Evaluation of Greenwich and Bexley Community Hospice Dementia Service

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Project

• Improving the experience of people with dementia at the end of life in Greenwich and Bexley Boroughs, through expert support, training and partnership working

• Supported by a St James’s Place Foundation Grant, managed by Hospice UK
Three conclusions

1. A high quality service that demonstrates how integrated services open the door to earlier, more appropriate, community based services for people living with advance dementia.

2. The service shows demonstrable evidence of improved care, sustained family support, and reduced anxiety and crisis.

3. The evidence points to a more effective use of the health care system with better outcomes at the end of life with a reduced use of unplanned care.
Five domains of outcome

1. Increased accessibility
2. Improved integration of services
3. Improved outcomes
4. Better system effectiveness
5. Higher quality of care
1. *Increased accessibility*

- The dementia service has increased access to expert end of life care by over 68% (comparing 2015 to 2016)

- A majority of new patients referred to the dementia service have come from GP and Hospital referral (57%)
Hospice Dementia service

- Hospital CNS (6%)
- Local GP referral 27%
- Hospital consultant/team 24%
- Hospice referral 9%
- Other (34%)
“The hospice project has broken through the barrier of referral for advanced dementia patients”

“A GP recognises an advanced dementia patient as an end of life patient and then feel able to engage the hospice”
2. Improved integration

- The connected hospice and community service for advanced dementia has opened the door to a range of expert end of life care services
- 94% of patients have accessed existing hospice community services
- 46% have also accessed one further hospice service and 37% go on to access two additional hospice services
- 22% have used the hospice IPU either for complex symptom control or care at the end of life
Time in the service for those who have died

- LT 2 wks: 45%
- 2 - 4 wks: 10%
- 4 - 6 wks: 10%
- 6 - 10 wks: 10%
- 10 - 20 wks: 5%
- 20+ wks: 5%
Time in the service for those still living with dementia

- LT 6 wks: 25%
- 6 - 12 wks: 15%
- 13 - 20 wks: 15%
- 21 - 30 wks: 10%
- 31 - 40 wks: 10%
- 40+ wks: 10%
3. Improved outcomes

- 97% of patients have achieving their preferred place of care. 93% of patients have died out of hospital either at home (47%) or in a nursing home (37%) or in the hospice (11%)
- The service has sustained carers who were losing their capacity to cope
- The service has provided exemplary care that enables peaceful and dignified death
- Professionals within the Hospice and the Community service report wider reach, better coordination and professional learning
Place of death and PPD

Place of Death

- Home: 45%
- Nursing Home: 37%
- Hospice: 11%
- Hospital: 7%

PPD

- PPD achieved: 97%
- PPD not achieved: 3%
4. **Better system effectiveness**

- Evidence of wider and more effective reach to people living with dementia alongside end of life care needs
- Evidence of avoided crisis admission for 1 in 10 patients
- And evidence that integrated care avoids crisis in the first place through earlier engagement in planned care
- 17% of patients receive the care of 3, 4 or 5 hospice services with multiple episodes of care. 71% of these patients access the hospice IPU
Multiple episodes of care

% receiving multiple episodes of care

- 2 episodes of care: 31%
- 3 episodes of care: 8%
- 4 episodes of care: 10%
- 5 episodes of care: 10%
- 6 episodes of care: 3%
- 8 episodes of care: 10%

Greenwich & Bexley community hospice
Pathways

- 94% access a community service
- 26% access Hospice@home services
- 22% access the Inpatient Service Unit
- 21% access services from the Hospice Hospital team
- 11% rehabilitation, 5% social work or Helping Hands, 2% Day Hospice and 1% Counselling
5. Higher quality of care

- Giving invaluable support to the family
- Sustaining carers who are losing the capacity to cope
- Providing exemplary care that enables peaceful and dignified dying
- The importance of specialist dementia understanding
“Finding the moment to flip from intervention to palliative care is not easy”

Engaging end of life expertise increases the confidence of other professionals to avoid over-treatment and to avoid the dangers of under-treatment”
Invaluable support for the family

FB1: “the dementia project ... without whose help I would have been at a loss”

FB4: “no one told me anything until you nurses were called in and straight away they put my mind at rest”

FB6: “It was very reassuring that there was always someone able, willing and caring to give help and advice”

FB7: “It made such a difference to have you to talk to and discuss mum’s changing medical issues”
<table>
<thead>
<tr>
<th>Name</th>
<th>Quote</th>
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<tr>
<td>FB9</td>
<td>“I feel there is a light at the end of the tunnel”</td>
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"I was desperate to keep Tony at home and he was desperate to stay here, but things were becoming extremely difficult, and I began to doubt that I could manage. I experienced a huge feeling of relief when Lisa arrived and proved so positive and capable. I realised at once that this would be a burden shared. The carers were incredibly wise and obviously experienced at working with people with dementia and I learned a great deal from them. I loved the way they were so kind and cheerful with Tony and he liked them too. The dementia project improved the quality of both our lives. Thank you."
I wasn't alone
Great comfort
Put my mind at rest
It made such a difference
My support and backbone
Without whose help I would have been at a loss

Very comforting
Huge feeling of relief
They have given much help and guided us a lot
A burden shared

Invaluable support

Most helpful
Very helpful
"Very helpful – answered all our questions and was very reassuring in terms of support and any worries we had"

"Questions answered happily. At end of telephone if needed desperately!"

"The dementia nurse was the only one who gave me some answers which I was always asking for ... I never got no answer until you came along"

"She was kind and explained everything very well"

"Our questions were answered clearly and promptly by Lisa at home several months before the end of Mum’s life"
“You will know more than most is both physically and mentally draining with no light at the end of the tunnel. However, I draw comfort from the fact that Lisa Morris is a phone call away and responds diligently to both our needs for which I am truly grateful”

“We are so grateful for the 24 hour access to the team and the support and information given to us”

“The support I received from Lisa Morris was invaluable to me. The knowledge that I could always contact her with a problem was a great comfort and gave me support when it was needed most”

“She was kind and explained everything very well and told me I could contact her at any time if I needed to, which is very comforting to know”

“We are so grateful for the 24 hour access to the team and the support and information given to us”
When Lisa left we all felt for the first time, a sense of relief that there was help for us.”

“I cannot imagine not having this service, where would we be if this never existed”

“things were becoming extremely difficult, and I began to doubt that I could manage. I experienced a huge feeling of relief when Lisa arrived and proved so positive and capable”

“Words alone cannot express my gratitude at the manner in which you gave love and care to June in her last hours”
“Words alone cannot express my gratitude at the manner in which you gave love and care to June in her last hours”

“Without this help I do not know how I would of coped”

“After having such little help at home Lisa came which was great she came with Donna and what a service!”

“It was a very stressful, heart breaking time we were going through. ... We don’t know what we would have done without all the help we were given”
“if it wasn’t for Lisa Morris getting mum into G&B Hospice I think her ending would have been a lot more painful and distressing”

“Lisa Morris in particular was instrumental in making my mother’s end of life passage dignified and peaceful”

“my mother, received exemplary care. The staff were kind, compassionate and caring”

“Honesty, reliable, dependable service that listens to the needs of the user”
My family wish to thank you for the help and kindness that you provided for my mother in her last days – it was second to none and given with such love.

My mother had the best care in her last two weeks of life at the hospice. Everyone there was extremely caring to mum and the rest of the family. It made her have the peaceful passing she deserved.

My dear dad was looked after with great care and dignity in his last week of life.

“You took care of his every needs until the end and ensured that his passing was dignified”
The importance of specialist dementia understanding

| FB3 | “It was so good to have the empathetic input and support of those who understood the needs of those caring for a loved one with advanced dementia” |
| FB12 | “I found it most helpful to talk to a specialist nurse about dementia and what would happen at the end of life” |
| FB13 | “The carers were incredibly wise and obviously experienced at working with people with dementia and I learned a great deal from them” |
| FB20 | “The presence of a dementia specialist made the assessment much more effective and appropriate palliative measures were put in place” |
The experience of professionals in an integrated service

“The integrated service has benefitted from the hospice expertise over pain management and the wider range of services around end of life care”

“The integrated service means that the hospice has benefitted from the community team’s ability to coordinate care in the community”
Three conclusions

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Other positives

- Raising the profile of dementia throughout the hospice
- Increasing confidence of all staff and volunteers
- A project template we can duplicate with other patient disease groups
Future plans…..

• What effect on length of stay in hospital if known to dementia service?
• Earlier intervention for ACP
• Evidence of effect on bereavement?
Closing Remarks

Dr Sarah Cox,
Chair of LCA Palliative Care Group