cost Savings of Greater Use of Home-And Hospice-Based End of Life Care in England*, National Audit Office.

### *Articles:*

'*Watchdog urges NHS to learn from "raw feelings of patients" in report on 16,000 complaints*', "News and events", Healthcare Commission 1/2/2007.

Gomes B, Higginson IJ. *Where people die (1974–2030): Past trends, future projections and implications for care*. *Palliative Medicine* 2008; 22: 33–41).

### *Best practice:*

*End of Life Care Good Practice Guide*, Commissioning Support for London, 2010.

Liverpool Care Pathway for the Dying Patient

[www.mcpcil.org.uk/liverpool\\_care\\_pathway](http://www.mcpcil.org.uk/liverpool_care_pathway)

The Gold Standards Framework: A Programme for Community Palliative Care

[www.goldstandardsframework.nhs.uk/](http://www.goldstandardsframework.nhs.uk/)

Hospice at Home

[www.dh.gov.uk/en/Policyandguidance/Researchanddevelopment/A-Z](http://www.dh.gov.uk/en/Policyandguidance/Researchanddevelopment/A-Z)

Preferred Place of Care Plan

[www.cancerlancashire.org.uk/ppc.html](http://www.cancerlancashire.org.uk/ppc.html)

If you need information about end of life care services in Sutton and Merton please contact the Patient Advice and Liaison Service (PALS):

0800 085 3182

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