

Hospice Care **in Barnet**



A Healthwatch Barnet Report
2016

Executive Summary

Purpose: why we visited hospices

The recent report '*A Review of Specialist Palliative Care Provision and Access*' shows that there is a huge variation in the overall quality and provision of end of life care across London (London Cancer Alliance, Palle8 and Marie Curie, September, 2015). With this in mind, the Healthwatch Barnet Group for End of Life Care (EoLC) carried out a mapping exercise of current provision and existing EoLC practices in local hospices, in order to identify and to share good practice relating to palliative care and EoLC.

Methodology: how we collected information

During January and February 2016, members of the Healthwatch Barnet End of Life Care Group visited six hospices in North and East London, and Hertfordshire, to carry out face-to-face interviews. Hospices were asked questions relating to their current practices in EoLC and palliative care, relationships between them and care homes, the challenges they face, their training and development needs, and future change anticipated in service provision; detailed anecdotal information was also gathered.

Main observations:

- Hospice care and care at home are increasingly the preferred place of care, compared to hospitals
- Although a few patients may receive hospice care at an early stage of their illness; overall there is a need for it to be offered at a much earlier stage of illness than is currently the case
- Hospices are experiencing budget constraints
- There is a variation in the quality of training and development for staff and volunteers within hospice care

Key themes and recommendations:

The following five key themes and associated recommendations have been identified. They have led to a range of strategic implications for commissioners and operational implications for providers.

1. Enabling choice for palliative and end of life care

- Review journey through care system from initial diagnosis to inform commissioning and improve practice
- Improve and promote information on EoLC for patients and their families

2. Resource management and how it is affected by budget constraints

- Include EoLC as a review priority in Health and Wellbeing Strategy refresh
- Consider and promote ways to encourage resource sharing
- Create an opportunity for the voluntary and community sector to develop partnership work together in EoLC

3. Staff and volunteer development

- Research and develop ways to attract and keep staff

- Identify training needs
- Ensure accredited training for staff and volunteers is available and accessible locally
- Ensure take up of training amongst volunteers

4. The engagement of healthcare professionals in providing end-of-life and palliative care

- Develop and implement engagement plan for GPs, primary care and care home professionals

Next steps

Further research is needed to see how patients and their families experience current hospice care provision, and with local care homes to get their views about local EoLC provision. This report will be shared with hospices, care homes, HOSC, HWBB, and the wider network of EoLC providers and commissioners.



1. INTRODUCTION

Death and dying are an inevitable part of life, and although people are living longer, they are experiencing longer periods of ill-health before the end of their lives. While some people experience good quality end of life care, many people do not. Although the UK ranked top out of 40 countries in its hospice care network and statutory involvement in End of Life Care (Quality of Death, 2010), the variation in end of life care practice has been highlighted in recent reports, including the Parliamentary and Health Ombudsman's 2015 report Dying without Dignity, and CQC's 2016 report A Different Ending: Addressing Inequalities in End of Life Care.

What is Important to Me Review (2015) emphasises that there is a **national need** to improve End of Life and Palliative Care across the country. Among these needs are to enable individuals to make their choice of where to die and to be cared for, to enable access to the right services at the right time and place, and to create the space for individuals to be attended by trained and qualified professionals. The review also highlights these person-centred services can be highly expensive, but there is an opportunity for cost-saving and development.



Barnet's ageing population indicates that there is more likely to be an increasing need for specialist end of life and palliative care. The over-65 population is expected to grow three times faster than the overall population between 2015 and 2030; the 65+ population will grow by 34.5% by 2030, whereas the 85 and over population will increase by 66.6% (Barnet JSNA 2016-20). Coronary Heart Disease is the number one cause of death amongst both men and women, where men are expected to develop some long term conditions earlier than women. These indicators may suggest that there is a need for high quality EoLC in Barnet. (Barnet JSNA 2016-20). Death in hospital and in hospice care in Barnet is significantly higher than the England average (EoLC Intelligence profile, 2012).

Definitions

This project uses the following definitions of palliative and end of life care.

End of Life Care is described as a term commonly used when patients are identified as being likely to die within the next 12 months; this includes those people whose death is imminent and expected within the next few hours or days (GMC Guidance, 2013). Whereas, **Palliative care**, as defined by The World Health Organisation, is "an approach that improves the quality of life of patients and their families facing the problem associated with 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."

NICE uses a similar definition, referring to “the active holistic care of patients with advanced progressive illness” (End of Life Care JSNA for West London, 2016).

2. AIMS AND OBJECTIVES

Aims

This report is to shed light on end of life and palliative care practices in hospices, in order to inform commissioning and service development in hospices, care homes and all other end-of-life services. Healthwatch acknowledges that, looking into end-of-life care service provision across all other services, requires more resources. Therefore, the report acts as a first step to lay ground for further research for good practice and high quality care.

Objectives

- To undertake a ‘shallow dive’ insight-gathering exercise to uncover good practice of EoLC in hospices.
- To find out about current links between care homes and hospices with reference to partnership work or shared resources to support the delivery of EoLC.
- To inform hospices, care homes, CCGs, HWBB, and HOSCs of current service provision
- To make recommendations for future service improvement

3. METHODOLOGY

Between January and February 2016, Healthwatch Barnet End of Life Care Group visited six hospices in North and East London and Hertfordshire areas, and conducted semi-structured interviews with their management representatives. The hospices were Peace Hospice Care, St Luke’s, St John’s, St Joseph’s, Marie Curie Care, and North London Hospice. The questions aimed to tease out information on:

- Staff and volunteer development and retention in hospices
- Links between care homes and hospices
- Current challenges hospices face, and demand for end of life and palliative care
- General and specialist services provided by hospices

4. FINDINGS

4.1 Current hospice and EoLC provision

Hospice care offers high-quality holistic care that includes a range of services including a high staff-patient ratio, 24-hour specialised care, and a range of non-clinical services including alternative therapies, emotional support, and spiritual services besides many others. The current provision in hospices is as follows:

Community care

All hospices offer day care services either at the hospices’ premises, or in residential settings and at people’s homes. The services range from complementary therapies, such as massage therapy, physiotherapy, discussion groups, chaplaincy and spiritual services, bereavement counselling, information on finance and benefits, and signposting to specialist services related to the family’s individual needs. GP support is variable and there is often an issue with getting GPs into a patient’s home a maximum of a fortnight before death so that a death certificate can be signed.

In-patient care

All the hospices have an in-patient unit, where an individual is referred by a GP, hospital or other health professionals, and can be admitted for a short period of time, normally for two weeks, pending the complexity of their health condition, and whether or not the hospice is their preferred place of death.

Educational support

Some hospices work closely with a range of other professionals including GPs, care homes, and other hospices. Some hospices share educational resources with other hospices, offering both staff and volunteer development. One hospice assigns a care home coordinator to offer training to care home staff, in care planning for End of Life Care. Some hospices utilise Gold Standards Framework (GSF) training with GPs and other services, although the uptake from GPs is low.

4.2 Local capacity

The hospices' workforce consists of paid staff to deliver medical care and management roles, and of volunteers to carry out additional emotional and social support, and frontline administration. Volunteers usually account for the majority of the hospice workforce, working in shops and carrying out some in-hospice roles. Some hospices may prefer to recruit newly qualified nurses who may need an extra support structure in EoLC.

Staff turnover tends to be variable, specifically Health Care Assistants. Some HCAs move to a nursing or other role. There seems to be a lack of opportunity for personal and professional development particularly in nursing. Nurses, working in EoLC, are more likely to feel deskilled, and therefore, often seek opportunities for career progression outside the organisation.

Qualifications and training requirements for staff and volunteers vary based on roles. Clinical roles have a set of qualifications and training requirements, with some roles requiring work experience. Consultants, GPs, medical directors, neurologists, nurses and other clinicians carry valid registration as per their professional area. However, recruiting to specific roles, such as EoLC nursing, is a constant challenge, due to a national shortage. Hospices, therefore, tend to hire registered nurses but they do not need to have had previous work experience in hospices or end of life care, as training in this area will be provided.

Non-clinical roles, such as befriending, administration, or facilitating community activities, are usually delivered by volunteers and may require some work experience. Relevant training will be provided. A role description and person specifications are usually advertised when recruiting for volunteers to deliver these roles.

4.3 How residents access local services

Referrals are accepted from GPs, hospitals, and other health professionals. Self-referrals are accepted if the patient gives consent to the hospice to seek their GP's consultation for further assessment and suitability for the hospice services. In this case, patients may not be able to

gain access to hospice care without a GP referral. Usually, patients attending community day services are known to the hospice through their in-patient units.

4.4 Hospice learning and development

All staff and volunteers are required to complete their hospice's training programme. Staff training is mandatory, which includes health and safety procedures, manual handling of equipment, equality and diversity, safeguarding of adults at risk, and infection control. The staff programme, in some hospices, is complemented by having access to annual appraisals, supervision sessions and peer mentoring. Volunteers are usually required to attend an orientation programme about the hospice's policies and procedures, and role-specific training. Volunteers may have access to the mandatory training based on their role.

Training is available online and face-to-face. Volunteers' uptake of training can be challenging. A number of hospices has increased their volunteers' uptake by changing how the training is delivered.

4.5 How care homes and hospices work together

There is no clear picture of how hospices and care homes are working together as this varies from one hospice to another. However, the links, we observed, between hospices and care homes can be summed up as follows:

- **Education:** Hospices have the skill and expertise to provide training in palliative and end of life care to care home staff. However, care homes have no mandatory contractual obligations for staff development with hospices, and therefore, staff may not necessarily be encouraged to seek professional or personal development
- **Care provision:** hospices provide clinical support and advice when requested to some individuals in care homes

5. KEY THEMES

Key theme 1: Enabling choice for palliative and end of life care

- Hospices and being cared for at home are more increasingly the preferred place of care, compared to hospitals
- Patients may not be aware of the choices available to them and the way to access those choices.

Key theme 2: The quality of care provision

- Hospital discharge into hospices can be a long process. The triage system at different hospices may vary.
- Referrals to hospices usually come at a late stage in the development of a patient's symptoms
- The preferred priorities of care are dealt with too late, making the creation of difficult conversations more stressful and challenging
- There is a need for hospice care at a much earlier stage than is currently happening, although a few patients may benefit from hospice care at an early stage of their illness
- Some beds are left empty in order to accommodate patients with more complex needs and staffing capacity



- Concerns about the shortage of nurses in order to provide high quality care both in the hospice and in the community

Key theme 3: Resource management and how it is affected by budget constraints

- Hospices are considering re-allocating more of their budget from in-patient to community care
- Budget constraints increase both competition and call for resource-sharing between hospices
- There seems to be a need for sharing good practice and learning lessons about patient care between hospices, in a manner that facilitates further partnership work and efficiency
- Some hospices have more access to research which may have an impact on creating more development opportunities

Key theme 4: Staff and volunteer development

- The content and mode of staff training varies across hospices
- There is a huge variation in the quality of volunteer training, yet the proportion of volunteers is a large part of the hospice workforce
- High staff turnover has an impact on building good knowledge, retaining experience, and providing a sound training base
- Although larger organisations attract more highly qualified staff, there is a difficulty recruiting nurses to permanent posts
- Lack of staff retention is evident especially among, nurses, doctors, and HCAs as they feel they are being de-skilled working in EoLC only

Key theme 5: The engagement of healthcare professionals in providing end-of-life and palliative care

- Lack of engagement from care homes due to staff unavailability and non-contractual requirements for staff development with hospices
- Variation in engagement with GPs



6. RECOMMENDATIONS

A number of reviews and reports (West London JSNA EoLC, Wiltshire CCG Review of EoLC 2015) on End of Life Care emphasise the need for the early identification of people with EoLC needs, providing guidance and training to professionals and families as to how access and make use of existing EoLC services, and also ensuring a consistent approach to quality management in EoLC.

There are strategic and operational implications for commissioners and providers respectively, as follows:

For commissioners	<ul style="list-style-type: none">• Include EoLC as a review priority in the Health and Wellbeing Strategy refresh• Ensure accredited training for staff and volunteers is available locally• Create an opportunity for the voluntary and community sector to develop partnership work together in EoLC
For providers	<ul style="list-style-type: none">• Ensure take up of training amongst volunteers and set up a personal development plan
For commissioners and providers	<ul style="list-style-type: none">• Consider and promote ways to encourage resource sharing• Identify training needs• Research and develop ways to attract and keep staff• Develop a strategy for training, recruiting and retaining nurses• Review patient journey through care system from initial diagnosis to inform commissioning and improve practice, e.g., shared records• Improve and promote information on EoLC for patients and their families• Develop and implement engagement plan for GPs and primary care professionals, and to support them in keeping their EoLC register up to date

7. NEXT STEPS

These findings are the first step to capture the overall view of current EoLC practices, and of opportunities for development and improvement. The long-term aim is to identify opportunities for capacity-building EoLC in hospices, care homes and other end-of-life services. Further research is needed to see how patients and their families are experiencing the current hospice care provision, and local care homes to get their views about local EoLC provision.



8. REFERENCES

- End of Life Care Guidance, General Medical Council, 2013
- The Quality of Death: Ranking end-of-life care across the world, the Economist Intelligence Unit, 2010
- Exploring the Experience of End of Life Care, Project Report for NHS Wiltshire CCG, 2015
- Place of Dying and End of Life: Summary of Shallow Dive Study Final Report, Healthwatch Cornwall, 2015.
- National End of Life Care Profiles for Local Authorities: Barnet, 2012
- Joint Strategic Needs Assessment, Barnet, 2015-2020
- Policy Briefing: What's Important to Me: A Review of Choice in End of Life Care, Executive Summary, Healthwatch Merton, 2015
- End of Life Care: Key Themes and Recommendations, Joint Strategic Needs Assessment Report for Hammersmith and Fulham, Kensington and Chelsea, and Westminster, 2016
- <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/dying-without-dignity>
- <http://www.wiltshireccg.nhs.uk/wp-content/uploads/2015/05/Final-Patients-Association-End-of-Life-Care-Report-for-Wiltshire-CCG-2015.pdf>
- <http://www.healthwatchcornwall.co.uk/wp-content/uploads/2015/01/FINAL-PLACE-OF-DYING-EOL-INSIGHTS-AND-EXPERIENCES.pdf>
- <https://www.barnet.gov.uk/dam/jcr:4b3e6328-6d3e-404b-a7a0-8ffb939b992d/Barnet's%20JSNA%202015-2020,%20Executive%20Summary.pdf>
- http://www.healthwatchmerton.co.uk/sites/default/files/policy_briefing_-_whats_important_to_me_2.pdf
- http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_2012_pdfs
- <http://www.jsna.info/sites/default/files/EOLC%20Key%20Themes%20Report.pdf>
- <http://www.healthwatchlewisham.co.uk/news/review-choices-end-life-care>,
- <http://www.healthwatchkent.co.uk/news/have-you-experienced-end-life-care-recently>

9. ACKNOWLEDGEMENT

Marie Curie Hospice
North London Hospice
Peace Hospice
St Luke's Hospice
St John's Hospice
St Joseph's Hospice
Healthwatch Barnet staff and volunteers