Supplementary Report 5: Lothian Palliative Care Managed Clinical Network, Report of the Bed Capacity Sub-group
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Lothian Palliative Care Managed Clinical Network

Bed Capacity Review Sub-Group

1. INTRODUCTION

1.1 The review group

This is the report of the Bed Capacity Review Group, a short life working group established by the Lothian Palliative Care Managed Clinical Network.

The group was established in December 2007 to respond to NHS Lothian’s request for advice on the specialist palliative care bed capacity required for the future. The group met seven times between December 2007 and the end of August 2008.

Membership of the Bed Capacity Review Sub-Group is outlined in appendix 1 to this report.

2. EXECUTIVE SUMMARY

Delivering palliative care to all who require it relies on the work of a wide range of clinicians in many disciplines, specialities and settings across Lothian. This provision is supported by the wider multidisciplinary team including for example the social worker, home care, and care home staff. Specialist palliative care services are in place in Lothian, in hospital, hospice, and community settings to support the planning and delivery of care, including the provision of specialist in-patient beds in the two Lothian hospices.

This review aimed to consider specialist palliative care bed capacity in the context of the role of the in-patient unit in supporting the care delivered by others. The review also recognised the changes in cancer demand (incidence, mortality, and survivorship) and the need to better respond to a significantly greater number of people requiring non-cancer related palliative care.

The review looked at the current specialist palliative care service utilisation in Lothian, acknowledging the limitations of data and the ‘invisibility’ of much ‘generalist’ palliative care activity. Mortality data, including cancer mortality projections, were used to help estimate future demand. Mortality data was also used to help consider in more detail than has been undertaken before in Lothian those on the non-cancer ‘trajectories of dying’. The review also made use of the limited UK comparative data on specialist palliative care provision.

Analysis of activity in the specialist palliative care in-patient units in Lothian shows clear differences in geographical service coverage, and highlights the need to agree formal catchments to underpin planning and delivery. Length of stay, throughput and staffing levels are also distinctly different between the two Lothian units, raising issues of best value and issues for future commissioning and joint development of strategic plans. Specialist in-patient beds in both units are almost exclusively focussed on cancer related palliative care. Discharge destination from hospice units in Lothian clearly shows the role of hospice beds in supporting packages of care delivered at home, with just under half of all episodes resulting in transfer home.
Just under 8000 Lothian residents die in Lothian each year (approximately 57% in hospital, 21% at home, 14% in care homes and 8% in Lothian hospices). At a level of 21% of deaths at home, Lothian is under the national average for this important indicator, quoted in the literature (for England and Wales) at 24%.

The ‘trajectories of dying’ framework has been used to give a feel for the volume in each trajectory grouping in Lothian. Whilst further work is required on precise coding and mapping to trajectories, use of the trajectory analysis presented should assist with developing plans to improve and shift the balance of care. Currently an equal proportion of cancer deaths (50/50) occur in hospital and non-hospital settings. Organ failure deaths occur more frequently in hospital than non-hospital settings (60/40), whilst the pattern is reversed (40/60) for those with a progressive neurological condition as principal cause of death.

The number of people admitted to hospice beds in Lothian varies widely by Local Authority area and reflects the different service arrangements in place locally. In Edinburgh 1 person is admitted to a hospice in-patient bed for every 7.2 deaths, in West Lothian the figure is 1 in 24.8 deaths. The reliance on community hospitals and integrated specialist palliative care teams particularly in West and East Lothian is a key issue, and ensuring continued capacity and supporting improvements in these areas in future is critical to an overall Lothian model with sufficient capacity.

The characteristics of an effective integrated community model of palliative care provision are set out in the report and Community Health and Care Partnerships in Lothian are encouraged to consider this framework.

Clear opportunities to develop the response to non-cancer related palliative care exist. Both Lothian Independent Hospices wish to develop new models of provision with their community partners, including community hospitals. These include for example developing specialist consultancy support services aimed at NHS Continuing Care Units, and Care Homes in Lothian. These potential developments, alongside other recent developments in General Practice and Unscheduled Care services etc. should form part of the NHS Lothian Palliative Care Services Strategy.

Recommendations from the review include:

- the development of further community based models of delivering palliative care, supported by specialist palliative care teams;
- retention of the current specialist bed complement (at 57 beds);
- the development of clear hospice catchments;
- improved commissioning for hospice in-patient units to obtain best value;
- hospices and CHP’s to take the lead role in planning and developing integrated services;
- greater availability of data and improved use of data in Palliative Care services;
- and the development and establishment of agreed, joint, high-level indicators to measure progress towards shared strategic goals.
3. AN OVERVIEW OF PALLIATIVE CARE SERVICES IN LOTHIAN

3.1 Service composition

Palliative care services in Lothian are provided within a model of generalist delivery of palliative care enhanced by specialist services and clinical systems. The aim of palliative care services in Lothian is to deliver high quality service to all patients irrespective of age, geographical location or diagnosis. The majority of clinicians in Lothian, whether surgeons, physicians or nurse specialists in hospitals, or General Practitioners and Community Nurses in CH(C)P’s, routinely provide palliative care as part of their job. High quality palliative care needs to be delivered in all settings in Lothian and a range of specialist palliative care services are in place to support this.

In Lothian, there are two specialist palliative care inpatient units, the Marie Curie Hospice, Edinburgh and St Columba's Hospice, Edinburgh. All specialist palliative inpatient beds available in Lothian are provided by the 2 Lothian independent hospices. The Marie Curie Edinburgh Hospice has a bed complement of 27 inpatient beds, and St Columba’s Hospice has a bed complement of 30 inpatient beds. Patients are admitted to these units for specialist inpatient care in the last few days or weeks of life, for symptom control, and the assessment and management of complex needs. Both of the hospices also provide telephone advice and information services (including a 24 hour advice service). Advisory services are available for all Lothian hospitals and throughout the Community Health (and Care) Partnerships across Lothian.

Both of the Edinburgh hospices also provide day care unit services. Additionally, the Macmillan Day Centre in West Lothian provides day services, outpatient services, and links to the wider West Lothian specialist multidisciplinary team.

Three hospital specialist teams operate in Lothian, one in each of the main sites (RIE, WGH and SJH). These teams work in collaboration with other professionals, who remain responsible for the patient's care.

There are four specialist palliative care community teams in Lothian comprised of the Marie Curie Hospice community team, the St Columba’s Hospice community team, and 2 further NHS community palliative care teams (1 in East and 1 in West Lothian). These teams work in collaboration with general practitioners and community nurses to provide specialist assessment of patients in their own homes, care homes or community hospitals. The teams provide advice on pain, symptom assessment and management; liaison with other professionals involved in the patient's care; psychological, spiritual and social support for patient and family; assistance to patients and their carers in making informed decisions about treatment and future care; and short-term bereavement support.

Lothian has supported a number of initiatives which enable palliative care advice and access to specialist advice and services to be available at all times. These include a combined palliative care Consultant on-call service; the palliative care community pharmacy network (which provides access to palliative care medicines for all community patients out of hours); a system for information transfer to the Unscheduled Care Service; and planned review of ‘at risk’ patients by the Unscheduled Care service at weekends and on bank holidays.
High quality provision of service in Lothian has also been enhanced by the development of clinical systems. The key systems are:

- Lothian Sign 44 initiative - formal pain assessment record
- The NHS Lothian Integrated ‘Do Not Attempt Resuscitation’ policy and framework
- The Gold Standards Framework Scotland – the development of Gold Standards in individual practices
- The Lothian Palliative Care Guidelines (which provide information and resources on the management of a wide range of palliative care problems).

3.2 Overall activity in 2006 / 2007

The total number of patients who received specialist palliative care in NHS Lothian in 2006 / 2007 was 2470 (all forms of care).\(^1\)

Of these 2470, the Lothian independent hospices directly provided care to 1442 patients (per data from the hospice Audit Scotland questionnaire returns), representing 58% of the Lothian total.

Palliative care teams in Lothian hospitals provided specialist input to 1127 in-patients in 2006 / 2007, all of whom where occupying non-specialist palliative care beds.\(^2\)

Of the 1127 in-patients cared for by the hospital specialist palliative care team, an estimated 17% (189) were non-cancer patients (comprising 71 organ failure, 3 dementia, 16 neurological, 99 ‘other not specified’). This compares to a level of approximately 3.8% of hospice in-patients drawn from non-cancer groups in 2006 / 2007.

The St. John’s Hospital Macmillan Centre provided 933 day-patient days in 2006 / 2007, and integrated specialist palliative care teams at St. John’s and the Western General Hospital provided 306 out-patient contacts. The specialist palliative care community liaison service in East Lothian and West Lothian received 297 new referrals to the community teams in 2006 / 2007.

\(^{1}\) Source: Audit Scotland Review of Palliative Care Services: Hospice Survey and NHS Board Surveys 2007.
\(^{2}\) NHS Lothian’s Hospital Specialist Palliative care service operates a liaison model (covering 3 main sites) and is not a bed holding speciality.
4. THE BED CAPACITY REVIEW EXERCISE

4.1 Factors influencing the need for a review

The need for this review was stimulated by discussion, in late 2007, between St. Columba’s Hospice and NHS Lothian regarding the charity’s intention to take forward its proposed capital plan to redesign and rebuild the hospice’s ageing in-patient unit.

Previously, in 2005, the governors of St. Columba’s Hospice asked NHS Lothian how many beds the hospice should provide. Following this, in 2006, the Palliative Care Managed Clinical Network undertook an interim exercise to help to determine the number of specialist beds required in Lothian. This report acknowledged the need for ongoing review. Following presentation to the MCN in September 2006, further action was specified to complete the work required to provide clear commissioning advice in this area. Further work on bed utilisation and consideration of bed capacity in the wider context of generalist palliative care capacity was recommended. Prior to this work, a preliminary assessment of need for Palliative Care for cancer in Lothian was undertaken, and was completed in March 2004. This flagged the need to undertake more work on a range of cancer related palliative care initiatives, including the need for ‘active treatment’ beds.

A number of relevant national policy developments in 2007 also influenced the need for the review exercise. The Audit Scotland Review of Palliative Care Services in Scotland was underway, representing the first detailed look at activity and costs of palliative care services across Scotland. Additionally, the Scottish Government, in 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. “Living and Dying Well”, the Scottish Government’s plan, was published in October 2008.

Key strategic drivers for the review include the anticipated increase in cancer mortality associated with an ageing population, and an increased complexity of cancer related palliative care associated with patients living longer with cancer. Across the UK it remains the case that activity in Specialist Palliative Care is largely cancer related, however specialist input to the management of deaths from other causes, where appropriate, is required. The trajectories of dying from organ failure and neurological conditions are now better understood and there is an acknowledged requirement to extend the reach of palliative care services to better meet the needs of patients in these groups.

Hospice provision in Lothian is changing also. As well as the capital and modernisation plan being developed by St. Columba’s Hospice, the Marie Curie Edinburgh Hospice has also considered its future role, via participation in the Marie Curie ‘Making the Most of the Hospices’ programme. This programme has produced a local action plan to develop the

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role and function of the Edinburgh hospice and its services for the future. Additionally the Marie Curie Cancer Care charity has recently adopted the high-level objective of increasing the number of people with cancer accessing its services, supporting a reduction in cancer deaths in hospital by 10%, and significantly increasing the care provided for people with other illnesses. The St Columba’s charity has always been based on need not on a diagnosis of cancer. Both St Columba’s Hospice and the Marie Curie Edinburgh Hospice are open to referral of patients with non-malignant conditions and clear opportunity exists to develop the role of each service to provide and support non-cancer related specialist palliative care services.

4.2 Scope and remit of the bed capacity review sub-group

The scope of the review group was to consider the future specialist palliative care inpatient bed capacity requirement in Lothian. A generalist palliative care service model is currently in operation in Lothian (i.e. generalist delivery supported by specialist care where required) and therefore the group considered specialist palliative care capacity in this service context.

The group aimed to make recommendations to NHS Lothian and both independent hospices on specialist bed capacity, and support for generalist palliative care in Lothian.

The remit agreed by the sub-group is fully outlined in appendix 2 to this report.

4.3 Limitations of the review

At the time of conducting the review few direct comparisons could be made between hospice services. The independent hospice movement in the UK has developed over the last 40 years and has produced various approaches to hospice care with a wide divergence of role and function amongst units. The recent Audit Scotland exercise, undertaken at the same time as this review, has improved the situation. Directly comparing units however and establishing benchmarks for best practice is not straightforward.

In Lothian, the non-availability of activity data was a key constraint throughout the review process.

As part of the review a specific exercise was taken forward to pull together an adequate amount of quality assured Scottish Morbidity Record data relating to hospice in-patient activity (SMR01).

Partial data was obtained from the palliative care hospital services in Lothian (with only the RIE team activity data available). It was not therefore possible to build a clear picture of activity supported by the specialist palliative care teams across the hospital system in Lothian. Additionally, hospital palliative care team data is not routinely collected as part of the SMR record. This occurs because patients receiving input from hospital palliative care teams remain under the care of another speciality at all times, and episode related activity is recorded against the specialty directly.

Gaining a full picture of generalist palliative care activity is not possible using routine data. Whilst some specific data is available from community specialist palliative care teams, and may be (increasingly) available from General Practice registers, much of the palliative care
provided by generalists in hospital and community settings is appropriate care and is not recorded. Data is therefore not routinely available for review.

5. REVIEW METHODOLOGY

The review considered the use of current in-patient specialist palliative care services to provide insight into the utilisation and estimated need for palliative care services. Variation in how the model of specialist palliative care service delivery in Lothian is implemented was considered by (council) area of Lothian. Some other models of specialist service delivery in the UK were considered also, to examine the features that might inform future improvement to Lothian services. Mortality data was also used to estimate the need for palliative care services by considering deaths by place of death and cause.

The review used activity data (Scottish Morbidity Record - SMR01) from specialist palliative care services to profile utilisation. Incidence of mortality data for Lothian residents was used to examine deaths in Lothian. Cancer scenarios data (2004 data) was used as a guide to forecast the future number of deaths from cancer in Lothian. SMR01 data and GROS mortality data was linked to create a dataset relating to the time period November 2006 to October 2007. This period was selected because of the availability of SMR01 data from both Lothian hospices. The same time period was used for all analyses undertaken.

Data on inpatient unit staffing ratios and skill mix for nurse staffing was supplied by both Lothian hospices. National Council for Palliative Care survey data was also used to allow comparison to units surveyed in England, Wales and Northern Ireland. Data from the Audit Scotland Review of Palliative Care Services in Scotland has also been used.

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6. PROVISION OF SPECIALIST PALLIATIVE INPATIENT CARE IN INDEPENDENT HOSPICES IN LOTHIAN – CAPACITY PLANNING WORK PREVIOUSLY UNDERTAKEN BY THE MCN

The Lothian Palliative Care Managed Clinical Network undertook an interim exercise in 2006 to help to determine the number of specialist beds required in Lothian. The report from this exercise distinguished between beds used for the provision of generalist palliative care and beds used to support the provision of specialist palliative care to offer active treatment for specialist assessment, symptom control, limited rehabilitation, and end of life care for patients with complex needs.

Formal estimates, although acknowledged to be imprecise, were outlined for the specialist / ‘active treatment’ beds and these ranged from between 18 to 27 beds for a population of 500,000, assuming specialist bed occupancy levels at 76%, average length of stay at 12.5 days and the ratio of new to total admissions of 0.7. Using the upper estimate, this equates to an estimated requirement of a total of 43 specialist / ‘active treatment’ beds for a population the size of Lothian, at an 801,330 population estimate at the mid year point of 2006.\footnote{Population figures taken from GRO(S) 2006 Mid Year Estimates} Bed number estimates referenced in the report related to survey data from an inner London area and the report acknowledged that this may produce an underestimate when considering the overall Lothian area, with semi-rural areas around the city of Edinburgh and main conurbations.

The report concluded that overall the number of beds in Lothian, and the balance of active treatment to general palliative care, would seem to be sustainable at the present level, with no need for any further active treatment beds at the time. The report acknowledged that it may be beneficial to consider hospice catchment areas in Lothian, and review the impact of new community hospital facilities as they develop.

7. SPECIALIST PALLIATIVE CARE INPATIENT BED UTILISATION

7.1 Estimating the numbers requiring support based on service use

Higginson has quoted studies suggesting that in the UK between 15 and 25% of cancer deaths received inpatient care in a hospice, and between 25 and 65% received input from the wider specialist support team.\footnote{http://hcna.radcliffe-oxford.com/pdfs/004HCNA_chap4.pdf} Using Lothian’s mortality figures for cancer in 2006 – 2007, this would translate into an estimate of between 312 and 520 receiving in-patient hospice care, and between 520 and 1353 receiving support from specialist support teams. Higginson notes however that the value of estimates based on service use nationally is limited given the piecemeal fashion in which services have developed. Estimates derived in this way are likely to produce an underestimate of the numbers requiring admission and support. Similar proportions have been estimated for non-cancer palliative care however it is acknowledged that estimates for non-cancer are known to be less reliable as most specialist palliative care services have historically been largely restricted to cancer care.

The data outlined in the next section of this report illustrates utilisation of specialist in-patient beds in Lothian. 794 patients were admitted to Lothian hospice in-patient units (with many patients admitted more than once), almost all for cancer related palliative care. NHS Lothian’s submission to the Audit Scotland Review of Palliative Care Services in...
2007 showed a total of 2470 patients receiving support from specialist palliative care services.

Lothian’s activity is clearly over the estimates derived from application of Higginson’s use of UK studies. We cannot estimate reliably for non-cancer related palliative care using routine data.

7.2 Audit Scotland Review of Palliative Care Services in Scotland – staffed specialist palliative care beds per each 100,000 population

The Audit Scotland review found variation in the specialist palliative care provision per 100,000 of the population. For all Scotland, the average number of staffed palliative care beds was 7.3 per 100,000 in 2006 / 2007. In Lothian the ratio is 7.1/100,000. The range for mainland Boards was 15.5/100,000 to 3.3/100,000 and the data highlights the different emphasis on day and community services in some areas. Lothian’s ratio of day care places per week / 100,000 was 17.0 against an all Scotland average of 19.5.

7.3 Bed utilisation in Lothian in 2006 / 2007 - Activity and access by Lothian Local Authority area

All specialist palliative care inpatient beds available in Lothian are provided by the 2 Lothian independent hospices. SMR01 data was obtained for both Lothian hospices for the period 1 November 2006 – 31 October 2007.

A total of 794 patients were admitted in the period from across Lothian (both hospices combined), in 973 episodes. Breaking this down, the Marie Curie Edinburgh hospice admitted 461 patients (in 549 episodes) and St Columba’s Hospice admitted 333 patients (in 424 episodes).

The charts below shows the geographical distribution of patients admitted from across Lothian.

No formal catchment areas have yet been agreed by Lothian Hospices. It is clear however that St Columba’s hospice serves the City of Edinburgh (largely the northern side of
Edinburgh), and East Lothian exclusively. The Marie Curie Edinburgh hospice admitted patients from all areas of Lothian. It is focussed on the City of Edinburgh (largely the southern side of Edinburgh) and Midlothian, and to a lesser extent West Lothian, with a relatively small number of East Lothian admissions.

The table below relates to all admission episodes for both hospices combined and shows the percentage of admissions relative to population size by area of Lothian.

Admissions to both Lothian hospices combined: (all episodes) by Council Area

<table>
<thead>
<tr>
<th>Hospice Admissions</th>
<th>Lothian Population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of admissions</td>
</tr>
<tr>
<td>City of Edinburgh</td>
<td>73.9% 719</td>
</tr>
<tr>
<td>East Lothian</td>
<td>6.7% 65</td>
</tr>
<tr>
<td>Midlothian</td>
<td>12.6% 123</td>
</tr>
<tr>
<td>West Lothian</td>
<td>6.8% 66</td>
</tr>
<tr>
<td>Grand Total</td>
<td>100.0% 973</td>
</tr>
</tbody>
</table>

Both Edinburgh and Midlothian account for a higher percentage of admissions than would be expected from their respective share of the Lothian population. East Lothian and particularly West Lothian account for a significantly lower percentage of admissions than would be expected considering the population share.

### 7.4 Admissions by deprivation quintile within NHS Lothian based on 2006 Scottish Index of Multiple Deprivation (SIMD)

The proportion of total admissions to Lothian hospices is shown in the chart below by deprivation grouping. The proportion of the Lothian Health Board population in each deprivation category is also illustrated for reference.

Overall the proportion of hospice admissions in DEPCAT 3 is below the proportion of the Lothian population in that group. The proportion of admissions from DEPCATS 4 and 5 is however over the proportion of the Lothian population in those groups. In all areas of Lothian the most deprived quintiles (DEPCAT 4 and 5) were over represented in admissions to hospice. This pattern of utilisation reflects the incidence of cancer by
deprivation, with a higher number of cancers diagnosed each year in the most deprived groups compared to the least deprived.

Of particular note is the profile of admissions by deprivation group in West Lothian where 71% of hospice admissions from the area were from the most deprived groups (compared to an average of 45% for all Lothian).

7.5 Average length of stay, occupancy levels and throughput

The table below details inpatient activity from both Lothian hospices.

<table>
<thead>
<tr>
<th></th>
<th>Both Hospice Providers combined</th>
<th>Marie Curie Edinburgh Hospice</th>
<th>St Columba's Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed complement</td>
<td>57</td>
<td>27</td>
<td>30</td>
</tr>
<tr>
<td>Total number of patients admitted</td>
<td>794</td>
<td>461</td>
<td>333</td>
</tr>
<tr>
<td>Throughput</td>
<td>13.9</td>
<td>17.1</td>
<td>11.1</td>
</tr>
<tr>
<td>Total number of episodes</td>
<td>974</td>
<td>550</td>
<td>424</td>
</tr>
<tr>
<td>Total number of occupied bed days</td>
<td>16579</td>
<td>7704</td>
<td>8875</td>
</tr>
<tr>
<td>Average Length of stay (days)</td>
<td>17</td>
<td>14</td>
<td>20</td>
</tr>
<tr>
<td>Occupancy level</td>
<td>79.7%</td>
<td>78.2%</td>
<td>81.1%</td>
</tr>
<tr>
<td>% of patients with 1 episode only</td>
<td>82%</td>
<td>84%</td>
<td>79%</td>
</tr>
<tr>
<td>% of patients with &gt; 1 episode</td>
<td>18%</td>
<td>16%</td>
<td>21%</td>
</tr>
<tr>
<td>% of episodes cancer related</td>
<td>96%</td>
<td>95%</td>
<td>97%</td>
</tr>
<tr>
<td>% of episodes non-cancer related</td>
<td>4%</td>
<td>5%</td>
<td>3%</td>
</tr>
</tbody>
</table>

The National Council for Palliative Care (NCPC) 2007 survey showed an average length of stay of 16 days for units of over 25 beds. Mean bed occupancy in the NCPC survey was 76%. The mean throughput per unit (numbers admitted per bed per year) was 21.2. The occupancy level in the Lothian units was higher than the NCPC mean bed occupancy however comparisons of overall mean length of stay and throughput are unfavourable. The occupancy level observed in units of over 20 beds in the Audit Scotland review of Palliative Care Services in Scotland was 80%, for comparison.

There is a clear difference in the overall turnover however between the two Lothian hospices, reflecting different operational policies and approaches in place in 2006 / 2007.

7.6 Episodes by main diagnosis

Admissions for cancer related palliative care represented 96% of admissions to Lothian hospices. Lung cancer, breast cancer, bowel cancer, prostate cancer and upper gastrointestinal cancers were the largest single main diagnostic groups represented in admissions. This pattern reflects the major causes of cancer deaths in 2006 / 2007. The chart below outlines the proportion of episodes by main diagnosis.
7.7 Discharge destination

Overall, just under half of all episodes of hospice inpatient admission in the year resulted in patients transferring home (43% to private residence) or transferring to hospital (4%). In 53% of episodes the patient died in the hospice. This pattern of discharge destination was identical for both Lothian hospices. This illustrates clearly the role of hospices in supporting packages of care in the community.

The data overall suggests that there are 2 distinct groups being admitted to hospice inpatient units. The single episode group: a large proportion of episodes were single admission (often ending in death in the hospice unit). The readmission group: a smaller proportion made up of two or more admissions (almost exclusively ending in transfer home). It would be useful to explore further whether these groups have distinct characteristics, to inform service planning. In order to explore this question further a cohort study would be required.

7.8 Inpatient unit staffing models

In Lothian the nurse to bed ratio was 1.83 and 2.17 for the Marie Curie Edinburgh Hospice and St. Columba’s Hospice respectively. This relates to nurses of all grades, trained and untrained. The National Council for Palliative Care (NCPC) survey comparison was 1.94. The proportion of trained to untrained nurses in the Marie Curie hospice inpatient unit was 54% trained, 46% untrained. The proportion of trained to untrained nurses in the St. Columba’s hospice inpatient unit was 74% trained, 26% untrained. The largest difference was in the ratio of AfC band 5 nurses per bed (the ratio being significantly higher in the St Columba’s Hospice model: 1.46:1 compared to 0.8:1 in the Marie Curie Edinburgh Hospice). The National Council for Palliative Care (NCPC) survey showed a mean of 0.94 band 5 nurses per bed.
8. DEATHS IN LOTHIAN

8.1 Place of death

Just under 8000 Lothian residents die in Lothian each year. Of these, approximately 57% die in NHS Lothian hospitals, 21% at home, 14% in a care home or private hospital etc, and 8% in a hospice. The chart below shows the five year trend for place of death.

Trend - place of death over 5 years:

The proportion of deaths at home is a key indicator for the planning of palliative care services. At a 21% 5 year average the proportion of domiciliary deaths in Lothian is under the national average (for England and Wales) of 24%. The proportion of domiciliary deaths varies by area of Lothian. West Lothian has the highest proportion at a 26% 5 year average, Midlothian at 22%, East Lothian at 20% and Edinburgh at 19%.

The picture for the single year 2006–2007 shows a 22% proportion of domiciliary deaths overall (West Lothian: 28%, Midlothian at 21%, East Lothian at 22% and Edinburgh at 20%). In most areas therefore this illustrates positive recent movement but highlights the need to consider further the adequacy of community nursing, home care and the input and deployment of specialist palliative care services in each area to maintain or increase the proportion of deaths at home.

8.2 Cause and place of death

The top 10 causes of death in Lothian NHS Board area were calculated for the year 2006/07 (period 01 November 2006 to 31 October 2007). The top 10 causes can be seen in appendix 3 of this report. Deaths from selected causes are outlined in the table below, and the proportion of each cause by place of death is shown. Note that deaths in hospices (coded as ‘contractual hospitals’ in the GROS mortality data) are included in the hospital column in the table below.

<table>
<thead>
<tr>
<th>2006/07 Selected causes of death</th>
<th>All places</th>
<th>hospital</th>
<th>non-institution</th>
<th>other institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>2081</td>
<td>1575</td>
<td>425</td>
<td>81</td>
</tr>
<tr>
<td>Ischaemic heart disease</td>
<td>1264</td>
<td>630</td>
<td>520</td>
<td>114</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>677</td>
<td>430</td>
<td>81</td>
<td>186</td>
</tr>
<tr>
<td>Chronic lower respiratory disease</td>
<td>423</td>
<td>293</td>
<td>93</td>
<td>37</td>
</tr>
<tr>
<td>Dementia and Alzheimer’s disease</td>
<td>441</td>
<td>176</td>
<td>11</td>
<td>254</td>
</tr>
</tbody>
</table>

This helps to illustrate some key issues, for example three-quarters of cancer deaths are managed in hospitals (including hospices), with the remaining quarter being managed largely at home, with some in a care home setting. Almost 60% of deaths from Dementia and Alzheimer’s disease occur in care homes.

8.3 The trajectories of dying, cause and place of death

The three charts outlined in Figure 1 below illustrate the different trajectories of dying. These are now well recognised as conceptual models to assist in understanding need and to help consider clinical and service planning.

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The trajectory groups do not represent all patients who might require a palliative care approach; rather they outline common characteristics for selected groups to help inform the development of service responses for these groups. As part of this review an attempt has been made to analyse Lothian mortality data, for one year, based on apportioning deaths from selected causes into each of the trajectories. The main findings from this analysis are outlined below. These are presented as best estimates however the review group was conscious that interpretation should be approached with some caution, the principal problem being that no precise clinical coding has been specified and agreed to map causes of death to each trajectory. Furthermore it is not entirely possible to determine with any precision from GROS mortality data alone which deaths were in fact marked by notable progressive decline, or other patterns, regardless of principal cause of death recorded in the record. A significant number of deaths are also recorded in general categories and without the assistance of a clinical coder a totally precise capture of all selected deaths is not possible. Nevertheless in order to give another insight into our current service response, and support a discussion around potential strategic service change and development, the trajectory framework was used to reveal the current picture in Lothian.
Deaths from selected causes were identified and the mortality data was grouped into ‘Cancer’, ‘Organ Failure’ and ‘Neurological’ groupings. All cancer deaths were included. Where necessary, for the other two groups, an attempt was made to remove all acute causes from the data (for example in the organ failure group almost 600 deaths recorded as ‘Acute Myocardial Infarction, Unspecified’, and over 100 deaths coded ‘Acute Ischaemic Heart Disease, Unspecified’ etc. were removed from the years worth of data). A full list of principal causes of death included in each trajectory in the Lothian analysis, including ICD coding, is outlined in appendix 4 of this report.

The pie charts below outline the proportions of death by place of death in Lothian for each trajectory grouping.

**Cancer – (pattern = short period of evident decline)**

In the year considered there were a total of 2081 cancer deaths. Half of these deaths occurred in NHS hospitals (n=1000), just over a quarter in Lothian hospices (n=575) and a quarter at home (n= 505, either in a private residence or care home).
Organ Failure – (pattern = Long term limitations with intermittent serious episodes)

This group includes all deaths coded with a principal cause of death of:

- Heart Disease (including Hypertensive, Atherosclerotic, Chronic Ischaemic, and Other forms of Chronic Heart Disease)
- Heart Failure (including Congestive and Left ventricular)
- Cardiovascular disease
- Chronic Obstructive Pulmonary Disease
- End Stage Renal Disease
- Chronic Renal Failure

There were a total of 1059 deaths from these causes in the period. Almost 60% of deaths occurred in NHS Hospitals (n = 601), and just over 40% occurred at home (n= 444, either in a private residence or care home). Only 1% of the total (n = 9) occurred in a hospice.
Neurological – (pattern = prolonged dwindling)

This group includes all deaths coded with a principal cause of death of:

- Dementia (including multi-infarct, vascular)
- Mental and Behavioural Disorders (F00 – F99)
- Alzheimer’s Disease
- Motor Neurone Disease
- Diseases of the Nervous system (GOO – G99)

There were a total of 529 deaths from these causes in the period. Over half of these deaths occurred in a care home setting (n=318). Only 2% (n=9) occurred in a hospice and 4% (n=22) at home. 39% of the total died in NHS Hospitals (n=220).
8.4 Shifting the balance of care

Broadly, from the data above, the proportions of deaths in hospital VS non-hospital settings for each trajectory are as follows:\(^{15}\)

<table>
<thead>
<tr>
<th>Group</th>
<th>Hospital / Non-hospital setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>50 / 50</td>
</tr>
<tr>
<td>Organ failure</td>
<td>60 / 40</td>
</tr>
<tr>
<td>Neurological</td>
<td>40 / 60</td>
</tr>
</tbody>
</table>

Cancer

Whilst the mortality rate from cancer is falling, the overall number of deaths from cancer is projected to rise in line with an increasing elderly population. Cancer related palliative care remains the core activity of Lothian hospices. In order to deal with increasing numbers of cancer deaths a higher proportion will need management at home with input from hospice community teams. Hospice inpatient beds are expected to be increasingly utilised for more complex cancer related palliative care, as people live longer with cancer. This expected change in case complexity sits alongside the need to increase throughput and reduce length of stay in the in-patient units to increase the value and efficiency of inpatient units, and to support more care packages at home. Hospital systems will face the same expected rise in case complexity and demands on the Palliative Care liaison team will increase. With the overall number of deaths (all causes) in Scotland falling over the next decade (GROS data), this may reduce slightly the numbers dying in hospital and to a degree offset the impact associated with an increase in cancer deaths for ward teams. The projected change in the all-cause mortality trend is not uniform across all Lothian council areas however therefore the impact on Lothian hospitals might be expected to be variable, and factors such as increasing age, co-morbidities and management complexity need to be considered also. Bed pressures in hospitals, and the growing evidence on the preferred place of death for many end-of-life patients, means that increasingly community packages will be required to provide the option to manage an increased number of deaths at home.

Projected deaths from cancer

Further to the analysis of cancer mortality by place of death, this data was also analysed by tumour group. Cancer scenario mortality projection data to 2014 was then used to estimate the future number of deaths from each cancer. The proportion expected to die in future in each setting was calculated based on the current distribution of place of death.

Overall there is a projected 15% increase in the number of cancer deaths in 2014 compared to 2006/2007 (an increase of approximately 300 deaths to a total of circa 2400 projected in 2014). This may however represent an overestimate given actual numbers of deaths recorded in previous periods show a lower number than estimated in cancer

\(^{15}\) Note that deaths in hospices are included in ‘non-hospital settings’ category in this analysis, given that hospices are an alternative to NHS hospital care per referral guidelines. If however one classifies hospices as hospitals and includes these deaths in the hospital data the proportions for cancer would change to 75 / 25, highlighting the need to continue to develop community support services to increase the numbers able to die at home. Proportions in the other two groups would remain unchanged.
scenarios. All indications however do show some increase in the number of cancer deaths and predicted increases are particularly notable in oesophageal and stomach cancers, head and neck cancers, prostate and kidney cancers, breast cancer and colorectal cancers. Whilst mortality in a few tumour groups is projected to be reducing (lung, brain, skin) the numbers are small and the effect is that the level remains almost static at 2006/7 levels by 2014.

An increase in the number of cancer deaths will impact on all parts of the system. If the proportion of deaths from cancer by place of death remains the same in 2014 as currently, the end-of-life care impact will be felt primarily in hospital wards and Palliative liaison services, and hospice in-patient units. The numbers requiring domiciliary management will increase also for the current level of 20% of cancer deaths at home to be maintained, which adds to the challenge of increasing the overall proportion of domiciliary deaths.

Organ failure

Currently a relatively low proportion of specialist palliative care activity is associated with deaths from non-cancer causes. This is despite demand estimates (number who may benefit) for specialist palliative care input for patients on recognisable non-cancer trajectories of dying being approximately equal to if not greater than current cancer demand. Strengthened community models of care need to be specified for organ failure deaths building on best practice guidelines where available, to focus on palliative care planning, increase the level of palliative care provided, and increase the level of input from specialist palliative care teams. An increase in capacity to minimise the need for emergency hospital admission, and manage a greater number of deaths at home (either private residence or care home setting) is the overall goal. Schemes to increase support from specialist palliative care services to community hospital teams also need to be developed as part of community services planning with a view to maximising the role of community hospitals. Place of death for selected organ failure deaths should be routinely monitored to provide a proxy measure of progress.

Neurological

For progressive neurological conditions a further increase in the proportion of deaths managed in care home settings would be achieved by Pan-Lothian implementation of the Gold Standards Framework in Care Homes project. This action research project was implemented in Midlothian in 2007 / 2008 with 7 care homes participating. It has been positively evaluated and demonstrated a significant reduction in inappropriate hospital admissions, and fewer deaths in hospital (a reduction from 15% of residents dying in hospital prior to the project, to 8% in the year of the project).16

9. MODELS IN OPERATION IN LOTHIAN AND OTHER MODELS CONSIDERED

9.1 Differences in Lothian

The table below outlines deaths and hospice admissions in the 2006 – 2007 period by Lothian Local Authority and trajectory.

## All deaths Nov 2006 - Oct 2007: Estimates by trajectory

<table>
<thead>
<tr>
<th>East Lothian</th>
<th>Cancer (ICD10 group C)</th>
<th>Organ Failure (Selected from ICD10 groups I, J &amp; N)*</th>
<th>Progressive Neurological (Selected from ICD10 groups G &amp; F)</th>
<th>Other causes</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths 06 - 07</td>
<td>302</td>
<td>153</td>
<td>73</td>
<td>499</td>
<td>1027</td>
</tr>
<tr>
<td>As % of East Lothian Deaths</td>
<td>29</td>
<td>15</td>
<td>7</td>
<td>49</td>
<td>100</td>
</tr>
<tr>
<td>As % of total Lothian deaths</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Death rate per 100,000</td>
<td>329</td>
<td>156</td>
<td>79</td>
<td>338</td>
<td>1168</td>
</tr>
<tr>
<td>Number of distinct patients admitted to hospice IP bed 06 - 07</td>
<td>53</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>53</td>
</tr>
<tr>
<td>% of all patients admitted to hospice beds in 06 - 07</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Rate of hospice admission (patients per 100,000 population)</td>
<td>27</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>53</td>
</tr>
<tr>
<td>1 person admitted to hospice IP bed for every x deaths</td>
<td>5.7</td>
<td>#DIV/0!</td>
<td>#DIV/0!</td>
<td>#DIV/0!</td>
<td>19.3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Edinburgh</th>
<th>Cancer (ICD10 group C)</th>
<th>Organ Failure (Selected from ICD10 groups I, J &amp; N)*</th>
<th>Progressive Neurological (Selected from ICD10 groups G &amp; F)</th>
<th>Other causes</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths 06 - 07</td>
<td>1149</td>
<td>576</td>
<td>292</td>
<td>2224</td>
<td>4241</td>
</tr>
<tr>
<td>As % of Edinburgh Deaths</td>
<td>27</td>
<td>14</td>
<td>7</td>
<td>52</td>
<td>100</td>
</tr>
<tr>
<td>As % of total Lothian deaths</td>
<td>15</td>
<td>8</td>
<td>4</td>
<td>30</td>
<td>57</td>
</tr>
<tr>
<td>Death rate per 100,000</td>
<td>248</td>
<td>124</td>
<td>63</td>
<td>480</td>
<td>915</td>
</tr>
<tr>
<td>Number of distinct patients admitted to hospice IP bed 06 - 07</td>
<td>160</td>
<td>6</td>
<td>13</td>
<td>7</td>
<td>58</td>
</tr>
<tr>
<td>% of all patients admitted to hospice beds in 06 - 07</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Rate of hospice admission (patients per 100,000 population)</td>
<td>121</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>126</td>
</tr>
<tr>
<td>1 person admitted to hospice IP bed for every x deaths</td>
<td>2.1</td>
<td>36.0</td>
<td>22.5</td>
<td>317.7</td>
<td>7.5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Midlothian</th>
<th>Cancer (ICD10 group C)</th>
<th>Organ Failure (Selected from ICD10 groups I, J &amp; N)*</th>
<th>Progressive Neurological (Selected from ICD10 groups G &amp; F)</th>
<th>Other causes</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths 06 - 07</td>
<td>228</td>
<td>113</td>
<td>70</td>
<td>368</td>
<td>772</td>
</tr>
<tr>
<td>As % of Midlothian Deaths</td>
<td>29</td>
<td>15</td>
<td>9</td>
<td>47</td>
<td>100</td>
</tr>
<tr>
<td>As % of total Lothian deaths</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Death rate per 100,000</td>
<td>259</td>
<td>138</td>
<td>85</td>
<td>444</td>
<td>932</td>
</tr>
<tr>
<td>Number of distinct patients admitted to hospice IP bed 06 - 07</td>
<td>94</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>99</td>
</tr>
<tr>
<td>% of all patients admitted to hospice beds in 06 - 07</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Rate of hospice admission (patients per 100,000 population)</td>
<td>119</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>126</td>
</tr>
<tr>
<td>1 person admitted to hospice IP bed for every x deaths</td>
<td>2.4</td>
<td>58.5</td>
<td>35.0</td>
<td>368.9</td>
<td>7.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>West Lothian</th>
<th>Cancer (ICD10 group C)</th>
<th>Organ Failure (Selected from ICD10 groups I, J &amp; N)*</th>
<th>Progressive Neurological (Selected from ICD10 groups G &amp; F)</th>
<th>Other causes</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths 06 - 07</td>
<td>402</td>
<td>209</td>
<td>94</td>
<td>685</td>
<td>1395</td>
</tr>
<tr>
<td>As % of West Lothian Deaths</td>
<td>29</td>
<td>15</td>
<td>7</td>
<td>49</td>
<td>100</td>
</tr>
<tr>
<td>As % of total Lothian deaths</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Death rate per 100,000</td>
<td>243</td>
<td>126</td>
<td>57</td>
<td>413</td>
<td>838</td>
</tr>
<tr>
<td>Number of distinct patients admitted to hospice IP bed 06 - 07</td>
<td>53</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>56</td>
</tr>
<tr>
<td>% of all patients admitted to hospice beds in 06 - 07</td>
<td>12</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Rate of hospice admission (patients per 100,000 population)</td>
<td>32</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>34</td>
</tr>
<tr>
<td>1 person admitted to hospice IP bed for every x deaths</td>
<td>7.6</td>
<td>104.5</td>
<td>34.0</td>
<td>#DIV/0!</td>
<td>24.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>All Lothian</th>
<th>Cancer (ICD10 group C)</th>
<th>Organ Failure (Selected from ICD10 groups I, J &amp; N)*</th>
<th>Progressive Neurological (Selected from ICD10 groups G &amp; F)</th>
<th>Other causes</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of deaths 06 - 07</td>
<td>2081</td>
<td>1051</td>
<td>529</td>
<td>3690</td>
<td>7437</td>
</tr>
<tr>
<td>As % of total Lothian deaths</td>
<td>29</td>
<td>15</td>
<td>7</td>
<td>49</td>
<td>100</td>
</tr>
<tr>
<td>Death rate per 100,000</td>
<td>290</td>
<td>131</td>
<td>66</td>
<td>465</td>
<td>929</td>
</tr>
<tr>
<td>Number of distinct patients admitted to hospice IP bed 06 - 07</td>
<td>256</td>
<td>120</td>
<td>60</td>
<td>354</td>
<td>770</td>
</tr>
<tr>
<td>% of all patients admitted to hospice beds in 06 - 07</td>
<td>12</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Rate of hospice admission (patients per 100,000 population)</td>
<td>95</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>99</td>
</tr>
<tr>
<td>1 person admitted to hospice IP bed for every x deaths</td>
<td>2.7</td>
<td>105.1</td>
<td>32.1</td>
<td>461.3</td>
<td>9.4</td>
</tr>
</tbody>
</table>

For cancer in Lothian overall 1 person is admitted to a hospice in-patient bed (perhaps involving more than one episode) for every 2.7 deaths from cancer. The range is 1 in 2.1 in Edinburgh to 1 in 7.6 in West Lothian. The same range can be seen in the ratio of persons admitted to all deaths in each area. This highlights the differences in the operation of current models of specialist palliative care in Lothian. Both Lothian hospices are in the City of Edinburgh and admission rates reflect local access. Midlothian benefits from proximity to the Marie Curie Hospice. East and West Lothian have more reliance on local hospitals for admission where required, and in West Lothian a reliance on integrated working across hospital, specialist palliative care team and community teams, to support more deaths at home and in local hospitals.

Almost a quarter of all deaths in the year considered are in the organ failure and neurological trajectories, based on the selected causes of death used. Although specialist palliative care services in Lothian have always been open to referrals for non-cancer palliative care in practice the number of such referrals has been low, with very few admissions to hospice in-patient care. The majority of care provided to patients in these groups is delivered by generalists with input from hospital speciality teams as required. Section 9 below outlines the role Lothian hospices could develop to provide an increased specialist input to non-cancer related palliative care.
9.2 Community Models

The review group recognised the need to specify the characteristics of an effective integrated community model of palliative care. **These are outlined in Appendix 5.** These features are required in all parts of Lothian, particularly so in East and West Lothian where the distance from dedicated in-patient specialist palliative care bed provision is an additional issue for hospital and community teams. Learning from the features of other UK models, as below, may also assist development in Lothian.

9.3 Other UK models considered

In 1987 the West Cumbria Hospice at Home was established\(^{17}\). This innovative community based hospice chose to focus its operation not on a physical building but rather on providing nursing and medical services for terminally ill patients in their own homes.

This hospice was developed to support the large geographical area with a dispersed population where it was deemed unlikely that a single hospice building could adequately meet the needs of the whole community. A hospice at home depends on family members and friends being close at hand to act as informal carers.

With home nursing at the heart of its operation, the majority of referrals are accepted through the General Practitioner and District Nurse, although self referrals are also accepted. This “Nursing Service” model is currently provided by the Marie Curie Cancer Care Nursing Service. The Medical Director, specialist in palliative medicine, is available to support and advise GP’s and also oversees four beds in the acute hospital.

Day Care Services are also provided in a variety of surrounding locations to provide “traditional” care, with an emphasis on the “social side” including Carer support, through the “Drop In” clinic and Bereavement support.

10. LOTHIAN HOSPICE DEVELOPMENT PLANS – IN-PATIENT CAPACITY, OUTREACH SERVICES AND SPECIALIST LIAISON SUPPORT

As part of the review process both of the Lothian Independent Hospices presented their current service plans and ideas for future development. The presentations (and a further brief paper from St Columba’s) are appended to this report in full at **Appendix 6.**

10.1 Marie Curie Hospice Edinburgh

The Marie Curie Hospice vision is based on a new design of hospice care which is integrated with local services and delivered in a variety of settings with care designed around illness trajectories. The vision is underpinned by a policy of supporting choice, by discussing preferred place of death and personalising care planning based on decisions made. The Marie Curie Edinburgh Hospice team believe that the in-patient specialist palliative care bed provision will struggle to meet future demand without developing integrated community models to increase capacity.

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\(^{17}\) Hospice Without Walls Andrew Bibby. Calouste Gulbenkian Foundation 1999
A defining feature of the Marie Curie Edinburgh vision is the desire to explore new ways of delivering and supporting in-patient care in non-hospice settings, including potentially changing the bed capacity and function of the hospice itself to enable developments in other settings.

10.2 St Columba’s Hospice, Edinburgh

The St Columba’s Hospice vision is based on developing a new 30 bed unit and ‘outreach services’. The vision is based on responding to changing patterns and trajectories of dying and underpinned by a policy of supporting choice, by discussing preferred place of death and personalising care planning based on decisions made. A new 30 bed unit will increase capacity by achieving a unit design with more single rooms thereby allowing increased throughput. The hospice is committed to developing outreach services including out-patient clinics, day services and providing more support in care home and NHS continuing care unit settings. A major part of the service provided, and the future vision, is education and training.

A defining feature of the St. Columba’s Hospice vision is the single-site model for in-patient beds (new 30 bed unit on the Challenger lodge site) combined with a range of outreach services.

10.3 Responding to non-cancer related palliative care

Both hospices have the objective of increasing access to specialist palliative care services by providing advice and review for complex patients in an out-patient or domiciliary setting, via telephone advice or day service provision. Appendix 7 outlines individual unit plans.

In particular Lothian hospices wish to develop new models of provision with community hospital teams, and develop specialist consultancy support services aimed at NHS continuing care units and care homes.

Collaborative developments are also emerging under programmes such the Long Term Conditions programme which will provide further routes to increase specialist input. These schemes will also facilitate generalists to meet the palliative care needs of patients with long term conditions at home and in care homes, acute and community hospitals.

Significantly increasing the number of patients admitted to specialist palliative care in-patient beds in the hospice is not regarded by Lothian hospices as an immediate response to opening up access. Historically although open to all referrals, hospices have not received high numbers of requests for transfer of non-cancer patients. This aspect requires further review and exploration as education and training, models of care, and approaches to integrated working develop in Lothian.
11. OPPORTUNITIES FOR DEVELOPMENT AND MAIN RECOMMENDATIONS

11.1 Development framework

NHS Lothian’s Palliative Care Strategy is based on need not diagnosis and all specialist palliative care services, including Lothian Independent hospices, are open to referrals based on need. Both of the Lothian Independent hospices now have the objective of developing responses to non-cancer related palliative care in their corporate plans. A good degree of integrated working is already in place across the hospital, hospice and community teams in the in-patient and community setting. Whilst Lothian hospices have different delivery strategies in mind for the provision of specialist in-patient beds there is agreement that, with 57 beds, the bed complement is adequate for the current population size and in line with national comparators. Furthermore there is agreement that in the hospice setting bed utilisation should improve, and that further plans require to be developed in partnership with community providers to take forward new joint schemes to widen access to specialist palliative care for those with non-cancer palliative care needs.

The following framework fits the findings of this review (and is supported by the review data), the major development plans of providers of specialist palliative care in Lothian, and the theoretical work and evidence base which is developing. All constituent members of the Lothian Managed Clinical Network are encouraged to accept this framework and work in partnership to achieve service improvement in the trajectories and settings specified.

<table>
<thead>
<tr>
<th>Setting</th>
<th>Trajectory</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice, Hospital and community services</td>
<td>Cancer (Rapid)</td>
<td>Retain hospice provision for cancer trajectory, maximise efficiency and effectiveness of utilisation, prepare for increasing complexity of cancer case mix. To keep in review demand and needs arising (particularly potential need for admission) for patients on the organ failure trajectory. Provide support to hospital teams to increase capacity and help shift the balance of care. To increase the number of cancer deaths managed at home.</td>
</tr>
<tr>
<td>Hospitals and Community Services</td>
<td>Organ Failure &amp; Cancer (Erratic and Rapid)</td>
<td>Develop joint schemes (between hospice, hospital and community teams) to increase and improve the specialist palliative care provision offered in these settings. In particular develop ways of delivering specialist palliative care in community hospital settings and NHS Continuing Care wards / units.</td>
</tr>
<tr>
<td>Care Home and community services</td>
<td>Neurological (Dwindling)</td>
<td>Develop joint schemes (between care home, local authority, hospice, and community services) to increase the level of specialist support, increase the capacity of care home teams to manage deaths, and decrease transfers to hospital.</td>
</tr>
</tbody>
</table>

11.2 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 provided in appendix 5 of this 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 1 - MEMBERSHIP OF THE BED CAPACITY REVIEW SUB-GROUP

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Fred Benton</td>
<td>Medical Director, St Columba’s Hospice</td>
</tr>
<tr>
<td>Dr. Patricia Cantley</td>
<td>Consultant Geriatrician, University Hospitals Division</td>
</tr>
<tr>
<td>Margaret Dunbar</td>
<td>Nursing and Administrative Director, St Columba’s Hospice</td>
</tr>
<tr>
<td>Shirley Fife</td>
<td>Lead Nurse, Cancer and Palliative Care, NHS Lothian CHP’s</td>
</tr>
<tr>
<td>Diana Hekerem</td>
<td>Business Manager, Marie Curie Cancer Care</td>
</tr>
<tr>
<td>Peter McLoughlin (Chair)</td>
<td>Strategic Programme Manager, Lothian NHS Board</td>
</tr>
<tr>
<td>Phil Mackie</td>
<td>Specialist in Public Health Medicine</td>
</tr>
<tr>
<td>Dr. David Oxenham</td>
<td>Medical Director, Marie Curie Edinburgh Hospice and Lead Clinician, Palliative Care, NHS Lothian.</td>
</tr>
<tr>
<td>Dr. Bill O’Neill</td>
<td>Lead GP, Cancer and Palliative Care, NHS Lothian</td>
</tr>
<tr>
<td>Elizabeth Preston</td>
<td>Head of Service, Cancer and Palliative Care, University Hospitals Division</td>
</tr>
<tr>
<td>Dr. Juliet Spiller</td>
<td>Consultant in Palliative Medicine, Marie Curie Cancer Care</td>
</tr>
<tr>
<td>Maggie White</td>
<td>Caring Services Manager, Marie Curie Cancer Care</td>
</tr>
<tr>
<td>Anne Willis</td>
<td>Hospice Manager, Marie Curie Edinburgh Hospice</td>
</tr>
</tbody>
</table>

Irene Turnbull, PA to Directors at St Columba’s Hospice, provided support to the meetings.
APPENDIX 2 – REMIT OF THE BED CAPACITY REVIEW SUB-GROUP

FINAL AGREED VERSION

Palliative Care MCN

Bed Capacity Review Sub-Group

REMIT

To review General and Specialist Palliative Care in NHS Lothian to be able to make recommendations to the Board on the specialist bed capacity and support for General Palliative beds required in Lothian; on the options for delivery of this; and to state a preferred, agreed and feasible option.

The work will involve consideration of the following:

- The MCN’s workplan and emerging strategic direction
- The existing model of Palliative Care services in Lothian
- Definition of Specialist vs. non-specialist palliative care
- Current and Forecast demand for Cancer & non-cancer
- Current capacity & utilisation – Specialist services
- Benchmarking & other models of care
- Impact & potential of redesign in support services (diagnostics, pharmacy, social services, day & community services)
- Modernisation & service redesign potential

Reference resources:

- ‘Bed Modelling’ work already undertaken
- Trajectories of dying framework
- Emerging/ current models of care elsewhere
- ‘Better Health, Better Care’: Past model/ future model concept
- DoH ‘End of Life’ policy & action plan
- SPPC recommendations to Scottish Executive
- Audit Scotland review
- NHS Lothian Service Level Agreements – Specialist Palliative Care
- Bed management principles – flow / transfer / utilisation
- Cancer palliative care needs assessment
- VOICES report
- Scottish Government Health Department DCAQ resources and tools
## APPENDIX 3 – TOP 10 CAUSES OF DEATH IN LOTHIAN & SCOTLAND

### Top 10 causes of death, Lothian NHS Board area, for year 2006/07 (01 November 2006 to 31 October 2007)

#### By place of death

<table>
<thead>
<tr>
<th>Underlying cause of death</th>
<th>All causes</th>
<th>All deaths</th>
<th>Hospital</th>
<th>Other institution</th>
<th>Non-institution</th>
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<td>All causes</td>
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<td>Ischaemic heart diseases (I20 - I25)</td>
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<tr>
<td>Cerebrovascular diseases (I60 - I69)</td>
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<td>430</td>
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<tr>
<td>Malignant neoplasm of trachea, bronchus and lung (C33 - C34)</td>
<td>577</td>
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<td>138</td>
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<tr>
<td>Dementia and Alzheimer’s disease (F01, F03, G30)</td>
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<tr>
<td>Cancer - Unspecified</td>
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<tr>
<td>Chronic lower respiratory diseases (J40 - J47)</td>
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<tr>
<td>Influenza and pneumonia (J10 - J18)</td>
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<td>205</td>
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<td>Malignant neoplasm of colon, sigmoid, rectum and anus (C18-C21)</td>
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<td>External Causes Of Morbidity And Mortality (V01-Y98)</td>
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<tr>
<td>Diseases of the urinary system (N00-N39)</td>
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<td>104</td>
<td>29</td>
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<tr>
<td>Other causes</td>
<td>2776</td>
<td>1911</td>
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<td>576</td>
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Source: ISD Linked file May 2008
Ref: CB, HIU2267/glasgow_data, 18 September 2008

### Top 10 causes of death, Scotland, 2007

#### By place of death

<table>
<thead>
<tr>
<th>Underlying cause of death</th>
<th>All causes</th>
<th>All deaths</th>
<th>Hospital</th>
<th>Other institution</th>
<th>Non-institution</th>
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<tr>
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<td>10744</td>
<td>13084</td>
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<td>Ischaemic heart diseases</td>
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<tr>
<td>Cerebrovascular diseases</td>
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<td>Malignant neoplasm of trachea, bronchus and lung</td>
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<td>2283</td>
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<tr>
<td>Chronic lower respiratory diseases</td>
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<td>2143</td>
<td>331</td>
<td>630</td>
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<tr>
<td>Dementia and Alzheimer’s disease</td>
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<td>1951</td>
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<tr>
<td>Influenza and pneumonia</td>
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<td>1591</td>
<td>677</td>
<td>181</td>
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<tr>
<td>Malignant neoplasm of colon, sigmoid, rectum and anus</td>
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<td>Cirrhosis and other diseases of liver</td>
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<td>Diseases of the urinary system</td>
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<td>224</td>
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<tr>
<td>Malignant neoplasm of breast</td>
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<td>219</td>
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<tr>
<td>Other causes</td>
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<td>4967</td>
<td>1213</td>
<td>1332</td>
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### APPENDIX 4 – ICD10 CODES USED TO ESTIMATE TRAJECTORIES

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<tr>
<th>CANCER</th>
<th>CODES</th>
<th>ICD10 DESCRIPTION</th>
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<tbody>
<tr>
<td>C009 - C329 Cancer - Head &amp; Neck</td>
<td>C709 - C719 Cancer - Brain</td>
<td>I119 Hypertensive Heart Disease Without (Congestive) Heart Failure</td>
</tr>
<tr>
<td>C155 - C159 Cancer - Oesophagus</td>
<td>C800 Cancer - Unspecified</td>
<td>I251 Atherosclerotic Heart Disease</td>
</tr>
<tr>
<td>C160 - C169 Cancer - Stomach</td>
<td>C900 Cancer - Lung</td>
<td>I258 Other Forms Of Chronic Ischaemic Heart Disease</td>
</tr>
<tr>
<td>C180 - C20 Cancer - Colorectal</td>
<td>C33 Cancer - Lung</td>
<td>I259 Chronic Ischaemic Heart Disease, Unspecified</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I500 Congestive Heart Failure</td>
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<tr>
<td></td>
<td></td>
<td>I501 Left Ventricular Failure</td>
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<tr>
<td></td>
<td></td>
<td>I509 Heart Failure, Unspecified</td>
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<tr>
<td>C250 - C259 Cancer - Pancreas</td>
<td>G009 Cancer - Pancreas</td>
<td>J440 Chronic Obstructive Pulmonary Disease With Acute Lower Resp Infection</td>
</tr>
<tr>
<td>C33 - C349 Cancer - Lung</td>
<td>G309 Cancer - Lung</td>
<td>J441 Chronic Obstructive Pulmonary Disease With Acute Exacerbation, Unspecified</td>
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<tr>
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<td>J448 Other Specified Chronic Obstructive Pulmonary Disease</td>
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<td>J449 Chronic Obstructive Pulmonary Disease, Unspecified</td>
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<tr>
<td>C509 Cancer - Breast</td>
<td>G20 Diseases Of The Nervous System (G00-G99)</td>
<td>N180 End-Stage Renal Disease</td>
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<td>C539 Cancer - Cervix</td>
<td>G301 Alzheimer’s Disease With Late Onset</td>
<td>N189 Chronic Renal Failure, Unspecified</td>
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<td>C541 Cancer Corpus Uteris</td>
<td>G308 Other Alzheimer’s Disease</td>
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<td>C64 Cancer - Kidney</td>
<td>G35 Diseases Of The Nervous System (G00-G99)</td>
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<tr>
<td>C679 Cancer - Bladder</td>
<td>G110 Hypertensive Heart Disease With (Congestive) Heart Failure</td>
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**NEUROLOGICAL**

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<tr>
<td>F011 Multi-Infarct Dementia</td>
<td>J440 Chronic Obstructive Pulmonary Disease With Acute Lower Resp Infection</td>
</tr>
<tr>
<td>F019 Vascular Dementia, Unspecified</td>
<td>J441 Chronic Obstructive Pulmonary Disease With Acute Exacerbation, Unspecified</td>
</tr>
<tr>
<td>F03 Mental And Behavioural Disorders (F00-F99)</td>
<td>J448 Other Specified Chronic Obstructive Pulmonary Disease</td>
</tr>
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<td>G122 Motor Neuron Disease</td>
<td>J449 Chronic Obstructive Pulmonary Disease, Unspecified</td>
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**ORGAN FAILURE**

<table>
<thead>
<tr>
<th>CODES</th>
<th>ICD10 DESCRIPTION</th>
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</thead>
<tbody>
<tr>
<td>I119 Hypertensive Heart Disease Without (Congestive) Heart Failure</td>
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<td>APPENDIX 5 – Integrated Community Model of Palliative Care</td>
<td></td>
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<tr>
<td>---------------------------------------------------------</td>
<td></td>
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<tr>
<td><strong>SUGGESTIONS FOR FACILITATING APPROPRIATE ACCESS TO</strong></td>
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<tr>
<td><strong>GENERALIST AND SPECIALIST PALLIATIVE CARE - Based on the West</strong></td>
<td></td>
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<tr>
<td><strong>Lothian Model</strong></td>
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</table>

### Discharge from acute hospital
- discharge liaison nurse works alongside multi-disciplinary teams to identify and assess patients for discharge and liaises with community teams, OT, Physio and social work
- weekly meeting with specialist hospital team and discharge liaison nurse, chaplain, pall care social worker, pall care OT, pall care pharmacist
- Community hospitals used appropriately as generalist palliative care resource

### Community hospital beds used for generalist palliative care
- end of life care, continuing care and palliative care respite
- access from community, hospital and hospice – clear referral pathway
- referral documentation clearly identifies palliative care needs
- regular support/input from specialist pall care team
- MDT case note documentation (possibly adapted from hospice) – palliative care goals clearly identified
- Pain assessment documentation – Lothian Sign 44 Initiative and cognitive impairment pain tools embedded in nursing practice and supported by specialist team
- DNAR policy implemented and embedded in nursing and medical practice
- LCP implemented and supported by specialist team
- Ongoing pall care education for nursing and medical staff supported by specialist team

### Keeping patients at home
- strong links with between specialist team and community teams
- GP’s OOH special notes initiated, and encouraged by specialist team
- GSFS embedded in practice systems and supported by specialist team
- upskilled DNs through education and projects such as the palliative care shadowing project resulting in
  - increased confidence in managing pall care patients at home
  - increased willingness and enthusiasm for managing “specialist” interventions and treatments for patients at home (e.g. spinal lines, ketamine, methadone, opioid toxicity, complex psychosocial issues etc)
  - increased awareness of criteria for hospice admission and willingness to explore other options with patients and families
- access to an upskilled, confident, and cohesive OOH nursing service who practice anticipatory as well as reactive palliative care
- specialist palliative care social worker able to visit and assess patients at home.

### Access to palliative care social worker for whole team
- referrals from community team can pre-empt breakdown of care at home
- smooth transition between hospital and home
**Access to palliative care pharmacist for whole team**

- smooth transition between hospital and home
- strong links with local pharmacies to anticipate and resolve pall care drug issues
- advice resource for specialist and for generalist teams in all settings
The Vision

- A new Design of Hospice care which will provide ‘excellence in palliative care’ for patients in South Lothian which is
  - integrated within local services
  - delivered in a variety of settings
  - designed around future illness trajectories.

Towards the end of life, everyone will have access to quality care and support in their place of choice
Why?

- Changing trajectories of dying means traditional hospice care may not meet the needs of those ‘sick enough to die’
- Health Policy in Scotland
- Best use of Resources, Buildings
- Address Health Inequalities

Palliative care for all according to need

GP has 20 deaths per list of 2000 patients per year
Future Trends

Organ failure

Cancer

Dementia, frailty and decline

GP has 20 deaths per list of 2000 Patients per year

6

3

2

8

Advance care planning/ symptom management/ end of life care in all settings (LCP)

Traditional palliative care/hospice model

Improve provision of social care and nursing support in the community, day and night

Public campaign: “Health promoting Palliative Care”
Key Points

- Fewer people dying on ‘cancer’ trajectory (even if they have cancer)
- More requiring palliative care on ‘organ failure’ trajectory
- In patient palliative care beds and present hospice model of care may struggle to meet this demand
- Many organ failure trajectory patients better cared for in community/continuing NHS care
Potential future

• Retain hospice/sp pall care provision for ‘cancer’ trajectory
• Co locate ‘organ failure’ trajectory palliative care beds with community hospital (eg Midlothian) or equivalent.
• Support palliative care in nursing homes for ‘frailty/dementia’ trajectory
• More support for Primary Care to provide palliative care for all patients
  – Palliative care registers (GSF)

To Achieve this Vision we would

• Scope up a collaborative Project with Geriatricians/Community Hospitals re Marie Curie Inpatient provision on a co-located site.
• Scope up the scale of additional support for generalists working with and in Care Homes.
• Gain consensus for this model and talk with Users.
• Develop a Business case for a reduction in beds at MC Edinburgh in order to part fund this shift.
• Discuss an evaluation framework with the Primary Palliative Care Research Group.
Appendix 6 continued…

St. Columba’s Hospice

? circumstances
change rapidly

? needs change

SPECIALIST
PALLIATIVE CARE

GENERALIST
PALLIATIVE CARE

? process of care
? specific interventions

... a little more slack ... 

... more flexibility ...
• terminal care

• symptom control

• limited rehabilitation

• respite

• increasing age of our population

• changing needs of our patients

• society’s rising expectations

• changing needs of our colleagues
... dying differently ...

... natural history changing ...

... living with disease ...
PERFORMANCE INDICATORS

• Preferred place of care
• Gold Standard Framework
• Liverpool Care Pathway
• SIGN 44
• DNAR status

ST. COLUMBA’S HOSPICE
% BED OCCUPANCY (30 beds)
1998 - 2007
ST. COLUMBA’S HOSPICE
ADMISSIONS/DEATHS/DISCHARGES
1998 - 2007

<table>
<thead>
<tr>
<th>Year</th>
<th>Adm.</th>
<th>Deaths</th>
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<td>2007</td>
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ST. COLUMBA’S HOSPICE
MEDIAN LENGTH OF STAY
2007

<table>
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<th>Mar</th>
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<th>May</th>
<th>Jun</th>
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(DAYS)
### Patients in Hospital

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<th>Patients at Home</th>
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- **Care of the dying is urgent care** ...

- **One opportunity to get it right** ...

M. Richards, 2007

The First National Audit of the Care of the Dying in Hospitals in England.
Charities - fill a gap

? care
? education
? financial
ST. COLUMBA’S HOSPICE

? Challenger Lodge site

? 30 beds - economy of scale
   - NHS QIS, Care Commission Standards
   - a greater proportion of single rooms

? Day Hospice

? Community Palliative Care Team

? a greater provision of Out-Patient Services

? Teaching
ST. COLUMBA’S HOSPICE, EDINBURGH

In our discussions on the future development of Palliative Care Services in Lothian, and at St. Columba’s Hospice in particular, we have put emphasis on our development of a new In-Patient Unit of 30 beds. However, the initiative involves far more than a hospice ward:

- we are committed to expanding our Outreach Services comprising Out-Patient Clinics, providing more support in the Nursing Home and in the NHS Continuing Care Unit, and the further development of Day Hospice Services and Complementary Therapy Clinics.

One of our two Consultants allocates two sessions per week to expanding the existing Community Palliative Care Service in East Lothian, with a proposed Out-Patient Clinic at Roodlands Hospital.

Our commitment to education continues and the New Build will see an improvement in our educational facilities, with our purchase of the adjacent property at No. 17 Boswall Road.

We have no doubts that we require, and will continue to require, our 30 beds in the years ahead. This is equivalent to some 35 beds with the increased proportion of single rooms and consequently the throughput will increase. A Unit of this size also offers an economy of scale.

While some argue that more patients will die at home, at St. Columba’s Hospice we consider that this is not the case. While so many patients initially wish to die at home, there are various issues which will make this more difficult. These include: our ageing population, the loss of the extended family, the secularization of society, less emphasis on continuity of care and the remodelling of Out-of-Hours Services.

Barclay and Antony refer to ‘evidence of a slow decline in deaths occurring at home’. Gomes and Higginson make similar comments.

There will be an increased demand for specialist palliative care beds, not just for patients with a malignancy but also for patients with non-malignant conditions. In Lothian, demand for specialist palliative care for non-malignant diseases is in its infancy.

We know that the number of patients with malignant disease will increase and, while we would hope for improvements in cure rates, there will be an increasing number of patients living longer with their disease, with complex needs, needing palliative care for longer.

The training of future Specialists in Palliative Medicine and Nurse Specialists in Palliative Care – again, St. Columba’s Hospice is committed to this work and we believe that a 30-bedded Unit at St. Columba’s will give future Consultants an ideal training, with experience in our Outreach Services, our Community Palliative Care Service and Day Hospice Service, along with day-to-day responsibility for In-patients.
There is closer collaboration between the two Edinburgh Hospices, and the joint Consultant on-call rota and the joint first-on-call medical rota are testament to this. All six Consultants in Palliative Medicine in Edinburgh are committed to working more closely and, again, their weekly teleconference is evidence of this.

St. Columba’s Hospice does not forget that 50% of its funding is from our community and that community expects us to offer a flexible and humane response to the needs of those with far-advanced disease. Our in-patients should feel safe and, while it is easy to focus on physical issues and/or physical symptoms (complex or otherwise), there is more to our patients’ suffering and we must not forget the importance of being there with our patients.\(^5\)

M.F. Dunbar (Mrs.)
Nursing & Administrative Director

Dr. T.F. Benton
Medical Director

April 2008

REFERENCES


St. Columba’s Hospice has always, and will continue to admit patients according to need and not diagnosis. To date, only 5% of our in-patients have non-malignant disease.

Patients with non-malignant diseases, for the most part associated with age and degenerative pathologies, are thought to have a different disease trajectory than patients with cancer.¹ As we have discussed previously, there are the patients with organ failure, patients who are ill for many months or years but where the course is punctuated by acute exacerbations, and secondly patients, the frail elderly, who have a slow, insidious decline, again over months or years. The terminal phase for these two groups is likely to be short, if recognizable at all.²

In contrast, the majority of patients with cancer tend to have a more clearly identifiable terminal phase. Consequently, it is often easier to decide when to admit a patient with a malignant disease to the Hospice for end-of-life care.

There is inevitably a concern over the admission of patients with non-malignant conditions to the Specialist Palliative Care Unit. Is this their final admission or are they likely to improve sufficiently to return home, or are they more likely to improve a little but continue to need institutional care? Will this then put more pressure on the Specialist Palliative Care Unit’s beds – the beds could be ‘blocked’ and the patients will no longer have specialist needs. We do already have this dilemma with many of our patients with relatively indolent malignancies.

It will be more appropriate for the Specialist Palliative Care Unit to be more involved in an advisory capacity, offering a ‘consultancy’ service,² just as the Palliative Care Team in the hospital setting, supporting our colleagues in the Continuing Care Unit and in the Care Home. This Outreach Service would be supplemented by an Out-Patient Service.
Proposed Outreach Services from St. Columba’s Hospice:

- Telephone Advisory Service (as at present).
- Day Hospice attendance (as at present).
- Medical and/or Community Palliative Care Team visits to Continuing Care Unit and Care Home.
- Out-Patient Review Service at St. Columba’s Hospice.
- Arrangements for medical and nursing staff attachments at St. Columba’s Hospice from Continuing Care Units and Care Homes should also be more formalized.

Dr. T.F. Benton
Medical Director

Mrs. M. Dunbar
Nursing & Administrative Director

References:


IMT.
14.8.08.
Specialist responses to non-cancer palliative care

Marie Curie Edinburgh Hospice

VISION: SPECIALIST PALLIATIVE CARE SERVICES FOR PATIENTS WITH NON-MALIGNANT DIAGNOSIS

1. Increase Access to Specialist Palliative Care Services
   - Advice & review of complex patients via Our Patient or Home Visit
   - New models of provision in Community Hospitals
   - Clear information for referrers / disease specialists re Referral Options

2. Collaborate with CEP’s, Long Term Conditions Teams and Disease Specialists to provide
   - Self-managed Care Programme
   - Care services at home
   - Community nursing support (MCNS)

3. Develop Palliative Care Systems in Partnership with CEP’s, Generalists Disease Specialists
   - End of Life Care Planning OOH DNAR AC Plans
   - LSF in Practice & Care Homes
   - Education advice re identification of EOL Care

Decreasing numbers of deaths in hospitals and increasing care in community settings:
2006 (Lothian all deaths) Hospital 4140 Other settings 3590

Expected no. of deaths from organ failure requiring SPC in 2016 – 3288

Decreasing numbers of deaths in hospitals and increasing care in community settings:
2016 (Lothian all deaths) Hospital 2000 Other settings 5000