

DRAFT

Living & Dying Well in Lothian



Prepared by the Lothian Palliative Care Steering Group as part of the development of the Lothian Palliative Care Strategy 2010-2015: Living and Dying Well in Lothian

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1. EXECUTIVE SUMMARY

In 2008 Audit Scotland published the first national review to have been undertaken of the activity, costs and quality of specialist and general palliative care services in Scotland. The principal finding of the review was that good quality palliative care is not yet available to everyone who needs it. Our strategy, outlined in this paper, seeks to address this in Lothian by focussing our quality improvement work and taking forward a new model of integrated palliative and end of life care.

This strategy was developed by a steering group which brought together representatives from across Lothian working in both generalist and specialist services in community and hospital settings. The strategy has been jointly developed in collaboration with both of the independent hospices in Lothian. To inform the development of the strategy two stakeholder events were held with a range of health and social care professionals, and with carers in Lothian.

Our **vision** is for high quality Palliative and End of Life care available in all settings, utilised by all who require it, and prioritised according to the patient's need, rather than medical condition. By 2015 clinical teams in all settings across Lothian will be reliably identifying and assessing patients as they reach a palliative phase of their illness, and developing and updating integrated care plans for them and their carers, based on patients and family preferences. More people will die in the place of their choice. We have identified our key challenges to be:

1. To improve care for people living with any life limiting illness
2. Identification of people who are in the palliative phase of their illness in all care settings
3. To provide palliative care and support throughout the palliative phase rather than just in the terminal stage, and to maximise the use of Anticipatory Care Planning for patients with palliative needs in all settings
4. To provide high quality integrated palliative care to more people in the setting of their choice, including support for preferred place of death
5. To better care for all aspects of the person, physical, psychological, social, spiritual and to improve patient experience
6. To have effective systems to share information, between the people involved in a patient's care
7. To provide people with optimal care in the last few days of life
8. To promote community involvement and a public discourse about death and dying

Our actions will focus on improving systems of identification, care planning and communication in palliative and end of life care for all. In Lothian we will face increasing challenges posed by the growth in the number of older people as a proportion of the Lothian population. More people will be living with long term health conditions and will have multi-morbidities. We expect that the number of deaths in Lothian will fall over the next 5 years, with a steady rise in the numbers of deaths per year from around 2015/2016.

This emphasises the need for service improvement in palliative and end of life care in Lothian now, to meet the demands associated with a rise in the number of deaths and increased case complexity due to multi-morbidities. Because of these factors, we will take forward a model of palliative care which will support the integration of disease modifying treatment and palliative care. It will aim to do this by breaking down palliative care planning and delivery into 3 tiers:

- Working with people with **Long Term Conditions** to make sure that the need for palliative care is identified as part of routine care at the earliest stage appropriate, helping people to plan, direct and be actively involved their own care.
- Adopting the **Palliative Care Approach** from as early a stage as is agreed appropriate. The palliative care approach seeks to maximise quality of life, by maintaining good symptom control, offering holistic assessment including family and carers needs, and seeks to agree choices around treatment options, place of care and preferred place of death.
- Planning for and managing **end of life care** in the last days of life in a tightly co-ordinated and structured manner.

To assist in guiding our implementation and focussing action our model will use the construct of 'trajectories of dying'. This is a framework, drawn from research, which divides people with any life limiting illness into three main groups based on expected patterns of decline to death (or 'trajectories of dying'). As a framework within our model this helps us to identify groups with common features and needs, and will therefore support targeting our improvement work.

This strategy pulls together a number of strands of the Lothian palliative care programme:

1. Our Living and Dying Well Delivery Plan for 2009 – 2011. This provides a focus to development and implementation in the first 2 years of the strategy term.
2. The Palliative Care Managed Clinical Network review of Specialist Palliative Care Bed Capacity. Delivering the recommendations from this will improve partnership working, value for money and help to take forward actions to develop the future role of specialist palliative care services to support delivery of this strategy.
3. The Lothian action plan in response to the Audit Scotland review of Palliative Care Services in Scotland

As part of this strategy, we will support a policy of establishing a preferred place of care and death, seeking to assess and understand this with patients and using this to support planning and delivery of care. Patients and carers have also told us that they want choice around where they die. Successful implementation of this policy will result in a shift in the balance of care from acute settings to community care settings. Therefore to measure our progress in delivering this the following proxy measures will be used¹:

1. We will decrease the proportion of deaths in acute hospitals in Lothian (Royal Infirmary, Western General, St Johns and the Royal Hospital for Sick Children) from a 2008 baseline of 42.3% to 38% by the end of 2015.

¹ Full baseline for Place of Death in Lothian in 2008: Acute Hospital 42.3%, Care Homes 13.6%, Home Deaths 20.8%, Hospices 9.0%, NHS Continuing Care Hospitals 8.3%, Other settings 5.9%.

2. To support the achievement of this we aim to increase the proportion of deaths occurring in community settings, including in patients own homes and care homes from 34.4% in the baseline year to 38.8% in 2015.

Following consultation on this strategy we will further develop our delivery plan and priorities for implementation.

2. DEFINITION OF PALLIATIVE CARE, TRAJECTORIES OF DYING, & POLICY CONTEXT

Definitions

The World Health Organisation defines Palliative Care as *'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'*²

The World Health Organisation has also recommended that planning for care at the end of life should be responsive to patient choice regarding place of care and place of death.³

The Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee outlined the following definition of palliative care, which usefully emphasises the progressive component of illness, and the co-ordination of care⁴.

Palliative care is active total care offered to a patient with a progressive illness and their family when it is recognised that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms within the framework of a co-ordinated service. Palliative care neither hastens nor postpones death; it provides a relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition it offers a support system to help during the patient's illness and in bereavement. 'Family' is used as a general term to cover closely-attached individuals, whatever their legal status.

Trajectories of Dying

Throughout this strategy we draw upon the conceptual model of 'Trajectories of dying' to help explain how people die, and their needs. An explanation of this model is outlined below.

One of the hurdles to providing palliative care for all has been our concept of how people die. We have assumed that there is a progressive decline towards death and that, if we were better at spotting the beginning of this decline, we would be able to provide palliative care to more people. Research has now developed a conceptual model which divides people with any life limiting illness into three main groups based on expected patterns of decline to death or 'trajectories of dying'. It is intended as an overall framework to illustrate groups with common features and needs, which match different service and care needs. Our own detailed analysis of mortality data in Lothian confirms that this model reflects broad patterns of dying in Lothian. We have therefore used this model to focus our

² World Health Organization. Palliative Care: the solid facts. World Health Organization, Geneva: 2004

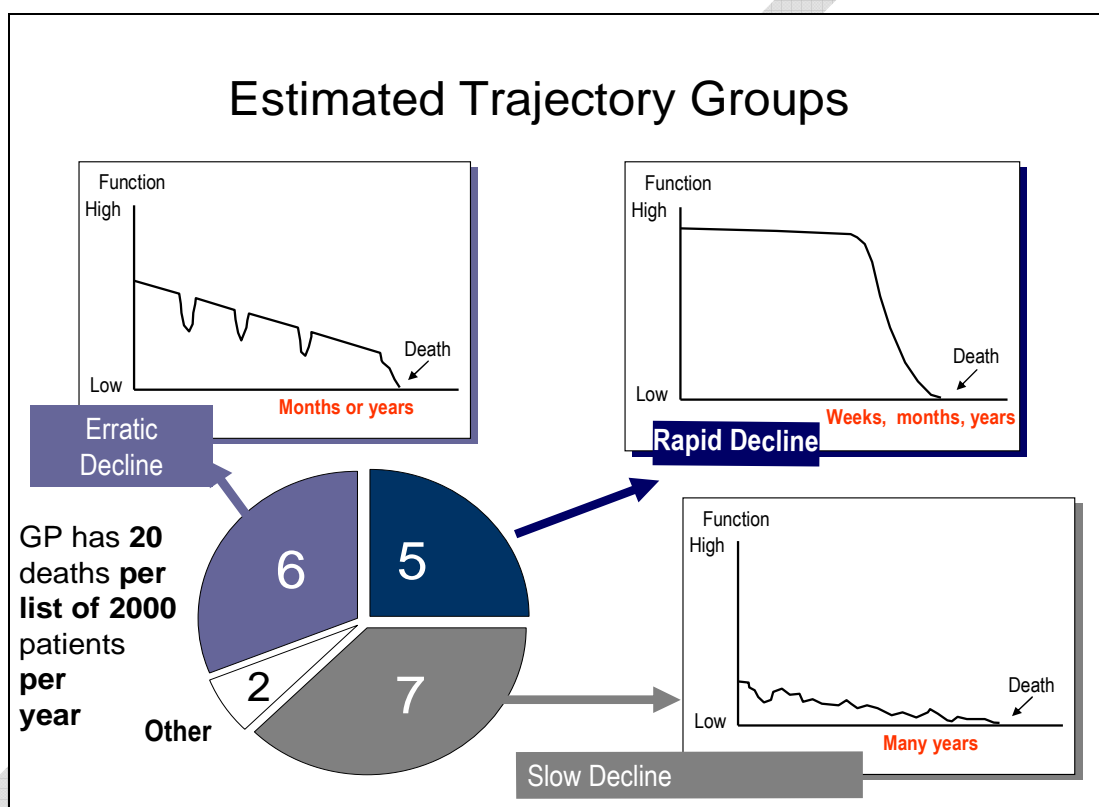
³ World Health Organization. Palliative care for older people. World Health Organization, Geneva: 2004

⁴ Standing Medical Advisory Committee and Standing Nurse and Midwifery Advisory Committee. The Principles and Provision of Palliative Care. London: Joint Report of the Standing Medical Advisory Committee & Standing Nurse & Midwifery Advisory Committee, 1992.

strategy and target service improvement work. The chart below illustrates the trajectory groups⁵.

People in the Erratic Decline group are mainly those with organ failure diseases such as heart failure, COPD and renal failure. Those in the Rapid Decline group are mainly those with cancer, and other non-malignant conditions where life expectancy after diagnosis is short, perhaps a few weeks. People in the Slow Decline trajectory group are mainly those with progressive neurological conditions, frail elderly people, people with dementia, and patients with multiple co-morbidities.

This overall pattern can also be shown against GP lists per 2000 patients.



Policy context in Scotland

Better Health Better Care

Better Health Better Care stated a commitment to the delivery of high quality palliative care based on need rather than diagnosis and stated the intention to publish a national action plan for palliative care in 2008.⁶

5 Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ*. 2005; 330:1007-1011.

6 The Scottish Government. *Better Health Better Care: An Action Plan*. Edinburgh. December 2007.

Audit Scotland Review of Palliative Care Services

The Audit Scotland Review of Palliative Care Services in Scotland was published in 2008. This was the first detailed look at activity, quality and costs of palliative care services across Scotland.⁷

Living & Dying Well

'Living and Dying Well', the National Action Plan for Palliative and End of Life care in Scotland, was launched by the Scottish Government in October 2008.⁸ Living and Dying Well uses the concepts of planning and delivery of care, communication and information sharing as a framework to support a person centred approach to delivering consistent palliative and end of life care in Scotland.

Living and Dying Well focuses on taking forward improvement and development work in the following areas:

- Identification of all people who would benefit from palliative care
- Assessment and review of patients with palliative care needs
- Planning and delivery of care
- Communication and co-ordination of care by different providers
- Education, training and workforce development
- Implementation and future developments, to support local NHS systems and their partners in delivery

Shifting the Balance of Care

Improving Palliative and End of Life Care has been identified as one of eight Shifting the Balance of Care high impact areas selected as key to the delivery of national and local outcomes and targets⁹. Health Boards and their partners will use the approach to agree baseline positions and the range of actions that will lead to measurable shifts in the balance of care in selected areas of the Framework. Section 10 of this strategy outlines how we will support shifting the balance of palliative and end of life care in Lothian, alongside implementing our Living and Dying Well Delivery Plan.

⁷ Audit Scotland Review of Palliative Care Services in Scotland. Edinburgh August 2008 .ISBN 978 1 906752 12 5

⁸ Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland. Edinburgh October 2008.

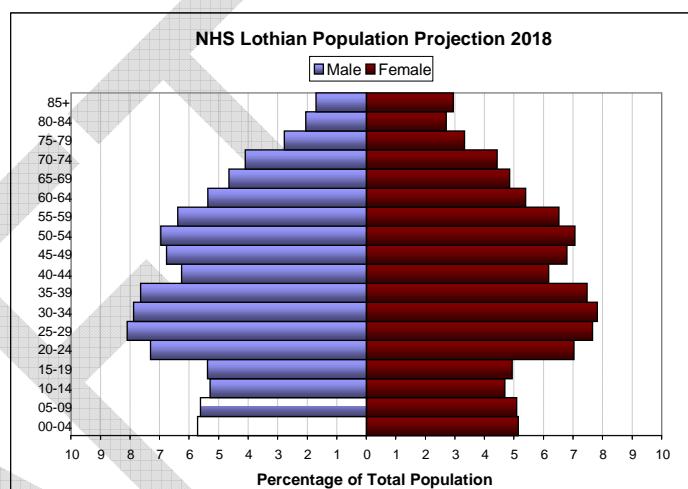
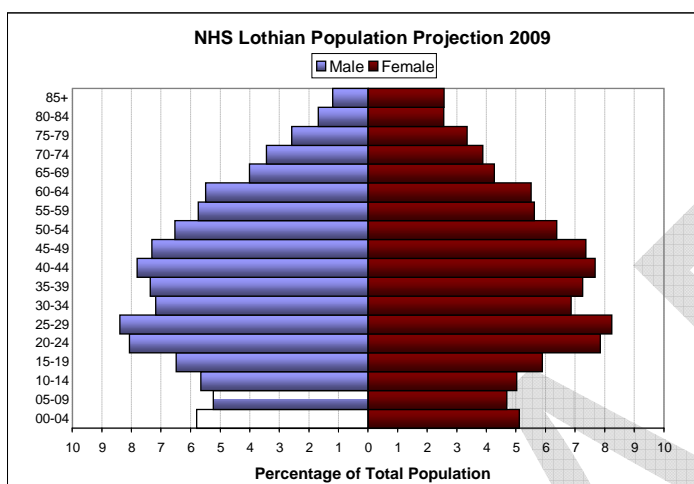
⁹ shifting the balance of care improvement & resource framework, January 2009

3. BACKGROUND

Living and Dying in Lothian

Population changes

Over the next ten years Lothian's population is expected to increase. In addition, as life expectancy increases, the population aged 60 and over is projected to increase by approximately 24%. The graphs below show population pyramids for 2009 and 2018 for Lothian¹⁰. Older people generally have greater and more complex health care needs. The expectation is that there will be more people living with long-term conditions, many with multiple co-morbidities.



Deaths in Lothian – causes of death and patterns of dying

Each year in Lothian there are around 7,500 deaths. The majority of deaths occur following a period of illness associated with conditions such as cancer, heart, liver, renal, cerebrovascular (including stroke), chronic respiratory and neurological diseases, and dementia. An analysis of the top ten causes of death for Lothian residents and all Scotland residents in 2008, by place of death, is shown in Appendix 3, table 1.

Analysis of deaths using the trajectories of dying model shows that people in the Slow Decline group represent approximately 35% of all deaths each year in Lothian. People in the Erratic Decline group represent approximately 30% of deaths each year. Those in the Rapid Decline Group represent approximately 25% of all deaths in Lothian each year. Other deaths, which include sudden and accidental deaths, represent approximately 10% of deaths each year. As outlined in our model of care in section 7 this analysis helps us to think about how and where we might target support in future to improve care, based on identification of groups with common needs.

Place of death

Analysis of the proportion of deaths by place of death in Lothian (5-year average) shows that 57% are deaths that occur in a hospital setting (acute hospitals, NHS continuing care units, and other hospitals), 21% at home, 14% in a care homes or private hospital, and 8% in a hospice.

¹⁰ Source: General Register Office of Scotland 2006-based population projections

Many people move to continuing care settings at the end of their lives and that setting becomes the person's place of residence (their home). This paper therefore distinguishes between NHS continuing care units (where palliative care deaths are expected and may increase in number) and acute hospitals (where many deaths occur however for some this setting may not be the preferred place of death). We have therefore divided 'hospital deaths' into 2 distinct groups – acute hospitals and NHS continuing care settings.

The table below outlines the proportion of deaths in Lothian, by care setting, over 5 years. The trend for deaths in acute hospitals in Lothian is falling. The trend for deaths in NHS Continuing Care Units is rising, as is the proportion of deaths occurring in hospices in Lothian. The proportion of domiciliary deaths and deaths in care home settings are almost static over the 5 year period.

Summary of deaths in Lothian 2004-2008, by care setting

Setting	2004		2005		2006		2007		2008	
Acute hospitals ¹	3385	43.8%	3528	44.1%	3369	44.0%	3221	42.2%	3237	42.1%
Care homes ²	1076	13.9%	1029	12.9%	1012	13.2%	1043	13.7%	1045	13.6%
Domiciliary deaths	1601	20.7%	1645	20.6%	1521	19.9%	1640	21.5%	1602	20.8%
Hospices ³	549	7.1%	596	7.5%	617	8.1%	628	8.2%	693	9.0%
NHS Continuing Care hospitals ⁴	527	6.8%	571	7.1%	579	7.6%	593	7.8%	641	8.3%
Other deaths	582	7.5%	625	7.8%	554	7.2%	506	6.6%	476	6.2%
Grand Total	7720	100.0%	7994	100.0%	7652	100.0%	7631	100.0%	7694	100.0%

1 Royal Infirmary of Edinburgh, Western General Hospital and St John's Hospital

2 Nursing homes and residential homes. Excludes children's homes and institutions for homeless people.

3 St Columba's Hospice and Marie Curie Hospice Edinburgh

4 All deaths at the Astley Ainslie Hospital, Corstorphine Hospital, Edenhall Hospital, Ellen's Glen House, Ferryfield House, Findlay House, Loanhead Hospital, Roodlands General Hospital, St Michael's Hospital and Tippetthill Hospital

Research suggests that more people may prefer to die at home than currently do so, though many will continue to want or need in-patient care at the end of life¹¹. In Lothian however, as in the rest of the UK, there is a longer-term trend (over the last 25 years) towards fewer domiciliary deaths¹². There is obvious concern over the desirability of this trend given the apparent evidence on patient choice and preference.

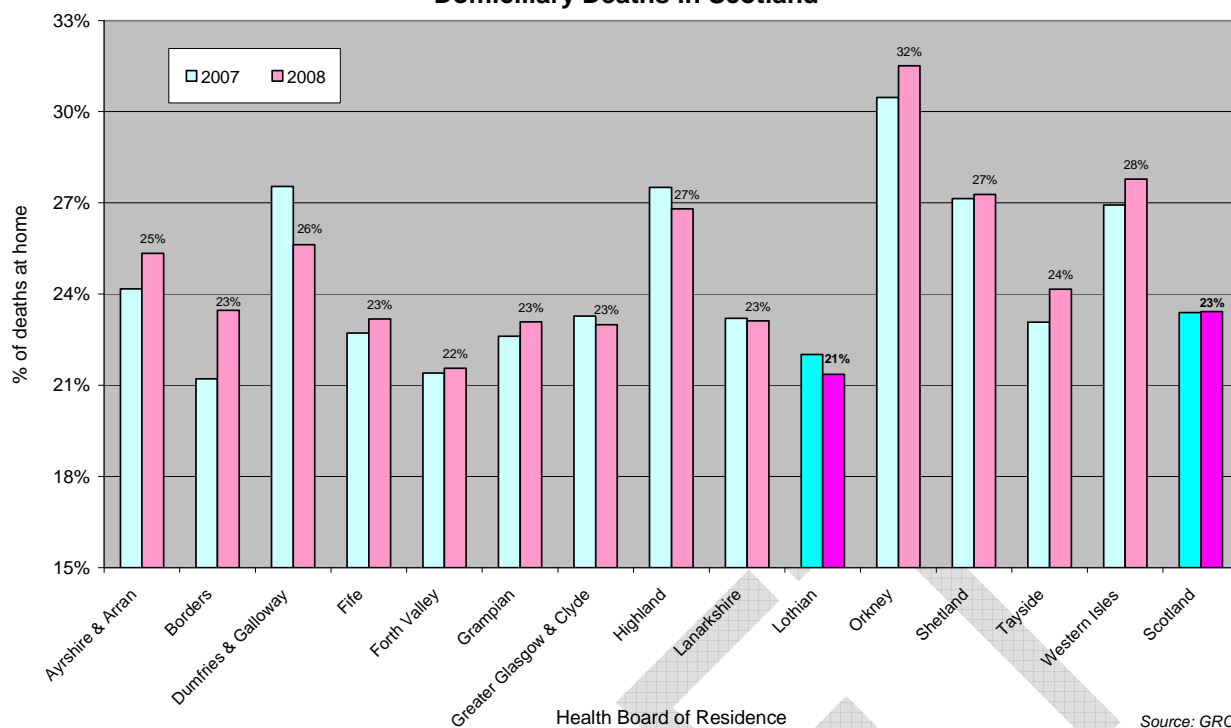
The chart below shows the proportion of domiciliary deaths for each NHS Board area in Scotland for 2007 & 2008. At 21% in 2008 Lothian has the lowest proportion of domiciliary deaths in Scotland, and is under the all Scotland average of 23%. Monitoring the proportion of domiciliary deaths may provide a useful indicator of how the health and social care system in Lothian is responding to End of Life care needs, and supporting choice. Appendix 3 of this strategy gives longer term trends over time and section 10 of this paper outlines the strategic indicators, adopted as part of this strategy, to show how we aim to shift the proportion of deaths by care setting over the next 5 years.

¹¹ Glare

¹² Gomes, B and Higginson, I. (2008) Where People Die (1974- 2030): Past trends, future projections and implications for care

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Domiciliary Deaths in Scotland



Deprivation and home deaths

There is an association between the proportion of home deaths and deprivation in Lothian, with a higher proportion of deaths occurring at home in the most deprived groups compared to the least deprived.

The table below shows the proportion of deaths that occurred at home in each deprivation category and by council area. For example in Edinburgh, of all deaths in deprivation category 1, 16% of these were home deaths.

	Deprivation category					All
	1	2	3	4	5	
East Lothian	32.1%	16.8%	22.6%	20.2%	24.7%	21.7%
Edinburgh	16.0%	17.2%	17.0%	20.8%	24.0%	19.3%
Midlothian	18.2%	14.0%	18.9%	26.3%	24.1%	21.7%
West Lothian	17.5%	22.1%	26.5%	28.5%	28.1%	26.8%
Lothian	17.3%	17.7%	20.0%	23.6%	25.1%	21.4%

Source: GRO(S)

1 Scottish Index of Multiple Deprivation (2006). Depcat1 includes the least deprived 20% of datazones within Lothian and Depcat5 includes the most deprived areas.

2 Includes 46 deaths for which geographical data is not available. 14 of these are home deaths.

Projected number of deaths

Over the period of this strategy, 2010 – 2015, it is predicted that the number of deaths in Lothian will fall slowly year-on-year from around 7,500 per annum to a low of 7,200 per annum in 2014 / 2015. From 2015 / 2016 the number of deaths each year is then predicted to increase slowly and steadily, with a long range projection of approximately 8,200 deaths in Lothian per annum by 2030/2031 (see appendix 3). These changes will, over time, increase the prevalence of people with palliative and end of life care needs. This emphasises the need for service improvement in palliative and end of life care in Lothian over the next 5 years to plan to meet the demands associated with a rise in the number of deaths and expected case complexity due to multi-multi-morbidities.

Estimating need - Non-Malignant Palliative Care

Specialist Palliative Care has historically been focussed on the care of people with cancer. Systems of assessment, referral and liaison between generalist and specialists providing palliative care for those with cancer are relatively well developed. A central challenge, and a key aim of this strategy, is to improve the quality of Palliative and End of Life care for people with non-malignant disease, whilst continuing to improve cancer care further.

Approximately 25% of deaths each year in Lothian are deaths from cancer, leaving 75% of deaths from other causes. We estimate that of this 75%, 10% are comprised of a range of sudden or acute deaths which because of their nature do not allow for palliative involvement. The 65% of deaths remaining per year (equalling approximately 4,900 people each year in Lothian) are deaths from a wide variety of non-malignant causes. This includes many frail elderly people with diseases of old age, including multiple co-morbidities, and people with diseases such as dementia and progressive neurological disease. Most often people dying of conditions such as these follow a slow decline and clear opportunities exist to improve care by focussing on improvement and support in people's own homes, care homes, care at home and community hospital care. Equally, a large proportion of non-cancer deaths are those primarily associated with organ failure (such as heart failure, COPD and renal failure) and a focus on community based anticipatory care and improving care in acute hospital settings is also required to improve palliative and end of life care for this group.

Data on the management of people in the palliative phase of a non-malignant illness will increasingly become available through schemes such as the Directed Enhanced Service (DES) for Palliative Care in General Practice, Locally Enhanced Services (LES) in General Practice, and the implementation of the Liverpool Care Pathway across care settings in Lothian. This data will be used by the Palliative Care Managed Clinical Network in Lothian to inform and develop service improvement plans which will be taken forward as part of the implementation of this strategy.

Table 2 in Appendix 3 provides an analysis of deaths in selected locations associated with palliative care in Lothian. Many deaths in these settings are deaths from a non-malignant cause, and further improving palliative and end of life care in these settings should be a major focus to ensure the provision of high quality palliative care beyond cancer.

Common pathways in palliative and end of life care are well understood for cancer related palliative care however in order to improve how we co-ordinate work across the whole system, particularly for non-malignant conditions, we would benefit from further specifying our pathways. This includes better identification of key issues around care management, transfer and handover points, and triggers for increasing care and services quickly when the need for palliative care increases. The research programme led by the University of Edinburgh Primary Palliative Care Research Group is helping to take this forward in

Lothian. The implementation of this strategy also provides an opportunity to further develop our understanding of pathways in palliative care, and to assess which areas require support for quality improvement, and to create initiatives to provide that support.

4. INTRODUCTION

Challenges in palliative care, and new concepts and models

For most of our lives health care is directed towards increasing length of life and improving quality of life. Palliative Care begins at the point in a person's life where these aims are not both achievable and choices may need to be made.

Identifying when a person reaches the palliative phase of their illness is difficult. Predicting prognosis in cancer care is difficult despite this being the area in which most palliative care provision has been focussed historically. Predicting prognosis in diseases such as heart failure and dementia is significantly more challenging, especially trying to predict when a person may be in their last year of life. However identification of people who are approaching the palliative phase of illness is crucial. It provides the opportunity to raise questions and issues about dying, to educate about the expected illness course, to begin to refocus care more onto supportive and palliative care, and to address concerns and fears about dying. Improving how we do this requires the recognition of a new approach that acknowledges that palliative care is triggered not by a specific prognosis but rather by the recognition that someone is *ill enough that death would not be unexpected or surprising*. This strategy embraces that approach and aims to support improvement to our abilities, right across the health and social care system, to recognise when an individual needs palliative care.

Delivering palliative care to all who require it relies on the work of a wide range of professionals in many disciplines, specialities, settings and organisations all across Lothian. Most palliative care is provided not by specialists in palliative care but rather by generalists for example GP's and community nursing teams (in and out of hours), and Consultants, nurses and allied healthcare professionals in hospitals. Social care teams including social workers, home care and care home staff are also central to the provision of good quality integrated palliative care. These professionals work across the entire spectrum of care: from providing care with a curative aim to managing chronic disease and long term conditions. They need clear systems, advice and support to assist them in recognising the need for palliative care planning, and co-ordination of high quality palliative and end of life care.

Health care delivery is likely to become more complex due to improvements and advances in healthcare, increasing survivorship from cancer, lengthening life expectancy, and changing social demographics. In Lothian we will face increasing challenges posed by the growth in the number of older people as a proportion of the Lothian population. More people will be living with long term health conditions and will have multi-morbidities. Because of these factors, this strategy proposes a model of palliative care which will support the integration of disease modifying treatment and palliative care. It will do this by breaking down palliative care planning and delivery into 3 tiers:

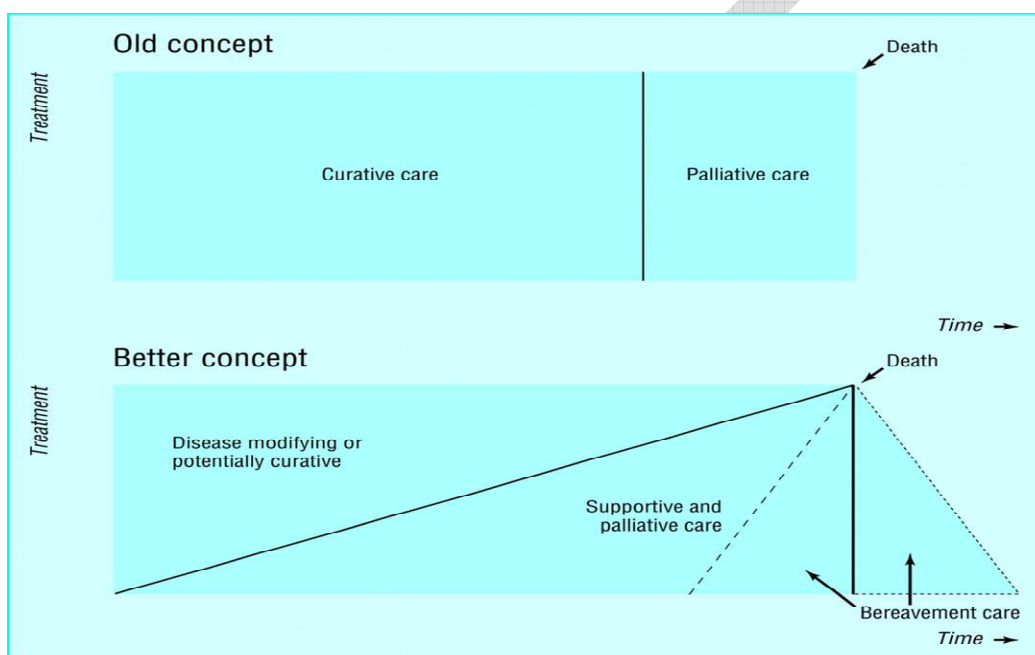
- Working with people with **Long Term Conditions** to make sure that the need for palliative care is identified as part of routine care at the earliest stage appropriate, helping people to plan, direct and be actively involved their own care.

- Adopting the **Palliative Care Approach** from as early a stage as is agreed appropriate. The palliative care approach seeks to maximise quality of life, by maintaining good symptom control, offering holistic assessment including family and carers needs, and seeks to agree choices around treatment options, place of care and preferred place of death.
- Planning for and managing **end of life care** in the last days of life in a tightly coordinated and structured manner.

Chart 1 below illustrates the integrated care which this strategy aims to support¹³

Chart 1:

Palliative care approach early, at diagnosis of life-threatening illness.



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5. HOW THIS STRATEGY HAS BEEN DEVELOPED

Drawing on the network and the strategy steering group

Lothian has an effective Managed Clinical Network for Palliative Care which helps to harness, synthesise and apply the wide range of work being undertaken across different settings. Representation from across this wide network was drawn upon to form a strategy steering group (appendix 1).

The strategy was developed concurrently with the production of the Lothian Living and Dying Well Delivery Plan which was submitted to the Scottish Government in March 2009.

¹³ Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005; 330:1007-1011.

The strategy has been jointly developed with Lothian Independent Hospices (Marie Curie Hospice Edinburgh, and St Columba's Hospice). An overview of the strategic direction of both Lothian Independent Hospices is outlined in appendix 5.

Review of Needs Assessments undertaken in Lothian and the literature on palliative care needs

Lothian is fortunate to have extensive local research on the palliative care needs of people with both malignant and non-malignant conditions. The findings of this and previous needs assessments have been synthesised and used to inform strategy development. The key findings are outlined in supplementary report number 1.

Engaging stakeholders

A palliative care stakeholders' event in January 2009 was attended by health and social care professionals from across Lothian. Additionally in March 2009 a workshop for carers was held in association with VOCAL. The following themes emerged from the events:

- Ensuring equity of access
- Effective co-ordination of Care
- Improving communication including communication between professionals
- Providing better support for carers
- Supporting choice in preferred place of care (PPC) and preferred place of death (PPD)
- Advice, support and information for patients and carers
- Increasing access and support for Community Care
- Better planning of complex discharges
- Respite care
- Recognition of generalist palliative care
- Providing education and training opportunities
- Changing culture
- Developing a health promoting palliative care approach

The reports from these events were developed with feedback from workshop participants, circulated to all delegates and any other interested people, and have been used to inform the development of this strategy. A range of supplementary reports have been written-up to support this strategy document and supplementary reports number 2&3 outline full details of the outputs from the events.

6. OUR VISION

Our **vision** is for high quality Palliative and End of Life care available in all settings, utilised by all who require it, and prioritised according to the patient's need, rather than medical condition. By 2015 clinical teams in all settings across Lothian will be reliably identifying and assessing patients as they reach a palliative phase of their illness, and developing and updating integrated care plans for them and their carers, based on patients and family preferences. More people will die in the place of their choice.

Our **aim** is to ensure access to high quality Palliative Care to all who need it, irrespective of diagnosis, age, gender, ethnicity, religious belief, disability, sexual orientation, and socioeconomic status.

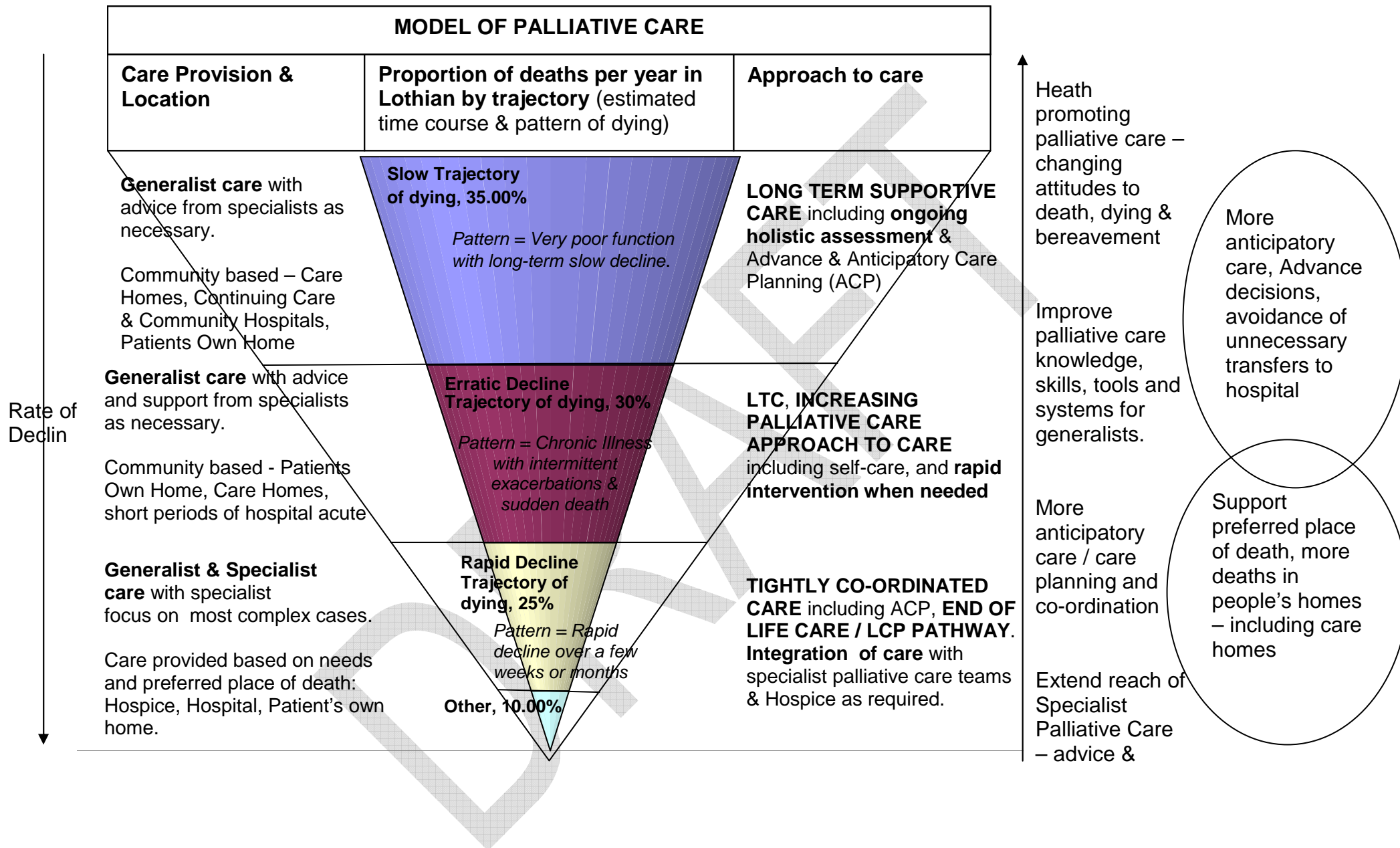
We have identified through local research, audit and public involvement eight **key challenges**:

1. To improve care for people living with any life limiting illness
2. To have in place clear processes in all care settings for identifying people who are in the palliative phase of their illness
3. To provide palliative care and support throughout the palliative phase rather than just in the terminal stage.
4. To provide high quality integrated palliative care to more people in the setting of their choice, including support for preferred place of death
5. To better care for all aspects of the person, physical, psychological, social, spiritual and to improve patient experience
6. To have effective systems to share information, between the people involved in a patient's care
7. To provide people with optimal care in the last few days of life
8. To promote community involvement and a public discourse about death and dying

7. MODEL OF CARE

Our proposed model of palliative care is illustrated in the schematic overleaf. This model supports the integration of curative and disease modifying care with palliative care¹⁴. It focuses on 3 tiers of palliative care planning and delivery: Managing within Long Term Conditions; Taking a Palliative Care Approach to care; and managing End of Life Care. The model utilises recognised 'trajectories' of dying' to help inform the associated approach to care that is required.

¹⁴ Disease-modifying means treatment to delay, change, or interrupt the natural course or progression of a disease



8. WHAT WE HAVE ALREADY COMMITTED TO DO

Palliative and End of Life Care Delivery plan

NHS Lothian has produced its Living and Dying Well Delivery Plan for 2009 – 2011 (Supplementary Report number 4). This forms part of the Lothian Palliative Care strategy, and provides a focus to development and implementation in the first 2 years of the strategy term. Our Delivery plan is centred on:

- Ensuring that we develop, introduce and use recognised tools & triggers to support the identification of palliative and end of life care needs across all care settings
- Ensuring appropriate assessment and review of identified patients in all care settings
- Ensuring timely, holistic and effective care planning is available for those with palliative and end of life care needs
- Ensuring that people with palliative and end of life care needs are included in primary care palliative care registers, and have their care and that of their carers co-ordinated
- Improving the NHS Lothian Community Pharmacy Palliative Care Network to ensure in and out of hours access to specialist palliative care medicines
- To improve information provision via the development of an information directory for use by health and social care professionals and by patients and carers
- Continuing to develop and implement our integrated 'Do Not Attempt Resuscitation' (DNAR) policy for palliative care in all settings.
- Supporting more care at home, NHS continuing care units and in care homes, including reliable access to appropriate equipment required for the care of those wishing to die at home
- Improving the transfer of patient information between the professionals involved in care, for any patient identified as having palliative and end of life care needs and who gives consent
- Continuing to develop palliative and end of life care education for health and social care staff in Lothian
- Improving commissioning and monitoring arrangements in palliative care service provision to ensure value for money

Lothian Palliative Care Managed Clinical Network Bed Capacity Review

In 2008/2009 the Lothian Palliative Care Managed Clinical Network completed a review of Specialist Palliative Care Bed Capacity. The key recommendations from the review include:

- The development of further community based models of delivering palliative care to all who need it
- Retention of the specialist bed resource and improved use of these beds
- The development of clear hospice catchment areas and zoning arrangements
- The development of alternative ways of providing specialist palliative care bed capacity and providing specialist input to support beds in other specialties
- The need to consider and pilot use of specialist beds for non-cancer palliative and end of life care

- The development of the Palliative Care MCN to agree and monitor whole-system goals around place of care and death
- To improve hospice commissioning and value for money
- To support Community Health Partnerships in developing models of access to generalist and specialist palliative care
- To develop models of generalist palliative care provision in hospitals; and to improve the capture and use of data

The full recommendations are outlined in appendix 2. The Bed Capacity Review report is available as Supplementary Report number 5 to this strategy document.

Lothian Response to Audit Scotland

In August 2008 Audit Scotland published its *Review of Palliative Care Services in Scotland* -the findings of its audit into the delivery of generalist and specialist palliative care services across Scotland. Included in this report was a self assessment for NHS Boards to complete. NHS Lothian used the findings of this self assessment to prepare a response to the Audit Scotland report, this can be found in supplementary report 6. Subsequently, many of the actions within this response have been incorporated into Living and Dying Well Delivery Plan.

9. OBJECTIVES OF THE STRATEGY

Identification of Patients with Palliative Care Needs

The key to providing appropriate palliative and end of life care is to identify those likely to benefit from it. There is a need to move away from expecting a clear prognosis towards recognising a time when a palliative approach to care is needed.

This may be through:

- criteria set out in an updated 'Prognostic Indicator Guide'
- using SPARRA data, as increasing frequency of admission often indicates a move to a palliative phase
- The surprise question (clinicians would not be surprised if the patient were to die within the next 12 months)
- diagnosing dying (recognising when a patient is in the last few days of life)

Through this strategy, to improve identification, we aim to:

- Collaborate closely with education providers to increase awareness of the concepts of trajectories of dying and palliative phase of illness, rather than link palliative care to either prognosis or diagnosis exclusively.
- Promote the use of the Prognostic Indicator Guide (or improved indicators as they become available) to identify people in a palliative phase of illness.

- Work with secondary care clinicians in hospitals to identify people who may benefit from palliative approach on discharge and communicate this information to G.P and primary care services.
- Support the Directed Enhanced Service (DES - Palliative Care) in General Practice to identify as many people as possible in the palliative phase of illness.
- Introduce the Liverpool Care Pathway in all settings to support identification and co-ordinated care for those in their last few days of life.

Assessment and Care Planning

Identifying people who are in the palliative phase of their illness allows this important information to be shared with the patient and family. This requires good clinical judgement, skill and sensitivity to avoid unnecessary distress as there will be some people who do not wish to consider a palliative approach to their illness. The key benefits of early identification and good end of life care planning are:

- A change of emphasis of care
- Planning for the future
- Identification of spiritual/existential issues
- Allowing a family to do and say important issues
- Potential for decisions about medical interventions in the future
- Acceptance that some treatments will not work
- Exploring preference for place of care and death

Through the implementation of this strategy we aim to improve our assessment and care planning processes in Lothian to help deliver these benefits.

Planning to improve care for people through the use of recognised trajectories of dying

The use of the trajectories framework helps us to identify common needs and patterns of care. Outlined below are case studies, and descriptions of the key issues and components of care required in each trajectory we have identified, and the main areas for development. Many aspects of the good care outlined in the case studies is already in place in Lothian, and focussing on areas for development will improve care further.

Improving care for people on an erratic decline trajectory

This trajectory comprises episodes of very significant ill health followed by periods of relative well-being. It is typified by organ failure diseases such as heart failure, COPD and renal failure with a large overlap with long-term conditions. People on this trajectory receive care in all care settings.

Case study

Mrs. R is a 62 year old woman who has had emphysema for 15 years. She is always breathless and can't remember the last time she felt 'well'. In the last year she has had four admissions to an acute hospital with worsening breathlessness, lasting up to 3 weeks. She is now mostly housebound and becomes breathless several times a day. She is on a host of medicines and these are kept in balance by her General Practitioner with the support of the respiratory nurse specialist. The district nurses visit regularly.

Unfortunately she found her last admission to hospital difficult and, although the care had been excellent, she felt she had come home little better than before she went in. She does not wish to go in to hospital again. She recognises that she will get worse in the future and wants to die at home. Her daughter, who visits regularly, understands and accepts her views.

Mrs. R's illness has a prognosis worse than many cancers but her precise length of life is impossible to predict. She is almost as likely to live six months as she is to die in a week. She will become more unwell again at some point and traditionally would be admitted to hospital for acute treatment. She and her daughter want to know if there another way for her and her care team to plan and manage her care which more closely matches her wishes and provide some form of "palliative" care?

Her GP and Community Nurse confirm with her that resuscitation would not be successful and give her a DNAR form to keep at home. They discuss the potential for keeping Mrs. R at home if she becomes unwell in the future. They confirm with her that she would not wish more treatment than she could have at home. They discuss medicines for managing symptoms at the end of life and arrange for these to be kept at home.

All of this information is discussed with her daughter and the plan of care is recorded in her GP notes and communicated to the Lothian Unscheduled Care Service.

The next time she gets more breathless she is treated with antibiotics and steroids and, instead of being admitted, additional care is provided at home. She improves and gets back to something like her usual level of function.

She has a further 6 episodes of deterioration over the next 18 months, during this time her care management is transferred to the District Nurse and a shared health and social care package provides care allowing her daughter to continue to work.

There are two possible endings in this case:

Scenario 1:

The next time she gets unwell, the situation does not improve and she is increasingly distressed by her breathing even with increased medication. She becomes sleepier and both she and her daughter feel that she requires someone with her all the time. Her daughter stops work to look after her. Injections of symptom relieving medicines are prescribed and the community nurses increase visits to administer these; neither Mrs R or her daughter wish to be involved in the administration of injections. The Marie Curie Nursing Service provide two nights of support, during the night Mrs. R condition deteriorates. The out of hours doctor visits and, because she is aware of the plan of care, they decide to start a syringe driver with medicine to keep Mrs. R comfortable. The District Nurses visit during the day, evening and overnight and she dies peacefully at home a few days later. The District Nurses verify the death and visit Mrs. R daughter to provide bereavement support.

Scenario 2

The next time she becomes unwell the situation does not improve and she is increasingly distressed by her breathing. She is prescribed medications to calm her breathing and relieve her distress, however in discussion with her GP, District Nurse and daughter Mrs. R decides that she wishes to be admitted to hospital. Her electronic palliative care record (ePCR) is accessed and understood. She does not improve and the doctors confirm that more intervention (ventilation etc.) will not improve her condition. Her symptoms are managed by the ward team with the help of the Lothian Palliative Care Guidelines and she dies peacefully in hospital after three weeks of good care.

Key components of this model of care are as follows:

- Recurrent admissions to hospital and reduction in function lead to the recognition that the patient is in a palliative phase of illness.
- Case management, especially if identified through SPARRA
- Palliative phase is agreed between secondary and primary care and communicated to patients, carers and the wider healthcare team.
- The person is entered onto palliative care register in general practice (providing the opportunity for holistic assessment, care plan, OOH communication, DNAR)
- Specialist palliative care teams are available to support GP and DN to address care needs, preferred place of care, end of life choices and wishes etc.
- Intermittent episodes of deterioration allow opportunities for end of life planning, but the unpredictability often causes distress and confusion.
- Deterioration causes changing care needs which trigger a review of care needs, via a shared health and social care assessment.
- Additional support at home may be required, and Marie Curie Nursing Service support may be offered as required
- Variability may create a difficulty in recognising the dying phase. The opportunity for Liverpool Care Pathway instigation may be missed.
- Liverpool Care Pathway triggers anticipatory prescribing, reassessment of patient and carer needs including preferred place of care, clarification of DNAR, and OOH contact information for family.
- Death at home expected and supported, with perhaps nurse verification of expected death.
- Bereavement support is required

The main areas for development are:

- Improvement in identification
 - through agreeing tools and triggers
 - education in all settings
 - developing systems for identification in secondary care and communication between primary and secondary care
 - finding appropriate ways to share information with patients and family
- Care planning
 - education in all settings
 - clarifying role of specialist services in supporting those with complex needs
- Improving links between specialist palliative care and long-term conditions' services.
- Development of the Marie Curie Nursing Service role for people on the erratic decline trajectory
- Implementation of Liverpool Care Pathway in all settings
- Monitoring shift of care from hospital to community setting

Improving care for people on a rapid decline trajectory

These patients are mainly cancer patients and the palliative phase of their illness has traditionally been easier for professionals to identify. Non-cancer patients on a rapid decline trajectory are currently seldom recognised until the last few days or hours of life and currently tend to die in the acute setting.

Case studies:

Sam

Sam is 54yrs old with a wife of 40 and 4 children (2 from previous marriage now seldom seen). He was diagnosed with squamous lung cancer following chest x-Ray which was arranged for cough and haemoptysis.

He has had radical radiotherapy treatment and is hopeful of several years prognosis.

3 months later admitted to oncology with jaundice and weight loss – ultrasound shows liver metastases (prognosis now weeks to months). Palliative phase identified by oncology team. Issues of poor prognosis and preferred place of care discussed. Lung Cancer nurse specialist discusses issues of concern for Sam including psychosocial needs, will and financial planning, and opportunity for contacting 2 children from previous marriage.

Discharged home to care of GP (primary health care team). GP contacted by phone by oncology team to update on palliative care needs and likely prognosis. Placed on GP practice palliative care register and palliative advance care planning starts. Other members of the primary healthcare team made aware of situation via the practice palliative care meetings. GP visits to discuss preferred place of care, actual and potential care needs, DNAR decision, and arranges for DNAR form to be left in the house.

Sam was independent and self caring at the time of discharge but becomes more fatigued and increasingly dependent over next three weeks. DN and GP facilitate ongoing care and discussion of end of life issues, wills, financial planning issues, and family issues. Electronic Palliative Care Summary (E-PCS) information uploaded as the care plan evolves. Family given contact numbers and information on how to contact GP and DN during the day and out of hours.

Sam's wife calls NHS 24 because he has increasing abdominal pain. Initial analgesics result in confusion and hallucinations. The GP contacts the hospice for telephone advice from specialist palliative care and to make a referral. Symptoms settle with medication changes.

District nurse organises equipment and additional care for Sam. Marie Curie Nursing Service arranged to compliment the DN input and provide additional support for family. The Community Palliative care nurse specialist (from the hospice) visits to ensure effective pain and symptom control is achieved and offer additional psychosocial support.

Sam continues to deteriorate over the next couple of weeks spending more time in bed. He is increasingly struggling to take oral medication. DN discusses deterioration with GP. They decide Sam is dying and agree there is benefit in starting to use the Liverpool Care Pathway. Medications changed to syringe driver and anticipatory medications are put into home with prescription. The Electronic Palliative Care Summary is updated and the palliative care register care plan details the change.

A sudden flare in pain prompts a call to the out of hours District Nurse service who visit and give breakthrough medication. Sam becomes confused and agitated and DN contacts the out of hours emergency medical service (LUCS). The out of hours GP visits and using Lothian Palliative Care Guidelines changes medication. When DN visits the next morning symptoms are still not effectively being managed, DN contacts the GP who decides to seek advice from specialist palliative care consultant. Medication changed using anticipatory drugs available in the house. Offer of hospice admission if agitation does not settle with change to medication. Sam dies peacefully in the early hours of the next morning with his family around him.

Sam's family contact the OOH DN who verifies death and the GP visits later that morning and leaves family with death certificate, written information, and an offer of bereavement contact. DN visits 2 days later to offer

bereavement support and organise equipment uplift. Community palliative care specialist nurse phones Sam's wife to offer support.

George

George is 54yrs old with a wife and 3 children. He had an MI (heart attack) 3years ago followed by stenting treatment and full recovery.

Some time later he presents with further MI – causing extensive cardiac damage and resulting in severe cardiac failure. He is nursed in Critical Care Unit (CCU) with invasive treatment and monitoring. He is stable enough to return to the ward after 8 days but bedbound due to breathlessness. There is no response to maximal medications and gradual deterioration in condition over next two weeks. Heart Failure Nurse specialist and medical team identify poor prognosis and palliative nature of condition using Prognostic Indicator Guidance. Issues of prognosis, preferred place of care, and psychosocial support are discussed with George and his family.

George is keen to be at home so an integrated health and social care package is set up, and equipment is delivered to the home. GP and DN informed and George is discharged home to remain in bed. Discussions about ePCS and DNAR form prior to discharge, and a DNAR form goes home with him in the ambulance. Seven day supply of medication plus anticipatory drugs are sent home on discharge also. A medication card is provided.

GP puts George on the practice palliative care register and a care plan and ePCS information is completed. George's family has contact numbers for the GP and DN, for daytime and out of hours services. DN assesses his care on ongoing basis and increases the number of visits accordingly. George remains bedbound and at home over the next two weeks. His breathlessness worsens and George struggles with oral medication. A syringe driver is commenced and George settles and remains at home. The community palliative care specialist nurse visits to support effective symptom management, and to offer psychosocial support.

George's wife calls NHS 24 because of sudden onset of chest pain and worse breathlessness. The GP manages pain with additional medication in light of ePCS information, and George remains at home. George dies peacefully in the early hours of the next morning. DN visits to verify death and the GP from his practice visits later in the morning to complete the death certificate. Bereavement support offered by GP / DN and community specialist palliative care nurse.

The key components of this model of care are as follows:

- Sudden event or a test result allows recognition of irreversible decline from which there is little or no chance of improvement
- The palliative phase is recognised and communicated to the patient, carer and wider healthcare team
- The patient is placed on the palliative care register in general practice (providing the opportunity for holistic assessment, care plan, OOH communication, DNAR)
- Rapid deterioration allows frequent opportunities to explore end of life wishes and choices
- Deterioration causes changing care needs which trigger a review of care needs, undertaken by health and social care. An increasing amount of care is likely to be provided by the Community Nursing Service
- The Marie Curie Nursing Service may be considered to support the family
- Rapid deterioration linked with symptom control issues may trigger GP or District Nurse to seek specialist palliative support
- If required specialist palliative care teams work with GP and DN to provide intense period of support to address symptom control, psychosocial issues, finance, care needs, preferred place of care, end of life choices and wishes etc. and to ensure communication across teams and OOH
- Continued expected deterioration allows easy recognition of the dying phase – and therefore the commencement of the Liverpool Care Pathway (LCP).

- LCP triggers anticipatory prescribing, reassessment of patient and carer needs including preferred place of care, clarification of DNAR form and OOH contact information for family.
- Death at home expected and supported
- Bereavement support offered.

Improving care for people on a slow decline trajectory

This is the largest and most challenging trajectory as for people in this group decline occurs over the course of a number of years. It is best exemplified by the elderly frail, people with dementia, neurological conditions, and those with multiple co-morbidities. Often patients merge into a palliative and end of life phase of their illness without this being specifically recognised and identified.

Most of the time people in this group will live in the community: their own homes, care homes and NHS Continuing Care units. They will be supported by family and or informal carers and a range of social and health services; including free personal care, social care and or an integrated social and health care package. One of the main challenges for this group of patients is identifying when they enter a palliative and or end of life phase of their illness, and finding appropriate ways to share that information with patients and family.

Case study

Jessie is an 85 years old widow with no family. She has Parkinson's disease, diabetes and had breast cancer many years ago. For the last 6 years, after her husband died, she has managed to live at home with the help of a mixed social and health care package, her neighbours and support from the Parkinson's Nurse Specialist.

Over the last few months the carers and neighbours have noticed that Jessie has not been eating as much and she has lost quite a lot of weight, her mobility is not as good and the carers are increasingly have to use the hoist to transfer from bed to chair. Jessie used to be able to wash and dress with some help but now the carers have to do this for her. Her medication doesn't seem to be working as well as it did despite input from the GP and the Parkinson's Nurse Specialist.

Jessie fell and was admitted to hospital. Whilst in hospital she expressed concern about her ability to remain at home. A multidisciplinary assessment was undertaken and care home placement arranged. On admission to the care home Jessie was assessed by the GP and the care home staff, they used the Surprise Question and Prognostic Indicator Guidance and they agreed that Jessie was probably now in her last year of life, they agreed to review this every two months or if there was deterioration in Jessie's condition. An anticipatory care plan was written and this included details of the 'living will' written by Jessie. As Jessie had indicated that she did not want life-prolonging treatment and due to her general frailty a DNAR form was completed.

Jessie was well for the next ten months and during this time the care home staff helped Jessie to get her finances in order, discussed funeral arrangements. Jessie quickly deteriorated, when the care home staff and GP repeated the Surprise Question all agreed Jessie was in last weeks / days of life. The District Nurse visited the care home to assess Jessie and offer support to the care home staff to provide end of life care and to use the Liverpool Care Pathway. Jessie died six days later in her room in the care home, where she had wanted to die. The care home staff spent time with the other residents who were upset by Jessie's death, some of the residents and staff went to the funeral.

Key components of this model of care are as follows:

- Care often provided by families and informal carers for long periods (years) and respite needs should be assessed.
- Care may be supplemented by social and or health care via a simple or complex care package.
- A few people may require NHS Continuing Healthcare
- Services may be for prolonged periods but not necessarily for life, subject to regular review.
- The palliative phase of illness is recognised and communicated to patients, carers and wider healthcare team.
- The person is entered onto the palliative care register in general practice (providing opportunity for holistic assessment, advanced care planning including anticipatory care plan, preferred place of care, end of life choices and wishes, OOH communication, DNAR).
- The need for specialist palliative care is likely to fluctuate during course of illness
- Opportunities should be used to discuss end of life planning as early in illness trajectory as possible, as over time the person may increasingly lose the capacity to be as involved in their care planning directly
- Slow decline creates difficulty in recognising the end of life phase and the opportunity for Liverpool Care Pathway may be missed.
- LCP triggers anticipatory prescribing, reassessment of patient and carer needs including preferred place of care, clarification of DNAR, OOH contact information and Nurse Verification of Expected death.
- Marie Curie Nursing Service support may be offered to support those being cared for at home
- Death in preferred place: own home, care home, NHS continuing care unit expected and supported.
- Bereavement support offered

The main areas for development are:

- improvement in identification
 - through agreeing tools and triggers
 - education in all settings
 - developing systems for identification of palliative care and end of life phase
- advanced care planning
 - Lothian wide anticipatory care template implemented
 - Supported self management
 - Education in all care settings
 - Supporting the assessment and management of incapacity with reference to legal frameworks
 - Clarifying role of specialist services in helping complex care planning and care delivery to those with non-malignant diagnosis
- Improving links between specialist palliative care, care home and NHS continuing care units,
- Developing the Marie Curie Nursing Service role for people with non-malignant disease on the slow decline trajectory and in the care home setting
- Implementation of Liverpool Care Pathway in all settings

Dementia

Anticipatory and advanced care planning present particular challenges for people with dementia, especially since comparatively few receive a diagnosis early in the condition. Dementia Services in Lothian are actively promoting palliative care for people with dementia. The development of an integrated care pathway for people with dementia includes sections on advance care planning and the use of the Liverpool Care pathway for end of life care.

The Scottish Government Health Department has funded the Dementia Services Development Centre (DSDC) at the University of Stirling to run a two-year programme in Lothian to develop measures that can improve the care and support provided to people with dementia. The program has already identified palliative care as a key area for improvement. As a result the programme will aim to develop advance care planning and assessment of the needs of patient with dementia as part of pathway development work. NHS Lothian has also developed a training Course (2 days) 'Palliative Care for People with Dementia', which is open to staff from all care settings.

Minority Ethnic Health Needs

Research completed in central Scotland and published in February 2009 concluded that most [palliative care] services struggled to deliver responsive, culturally appropriate care¹⁵. Other research has highlighted the different needs of black and minority ethnic (BME) groups. For example, BME groups may have different belief systems and cultural values and many may have different religious beliefs which have implications for the delivery of end of life and bereavement care.

Work with BME communities, for example the Securing Care for Ethnic Elders (SCEES) project, has included listening events in partnership with the Lothian hospices, and has found that there are a range of issues which impact on BME patients and carers being able to access palliative and end of life services. Some of these are relevant to all health and social care services, for example the provision of culturally sensitive food – (e.g. halal or kosher). Others issues are specific to palliative and end of life care, for example, families may have different cultural approaches to discussing end of life issues and may perceive hospices to be culturally inappropriate. This strategy recognises that services must deliver culturally sensitive care that responds to the needs of all patients and their families, and seeks to support this by ensuring our aims to improve systems of identification, assessment, care planning and review are taken forward effectively for all.

¹⁵ Worth et al (2009) *Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study* BMJ vol 338 p526- 530

Supporting and Improving Care in Care Homes in Lothian

Providing support to care home teams to help them better identify, manage and co-ordinate palliative care with their residents, as required, is an important objective of this strategy. We have experience, through the Midlothian Gold Standards Framework for Care Homes project, of a scheme that helps to improve the focus on palliative care, build interest and knowledge amongst the care home team, and improves co-ordination of care¹⁶. This type of structured approach to working with the care home providers, with joint engagement of health and social care staff, needs to be developed and applied across the care home sector in Lothian. Successfully implementing this will require effective partnerships and joint resourcing.

The *Anticipatory Care Enhanced Service for Patients in Care Homes for Older People* was introduced in April 2008. This is a Locally Enhanced Service (LES) running under GP contracting arrangements. The aim of the new contract is to ensure a more systematic and integrated approach to service provision in a number of core areas: patient records; assessment and care planning; liaison and communication; and additional 'Lead GP practice' responsibilities. 112 GP practices in Lothian are participating (at April 2009) covering 113 care homes and a total of 4008 patients. A recent evaluation showed that overall there was a significant reduction in emergency admissions to hospital.

A Lothian Care Home Providers Palliative Care Reference Group is chaired by our Lead Nurse for Cancer and Palliative Care. The group has a remit which includes development of collaborative relationships between independent providers, Local Authorities, NHS, and specialist palliative care providers and to promote high quality palliative care of people in the care home setting.

A key action in implementing this strategy therefore will be to develop further linkages and support schemes with care homes, harness support from our specialist palliative care services, and build the relationship with providers to help specify and take forward improvement work.

Supporting and Improving Care in General Practice and Community Health Partnerships

Eighty three percent of Lothian General Practices now participate in the Palliative Care Direct Enhanced Services (DES) to support the development of palliative and end of life care within primary care. This scheme covers all people registered with a participating general practice in Lothian, including residents of care homes. The DES started effective November 2008. The focus of this DES is identification of patients, registering patients on the practice Palliative Care register, and developing clear care plans for those people including communication with unscheduled care services.

Community Health Partnerships plan to support the implementation of this strategy, and Living and Dying Well, through the establishment of multi-agency working groups. These groups will have an operational management focus and partnership approach. They will provide a vehicle to develop further joint working and specifically care co-ordination and case management and build upon work being progressed via the Long Term Condition Agenda, and Shifting Balance of Care.

¹⁶ The Midlothian 'Gold Standards Framework in Care Homes' project, Dr Jo Hockley, Julie Watson, Professor Scott Murray

Respite care

People living with long term chronic conditions often require assistance from family to carry out activities of daily living. A person in the erratic or slow decline trajectory of dying may require support and care provided by family members on a regular basis for many years and this needs to be recognised. Carers have identified the need for respite care that is provided in the right setting and by carers with the right skills and knowledge. As part of consulting on this strategy, and in the early stages of implementation, we will assess the adequacy of current respite arrangements in Lothian in relation to Palliative and End of Life care and consider what may be required to improve care. This will be taken forward in conjunction with the work of our other strategic programmes, for example the Older People's programme.

Supporting and Improving Care in Hospitals

The acute hospitals in Lothian play an essential part in the provision of palliative end of life care. The diagnosis of a life-limiting illness is commonly made and communicated to the patient and their family in this setting. Episodes of inpatient and out patient care may be required for assessment and treatment throughout the palliative phase of the illness. This can include investigations and interventions for managing difficult symptoms which cannot be provided or initiated within the community. In addition, many people die in hospital. During 2004-2008, over 40% of deaths in Lothian occurred at the Western General Hospital, Royal Infirmary of Edinburgh and St. Johns Hospital.

Yet, delivering holistic palliative and end of life care within the busy, acute hospital environment, where the main emphasis is disease modifying and curative treatments presents a number of key challenges. This includes ensuring continuity of care, particularly where people move across different clinical areas and are cared for by a number of professionals.

A key aim of this strategy is to avoid people being re-admitted to hospital where good advance care planning could have avoided this, and reduce the number of deaths in hospital for those who would prefer to die at home. Equally, we recognise the need to address the challenges to delivering high quality palliative and end of life care within Lothian hospitals for the significant number of people for whom admission is appropriate, and for those who choose to die in this setting.

The Lothian Living and Dying Well implementation plan outlines how we plan to do this;

- An acute hospitals working group will provide local focus to delivering key actions of Living & Dying Well. Representation from Clinical Management Teams, key clinicians, AHPs, specialist palliative care, Continuous Professional and Practise Development (CPPD) and Clinical Governance teams will support a collaborative approach across different clinical specialties and integrate palliative care within hospital processes and systems.
- We will support clinical teams to identify and address palliative and end-of-life care needs by implementing standards and tools for generalist palliative care in hospitals, including the Lothian Palliative Care Guidelines, Liverpool Care Pathway and those being developed by the national Living & Dying Well project groups.

- We will explore ways to effectively communicate a patient's diagnosis, transition to the palliative phase of their illness or ongoing palliative care needs to the primary care team on discharge. This will facilitate ongoing assessment, review and continuity of care across settings.

We will develop solutions to ensuring access to education for professionals and staff which is relevant to the key challenges of providing high quality palliative and end of life care within the hospital setting.

We will strengthen the capacity of our hospital palliative care teams to extend a specialist service to people with non malignant life-limiting illness, their families and professional teams.

Improving care for children and adolescents with palliative care needs

Responding to the needs of children with any life limiting illness involves consideration of the specific needs of children as distinct from the needs of adults with life limiting illness. Children and young people have specific medical, healthcare and psychosocial needs and medical conditions often require management over number of years. Children are growing and developing emotionally and physically; their level of understanding will vary; their lives include the added dimension of education as a statutory requirement; they will be largely depended on their families for their every day needs and they may have siblings whose lives will also be significantly affected. This raises challenging issues such as managing transition to adulthood, clinical assessment and review, and when to introduce an approach to care that is more focussed on palliative and End of Life care. Family, carers, friends and peers are all affected and care plans need to respond the needs of all of these people.

NHS Lothian's previous palliative care strategy, developed in 1998, recognised the distinct care co-ordination needs of children and young people. It also highlighted the need to take account of children's continuing emotional, psychological, spiritual and cognitive development which affects communication and understanding of their illness and death.

Our recent work with health and social care professionals in children and young people's services, to inform the development of this strategy, has confirmed that the issues outlined above should form part of the planning to improve care in Lothian. Specific areas highlighted by stakeholders in Lothian included:

- Supporting choice of place of care and death
- Effective co-ordination of care
- Developing palliative and end of life care services that can respond to the specific needs of children and young people
- Education and training
- Supporting families

It was also recognised that much of the overall framework for adult palliative care, and the development of systems and tools to support improvements in practise, were relevant and could be adapted for use with children and young people.

Managing the transition for adolescents into adult services can be particularly important however. Transition is: *'a purposeful, planned process that addresses the medical,*

*psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult orientated health care systems.*¹⁷ Children's services within Lothian are working in partnership with the Scottish Children & Young Peoples Palliative Care Network (SCYPPCN) to take forward development and quality improvement work. In the hospital setting the Association of Children's Palliative Care 'ACT Pathway' standards will be used to develop multi-agency care pathways and transition care arrangements for children with life limiting illness. The ACT Transition Care pathway provides clear guidance for develop appropriate Transition pathways.

In addition NHS Lothian's Living and Dying Well Delivery Plan contains actions specific to developing children's palliative care. These include:

- Conducting an End of life Paediatric Services Audit in 2009/10 to establish a baseline position against which to assess development priorities
- Development of a Do Not Attempt Resuscitation policy within the paediatric setting in 2009/10
- Explore the gap in OOH Community Children's Nursing Provision and develop proposals to improve future provision
- Education and development of staff to ensure health and social care professionals are equipped with the knowledge, skills, competence and confidence to care for children and young people and their families living with and dying from any advanced, progressive or incurable condition

Redesigning palliative care pharmacy services

Speedy and equitable access to appropriate medicines for symptom management is key to the success of a range of elements of the strategy. This requires both appropriate anticipatory prescribing and an equitable and sustainable out of hours palliative care pharmacy service across Lothian.

Anticipatory prescribing will be supported through information in the Lothian Palliative Care Guidelines and through implementation of the Liverpool Care Pathway. The palliative care Directed Enhanced Service promotes the use of anticipatory care plans and anticipatory prescribing. This work, particularly with care homes, will promote palliative care planning and includes the provision of anticipatory care drugs. The existing NHS Lothian Palliative Care Pharmacy network will be reviewed to provide access to medicines at all times in order to support this initiative.

Additional specialist palliative care pharmacy resource will support enhanced communication with primary care teams and community pharmacies by providing advice on the safe and effective use of medicines verbally and by written information. There will be a smoother transfer of pharmaceutical care issue from the acute hospitals to the community settings, and increased opportunities for education and training on pharmaceutical issues to a range of health professionals (medical, pharmacy and nursing).

¹⁷ Blum RW et al 1993.

E-health development and improved use of data

The transfer of information relating to palliative and end of life care between different care providers is an important aspect of integrated care. Participants in the Lothian palliative care stakeholder event and the carer's event highlighted that communication and sharing of information needs to improve in order to support the delivery of better care. Equally we are aware that we need to improve monitoring of activity and the availability of information for service planning. To respond to this we will target work in three key areas:

Installation of N3 Connections to both NHS Lothian Hospices

To support the secure exchange of clinical information and allow future electronic referral, network connections will be installed to both Lothian independent hospices. This will allow hospices to join the NHS secure data network.

Pilot and development the Electronic Palliative Care Summary (ePCS)

As part of the implementation of Living and Dying Well, the Scottish Government is developing an electronic Palliative Care Summary (ePCS). Lothian will be the first Board area to roll out ePCS. Subject to successful testing and Lothian evaluation, the ePCS will be rolled out nationally from late 2009. The ePCS will, with patient consent, allow twice daily automatic updates of information collected by GP practices to a central information store. From here information will be available to OOH services, NHS24 and Accident and Emergency services.

Developing Existing Systems and activity monitoring

To support the management and sharing of clinical information as well as facilitate improved recording of activity we will scope the potential to further integrate hospital specialist palliative care administrative data systems. We will also develop a more comprehensive approach to whole systems activity monitoring, and develop local health intelligence reports based on key indicators of performance against strategic goals.

Education and training

Facilitating a good death should be recognised as a core clinical proficiency, as basic as diagnosis and treatment¹⁸.

The provision of palliative care education for health and social care teams is essential to successfully achieving the aims of this strategy. The Lothian Palliative Care Managed Clinical Network (MCN) Education Group, with representation from all education providers in Lothian, will work collaboratively with NHS Education for Scotland (NES) and the Lothian Education Champion to ensure that learning opportunities and educational initiatives support the successful implementation of this strategy and the Living & Dying Well (L&DW) Lothian delivery plan.

In 2008 the MCN education group mapped palliative care education provision in Lothian. The results demonstrate that a number of the key elements of L&DW are already reflected

¹⁸ Murray SA, Sheikh A. Making a Difference Palliative Care Beyond Cancer Care for all at the end of life BMJ, 2008, 336:958-959, doi: 10.1136/bmj.39535.491238.94

in our palliative care education programmes. The next step will be to explore in more detail current vocational, pre- and post-qualification palliative care education for all staff groups provided by NHS Lothian, the voluntary sector (including hospices), and higher education. This mapping exercise will act as a benchmark for future developments which can build on existing good practice to reflect the Lothian model for palliative care.

The MCN education group will work collaboratively to:

- Deliver a range of creative learning and development approaches to palliative care education at all levels, to ensure an appropriately skilled health and social care workforce.
- Ensure information on education initiatives in specialist and generalist palliative care are made available in a range of formats, both electronic and paper-based. This will ensure maximum accessibility of information to staff and managers
- Encourage health and social care providers to realise the value of palliative care education to supporting their practice
- Explore opportunities for resources to allow staff to access education.
- Ensuring education providers adopt an approach which provides flexible learning for all
- Integrate and dovetail palliative care education with other relevant projects and initiatives for example, Long Term Conditions to address key themes identified within this strategy.

Our previous mapping of education provision highlighted that whilst there is an extensive range of educational opportunities available, these are not always accessible to those who need them. There are challenges in releasing and funding staff who wish to engage in palliative care education, and to ensuring awareness of the opportunities available. In particular, social care staff are often unaware of palliative care training opportunities. One of the key challenges ahead will be addressing the barriers to staff engaging in palliative care education related to:

- Identifying the palliative and end of life phases of life-limiting illness,
- Communication skills
- Using frameworks, guidelines and tools to apply the principles of palliative care in practice including the Liverpool Care pathway
- Advance Care Planning, which includes DNAR decision making processes,

Health and social care workers need the knowledge, skills and values which are integral to the palliative approach in order to provide effective care in all setting. Education and training will support the implementation of this. The Lothian model cannot be implemented successful without pertinent education and training. This will help provide staff with the core skills required when working with people with life limiting illness and their families.

Workforce

Workforce changes impacting on this strategy are described in the NHS Lothian Workforce Plan 2008-09¹⁹. The table below outlines the Specialist Palliative Care Workforce by WTE at August 2009.

	Total WTE	NHS Lothian	Marie Curie	St. Columba's
Consultants in Palliative Medicine	5.8	2.3	1.5	2.0
Palliative Medical Staff Grades/Specialty doctors	5.0	0	2.1	2.9
Years 1 & 2 GP Specialist Trainees	1.0	0	0	1.0
Foundation Year 2 doctors	1.0	0	1.0	0
Palliative Medicine Specialist/Specialty Registrars	2.2	1.2	1.0	0
GPs with Specialist Interest	0.2	0.2	0	0
Specialist Nurses	28.4	12.8	5.6	10.0
Registered Nurses	73.2	1.4	25.1	46.7
Specialist Pharmacists	2.5	2.5		
Health Care Assistants	39.4	0	22.5	16.9
Total	158.7			

Future workforce issues to consider in relation to the planning of services within each trajectory

- The integration of workforce between health and social care providers in order to streamline provision and make effective use of staff.
- Establishing workforce planning linkages for specialist and generalist services.
- The development of the Volunteer and Carer workforce in all settings.
- The development of 'generalist' staff in all settings to provide better palliative and end of life care

Developing the palliative care Managed Clinical Network (MCN)

The Lothian Palliative Care MCN needs to find ways to effectively incorporate all contributors to palliative care in Lothian by:

- focussing on developing general provision of palliative care
- including a wider range of staff – those who care principally for people with conditions other than cancer, and promote palliative care principles in their working practices

¹⁹ Generalist Workforce Information : NHS Lothian 2008 (NHS Scotland WF Statistics . 30/06/09)

- further engaging the active support of all organisations involved in the network, both managers and professional leaders.

The MCN will actively promote good practice by effectively promulgating national and local care standards and guidelines. The MCN will engage with the clinical governance organisation in NHS Lothian to carry out evaluations and audit and feed back results to staff, patients and carers. The MCN work-plan will underpin delivery of this strategy over the term 2010 – 2015.

Working with Lothian local authorities

Many people, by the time they reach the end of life, will have multiple conditions with a range of complex health and social care needs that require a proactive, co-ordinated response from services. Lack of co-ordination between health and social services mean that people's preferences for care are not always communicated effectively which may result in admissions to acute hospital or delayed discharge. We will work with Local Authorities to build upon existing good practice for example in shared assessment and models of practice based on valuing people as individuals. We will work also collaboratively with Local Authorities and independent providers to develop plans for palliative and end of life services training and education.

Involving People in their Care

Research completed with patients and carers concludes that many patients and their carers are comforted by an open and honest discussion about what may happen as the patient approaches the end of life. This was confirmed by the carers who we spoke to, who said that *'they would like the opportunity to plan for the future and hear what the future might look like in partnership with healthcare workers'*. Although it was agreed that health and social care professionals should approach this topic sensitively.

We know that there are many tools which can be adopted by our services which will support this process. Some of these include:

- Prognostic Indicator Guidance
- The Integrated Lothian Do Not Attempt Resuscitation (DNAR) policy
- Anticipatory care planning to enable people to make decisions around preferred place of care and the preferred place of death
- The Electronic Palliative Care Summary

This strategy aims to enable more people to die in the place of their choice (which we believe will mean fewer choosing acute hospital settings, and more choosing to die in their place of residence). We will develop over time, starting with our consultation exercise for this strategy, a means of testing with patients and carers in Lothian the balance of care provided, and how this should look to deliver efficient and effective care and improve patient experience.

10. SHIFTING THE BALANCE OF CARE

Our principles guiding service redesign for Palliative and End of Life care, as outlined in this strategy, will support shifting the balance of care in Lothian. Our principles are:

- Community focussed care with support for specialist in-patient care where required
- Extend palliative care to all people in need, independent of diagnosis
- Integrated and Team based care
- Focus on Long Term Conditions, through to End of Life care
- Early holistic assessment and intervention
- Patients and Carers involved and engaged with their care
- Care planning which involves people, establishing and working towards achieving their preference for place of death
- Promote a public discourse about death and dying

Our goals to help shift the balance of palliative and end of life care:

As part of implementing the Lothian Palliative Care Strategy we will support a policy of establishing preferred place of care and death, assessing and understanding this with patients, and using this information to support care planning and delivery. Our objective will be to build systems of assessment and planning to work with people both to record preferences and needs but also to adapt care plans according to developing and changing wishes towards the end of life. As overall goals we will seek to increase the proportion of deaths each year in domiciliary and care home settings, and further support and improve the quality of palliative and end of life care in our community hospitals. We will continue to decrease the proportion of deaths in acute hospital settings.

To measure the outcome of this, the following proxy measures will be used:

We will aim to decrease the proportion of deaths in acute hospitals in Lothian (RIE, WGH, SJH, RHSC) from a 2008 baseline of 42.3%, to a level of 38% by the end of 2015.

To support the achievement of this we will aim to increase the proportion of deaths occurring in community settings, including in people's own homes and care homes, from 34.4% in the baseline year of 2008 to 38.8% in 2015.

Appendix 6 outlines the estimated shift in numbers of deaths by place of death required over the period of this strategy.

What we will measure and how

In order to monitor the goals outlined above we will report on:

	Measure	How	Comment
1	Number of people identified and placed on registers.	General Practice data derived from the Palliative Care Directed Enhanced Service and the Local Enhanced Service	
2	Deaths by place of death in Lothian	Using General Register Office of Scotland (GROS) validated data we will produce a report twice per year. Our Health Intelligence Unit will produce this report and, as required, use weekly data supplied by GROS to monitor trends.	The Lothian Palliative Care Managed Clinical Network will take responsibility for assessing and action planning to achieve the shifts required.
3	Referrals to specialist palliative care	Via a specific report from specialist services co-ordinated by the MCN	The report will cover activity in either community or hospital settings, by cancer and non-cancer.
4	The number of people dying where staff have used the Liverpool Care pathway (LCP)	Through the charge nurse ward review as part of the Scottish patient Safety programme.	
5	The number of people on palliative care registers with information available to Unscheduled Care Service.	As recorded from the electronic palliative care summary	

11. HEAT TARGETS

Palliative Care and the HEAT Targets

Successful implementation of this strategy will develop increasingly integrated care, and will also support NHS Lothian in meeting key aspects of the HEAT framework²⁰. The relevant HEAT targets have been identified below:

Efficiency

- E4 NHS Boards to deliver agreed improved efficiencies for non-routine inpatient average length of stay:

Treatment

- T8 Increase the level of older people with complex care needs receiving care at home.
- T11 To support shifting the balance of care, NHS Boards will achieve agreed reductions in the rates of attendance at A&E, between 2007/08 and 2010/11.
- T12 By 2010/11, NHS Boards will reduce the emergency inpatient bed days for people aged 65 and over, by 10% compared with 2004/05

It is anticipated that in 2010 / 2011 the HEAT framework may include a specific target for Palliative and End of Life care for the first time. Through implementation and development of the work streams referenced in this strategy we will support delivery against this measure.

12. FINANCIAL PLANNING AND PRIORITIES

The Audit Scotland Review of Palliative Care Services in Scotland acknowledged that currently it was not possible to calculate the costs of the provision of palliative care, largely because much activity is hidden within in the workload of 'generalist' health and social care professionals. The cost of Specialist Palliative Care services can however be described. Our work with Audit Scotland in 2007/8 showed the expenditure in Lothian on Specialist

²⁰ The HEAT Targets measure the contribution made by NHS Scotland to achieving the government's objectives. There are HEAT targets on Health improvement, Efficiency and Governance, Access to Services, Treatment.

Palliative Care services was almost ten million pounds in 2006/7. This includes expenditure on all NHS Lothian specialist palliative care services, NHS Lothian contribution to children's hospice care, NHS Lothian expenditure to support the operating costs of independent hospices in Lothian, and the additional expenditure by independent hospices themselves in Lothian.

The vast majority of this expenditure on specialist care has been on cancer related palliative and end of life care. Our priorities for the future include focussing on improving value for money by taking forward recommendations from our review of specialist palliative care bed capacity, and improving our partnership arrangements between the Lothian Hospices and NHS Lothian. We also need to extend high quality palliative care beyond cancer, and we aim to do this both by supporting systems development and improvement work in a variety of 'generalist' healthcare settings, and by focussing more of our existing specialist resources onto non-cancer palliative and end of life care. It is expected that schemes to support the work of clinical teams in settings such as care homes, community hospitals, and domiciliary care, as well as improving acute hospital palliative and end of life care, will be the focus of future additional investment and redesign of current resources.

Through the national work streams of 'Living & Dying Well', elements of referral, assessment, care planning and other improvement work aimed at improving non-cancer palliative care in all settings are being progressed. Locally work on tools for use in anticipatory care, long term conditions, resuscitation etc. is also developing and will require application to non-cancer palliative and end of life care management as well as to cancer care.

Our initial priorities for future investment have been considered and the schemes listed below have been initially considered, however the appropriateness of these will be tested during consultation, as well as considering alternatives:

- Liverpool Care Pathway implementation in community settings
- Community specialist palliative care nurse for West Lothian
- Medical Staffing in the RIE & WGH to support non-malignant related palliative and end of life care
- Increasing the Marie Curie Nursing Service capacity (for non-cancer conditions)
- Enhanced palliative care delivery by community nursing services in Midlothian.

In order to further develop our implementation plan for this strategy and to determine final schemes for investment we wish to consult widely on the aims and objectives of this strategy and to refine it as required following feedback. Decisions on future investment will be based on how best to achieve delivery of the finalised goals of the Lothian strategy.

13. RAPID IMPACT ASSESSMENT

As this strategy has been developed, we have reviewed a range of literature which considers the views of patients, carers and health and social care professionals. This can be found in supplementary report 3 - *'Review of Needs Assessments Undertaken in Lothian and Literature on Palliative Care Needs'*. The findings of this have been used to inform and develop the strategy. In addition to this, we have identified the following points:

- The Audit Scotland report highlighted that most palliative care is delivered to people with terminal cancer. This strategy identifies how in future, the scope and delivery of palliative care will change to ensure there is access for all people based on need, not diagnosis.
- A key aim of this strategy is to increase domiciliary deaths. We know that across Lothian there is a relationship between domiciliary deaths and deprivation. This is detailed in further detail on page 12. This relationship will require further analysis as we implement this strategy.
- The Specialist Palliative Care Bed Capacity review (supplementary report 5), identified a relationship between geographical areas and number of admissions to the hospices. As this strategy is implemented, a number of actions, including setting out catchment and zoning areas for the hospices, will be taken forward.

As part of the consultation for this strategy, we will undertake a full Rapid Impact Assessment (RIA). The RIA exercise to be held in October 2009 will be led by NHS Lothian's Head of Equality and Diversity and will include representatives from the strategy steering group as well as from Voice of Carers across Lothian (VOCAL). Findings from the full RIA will be used to inform consultation and to further develop the palliative care strategy.

14. EVALUATION AND RESEARCH

We believe that successful implementation of this strategy will improve care in all settings and will achieve the shifts in the balance of care outlined as necessary. We will monitor how we are progressing by reporting on the indicators outlined in section 10 of this paper.

Changing and developing our use of current resources and introducing new systems and ways of working however will require specific evaluation. In Lothian we are fortunate to have a strong community based primary palliative care research programme, led by the Professor Scott Murray, St. Columba's Hospice Chair of Primary Palliative Care, University of Edinburgh. Aspects of this programme will be developed to assist in evaluating and developing key parts of this strategy, especially those that are hard to capture numerically, for example assessing the time and effort that specialist palliative care expends in supporting and training generalists. The group will also research how the Direct Enhanced Service (DES) for palliative care is being operationalised in Lothian in 2010, with a view to recommending how it can be optimised in future years (central funding for this work has been approved from the national Living and Dying Well programme). The group will also pilot innovative studies in which current specialist resources are targeted at training and supporting generalists in the community. The group will also consider projects in promoting a public discourse about, and public involvement in, end of life care in Lothian. Professor Marie Fallon, St Columba's Hospice Chair of Palliative Medicine, leads a research programme which will continue to evaluate pain control throughout Lothian.

All developments and training will have an integrative evaluative component, to develop an evidence base for future care.

15. APPENDICES

Appendix 1: Membership and remit of the steering group

Organisation / Team Representing	Name
NHS Lothian Managed Clinical Network	David Oxenham
Edinburgh CHP- Clinical Representative (& Lothian Lead Nurse for Cancer & Palliative Care)	Shirley Fife
Edinburgh CHP- Management	Craig Beveridge
East & Mid CHP- Clinical	Duncan Brown
East & Mid CHP- Management	Mairi Pollock
East & Mid CHP- Management	Mairi McMillan
East & Mid CHP- Management	Robert Clement
West CHCP- Clinical	Juliet Spiller
West CHCP- Management	Dot Partington*
Lothian Lead GP for Cancer & Palliative Care	Bill O'Neill
Marie Curie	Anne Willis
St Columba's	Fred Benton
NHS Lothian Finance	Jacqui Hamilton
Acute Specialist Palliative Care Team	Patricia Black
Children's Palliative Care	Jayne Scotland
Public Health	Ken Black
NHS Lothian Strategic Planning & Modernisation	Thomas McCarthy
NHS Lothian Strategic Planning & Modernisation / NHS Lothian Palliative Care Lead	Peter McLoughlin
University of Edinburgh, Primary Palliative Care Research Group	Scott Murray
Palliative Care Educators	Joan Adam

*Dot Partington resigned from NHS Lothian for a new post in May 2009. Representation for all aspects of West Lothian CHCP was subsequently led by Juliet Spiller.

Appendix 2: Recommendations of the Palliative Care Managed Clinical Network Bed Capacity Review

Recommendations

1. The main recommendation from this review is that further community based models of delivering palliative care, supported by specialist palliative care teams, should be developed rapidly in Lothian. The aim of this recommendation is to increase capacity to manage more cancer deaths at home, increase capacity for non-cancer related palliative care, and support improved utilisation of hospital and hospice beds. It is anticipated that this will be achieved by developing plans for more integrated working with generalists, organ specialists, charitable organisations, local authority and private sector care homes, and patients and their carers. Enhancing the capacity of specialist and generalist hospital services to deliver palliative care and work effectively with developing models of community palliative care provision will also be necessary to maximise benefit.
2. The review team recommends that the current number of specialist palliative care in-patient beds is retained, and plans to improve the utilisation of this resource are specified and agreed in the Service Level Agreements between NHS Lothian and Lothian Independent Hospices.
3. The redevelopment of St. Columba's Hospice with a bed complement of 30 in-patient beds is recommended, noting that throughput will increase (largely due to increased single room design), and that the St. Columba's plan includes the development of outreach services.
4. That Lothian Independent Hospices work in partnership with NHS Lothian and other agencies to develop new models of hospice care. This may include 'hospice plus' models to scope and pilot alternative ways of providing specialist palliative care bed capacity, and specialist input to support beds in other specialties, and working to maximise the value and effectiveness of hospice in-patient units directly. Such developments should be based on the requirements of each catchment area and populations served.
5. The potential need to dedicate a proportion of the existing specialist palliative care in-patient bed complement to non-cancer related palliative care should be kept under review. National and local data and projections for non-cancer palliative care should become increasingly available, and service responses for these groups will be developed and tested over time, which should inform the utilisation of specialist resource.
6. The Lothian Palliative Care Managed Clinical Network should develop high level targets and indicators to measure movement and progress towards shifting the balance of palliative care (Increasing the proportion of domiciliary deaths, decreasing the proportion of hospital deaths, increasing the proportion deaths managed in care home settings, etc).
7. That NHS Lothian improves the commissioning model for hospice in-patient units by utilising the national comparative data now available following the Audit Scotland

Review of Palliative Care Services, and the 2007 National Council for Palliative Care survey of units in England and Wales.

8. Both Lothian Independent hospices should agree catchment areas based on analysis of activity and current service base, as outlined in this report (and with suitable flexibility to allow out of catchment referrals when deemed necessary). The data shows St Columba's Hospice servicing North Edinburgh and East Lothian in the main, and Marie Curie Edinburgh Hospice servicing South Edinburgh, Midlothian and (with a lower admission ratio) West Lothian.
9. NHS Lothian should accept the bed capacity recommendations outlined in this report, for the purposes of commissioning specialist palliative care, and ensure clear hospice catchment areas underpin service contracts and future planning.
10. Each hospice should take a lead role in working with CHP's and other agencies in their catchment area to develop integrated community support services. Developing capacity in community services (domiciliary, community hospitals, care homes) is key to obtaining best value from in-patient beds, and increasing capacity for non-cancer related palliative care.
11. Community Health (and Care) Partnerships in Lothian should be encouraged to use the model of 'Facilitating Appropriate Access to Generalist and Specialist Palliative Care', as outlined in the Bed Capacity Review Report, to assist in developing integrated care.
12. Develop models of generalist palliative care provision within Lothian hospitals thereby maximising the appropriate use of specialist beds and supporting achievement of preferred place of care for patients and families.
13. Scottish Morbidity Record (SMR01) data should be reliably transferred monthly from each Lothian hospice to ISD Scotland per the national data reporting schedule.
14. Hospital Specialist Palliative Care Teams in Lothian should complete the work on standardising the activity dataset which is routinely captured, and the common database application, with the aim of being able to routinely report on activity across all main hospital sites.
15. The Health Intelligence Unit in NHS Lothian should report to the MCN, 6 monthly, the overall proportion of domiciliary deaths in Lothian for the last 12 months, by principal cause of death. The Health Intelligence Unit should work with the outputs from this review to specify with the MCN a routine analysis to regularly report on deaths by place of death and estimated trajectory of dying.

Appendix 3: Mortality Data

Changes in proportions of death in Lothian by place over the last 25 years

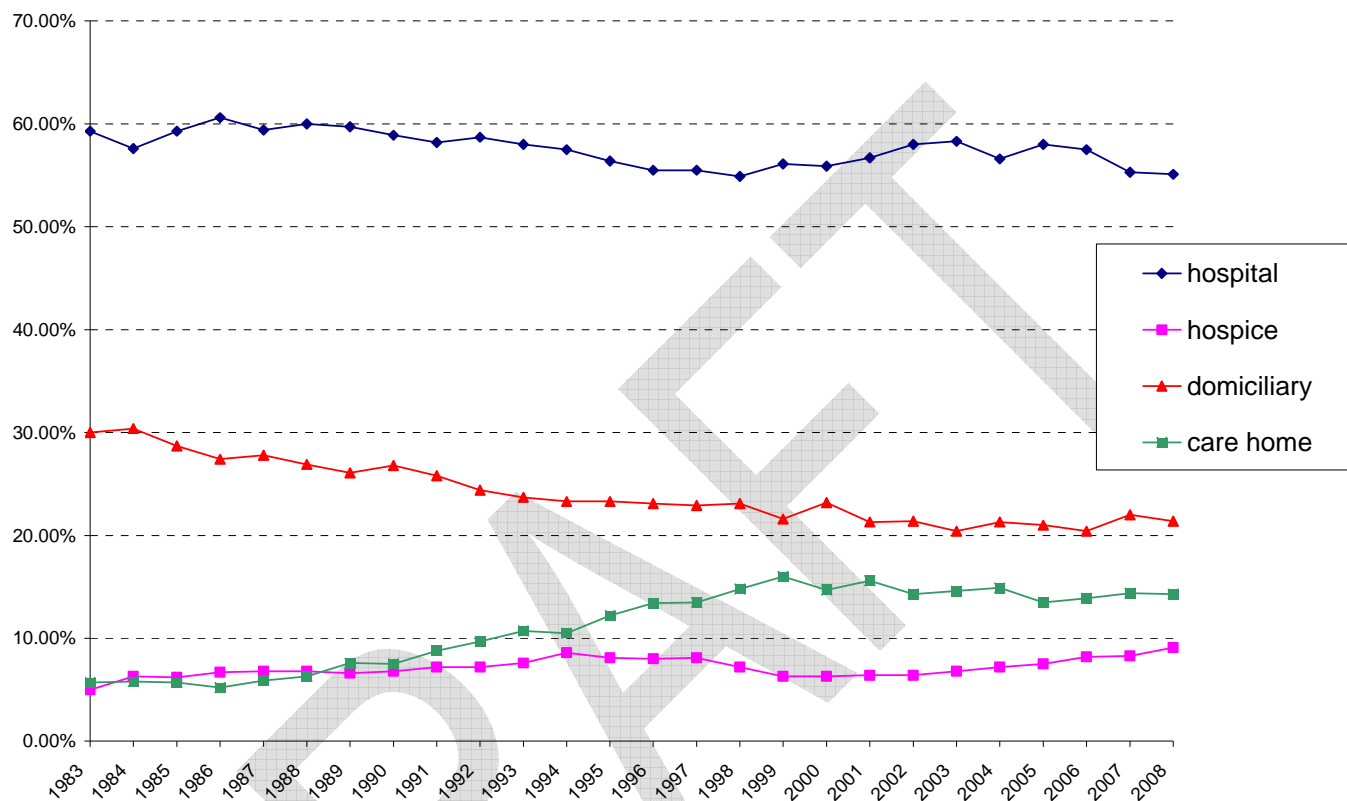


TABLE 1: TOP TEN CAUSES OF DEATH FOR LOTHIAN / ALL SCOTLAND RESIDENTS IN 2008, BY PLACE OF DEATH²¹

LOTHIAN RESIDENTS

<u>Underlying cause of death</u>	<u>Deaths</u>	<u>% of total</u>	<u>Hospital deaths</u>	<u>Other institution</u>	<u>Domiciliary deaths</u>	<u>% domiciliary</u>
Cerebrovascular disease (including stroke)	725	9.7%	473	200	52	7%
Acute myocardial infarction	610	8.1%	323	44	243	40%
Lung cancer	558	7.4%	264	177	117	21%
Chronic ischaemic heart disease	516	6.9%	260	56	200	39%
Dementia	391	5.2%	148	225	18	5%
COPD	368	4.9%	283	24	61	17%
Pneumonia	268	3.6%	185	58	25	9%
Colorectal cancer	207	2.8%	72	81	54	26%
Stomach/oesophagus cancer	179	2.4%	61	73	45	25%
Diseases of the urinary system	157	2.1%	115	34	8	5%
Other causes	3521	46.9%	1950	792	779	22%
TOTAL	7500	100.0%	4134	1764	1602	21%

SCOTTISH RESIDENT

<u>Underlying cause of death</u>	<u>Deaths</u>	<u>% of total</u>	<u>Hospital deaths</u>	<u>Other institution</u>	<u>Domiciliary deaths</u>	<u>% domiciliary</u>
Cerebrovascular disease (including stroke)	5335	9.7%	3354	1507	474	9%
Acute myocardial infarction	4941	8.9%	2314	478	2149	43%
Lung cancer	4009	7.3%	2228	738	1043	26%
Chronic ischaemic heart disease	3503	6.3%	1692	390	1421	41%
COPD	2814	5.1%	2022	251	541	19%
Dementia	2569	4.7%	852	1610	107	4%
Pneumonia	2431	4.4%	1649	599	183	8%
Colorectal cancer	1533	2.8%	730	362	441	29%
Stomach/oesophagus cancer	1329	2.4%	660	252	417	31%
Diseases of the urinary system	1235	2.2%	908	248	79	6%
Other causes	25521	46.2%	15361	4083	6077	24%
TOTAL	55220	100.0%	31770	10518	12932	23%

²¹ Source: GRO(S)

Projected number of deaths for Lothian and all Scotland 2006 – 2031 (source: General Register Office for Scotland 2007)

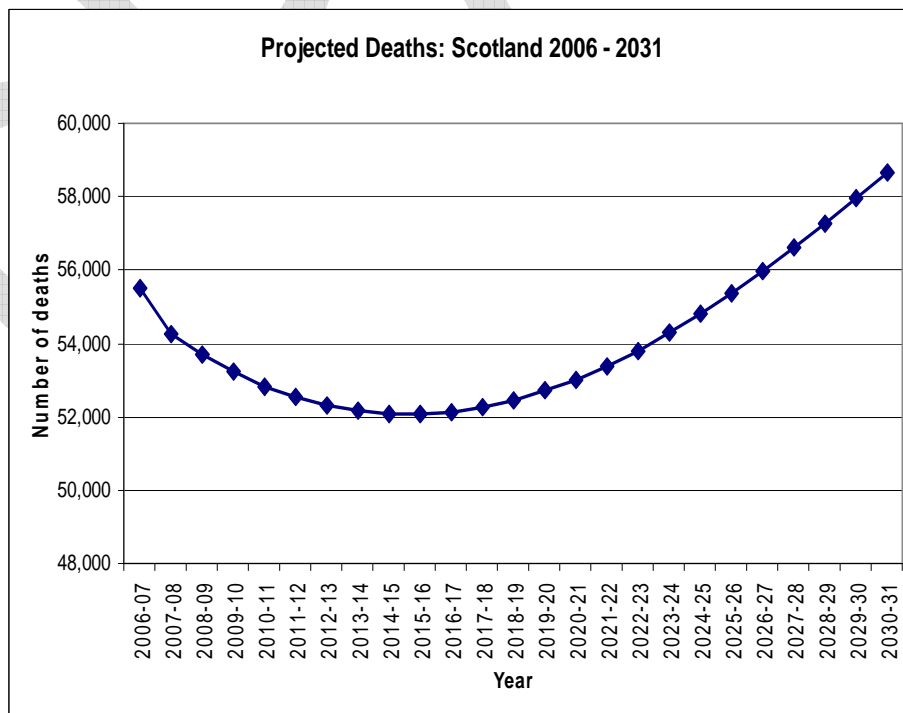
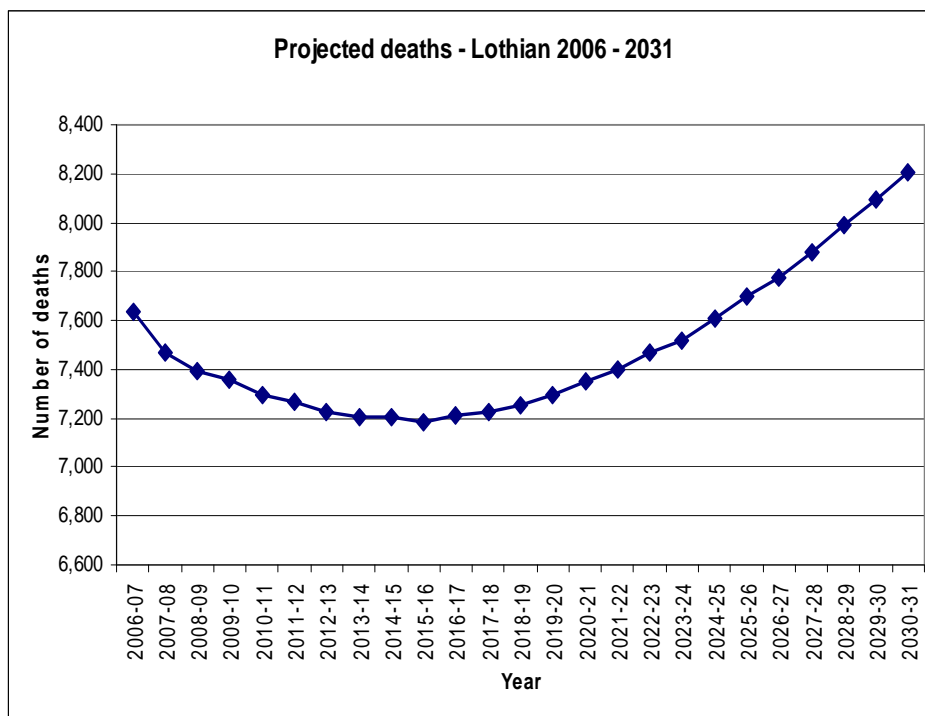


TABLE 2: Deaths in Lothian locations associated with palliative care, 2003/04 to 2007/08¹

	2003/04	2004/05	2005/06	2006/07	2007/08
Hospices	562	547	613	610	658
<i>St Columba's Hospice</i>	244	269	299	285	297
<i>Fairmile Marie Curie Centre</i>	318	278	314	325	361
Care homes²	1141	1113	972	1016	1097
<i>Nursing homes</i>	997	951	852	862	943
<i>Residential homes</i>	144	162	120	154	154
NHS Continuing Care hospitals³	549	547	567	586	625
<i>Astley Ainslie Hospital</i>	91	106	127	95	93
<i>Corstorphine Hospital</i>	56	57	60	66	72
<i>Edenhall Hospital</i>	26	27	32	37	31
<i>Ellen's Glen House</i>	23	39	34	40	34
<i>Ferryfield House</i>	51	47	38	41	71
<i>Findlay House</i>	26	36	39	39	47
<i>Loanhead Hospital</i>	31	22	35	34	31
<i>Roodlands General Hospital</i>	174	130	126	141	128
<i>St Michael's Hospital</i>	27	23	16	26	34
<i>Tippethill Hospital</i>	44	60	60	67	84
Former hospice residents⁴	79	48	57	68	96
<i>Domiciliary locations</i>	46	29	35	41	69
<i>Acute hospitals</i>	29	17	21	24	24
<i>Other locations</i>	4	2	1	3	3
Domiciliary deaths⁵	1616	1527	1608	1493	1559
<i>External causes of mortality⁶</i>	195	211	201	188	203
<i>Other domiciliary deaths</i>	1421	1316	1407	1305	1356
Deaths associated with palliative care (est.)⁷	3752	3571	3616	3585	3832
Total number of deaths	7897	7679	7650	7459	7462
% domiciliary deaths	20%	20%	21%	20%	21%
% associated with palliative care	48%	47%	47%	48%	51%

Sources: GRO(S), ISD
SMR Linked Dataset

1 Numbers of deaths of Lothian residents for years ending 31 March.

2 Excludes children's homes and institutions for homeless people.

3 All deaths in the listed hospitals are included.

4 Former residents of either St Columba's Hospice or the Fairmile Marie Curie Centre. Former residents who died in a care home or a Continuing Care hospital are excluded to avoid double counting.

5 Domiciliary deaths for former hospice residents are excluded to avoid double counting.

6 Includes deaths from unintentional injury, suicide and homicide.

7 Hospice deaths (including former residents), deaths in care homes, deaths in NHSCC hospitals and domiciliary deaths (excluding external causes).

Appendix 4: Findings from the Carers Event

1. Equity of Access

Discussions across both groups revealed that participants all had very different experiences in relation to the care and support they received from health and social care services. This was also a common theme highlighted in the wider research. Participants thought that there should be access to a wide range of services to all patients at the end of life, regardless of the diagnosis of the patient, for example patients should have access to holistic care, including complementary therapies, spiritual support and symptom management.

There were a number of solutions suggested to overcome some of these challenges. Participants recognised that palliative care does not need to be delivered by specialists; however they thought that education and training to up skill staff was important to make this a reality.

2. Support for Patients and Carers

Much of the conversation with participants was around the provision of advice and support for patients and carers. Many participants felt at times they had been supported; however, all had valued the input of VOCAL in supporting them to care and were clear that the voluntary sector was crucial in the delivery of these services. It was pointed out by a group member, that there is potential conflict between the protecting the patients confidentiality and the informing the carer. There needs to be a clearer understanding of this challenge and how to best manage any resulting conflicts of interest.

Participants discussed the challenges of living in modern society where death and dying takes place away from day to day living. It was suggested that there should be consideration given to providing more information around what happens before a patient dies and following death, including planning funerals and attending to any legal issues that have to be taken care of.

One of the groups had a lengthy discussion around respite care. There was universal agreement that respite care was difficult to access and wasn't always appropriate to the needs of patients and carers. Some relied on the extended family to give them a break.

There was a discussion around where participants thought the most appropriate place of death should be. There were mixed views on this, some thought that dying at home should be supported, however others raised concerns about the pressures that this would place on the carers and the extended family and friends. One participant thought that dying at home might lead to carers, relatives and friends not wanting to go in that room or sleep in that bed. It was agreed that patients and carers should have choice around place of death.

3. Who Provides Palliative Care

Prior to the event there was information that was circulated outlining what palliative care is and who provided palliative care. Many participants commented that they had never thought of the care and support they received from generalists (such as district nurses and GPs) as palliative care before. There was a recognition that these generalists can provide very good palliative care, however others suggested that staff needed support and training to be confident in delivering palliative care. However it was recognised that there was potential conflict between the curative role and the palliative role. Most healthcare settings including hospitals are focussed on curing the patient.

One participant thought that the role of the carer in providing care shouldn't be underestimated. It

was also suggested that given that there are such pressures on staff time, carers could be 'up skilled' if they are able to take on aspects of the provision of the care, for example, fitting canulas. However it was stressed that this would depend on the access to appropriate resources such as dressings. There was recognition that there needs to be support for the bereavement process, including the acceptance of death and pre-bereavement support for carers and relatives.

4. Communication and Coordination

The research highlighted that many patients and carers were generally more distressed by a lack of information and communication rather than the communication itself. There were different views amongst participants around this; one participant recounted how they felt that the decision to end treatment for the person they cared for was recounted in a very casual way.

Other participants described feeling very frustrated by the lack of information that came from their GP; however there was a consensus that the GPs role is crucial in the provision of care, especially in the early days of diagnosis as they are generally one of the first healthcare workers you will see.

Participants also commented that they thought that there were challenges in sharing communication between the hospital and their GP and that there was a lot of repetition involved talking to different health and social care staff. It was suggested that there should be clear protocols and information handover to ensure continuity of care. One idea was that NHS 24 computer systems should indicate if patients have been identified as being in the palliative phase of their illness. Another participant thought that patient held care plans should be developed and regularly updated.

It was stressed by all participants that any communication around palliative and end of life care should be sensitive to the feelings of patients and carers and that some may want to know more than others. It was thought that this would depend on how quickly people came to terms with their diagnosis. One group member thought that it would be useful to use the trajectories as the basis to map different services and identify services that are available at different points.

5. Issues Relating to the Wider Health and Social Care Services

There were a range of issues identified that are not exclusive to patients with a palliative care diagnosis. Many of these related to the provision of care in hospital or what happened during an admission or discharge to hospital. It was commented that patients and carers feel that there is too much of a focus on one aspect of a patients care and don't treat the whole person. It was suggested that one way to do this would be to provide more dual trained staff, so people could care for the mental and physical health needs of patients.

Some participants thought that an area needing attention was the discharge of patients from hospital. A number of challenges and frustrations with this process were identified. These range from complex processes in the hospital causing delays to difficulty in reinstating packages of social care.

Appendix 5: The strategic direction of independent hospices in Lothian

Marie Curie Hospice

In order to support the delivery of this NHS Lothian Palliative Care Strategy Marie Curie Cancer Care welcomes the opportunity to link the key principles of its own 3 year Strategic Plan for 2008-2011 with the targets and direction which NHS Lothian wishes to develop.

Marie Curie Cancer Care provides care for patients in NHS Lothian from the Hospice at Fairmilehead as well as through the Marie Curie Nursing Service .

The view of the Charity is that we will aim to continue to play an active and leading role in the development of services which will improve end of life care for patients in NHS Lothian and to achieve this we are delighted to support this strategy.

In particular from 2008 – 2011 we will be focusing on the following ,-

- Delivering Growth through the Marie Curie Nursing Service and the Hospice
- Introducing new services to make care easier to access and providing better information for patients
- Supporting a reduction in cancer deaths in hospital by 10%
- Campaigning for quality end of life care delivered in the place of choice

St. Columba's Hospice

Our Purpose:

- To improve the quality of life for those individuals with progressive, far advanced disease and to support their families and carers
- To support our generalist colleagues as well as providing specialist care
- Allied to and complementing this role is our promotion and sharing of education and research into palliative care

Our Vision is clear:

- In partnership with our colleagues outside the hospice, we aim to ensure that the palliative care needs of Lothian will be met.

Our Purpose and Vision are underpinned by four clear values:

- Our patient, family and carer centred service
- High quality care
- Care encompassing compassion, support and honesty
- Our autonomy and independence and our ability therefore to ensure a prompt and flexible response to needs

Our Aim:

- To increase awareness of the hospices availability for patients with non-malignant conditions and to assist their health care professionals in the support of these patients
- To support patients and families to achieve their preferred place of care where possible

- To provide an appropriate service resulting in a higher bed occupancy, shorter length of stay and an increased discharge rate
- To support improvement in End-of-Life care through our education programmes
- To increase support to Care Homes and Continuing Healthcare Units
- To support the implementation of the Liverpool care Pathway in all areas of Lothian
- To maintain a 30 bedded In-Patient unit while developing specialist Out-Patient clinics and Day Services
- To support our generalist colleagues in primary and secondary care, not only by giving advice and support but by providing specialist education at first degree and Masters level.

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Appendix 6: Shifting the balance of place of death

Estimated change required based on the number of deaths in 2008.

Note: The number of annual deaths predicted (GROS) is declining over time from 2010 to 2015. The impact of this on capacity needs to be considered against other changes such as case complexity etc. The rate of targeted change and predicted numbers of death in each of the 5 implementation years will require to be modelled out in implementation planning.

Setting	% of deaths PA in 2008	Number of deaths PA	Targeted % of deaths PA by 2015	Number of deaths PA (based on 2008 number of deaths)	Est Difference in number of deaths by place PA
Acute Hospitals	42.3%	3258	38	2924	-334
<u>Residential Settings:</u>					
Care Homes	13.6%	1045	15.8	1216	171
Domiciliary deaths	20.8%	1602	23	1770	168
Hospices	9.0%	693	9.0	692	-1
NHS Continuing Care Hospitals	8.3%	641	8.3	639	-2
Other settings	5.9%	455	5.9	454	-1
	100.0%	7694	100.0	7694	0

Proportion Acute	42.34%		38		
Proportion Residential: Domiciliary and Care Home	34.40%		38.8		
Proportion Other settings	23.25%		23.2		
	1.00		100		

1 Royal Infirmary of Edinburgh, Western General Hospital, St John's Hospital and the Royal Hospital for Sick Children (Edinburgh)

2 Nursing homes and residential homes. Excludes children's homes and institutions for homeless people.

3 St Columba's Hospice and Marie Curie Centre

4 All deaths at the Astley Ainslie Hospital, Corstorphine Hospital, Edenhall Hospital, Ellen's Glen House, Ferryfield House, Findlay House, Loanhead Hospital, Roodlands General Hospital, St Michael's Hospital and Tippetill Hospital

Appendix 7: Listing of supplementary reports available

1. **Supplementary Report One: Review of Needs Assessments undertaken in Lothian and the literature on palliative care needs**
2. **Supplementary Report Two: Report of the Palliative Care Strategy Development Stakeholders Event**
3. **Supplementary Report Three: Report of the Palliative Care Carers Event**
4. **Supplementary Report Four: NHS Lothian Living and Dying Well Delivery Plan**
5. **Supplementary Report Five: Lothian Palliative Care Managed Clinical Network, Report of the Bed Capacity Review Sub-Group**
6. **Supplementary Report Six: NHS Lothian Response to the Audit Scotland Review of Palliative Care Services**
7. **Supplementary Report Seven: Chart of the Palliative Care Strategic Framework in Lothian**