PALLIATIVE CARE STRATEGY

Improving Palliative Care and End of Life Services in Lanarkshire

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EXECUTIVE SUMMARY

Palliative Care is about improving the quality of life of patients and their families facing the problems associated with a life-threatening illness, from diagnosis onwards. It is not just concerned with pain and physical symptoms, but psychosocial and spiritual problems as well. Whilst the definition of palliative care is complex, we now understand it to involve all life-limiting illnesses, including cancer, organ failure/neurological conditions, frailty and dementia.

LANARKSHIRE’S VISION FOR PALLIATIVE CARE

Lanarkshire will meet palliative care needs and provide services in the setting of patient/carer choice, wherever possible. For the majority of people this will be in their own homes, or their care home of residence. Admission to an inpatient bed will only happen where absolutely necessary, with discharge facilitated as quickly as possible. All partner organisations (NHS Lanarkshire, North and South Lanarkshire Councils, voluntary and independent sectors) are committed to increasing the range of suitable alternatives.

NHS Lanarkshire (2012) made palliative care one of its four strategic priorities for A Healthier Future and is committed to ‘improve palliative care and supported end of life services.’ A palliative care strategy was commissioned to meet this strategic objective, and has been progressed at every stage in collaboration with partner organisations, recognising that none has lead responsibility for all aspects of palliative care. A series of stakeholder meetings was held during 2012 to identify what palliative care services we currently have and what perceived and actual gaps in service provision existed.

WHAT IS THE LEVEL OF PALLIATIVE CARE NEED IN LANARKSHIRE?

The majority of people with palliative or end of life care needs are elderly and we know that the trend is for a continued increase in the number of people 65 years and over. The number of single person households is also projected to rise by 50% in the next 10 years, meaning more people will need help in future. To realise the palliative care vision and meet people’s wishes to remain at home where possible, service provision needs to change. If more people are to be cared for and die at home, more community-based as opposed to inpatient generalist and specialist palliative care services are required.

WHAT PALLIATIVE CARE SERVICES DO WE CURRENTLY HAVE?

Our stakeholders noted that the majority of palliative and end of life care is provided by generalists with palliative care experience. They link with our small team of specialists for more complex needs.

WHAT GAPS IN OUR SERVICES NEED TO BE FILLED?

Stakeholders also identified the main gaps in service provision. These were gathered during the first and second events and confirmed as the consensus view by attendees at the third. It should be noted that where the considerable and commendable ongoing work of palliative care specialists and generalists was relatively unproblematic, stakeholders felt it did not need to be included in this strategy. They asked us to address seven main gaps and in the past six months various workshops and discussions have generated a number of possible options to fill them.

1. Palliative care specialist cover at weekends
   - Move to seven day cover, consider need for out-of-hours input, integrate hospital and community palliative care specialist nurses into one team

2. Palliative care hospital discharge management
   - Specialist input if required for links to discharge hub, step-up/down beds and enhance existing teams for families with major issues requiring emotional/psychological support
3. Carers involved in care planning
   • Raise awareness using existing carer educational materials, more identification of carers, access to carer emergency plans
4. Flexibility of equipment delivery/uplift for palliative care
   • Bereavement team to uplift beds after death, signpost to moving & assisting training for carers

Work on three of the gaps was led by a consortium of local hospice providers (St Andrew's, Strathcarron, Kilbryde and Marie Curie Cancer Care) and NHS Lanarkshire.

5. Palliative care respite/day services, including <65s
   • Increase access to palliative care respite beds, ask about respite during assessments, single point of co-ordination to meet respite needs, involve volunteers in some provision
6. Promote communication around death, dying and bereavement
   • Increase coverage of the ‘Addressing the Great Taboo’ programme, raise awareness of the need to talk about death, dying and bereavement and the advantages of living wills
7. Transport for non-malignant palliative care
   • Increase the capacity of drivers and escorts, enhance co-ordination of complex transport needs, ask about transport during assessments

WHAT IS THE INDICATIVE COST OF FILLING OUR GAPS?
None of the recommended options to address the gaps our stakeholders identified have been fully costed, but it would be difficult to give them due consideration in the absence of any financial detail. Much more detailed analysis is needed of these costs and this would be a critical component of strategy implementation. There are major workforce implications associated with some of the options, which would require careful capacity analysis, at both individual and team levels.

While some of the options have no additional cost implications, the total indicative cost of addressing all of the identified gaps is around £757,000. Investment is required at least over the next two years, and a variety of funding sources exist that may contribute:

- Innovative approaches from hospices/voluntary sector colleagues
- Change Fund
- Palliative Care budget
- Under-utilisation of specialist palliative care bed occupancy
- Care home budget
- Underspend of NHS Lanarkshire’s contribution to Kilbryde Hospice

Some evidence of bed days saved is available from the specialist palliative care weekend working pilot and evaluation of the Just in Case box anticipatory prescribing roll-out across Lanarkshire (Alexander et al, 2012). Evaluation of strategy implementation would determine whether or not any aspects prevented hospital admissions or facilitated speedy discharge, resulting in cost avoidance. There is a NICE Commissioning and Benchmarking Tool that can be used to estimate the potential savings from hospital admissions avoided, as used by Connelly & Sandeman (2012).

If it becomes necessary to prioritise the different options for filling the gaps in palliative care services, it would be simple to separate out those with no additional costs. Thereafter there would need to be agreement on appropriate criteria for assessing and ranking the benefits that would result from implementation of any of the options. It is not possible to give clear recommendations on prioritisation without involving key stakeholders and they have not thus far been asked to comment on the implications of implementing only some aspects of this strategy. It should also be noted that the Scottish Government is considering the recent Independent Review of the Liverpool Care Pathway and any recommendations from this work will need to be implemented in Lanarkshire.
Reshaping Palliative Care for A Healthier Future

1. WHAT IS PALLIATIVE CARE?

The World Health Organisation defines palliative care as:

‘an approach that improves the quality of life of patients and their families facing the problems associated with a 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.’

World Health Organisation (2010)

The Scottish palliative care action plan, Living and Dying Well notes that:

‘Palliative care is not just about care in the last months, days and hours of a person’s life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards.’

Scottish Government (2008)

We can see that the definition of palliative care is complex, and we now understand it to involve all life-limiting illnesses, not just cancer. It is provided for people with a wide range of conditions and the main ones (grouped according to the National Gold Standards Framework Centre, 2008) are:

- Cancer
- Organ failure – Chronic Obstructive Pulmonary Disease, heart disease, renal disease, neurological conditions (Motor Neurone Disease, Multiple Sclerosis, Parkinson’s Disease)
- Frailty and Dementia – frailty, dementia, stroke

Palliative care is no longer provided just at the end of life, rather needs are identified from the entirety of a person’s circumstances from diagnosis onwards. It is not just concerned with physical symptoms and the care extends beyond the patient to their families as well.

2. LANARKSHIRE’S VISION FOR PALLIATIVE CARE

Lanarkshire will meet palliative care needs and provide services in the setting of patient/carer choice, wherever possible. For the majority of people this will be in their own homes, or their care home of residence. Admission to an inpatient bed will only happen where absolutely necessary, with discharge facilitated as quickly as possible. All partner organisations (NHS Lanarkshire, North and South Lanarkshire Councils, voluntary and independent sectors) are committed to increasing the range of suitable alternatives.

NHS Lanarkshire (2012) made palliative care one of its four strategic priorities for A Healthier Future and is committed to:

‘improve palliative care and supported end of life services.’

A palliative care strategy was commissioned by NHS Lanarkshire to meet this strategic objective, and has been progressed at every stage in collaboration with partner organisations, recognising that none has lead responsibility for all aspects of palliative care. A series of stakeholder meetings was held during 2012 to identify what palliative care services we all currently provide and what perceived and actual gaps in services may exist. However, these need to be put in context of the level of need across Lanarkshire and links to other major strategies/ongoing developments, not least of which is the integration of health & social care.
Reshaping Palliative Care for A Healthier Future

3. WHAT IS THE LEVEL OF PALLIATIVE CARE NEED IN LANARKSHIRE?

Following publication of Living and Dying Well, the National Action Plan for Palliative Care (Scottish Government, 2008) NHS Lanarkshire created a delivery plan to address those aspects where it had lead responsibility. With the majority of these met or on target, the level of palliative care need can now be factored into A Healthier Future’s strategic aim.

How many people live in Lanarkshire?

Although the combined North and South Lanarkshire council population is 639,260 (GRO, 2012), people from Cambuslang, Rutherglen and the ‘Northern Corridor’ mainly access specialist palliative care services from NHS Greater Glasgow and Clyde, meaning the NHS Lanarkshire population is 563,185. Figure 1 shows the increase in the number of people aged ≥65 in the past 10 years. The trend is for a continued rise, with a 65% increase in the over 65s by 2035 and 88% for the over 75s. The number of single person households is also projected to rise by 50% over this period.

Figure 1 - Mid-2011 NHS Lanarkshire older people population estimates

How many people die in Lanarkshire each year?

There were 5,511 deaths in Lanarkshire in 2011, 28% were cancer-related, 72% from other causes including organ failure, stroke, and sudden deaths. Table 1 shows the recent trend in place of death.

Table 1 – Place of death (2008-2011) for the NHS Lanarkshire population

<table>
<thead>
<tr>
<th>Place of death</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute hospital</td>
<td>3004</td>
<td>2825</td>
<td>2788</td>
<td>2775</td>
</tr>
<tr>
<td>NHS Continuing care</td>
<td>320</td>
<td>307</td>
<td>276</td>
<td>233</td>
</tr>
<tr>
<td>Community hospital</td>
<td>80</td>
<td>80</td>
<td>96</td>
<td>94</td>
</tr>
<tr>
<td>Care home</td>
<td>733</td>
<td>735</td>
<td>806</td>
<td>793</td>
</tr>
<tr>
<td>Domicillary</td>
<td>1377</td>
<td>1367</td>
<td>1413</td>
<td>1407</td>
</tr>
<tr>
<td>St Andrew’s Hospice</td>
<td>171</td>
<td>170</td>
<td>245</td>
<td>207</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>TOTAL DEATHS</td>
<td>5690</td>
<td>5488</td>
<td>5627</td>
<td>5511</td>
</tr>
</tbody>
</table>

Source – IM&T Department, NHS Lanarkshire
* Rounded up to 0.1

Table 1 show that there has been a slight decrease in recent years in the number of people dying in our acute hospitals and a small rise in the number dying at home or in their care home of residence. National and local work Reshaping Care for Older People (Scottish Government, 2012) aims to deliver as much care as possible in people’s own homes/usual place of residence and avoid hospital admission where possible. The Balance of Care Group and National Audit Office (2008) have estimated that 40% of people dying in hospital are not receiving medical treatment that requires them to be there. However, there are resource implications associated with them dying at home.
Where do people say they want to die?
Leadbeater & Garber, 2010 reported that 66% of people said they wanted to die at home, which is more than currently do. Whilst two thirds wanted to die at home, only a quarter said they thought they would be able to look after someone dying at home. This rises to 50% feeling able to cope with a home death if the burdens for patients and carers are eased with medical and social support.

Why do people die in hospital instead of at home?
If more people are to achieve their wishes in relation to where they die, we need to understand the reasons why people with palliative care needs are admitted to hospital. In a recent audit Barrie et al (2010) found that 18% of emergency hospital admissions involved palliative care needs. Two thirds were admitted out-of-hours and the main clinical reason for admission was an uncontrolled symptom. Of the 71 people who provided further information, 20 said they would have preferred to stay at home. Despite having a range of health and social care support in place in their homes, most had agreed to the admission when told it was necessary by a professional.

Gomes & Higginson (2006) looked at some of the factors influencing death at home in terminally ill patients with cancer and produced Figure 2 to summarise their findings.

Figure 2 – Factors associated with place of death (home and hospital only)

Figure 2 shows that there are many factors influencing where people die, some of which could be altered to help prevent admission. Where people have a preference to be at home, have adequate social support and hospital beds are limited, they are more likely to die at home. Although these findings were generated from cancer patients, extension to non-malignant long-term conditions is likely to add to this model rather than question its validity, because the factors associated with non-cancer long-term conditions are the same as those influencing a home death in Figure 2, e.g. long length of disease, low functional status, and use of intensity of home care.

What palliative care services should we supply?
Living and Dying Well includes no guidance about the level of services required to meet palliative care needs and although Audit Scotland (2008) highlighted the need to plan for a predicted increase in demand and benchmarked current provision, it did not quantify any recommendations for action. Much
of the documentation on which to base the calculation of palliative care service need pre-dates both of these documents and although they can assist with the estimation of Lanarkshire need, we have to factor in local variation and planned/actual shifts in the balance of care e.g. if more people are to be cared for and die at home, more community-based as opposed to inpatient generalist and specialist palliative care services will be required. Primary drivers include developing the kind of alternatives to hospital beds that people want via the national programme *Reshaping Care for Older People* (Scottish Government, 2012) and responding to people’s expressed wishes to die at home instead of hospital.

Amongst the least harmonious guidance to apply to Lanarkshire is the calculation of how many specialist palliative care inpatient beds are required, as summarised in Table 2.

### Table 2 – Calculations of specialist palliative care inpatient beds

<table>
<thead>
<tr>
<th>Source</th>
<th>Calculation</th>
<th>Beds for Lanarkshire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Association for Palliative Medicine (2012)</td>
<td>16-18 per 250k popn.</td>
<td>36-40</td>
</tr>
<tr>
<td></td>
<td>1 per 20k popn. (mainly cancer)</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>20-25 per 250k popn. (cancer and non-cancer)</td>
<td>45-56</td>
</tr>
<tr>
<td>Help the Hospices (2013)</td>
<td>3175 beds for UK popn.</td>
<td>29</td>
</tr>
<tr>
<td>Franks et al (2000)</td>
<td>40-50 per million popn.</td>
<td>28</td>
</tr>
</tbody>
</table>

There are currently 30 inpatient beds in St Andrew’s Hospice (plus two for respite) and 6 in Strathcarron. On the basis of most of the published guidance in Table 2, Lanarkshire does not require any additional specialist inpatient beds.

The Association for Palliative Medicine (2012) arrives at three different estimates for the number of inpatient beds by reference to different publications. The highest estimate is out of step with other published figures and is based on a European paper. Given the differences between health services across Europe, this figure may not be entirely relevant to Lanarkshire. Current occupancy levels for the 36 inpatient beds we have at present do not suggest that our provision is too low. It is also the case that the majority of hospice inpatients have a cancer diagnosis and a question remains over whether or not people with other conditions will make more use of hospice beds in future. The trajectory of non-cancer conditions such as chronic obstructive pulmonary disease suggests that respiratory nurse specialists will continue to manage the serious exacerbations associated with the palliative phase.

In terms of equity of service provision, various ways of determining differences in access to palliative care services have been reported (e.g. Schuurman et al, 2010). Typically this work applies a one-hour road travel time as a reasonable maximum driving time for clients/families. The majority of Lanarkshire’s population is within a one hour car journey of St Andrew’s Hospice, Airdrie.

In terms of community specialist palliative care services, Tebbit (2004) recommends 23 clinical nurse specialists per million cancer patients and an another 11 for non-cancer conditions. In Lanarkshire this equates to 13 nurse specialists for cancer patients and 6 for non-cancer conditions. With our 12.6WTE community palliative care nurse specialists and 3WTE in the acute hospitals we are short of 3.4WTE palliative care nurse specialists. Tebbit’s calculation relates to palliative care nurse specialists and is in addition to any palliative care responsibilities of nurse specialists in cancer, respiratory, heart failure, renal and other conditions.

It is worth reflecting on how expectations of services can influence their use. A widely cited article in the *New Yorker* (Gawande, 2010) described a series of interventions provided long after any health benefit could be gained from them. The root problem was failure to acknowledge the transition into a palliative phase and the result was an expectation of recovery rather than sensitive communication leading to the realisation that the end of life was near.
4. WHAT PALLIATIVE CARE SERVICES DO WE CURRENTLY HAVE?

A series of three stakeholder meetings held during 2012 asked delegates to identify what services were currently available for palliative care. Some of these were specialist services, but the majority were generalist services that people with palliative care needs could access. Figure 3 summarises as many of the services currently available as were identified by stakeholders, but it may not be comprehensive.

Figure 3 – Current services provided / available for palliative care

Throughout the course of their disease progression, the majority of people with non-cancer conditions continue to receive care from condition-specific specialists (e.g. respiratory, heart failure, renal nurses and doctors) and generalists (e.g. community nurses, GPs etc.). Additional advice/input may be required from palliative care specialists, and this is most likely towards the end of life.

Best practice in palliative care

NHS Lanarkshire has promoted best practice via a programme of palliative care education and training, in organised courses, on-the-job input and individually tailored sessions. To support best practice implementation, various assessment and recording tools have been developed in Lanarkshire. These include our Anticipatory Care Plan (ACP), which requires sensitive discussion and subsequent recording of people’s wishes as their condition worsens, the principles of which are now part of the GP contract. We also have the Lanarkshire Palliative Care Assessment Tool (LPCAT) to enable sharing of information about symptom management and any need for more intensive intervention.

For the last hours/days of life, and as recommended in the national action plan, Lanarkshire has used the Liverpool Care Pathway for the Dying Patient (LCP) which documents the delivery of good quality care at the end of life. The Independent Review of the LCP (2013) found that it was not always properly applied in England and Wales. The Scottish Government is currently considering this report’s recommendations, and the output will be implemented in full in Lanarkshire. We will ensure that none of the improvements achieved in Lanarkshire are lost, many of which were as a result of investment in LCP training and correct use, although, as always, we remain open to learning from others’ experience.
5. WHAT GAPS IN OUR SERVICES NEED TO BE FILLED?

During 2012 stakeholders were also asked to identify the main gaps in service provision. These were gathered from the first and second events and re-presented to attendees at the third to ensure they were the consensus view.

It should be noted that where the considerable and commendable ongoing work of palliative care specialists and generalists was relatively unproblematic, stakeholders felt it did not need to be included in this strategy. Hence, there is no major focus on the care management undertaken by community nurses, much of which is for people with palliative needs. Neither is the work to roll-out anticipatory prescribing via ‘Just in Case’ boxes mentioned, despite the benefits cited by healthcare professionals and families in terms of immediate symptom relief and hospital admission avoidance.

Our stakeholders asked us to address seven main gaps:

5 1 Palliative care specialist cover at weekends
5 2 Palliative care hospital discharge management
5 3 Carers involved in care planning
5 4 Flexibility of equipment delivery/uplift for palliative care
5 5 Palliative care respite/day services, including <65s
5 6 Communication around death, dying and bereavement
5 7 Transport for non-malignant palliative care

The first two gaps relate to specialist palliative care, whilst the other five concern aspects of generalist provision for people with palliative needs. This balance reflects the fact that most palliative care is provided by generalists, with input from specialists as required.

There has been no attempt as yet to prioritise these gaps in provision, but it is recognised that some means of determining the benefit that would result from each, compared to the others, may be required.

This strategy does not exist in isolation, rather it is intimately linked to other developments. As we move closer to the integration of health and social care, initiatives from the North and South Reshaping Care for Older People programmes will be central to many of the solutions proposed to fill the identified palliative care gaps. Implementation of this strategy will also link to national strategies such as Dementia and the AHP National Delivery Plan.
5.1 PALLIATIVE CARE SPECIALIST COVER AT WEEKENDS

In relation to specialist palliative care cover at weekends, our stakeholders asked us to:

5.1 a Have Macmillan specialist palliative care nurses working at weekends (7 day working)
5.1 b Cover hospital palliative care specialist nurses for holidays and sick leave

What do we know?

When the Macmillan specialist palliative care nurses have been funded to provide telephone advice and support at weekends they have been able to offer symptom management and psychological support to patients, carers and other health professionals and a limited number of visits. Between 15.12.12 and 31.3.13 the team offered support to 19 people at risk of hospital admission and feel they helped to avoid this for 13 people (11% of the contacts). Table 3 gives an overview of the continuity of care that was provided via 114 telephone calls.

<table>
<thead>
<tr>
<th></th>
<th>Macmillan Nurse*</th>
<th>Community Nurse</th>
<th>Carer</th>
<th>Patient</th>
<th>Out of Hours GP</th>
<th>Care Home Nurse</th>
<th>Pharmacist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom control</td>
<td>17</td>
<td>15</td>
<td>12</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Drug enquiry</td>
<td>8</td>
<td>6</td>
<td>3</td>
<td>-</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Support call</td>
<td>19</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Visit needed</td>
<td>-</td>
<td>3</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Unspecified †</td>
<td>7</td>
<td>2</td>
<td>7</td>
<td>-</td>
<td>1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>51</strong></td>
<td><strong>26</strong></td>
<td><strong>25</strong></td>
<td><strong>3</strong></td>
<td><strong>4</strong></td>
<td><strong>4</strong></td>
<td><strong>1</strong></td>
</tr>
</tbody>
</table>

* Proactive calls by nurse on duty, mainly to patients/carers for symptom management or arranging GP/nursing interventions
† Related to hospital admission/discharge, beds (one still in house three weeks after death) or no medical notes available

At present many of the services provided in Lanarkshire either reduce or do not operate at the weekend. This is problematic because people remain just as unwell on Saturdays and Sundays, so service provision does not match the need for them. Some staff groups are beginning to change from five day to seven day working, and there are calls for this to become the norm (e.g. NHS Improvement, 2012). Although our stakeholders raised concerns about weekend cover, the overnight period also warrants consideration. In relation to cover for hospital palliative care specialist nurses, there is currently 1 WTE per acute hospital and no cover for holidays or sick leave.

What could we do to address the issues raised?

Although there are currently no plans to alter the working arrangements of community and hospital Macmillan palliative care nurse specialists, this may change in future in line with other staff groups.

5.1 a The Macmillan specialist palliative care nurses’ working arrangements could be changed to seven day cover. Issues such as continuity of care for individuals on the nurses’ caseloads and ability to link with the patients’ own GP over medication changes would have to be considered and an increase in capacity may be required. Based on widely used recommended levels (Tebbit, 2004) there should be 19 WTE palliative care nurse specialists for people with cancer and non-cancer conditions in Lanarkshire. We are currently short of 3.4WTE nurses. Further consideration of this proposal needs to be in line with broader plans for the NHS workforce

5.1 b The hospital and community Macmillan specialist palliative care nurses could be integrated into one team, although this would certainly require periods of shadowing and learning the nuances of the different environments. The issue of disparity of pay grades at present would also need to be reconciled. An alternative option would be to build on the remit of the ward palliative care link nurses, although this may impact on their main role. Secondment opportunities for staff nurses who have an interest in palliative care could widen the pool of people able to provide holiday or sickness absence cover, but would have implications for backfill arrangements. Any of these proposals would require more detailed modelling and fuller operational discussion
5.2 PALLIATIVE CARE DISCHARGE MANAGEMENT

In relation to this gap in provision, stakeholders asked us to consider:

5.2 a Having a single person take charge of people with palliative care needs, co-ordinating the input of any others needed
5.2 b Having one point of contact into the palliative care ‘family’ to trigger a fast response
5.2 c Involving specialist palliative care nurses, where appropriate

What do we know?

Discharge from acute hospital in Lanarkshire has changed considerably since the stakeholder meetings in 2012. It is now organised from a discharge hub in each hospital which aims to facilitate transfer out of hospital as quickly and smoothly as possible. The arrangements that our stakeholders felt needed to be improved continue to evolve and a fuller understanding of how people with palliative care needs are managed needs to inform any proposed changes to discharge management. In particular, developments funded via Reshaping Care for Older People such as ASSET and ICST form a vital link between community and hospital services, supporting many people with palliative care needs.

What could we do to address the issues raised?

The new discharge hubs mean that the issues raised by stakeholders can be resolved together rather than separately.

- Many people with palliative care needs are care managed when discharged back into the community. NHS Lanarkshire Information Services quarterly updates show the number to be between 650 and 700 at any one time, most with palliative care needs. However, there may be a few people where complex issues are paramount, meaning they need specialist input to support their wishes e.g. to die at home. In these cases it may be necessary for palliative care specialist nurses to link with the discharge hub. This could be hospital specialist nurses identifying people to the Discharge Co-ordinator or working with ward staff to forward plan for discharge. Similarly community specialist palliative care nurses may need to link with the discharge hub to support people’s wish to die at home, possibly before hospital staff may otherwise deem them clinically ready for discharge
- Where discharge home is not possible, palliative care specialists could assist in supporting the transfer to a step-down bed
- Where discharge is back home but additional palliative care support is needed, the patient/ family may require a short period of prolonged support to ensure they are comfortable at home before transfer to the usual level of service provision. This may be important for those people who do not need specialist clinical input, but who have major emotional/psychological issues. It could be provided by increasing the capacity of existing community generalist teams, although some people may need specialist support at this time
5.3 CARERS INVOLVED IN CARE PLANNING

For the avoidance of doubt, the definition of ‘carer’ is taken from *Caring Together: The Carers’ Strategy for Scotland 2010-15* (Scottish Government, 2010). Paid carers are included within the term ‘staff.’ Stakeholders agreed that the following needed to be addressed:

5.3 a Educate staff to recognise the vital role of carers
5.3 b Listen/talk to carers before discharge and provide them with information

What do we know?

Most members of staff are taught that information about individual patients cannot be discussed with anyone else without their permission. Whilst this may be accurate, it can lead to a default position of not sharing important information about someone’s care with the person who will mainly be responsible for ensuring the care plan is followed. It can mean needing to arrange additional meetings with relatives, who may have tried to ask questions when fewer members of staff are available e.g. ward visiting times. There may also be reluctance amongst hospital patients to consent to discussion with relatives as they do not want anything to delay their discharge. All of these can create a negative perception around involving carers in care planning. Our stakeholders considered a number of case studies of problems that arose when carers were not involved, even when their relative had given permission for them to be.

What could we do to address the issues raised?

The issues raised are mainly within the remit of our local carer organisations (South Lanarkshire Carers’ Network, North Lanarkshire Carers Together, Princess Royal Trust Lanarkshire Carers’ Centre), working with the statutory sector and other partners. Detailed discussions have identified a number of areas they are working on that could be progressed jointly to make a difference. They do not all relate specifically to one or other of the above issues, but are intended to respond to the underlying causes.

- There is a range of educational materials (e.g. DVDs, good practice protocols, web pages) that can be used to raise awareness of who carers are with staff. Some carer organisations are directly involved in the delivery of this training
- There is project work in secondary schools to raise awareness of young carers with staff and students
- Continue to improve the identification of carers, awareness of people with a caring role and the impact of this, possibly by being recorded on their GP carer register or, if acceptable, carrying a card. Many are reluctant to have this identity, but it may be a necessary step to ensure their involvement in care planning
- A worry for some carers is that if they become ill, no-one would know what to do for the person they care for, so many are developing their own emergency plans so the essentials can be accessed by someone else

It is worth noting that there are many aspects of support for carers that our local carer organisations can signpost to, many of which are highly valued by carers who already access them e.g. the Carers’ Support Team, befriending (especially for older carers), short breaks/respite, Haven /Care @ Home. Other support directly linked to includes those working with young carers, and they can provide information, short breaks and activities.
5.4 FLEXIBILITY OF EQUIPMENT DELIVERY/UPLIFT FOR PALLIATIVE CARE

The issues raised by stakeholders in relation to equipment provision were relatively specific. They asked us to:

5.4 a Look at differences in equipment availability and timescales in North and South Lanarkshire
5.4 b Understand who to contact about equipment
5.4 c Explore how to track equipment, including beds not being used
5.4 d Investigate moving and assisting training for carers
5.4 e Have one person take responsibility for bed uplifts, instead of distressing bereaved families over beds remaining in the house too long after someone has died

What do we know?

It should be said that the main item of equipment under discussion was beds rather than smaller aids & adaptations, since they cannot be sourced by families themselves and cannot be moved/dismantled after a death without specialist technicians. Provision of beds is usually given the highest ‘Priority 1’ by referrers and other items of equipment lower status (Priority 2). The Integrated Equipment and Adaptation Service (IEAS) supplies beds across North and South Lanarkshire and their current staffing capacity means that uplift of beds cannot be given priority over equipment provision. This means families can have a bed in the house for a number of weeks after someone has died. It forms a constant reminder of the person no longer there and can adversely affect the grieving process.

What could we do to address the issues raised?

Resolution of the equipment issues raised by stakeholders is not within the gift of palliative care, rather the following responses have been developed by colleagues in the IEAS, local authorities and carer organisations. They are as aware, if not more so than our stakeholders, of the distress that can be caused by equipment issues at the end of life.

5.4 a The IEAS is responsible for beds in both North and South Lanarkshire and there should be no difference in availability between the two council areas. There are different suppliers of other aids and adaptations and Change Funds have been invested to support equipment services
5.4 b The IEAS contact number is clearly displayed on all beds supplied. The numbers to contact about other items of equipment will be more widely publicised wherever possible, starting with the people who raised this lack of understanding at the stakeholder events
5.4 c The IEAS is in the process of commissioning a tracking system for its equipment that will enable referrers to find out what is happening to their request. The specification has not yet been fully agreed, but it may automatically email referrers and enable online tracking
5.4 d Discuss the need for moving & assisting training with carers and signpost them to training providers if more than immediately available is required. This may require someone to backfill their caring role to attend formal training sessions
5.4 e IEAS have proposed that they set up a bereavement team with responsibility for the uplift of beds no longer needed. Based on current monitoring of need, this team would require a technician, driver and administrative support and could dismantle and uplift five beds each day. Families could be given an exact time slot for uplift compared to the current process of fitting this in when possible. Such a team would benefit from bereavement training. The need for additional investment here may be offset to an extent by the savings when beds are no longer being damaged, sometimes beyond repair by people who attempt to remove them without the necessary technical support
SECTIONS 5.5 to 5.7

Colleagues in Lanarkshire’s Local Hospice Forum (St Andrew’s, Strathcarron & Kilbryde Hospices, Marie Curie Cancer Care and NHS Lanarkshire) felt they could take a lead in the development of options to address three of the main gaps in palliative care services. They adopted the Marie Curie Delivering Choices Programme methodology and were charged to involve key representatives of all relevant organisations. A high level business case (Connelly & Sandeman, 2013, summary at Appendix 1) was developed via short-life working groups that considered whether investment was needed, appraised a series of possible options and agreed a preferred way forward, including broad estimates of annual costs. A long list of options was appraised against five critical success factors, namely strategic fit, achievability, acceptability, affordability and flexibility. Given NHS Lanarkshire’s inclusion of palliative care as one of its main strategic priorities and the fact that the gaps had been identified via a robust stakeholder process, it was agreed that doing nothing was not an option.

5.5 PALLIATIVE CARE RESPITE/DAY SERVICES, INCLUDING <65S

Our stakeholders asked us to:

5.5 a Consider general provision and the need for step-down beds for people living alone or in need of support
5.5 b Define respite e.g. at home, short breaks, overnight, carer day off
5.5 c Understand what patients want, including those under 65 years of age
5.5 d Explore buddying/volunteer involvement
5.5 e Explore different locations for those under 65 years of age i.e. not care homes

What do we know?

There are no readily available statistics on the level of palliative care respite provided in Lanarkshire. People can access a variety of services, but their use by people with palliative care needs is not normally recorded, unless they are specialist providers. For example, the Marie Curie Nursing Service in Lanarkshire provided an element of respite for 46% of their patient visits during 2012/13. Although not specifically for palliative care, an indication of the level of respite bed use can be gleaned from the annual care home census (Scottish Government, 2012) which showed that the number of short stay/respite residents in north and south Lanarkshire care homes fell between 2010 and 2012 from 272 to 160. This may be linked to stakeholders identifying a need for more step-down beds in Lanarkshire. Work is currently underway in Lanarkshire to review day care respite and community hospital bed capacity and implementation of any options would be taken forward in the context of this ongoing work.

What could we do to address the issues raised?

The options that were agreed as the preferred way forward were:

5.5 a Increase access to palliative care respite beds. This would require additional provision, and although appropriate locations are yet to be agreed, this may involve partners in the independent and voluntary sectors, with implications for nursing cover from generalist and specialist staff
5.5 b Build questions about respite support needs into routine assessments carried out by healthcare staff
5.5 c A single point of access and co-ordination for respite support options to ensure that the most up-to-date information was available and individual healthcare professionals could request availability without having to know about them all. This would include a function to identify what kinds of respite provision would be acceptable, particularly for those under 65 years of age
5.5 d Flexible volunteer service for patients and carers available from point of assessment, incorporating Buddies and Time-out for carer services. There are a number of innovative approaches in this respect e.g. volunteering with the ‘Care @ Home’ project across Lanarkshire
5.5 e See 1.5.5c above
5.6 PROMOTE COMMUNICATION AROUND DEATH, DYING AND BEREAVEMENT

During the stakeholder events there was almost universal endorsement of the need to encourage the general public to be more comfortable talking about death, dying and bereavement. Specifically they asked us to:

5.6 a  Deliver more education for staff
5.6 b  Encourage families to talk about death and dying
5.6 c  Talk about living wills

What do we know?

Our society has changed in recent decades to the point where death and dying is much less a part of normal life than it used to be. Although we live longer, we are far less likely to die at home and families are generally not directly involved in the last offices. Living and Dying Well convened a short-life working group to explore the public health/health promotion perspective of palliative care, in recognition of the difficulties that can arise if health care professionals are unable to have difficult conversations with people who may be dying. Indeed the people of Scotland have agreed that society does not discuss death and dying enough (SPPC, 2003). In the latest British Social Attitudes Survey (NatCen, 2013) 67% of people said they would prefer to die at home, but this proportion is matched by the 68% that had not discussed their wishes for end of life care with anyone. St Andrew’s Hospice has developed a short introductory session called Addressing the Great Taboo, a structured conversation about death, dying and bereavement. It has evaluated well and a short taster session was endorsed by stakeholders. The development of Anticipatory Care Plans in Lanarkshire provides a useful prompt to initiate the kind of sensitive communication that is needed when discussing dying.

What could we do to address the issues raised?

The options included in the preferred way forward were:

5.6 a  Increase the coverage of Addressing the Great Taboo by adopting a ‘train the trainers’/cascade approach. This would have to include support mechanisms, which have been integral to the piloting of this programme and may enable staff to find ways of recognising the grief they feel following the death of someone they have cared for
5.6 b  Develop a programme of awareness and education to expand the delivery of talking about death, dying and bereavement (including using social media solutions) to reach and inform service staff, community services, voluntary organisations and schools. There is a wealth of valuable materials available via the Good Life, Good Death, Good Grief programme which were developed as a national response to the need to encourage more open discussion of death, dying and bereavement
5.6 c  Embrace opportunities to raise awareness of the advantages of living wills and the problems that can arise if you do not have a will
5.7 TRANSPORT FOR NON-MALIGNANT PALLIATIVE CARE

Transport for non-malignant palliative care was raised consistently by stakeholders, who asked us to:

5.7 a Ensure wheelchair accessible vehicles were available
5.7 b Consider paying mileage to relatives or local taxi companies
5.7 c Explore more volunteer group transport

What do we know?
Although Lanarkshire is made up of 18 main townships, it also has pockets of rurality, particularly in the Clydesdale area. People with cancer have access to transport provision that is not available to others with non-cancer conditions e.g. via the Lanarkshire Cancer Care Trust. The working group considering this gap in provision were highly creative in considering options for addressing it, and although not everyone with palliative or end of life care needs will need additional transport, its availability can greatly improve quality of life for those that do. It should be recognised that reliance on a variety of solutions to meet transport needs would require careful co-ordination, especially as it is likely to involve many different providers.

What could we do to address the issues raised?
In proposing options, participants combined the specific points raised by stakeholders, and agreed the following options as the preferred way forward to address them all:

- Increase the capacity of palliative care transport drivers and escorts, using existing links with voluntary organisations
- Enhanced co-ordination of complex palliative care transport needs. This would incorporate Community Transport, patient escorts and ambulances and the co-ordination function would include continuous assessment of Lanarkshire-wide transport need and unmet demand. It would also be responsible for raising awareness of existing transport provision via ongoing mapping e.g. linking with local web sites
- Incorporate the consideration of transport needs into palliative care assessment processes
6. WHAT IS THE INDICATIVE COST OF FILLING OUR GAPS?

None of the recommended options to address the gaps our stakeholders identified in palliative care have been fully costed, but it would be difficult to give them due consideration in the absence of any financial detail. For that reason, very rough indicative costs have been calculated for each of the options and these are presented in Table 4. There is no guarantee that all the suggestions for filling the gaps in existing provision can be filled and there still needs to be a clear description of the real benefits that would result if each was able to be put in place. There are also major workforce implications associated with some of the options. Not only are current working arrangements subject to ongoing change/improvement, but additional responsibilities would require careful capacity analysis, at both individual and team levels. There may also be inconsistencies between partners, particularly if supporting people with complex needs in the community means any blurring of staff responsibilities across organisational boundaries. Much more detailed analysis is needed of the initial costs included in Table 4, and this would be a critical component of strategy implementation.

**Table 4 – Indicative estimates of costs of palliative care options to fill identified gaps**

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<th>Gaps identified by stakeholders and options to fill them</th>
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<th>£117k</th>
<th>£26k</th>
<th>£21k</th>
<th>£50k</th>
<th>Change funds invested</th>
<th>No additional cost</th>
<th>No additional cost</th>
<th>No additional cost</th>
<th>£84k</th>
<th>No additional cost</th>
<th>£170k</th>
<th>£52k</th>
<th>£100k *</th>
<th>£25k</th>
<th>£42k</th>
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<td>- 2 x 0.5WTE Band 5 + 2 x 0.5WTE to enhance existing teams</td>
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<td>- Link with carer organisations and utilise their training materials</td>
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<td>- Equipment availability north and south, additional if required</td>
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<td>- Moving &amp; assisting training for carers</td>
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<td>- Train the trainers in <em>Addressing the Great Taboo</em></td>
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<td>- Enhanced co-ordination of complex palliative care transport needs</td>
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<td>- Build transport needs into assessment processes</td>
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*Assume these co-ordination functions can be combined, so one investment of £100k

The information underpinning each of the options is not included in the interests of keeping this document as short as possible. However, the detailed assumptions and calculations are intended at this stage simply to provide rough indications of what filling the identified gaps may cost. As the strategy moves towards implementation, each of the costs in Table 4 will need to be subject to
Reshaping Palliative Care for A Healthier Future

considerable scrutiny and challenge, with particular attention on whether or not new investment is needed or if existing provision with a little enhanced capacity could fill the gap.

If Lanarkshire realises its vision to meet palliative care needs and provide services in people’s setting of choice, where possible, there should be a reduction in the number of palliative care patients in our acute hospitals. The above investment is designed to help us achieve this vision and meet the strategic aim of improving palliative care and supported end of life services. In common with the aims of Reshaping Care for Older People, it may be possible at some stage to convert bed days saved into closure of unused hospital beds. This assumes that thresholds for admission do not reduce (bed occupancy rates would be maintained) and the number of older people needing hospital admission does not exceed projected capacity. Although there can be no guarantee of achieving disinvestment in hospital beds, if it was realised, the indicative costs in Table 4 would only be required temporarily.

This strategy highlights that some investment is required, at least over the next two years. A variety of funding sources exist that may contribute:

- Innovative approaches from hospices/voluntary sector colleagues
- Change Fund
- Palliative Care budget
- Under-utilisation of specialist palliative care bed occupancy
- Care home budget
- Underspend of NHS Lanarkshire’s contribution to Kilbryde Hospice

Some evidence of bed days saved is available from the specialist palliative care weekend working pilot and evaluation of the Just in Case box anticipatory prescribing roll-out across Lanarkshire (Alexander et al, 2012). Detailed evaluation of the implementation of any aspects would determine whether or not they actually prevent hospital admissions or facilitate speedy discharge that could result in cost avoidance. There is a NICE Commissioning and Benchmarking Tool that can be used to estimate the potential savings from hospital admissions avoided, as used by Connelly & Sandeman (2012).

If it becomes necessary to prioritise the different options for filling the gaps in palliative care services, it would be simple to separate out those with no additional costs. Thereafter there would need to be agreement on appropriate criteria for assessing and ranking the benefits that would result from implementation of any of the options. It is not possible to give clear recommendations on prioritisation without involving key stakeholders and they have not thus far been asked to comment on the implications of implementing only some aspects of this strategy.
7. REFERENCES


Improving palliative care and supported end of life services is one of four strategic aims outlined in A Healthier Future 2012-2020. Workshops held in 2012 identified seven key priorities for palliative care service development in Lanarkshire. This High Level Business Case has been commissioned by the Lanarkshire Local Hospice Forum to consider options relating to three of seven related priorities, namely:

- palliative care respite/day services, including under 65s;
- palliative care transport services; and
- talking about death, dying and bereavement.

Moreover, the numbers of people aged over the age of 65 and over are projected to increase substantially in the coming years, with far-reaching implications for the levels and types of care that will be required.

The total estimated annual cost for these options is £559k, with the potential for efficiency savings through combining functions, introducing new roles and other workstreams and initiatives. These options were then shortlisted resulting in the identification of a minimum, intermediate (preferred) and maximum set of options under each key priority. APPENDIX 1

APPENDIX 1

Workshops attended by a range of service providers were held in January and February 2013 to generate the long lists of options for the three key priorities. These options were then shortlisted resulting in the identification of a minimum, intermediate (preferred) and maximum set of options under each key priority.