Hospice-enabled dementia care: joint working between a hospice and an acute dementia care unit

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Introduction Dementia is a life-limiting illness that is currently our biggest public health challenge. Despite being the leading cause of death in 2016 (Office for National Statistics, 2017), people living with dementia remain disadvantaged in terms of access to palliative and end of life care (Care Quality Commission, 2016). Hospices have the expertise to play a crucial role in driving improvements, but this challenge cannot be faced alone; what has been called for is ‘hospice enabled dementia care’ (Hospice UK, 2015) based on strong partnership working.

Background In 2017, a 14 bedded acute NHS mental health inpatient unit for people with dementia needed a temporary home while its own accommodation was being refurbished. It was agreed that this would be provided in an unoccupied wing of the local independent hospice. Our presentation is the story of this project and how the two services seized the chance to make the most of this unique opportunity of mental health and specialist palliative care services to share skills and expertise and work towards developing sustainable collaborative relationships.

Project description The presentation will take the audience on a journey beginning by introducing both services and the challenges that they each faced alone in providing end of life care for people with dementia. Then we will share reflections on the steps we undertook to develop relationships and share skills such as our programme of joint lunch and learn events and a buddy system. We talk about how strong relationships were formed based on shared values and passion for high quality person-centred care. We reflect on our experience of providing hospice-enabled dementia care by working creatively together, illustrated through case vignettes. Finally, we will share our evaluations and recommendations for others looking to improve end of life care for people with dementia.

Dementia pathway – from diagnosis to end of life

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The City Council invited local charities to tender to provide services that would contribute to sustaining and improving dementia diagnosis rates and enable the city to become a dementia friendly city.

Three charities came together and were successful in demonstrating how they would work in partnership to support a person with dementia from diagnosis to end of life working alongside statutory provision. The key objective for the new service was to support the person diagnosed with dementia and their carers through the allocation of a named ‘contact’ facilitating people and their carers to access and use services. The hospice in partnership with the service employs two Clinical Nurse Specialists (CNSs) who lead the complex dementia and end of life care support pathway aspect. Referrals are via a single point of access, including self-referrals and are prioritised according to a ‘RAG’ system leading to either ‘social’ support or the support of a CNS.

Support for patients with dementia and their carers is through a ‘drop in’ service where they can meet a member of the team, also through carer support groups, activity groups and training for carers. A Saturday morning coffee group has been set up to support those carers who work in the week and cannot attend week-day events; the service is now working later in the evenings. Clients are supported to remain in their preferred place for care and following death bereavement support is provided.

The service reports through KPIs to the Council; the two CNSs have seen 180 patients with complex dementia, and have supported 40 people with dementia to die within their ‘preferred’ place of care, working alongside the carers pre- and post-bereavement. An interesting observation is that the numbers of those people with dementia needing in-patient care through the hospice has not increased.

Delivering training to implement and embed the Namaste care programme in care homes

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Aim Dementia is a growing issue and increasingly part of national and international policy. At Countess Mountbatten Hospice we have secured funding for an 18 month pilot of the Namaste Care Programme, which will look at engaging care homes in providing a daily programme that aims to enhance and maintain quality of life for individuals with advanced dementia, at end of life.

Methods To develop robust training that will lead to the successful implementation of the programme, and through supportive working via visits and close correspondence, embed the programme into their daily care delivery for those individuals. This training is done by an initial full day
of training for those who are going to lead the programme in their home, including training for the managers to ensure it is well-led throughout the home, and then there are in-house sessions for the individual homes to inform the whole team.

**Results** Currently there have been 16 homes recruited and trained to implement the Namaste Care Programme. All homes are at varying degrees of the implementation phase due to individual circumstances of that home. There are some homes that have very early results that are showing both qualitative and quantitative improvements in individuals’ quality of life within their homes.

**Conclusion** We plan to review progress and publish results in March 2019.

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**COMPARING PLACE OF DEATH OF PATIENTS SUPPORTED BY A SPECIALIST DEMENTIA SERVICE WITH NATIONAL DATA**

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10.1136/bmjspcare-2018-hospiceabs.115

**Background** Dementia is the leading cause of death in the United Kingdom. Specialists in end of life care need to adapt to the needs of the increasingly older population which it serves. There is pressure on the National Health Service to provide cost effective, evidence-based care and to avoid unnecessary hospital admissions at the end of life. Recent national data shows that 32% of people with dementia die in hospital.

**Aim** To understand whether a hospice-led dementia team influences the number of hospital and home deaths in patients with dementia, compared with national data.

**Methods** A sample of patients who were supported by the specialist dementia team was selected retrospectively, to include all deaths between 1st June 2017 and 31st May 2018 (n=39). We have counted all the deaths using Excel spreadsheet and separated deaths into four different categories: Home, Hospice, Hospital and Care Home.

**Results** There were 39 deaths of patients with dementia that received support from the Dementia Nurse Specialists.

Of these patients 69% of them achieved their preferred place of death.

**Conclusion** Receiving care from a hospice-based dementia nurse specialist team was associated with a much higher home death rate of 49%, compared with the national figure of 8%. It was also associated with a lower rate of hospital deaths – 18% compared with 32%.

**Abstract P-90 Table 1 Comparing Hospice Team with national place of death data**

<table>
<thead>
<tr>
<th>Place of Death</th>
<th>Number of deaths under Dementia Team</th>
<th>Percentage deaths under Dementia Team</th>
<th>England (2012–14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>19</td>
<td>49%</td>
<td>8%</td>
</tr>
<tr>
<td>Care Home</td>
<td>10</td>
<td>26%</td>
<td>58%</td>
</tr>
<tr>
<td>Hospital</td>
<td>7</td>
<td>18%</td>
<td>32%</td>
</tr>
<tr>
<td>Hospice</td>
<td>3</td>
<td>8%</td>
<td>1%</td>
</tr>
</tbody>
</table>

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**DEMENTIA CARER SUPPORT IN A HOSPICE – AUDIT AGAINST NICE GUIDANCE**

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10.1136/bmjspcare-2018-hospiceabs.116

**Background** Much research has been conducted on the psychological implications of caring for family members with dementia (Watson, Tatangelo, McCabe, 2018). Support for carers may enhance the quality of care they provide and may reduce their distress (Abreu, Rodrigues, Sequeira et al., 2018). The National Institute for Health and Care Excellence (NICE) identifies assessment of carers’ psychological needs and interventions to address these needs as important aspects of care provision for people with dementia (NICE, 2010).

**Aims** To evaluate our hospice’s compliance with NICE Guidelines on support for carers of dementia patients.

**Methods** We examined the Integrated Palliative Outcomes Scales (iPOS) of all patients on our inpatient and community caseloads with a primary diagnosis of ‘dementia’ to assess how many had a score completed for the ‘family anxiety’ question and whether those who had severe or overwhelming anxiety had an offer of formal support.

**Results** Only 33% of patients had an iPOS ‘family anxiety’ score completed. Of those with severe or overwhelming anxiety, 78% were offered formal support.

**Conclusion** Evaluation of our practice shows that while we offered support to the majority of those who were identified as needing it, only a third of carers’ needs were assessed at the outset using the iPOS. It may be that a higher proportion of carers had their needs assessed informally as part of Multi-Disciplinary Team assessments and this was not captured in the audit data. To ensure carers’ needs are assessed consistently, we plan to educate staff regarding the importance of completing the ‘family anxiety’ question on iPOS, and are going on to complete a more detailed carers’ assessment and offer of formal support if needed.

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**GETTING IT RIGHT: HEPATIC FAILURE AND PALLIATIVE CARE**

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10.1136/bmjspcare-2018-hospiceabs.117

**Background** National work identifies that people with liver disease are less likely to receive palliative care, more likely to die in hospital, less likely to be satisfied with co-ordination of care (Kendrick, 2013) and more likely to be young, deprived and socially isolated (Public Health England – Liver disease profiles). Locally palliative care and hepatology services were struggling to connect.

**Aims** To audit local hospice and hospital outcomes for people with liver disease against the 2013 NHS report ‘Getting it right: improving end of life care for liver disease’ (Kendrick, 2013).

**Methods** Review of notes of people with a primary diagnosis of liver disease referred to the local hospice services or hospital palliative care team, 2015–2017.