Nurse Led End of Life Care

- Catherine Malia - St Gemma’s Hospice, Leeds
- Lynne Symonds - St Catherine’s Hospice, Scarborough
SETTING THE SCENE.........
Preferences for Place of Death 2014

Home  72%
Hospice  10%
Care home  2%
Hospital  6%

The desire to die at home tends to decrease with age, failing health and a non-cancer diagnosis.

(Gomes et al, 2013.)

Hospital  48% (57%)
Home       22% (18%)
Care home  22% (16%)
Hospice    6% (5%)
Setting the scene.....

• @ 50% of patients in North Yorkshire and Leeds die in a Hospital setting, despite national data suggesting that the majority would not choose to do so.

• Hospice beds are allocated based on individual needs of patients, including care at the end of life.

• Those with difficult symptom management or distress would be prioritised.

• Location of patient would also be considered and those patients comfortable in hospital would be unlikely to be prioritised.
Health Select Committee (2015)

Recommended that people with a non-cancer diagnosis, older people and people with dementia should have equal access to palliative care.

However, it is known that these groups continue to be at a disadvantage.
Getting it right for people...

- About 25% of all hospital beds are occupied by someone who is dying.
- The National Audit Office estimates that at least 40% of those people have no medical need to be there.
- Apart from the significant distress caused to the dying person and their family at not achieving their preferred place of care, there is a considerable cost to the healthcare sector.

Marie Curie’s “Understanding the cost of end of life care in different settings” document.
Benefits of Nurse Led, End of Life Hospice beds.

• Regardless of diagnosis, end of life care needs will be met by experienced nursing staff, with palliative care knowledge and skills.

• Patients may not have considered their preferred place of death until the last few days, during which time it may not be feasible for a patient to be discharged home from hospital.

• We aim to offer hospice as a choice for patients whose PPD is Hospice and/or do not need to be in an acute hospital as death approaches.
Partnership.....

“The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference”.

The Foreword: Ambitions for Palliative and End of Life Care
Saint Catherine’s
Caring for you at Hospice and Home

Nurse Led End of Life Care Beds

The Scarborough Experience
Sunny Scarborough!
In the beginning…..

• July 2012 – A proposal came from Scarborough and Ryedale CCG and senior managers at Scarborough Hospital.

• They wanted to commission Saint Catherine’s Hospice to take over the care of some patients on acute wards in the Hospital who were in the last days of life.
• These patients were unlikely to be previously known to specialist palliative care services and not have ‘specialist’ palliative care needs (e.g. intolerable symptoms, severe distress).

• These patients would include those not previously offered Hospice care i.e. dying from stroke, trauma, age related conditions

• These patients and their families would receive the benefits of Hospice care

• Would enable the Hospital to use their acute facilities more appropriately.
What did that mean for us?

- Decision made to introduce a new ‘Nurse Led’ model of patient care, where patients would be admitted and cared for by Hospice Nurses.
- Medical assessment and decision making should have taken place in the Hospital prior to admission to the Hospice.
- A Hospice doctor would briefly review the patient on arrival at the Hospice to ensure that appropriate medicines could be prescribed and for certification of death, but would not be expected to be involved with the patient’s care on a daily basis.
What did we have to do?

• Agree a Business Plan and Costings – 4 rooms
• Staffing numbers – recruitment – not just nurses, housekeeping, admin, catering etc
• Get staff on board – education, information, training
• Create a new referral form and unique template on S1 patient database
• Monitor and evaluate the service.
• Meet KPIs (Key Performance Indicators)
What else?

• Needed to make sure patients referred were appropriate
• Needed referral criteria:
  o That the patient was in the last week of their life
  o That all causes for their deterioration had been explored and treated if appropriate
  o That they and their family were aware of and had agreed to referral and transfer
  o That the patient was well enough to travel (Hospice only short distance from Hospital).
Outcomes:

• 4 nurse led end of life care beds opened Feb 2013

• Stats..............

• Total number of patients who have received care in Nurse Led End of Life Beds since then = 346 (to Dec 2016)
# Nurse Led Beds April 2016 – December 2016

<table>
<thead>
<tr>
<th>KPI Indicator</th>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
<th>Total</th>
<th>Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients assessed as suitable for the Nurse Led Beds after review by the Hospital Palliative Care Team</td>
<td>13</td>
<td>12</td>
<td>12</td>
<td>9</td>
<td>9</td>
<td>11</td>
<td>11</td>
<td>14</td>
<td>7</td>
<td>98</td>
<td>11</td>
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<tr>
<td>Patients offered a Nurse Led Bed</td>
<td>13</td>
<td>12</td>
<td>12</td>
<td>8</td>
<td>8</td>
<td>11</td>
<td>11</td>
<td>14</td>
<td>7</td>
<td>96</td>
<td>11</td>
</tr>
<tr>
<td>Nurse Led Beds Admissions</td>
<td>9</td>
<td>11</td>
<td>8</td>
<td>7</td>
<td>8</td>
<td>10</td>
<td>9</td>
<td>13</td>
<td>4</td>
<td>79</td>
<td>9</td>
</tr>
<tr>
<td>Reason for patient not transferring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/patient happy with care on the ward</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>No NLB Available</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>RIP Prior to transfer</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>PPC Home/Hospice at Home</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Other</td>
<td>2</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Total sum of bed days of patients in Nurse Led Beds</td>
<td>27</td>
<td>27</td>
<td>67</td>
<td>52</td>
<td>27</td>
<td>50</td>
<td>47</td>
<td>37</td>
<td>21</td>
<td>355</td>
<td>39</td>
</tr>
<tr>
<td>Nurse Led Beds % Cancer Referrals</td>
<td>33%</td>
<td>27%</td>
<td>50%</td>
<td>29%</td>
<td>62%</td>
<td>40%</td>
<td>56%</td>
<td>54%</td>
<td>25%</td>
<td>39%</td>
<td>42%</td>
</tr>
<tr>
<td>Percentage of patients transferred within 24 hours of referral to the hospice</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>88%</td>
<td>100%</td>
<td>88%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>96%</td>
<td>97%</td>
</tr>
</tbody>
</table>
Small staff survey

The aim of the survey audit was to collect thoughts and feelings from nurses regarding the nurse led bed service. The method of collecting data was by questionnaire with the following questions.

• What are the pros and cons for patients?
• What are the pros and cons for the families?
• How have you developed professionally?
• What are the challenges you have dealt with?

Only 10 from possible 30 returned
Challenges identified:

• Arrival of a patient who had died whilst being transferred or is imminently dying on arrival at the Hospice. Traumatic for families and gives nursing staff little time to form relationships with them. (Still can provide a good level of aftercare and support though.)
• Conflicting family views or inconsistent information given in the Hospital as to why loved one is coming to the Hospice.
• Those patients whose condition stabilises and are discharged; can be a shock to the family.
• Can be a quick turn over, more deaths and increased workload
How have you developed professionally?

• Communication skills improved. More confident in talking about the process of death and what may happen.
• Confidence in obtaining and completing a holistic assessment in a timely/efficient manner with the required information.
• More confidence in assessing symptoms, addressing these and being with patients who are dying and their families.
• Able to lead conversations and deal with any issues – less likely to have a breakdown in communications.
• Insight into other conditions.
Conclusion:

• Small sample, but gave some insights into the thoughts and feelings of nurses dealing with nurse led patients.

• Nurses appear to be developing their skills and recognising the challenges they need to deal with.

• Common themes around the patient who is transferred so close to death giving no time to get to know relatives. Despite that, nurses recognised that there were still benefits for the patient and family.
Are we there yet...............?
Are we there yet?

Working collaboratively with the acute trust, the nurse led beds initiative has also contributed to the development of skills of health care professionals in Hospital:

• To appropriately identify dying patients.

• To speak more easily with patients and families about death and dying.

 .......... and ultimately has reduced the number of patients who die in the acute trust and would have preferred to have died in a different environment.
• Flexible workforce
• Community referrals
• Competency based knowledge and skills assessments
• Nurse prescribers
• Nurse consultant role?
Background

• Leeds HNA 2013- Need for hospice style care for dying patients with generalist needs

• St Gemma’s Strategy 2015-2018
  Widen access and improve in-patient care for patients with non-specialist palliative care needs
  Develop Nurse led beds within IPU

• April 2015 – Successful Health Foundation Application enabled a 15 month pilot project
Objectives

• To achieve the patients preferred place of death
• To improve the quality of end of life care received by the patient and their family
• To reduce in-hospital deaths
• To maximise the use of in-patient hospice beds
• To reduce Hospice waiting times
• To widen access to Hospice Beds
• To develop the knowledge and skills of the nursing staff, supported by End of Life Care Competencies and End of Life frameworks.
Our model

• Nurse Consultant accountable for care of up to 4 patients in EOLC beds
• Patients are admitted by nursing team. Individualised care plan developed which includes prescription of medication
• All seen once by Dr to satisfy death certification reqs.
• Access to medical support and advice if required
• Access to full MDT support
Are we widening access?

As of 6\(^{th}\) Jan 2017
75 patients admitted
2 patients transferred from a SPC bed
Cancer = 46 (61%)
Non-cancer = 29 (39%)
## Patient demographics

<table>
<thead>
<tr>
<th></th>
<th>Mean Age</th>
<th>Mean Length of Stay</th>
<th>Median Length of Stay</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>87 (Range = 56 – 99)</td>
<td>7 days (Range 25 minutes to 61 days)</td>
<td>4 days</td>
</tr>
</tbody>
</table>


Outcome Measures
Outcome Assessment & Complexity Collaboration (OACC)

• Karnofsky Performance Scale (KPS) – is measured in % and is a description of performance status of the patient. Average KPS on admission = 15%

• Barthel Index measures patients’ ability to perform 10 activities of daily living. The lower the score (out of 100) the more dependent the patient is. The average Barthel was 7.5.

• Phase of illness:
  23 were classified as ‘deteriorating’
  53 were classified as ‘dying’
Are we enabling choice?

<table>
<thead>
<tr>
<th>Preferred place of death</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospice</td>
<td>56 (75%)</td>
</tr>
<tr>
<td>Family Decision</td>
<td>12 (16%)</td>
</tr>
<tr>
<td>Home 1st Hospice 2nd</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Home</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Care Home</td>
<td>2 (3%) discharged to care home</td>
</tr>
<tr>
<td>(2 patients discharged)</td>
<td></td>
</tr>
</tbody>
</table>
Are we reducing waiting times?

<table>
<thead>
<tr>
<th>Patient admitted same day</th>
<th>N = 41 (55%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waited 1 day</td>
<td>N = 19 (19%)</td>
</tr>
<tr>
<td>Waited 2 days</td>
<td>N = 9 (12%)</td>
</tr>
<tr>
<td>&gt; 2 days</td>
<td>N = 6 (8%)</td>
</tr>
</tbody>
</table>

Mean = 0.85 days
Range = 0 - 6 days
FEEDBACK
Care/Symptom management (N=18)

- Personal care
- Emotional support
- Religious cultural and spiritual support respecting wishes
- Relief of symptoms other than pain
- Relief of pain

- Very Satisfied
- Satisfied
- Neither Satisfied nor Dissatisfied
Listening and talking to your friend or relative

Supporting them emotionally

Treating them with respect and dignity

Caring and compassion

Co-ordinating their care

Care (N=18)

Very Satisfied
Satisfied
Neither Satisfied nor Dissatisfied
Dissatisfied
Very Dissatisfied
Feedback from IPU medical colleagues

I think the best thing to come out of this pilot was to witness the benefits of joint working.

I learnt from working with Catherine, in particular to take more time in decision making, ensuring everyone is up-to-date and comfortable with decisions being made.

Advice was sought appropriately if needed.

I feel the junior members of the medical team benefit a lot too.

It allows more flexibility in the patients we admit.

I think the best thing to come out of this pilot was to witness the benefits of joint working.
Referrers

• “I feel it’s good to be able to offer hospice as a place of care for uncomplicated dying patients and for those whose hospice was their preferred place of care but are not symptomatic.”
Achievements to date

• We have successfully piloted a project which has been sustained

• We have demonstrated that a nurse-led team can safely triage referrals and provide EOL care that is highly regarded by pts and their families

• We have widened access particularly to generalist pts, elderly pts and non-cancer pts

• We have created a model enabling hospice as PPD for patients without SPC needs offering an alternative to death in hospital/care home.
Achievements continued

• We have shared our progress via Hospice UK and Health Foundation (contact from 15 other hospices)
• We have up-skilled our nursing staff
• Presentation at 3 national conferences
What have been the challenges?

Model has been heavily dependent on Nurse Consultant

Training NMPs is lengthy

Nursing shortages delayed project start and remains an issue

Ensuring colleagues in LTHT and LCH are aware of the service
Our learning

• Communication and collaboration vital
• Ensure all relevant stakeholders are engaged and supportive
• Ensure all governance arrangements are in place
• Plan for training
• Consider the power of story telling
• Promoting a new service needs time and resources
Where are we now?

- HLT agreed to sustain current model within the IPU
- Ongoing refining of model
- Updated operational policy
- Successful recruitment of band 6 Nurse Practitioner
- Sharing our model
The future

• 7 day service

• Increase beyond 4 EoLC beds?

• Dedicated EOLC beds?

• Electronic referral systems
In conclusion

Nurse led End of Life Care Beds offer wider access and greater flexibility to Hospice in-patient beds enabling more patients the opportunity to die in their preferred place of death.