

7.29 End of life care

The national End of Life Care Strategy¹ published in 2008 provides a framework on which local health and social care services to build end of life care. The more recent Actions for End of Life Care 2014 -16² provide an action plan to enhance end of life care. Structures have been set up locally to map end of life care pathways and identify existing gaps in service and discussions with local partners have taken place.

The following documents have also been published between 2013-15

- Report of the Parliamentary Health Select Committee, 2015³
- NHS England's report on Developing a new approach to palliative care funding, 2015⁴
- National Survey of Bereaved People (VOICES), 2013⁵
- The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life, 2012⁶
- The Compassionate City and Community Charter.⁷

Much work has been done to improve and deliver robust and appropriate end of life care across Barking and Dagenham.

Changing patterns of end of life care

About 500,000 people die in England every year, with the number expected to rise by 17% between 2012 and 2030⁸. People will increasingly die at an older age, with the percentage of deaths among those aged 85 and over expected to rise from 32% in 2003 to 44% in 2030. In 2014, there were 1,266 deaths in Barking and Dagenham, of which 428 were in persons aged 85+ (33.8% of all deaths)⁹.

Comparison of 2014 data with 2013 shows a small increase in the proportion of elderly aged 85+ accounting for COPD deaths, with 410 of the 1,209 deaths being those aged 85+ (33.9%).

¹ End of Life Care Strategy - Promoting high quality care for all adults at the end of life, Department of Health, 2008
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277

² <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

³ <http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/80502.htm>

⁴ <http://www.england.nhs.uk/2015/03/05/palliative-care-funding/>

⁵ <http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/stb---national-survey-of-bereaved-people--voices-.html>

⁶ http://www.nuffieldtrust.org.uk/sites/files/nuffield/marie_curie_full_report_final.pdf

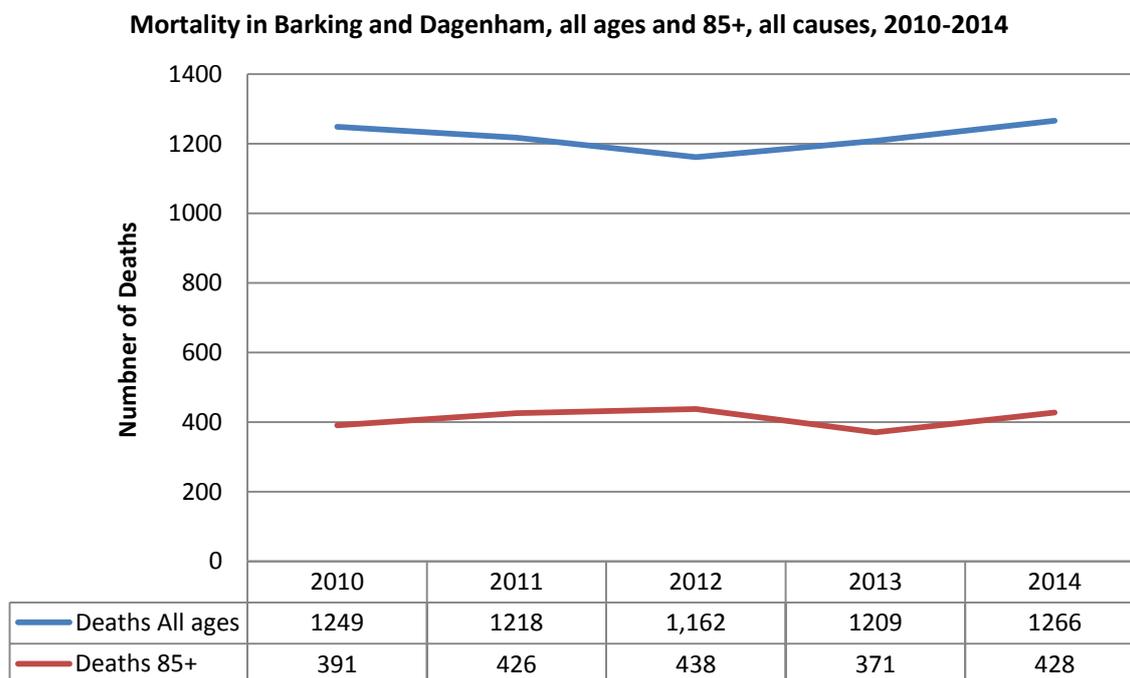
⁷ <http://charterforcompassion.org/cities>

⁸ <http://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

⁹ ONS, 2016, "Deaths Registered by Area of Usual Residence, UK" , [Online], available from;

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/deathsregisteredbyareaofusualresidenceenglandandwales> [last accessed 17 August 2016]

Figure 7.29.1: Mortality in Barking and Dagenham



Source : ONS⁹

Those who die at an older age are more likely to be suffering from complex multiple morbidities. A snapshot in August 2016 showed that there are a total of 52,369 registered Barking and Dagenham residents with one or more long term conditions. Previous data reported on those aged 19 or over, however figures for younger residents with long term conditions are given below in table 7.29.1. Of these residents, 3,023 were aged 0-18, 46,719 were aged 19-64, 13,240 were aged 65-84 2,627 were aged 85+. Therefore addressing the issues raised by residents dying at an older age with multiple morbidities will be a major challenge for both commissioners and providers of care.

Table 7.29.1: Patients with long term conditions by age, Barking and Dagenham registered population, 19/08/16

Age	LTC 1	LTC 2	LTC 3	LTC 4	LTC 5	LTC 6	LTC 7	LTC 8	LTC 9	Total
0-18	2,975	47	1	0	0	0	0	0	0	3,023
19-64	23,671	7,109	1,976	523	152	32	14	2	0	33,479
65-84	5,076	4,113	2,370	1,056	441	139	38	5	2	13,240
85+	670	760	600	345	162	61	21	7	1	2,627
Total	32,392	12,029	4,947	1,924	755	232	73	14	3	52,369

Source: Health Analytics

Of the total registered patients in the borough 4.51% of 0-18 year olds are registered as having one long term condition, along with 17.28% of 19-64 year olds, 30% of 65-84 year olds and 22.84% of 85+ year olds. In terms of 3 or more long term conditions the proportion of over 85 year olds with multiple conditions is considerably higher at 40.81% of all registered patients experiencing 3 or more conditions. This proportion

is much lower in younger age groups at 0.002% of 0-18 year olds, 1.97% of 19-64 year olds, and 9.93% of 65-84 year olds.

The majority of people in all age groups were registered as experiencing 1 or 2 long term conditions. However this difference will change significantly when we look at multi conditions (3 or more LTC). Only 1 person in the 0-18 age group is registered as experiencing multi conditions, in the 19-64 age group 1.5% are registered as experiencing multi conditions. However despite the majority in all age group experiencing 1 or 2 LTCs, older age groups the proportion experiencing multi conditions increases considerably, for the 65-85 year old age group 12% are registered as experiencing multi conditions, for the 85+ age group this proportion increases further to 45%. Overall approximately 15% of those registered as experiencing an LTC in Barking and Dagenham are experiencing multi conditions. (Table 7.29.2 below) In a recent study of multi morbidity by Melzer.et.al (2014)¹⁰ the percentage of 65 to 84 years old people in England with 3+ LTC was estimated 35.1% (95% CI: 32.9%-37.4%) and for 85+ years old population was estimated 55.1% (95% CI: 52.6%-57.5%), this shows significantly higher multi-morbidity rate than the health analytic data. This suggests that current local figures underestimate the number of people across all age groups experiencing multi conditions by a considerable amount.

Table 7.29.2: Number and percentage of long term one and 3+ conditions by age groups, Barking and Dagenham registered population 19 August 2016

Number of LTCs & %		Age Group			
		0-18	19-64	65-84	85+
1 Condition	%	98.4%	70.7%	38%	25%
	Number	2975	23,671	5,076	670
3 + Conditions	%	0.03%	8.06%	12%	46%
	Number	1	2,700	1681	1197

Source: Health Analytics

Data published in the End of Life Care Profiles¹¹ averages deaths for the period 2011-13 and shows that, in Barking and Dagenham, a significantly greater proportion of people die in hospital than is the case for England as a whole (56.3% for Barking and Dagenham compared with 48.7% for England). Of deaths in other places, significantly fewer people die at home (22.1% Barking and Dagenham, 29.7% England) and significantly fewer die in a care home (14.2% Barking and Dagenham compared with 20.0% England), suggesting that our care homes are less well able to care for people who are dying and residents of care homes are more likely to go into hospital to die. The proportion of deaths in hospices is also lower at 4.1%, compared with 5.8% for England.

¹⁰ Melzer, D., Tavakoly, B., Winder, R.E. et al, Much more medicine for the oldest old: Trends in UK electronic clinical records. *Age Ageing*. 2015;44:46–53.

¹¹ End Of Life Care Profiles, Fingertips "<http://fingertips.phe.org.uk/profile/end-of-life/data#page/0/gid/1938132883/pat/6/par/E12000007/ati/102/are/E09000002> [Accessed 9th of August]

Table 7.28.3: Place of death 2014

	Barking & Dagenham	England Average	England lowest	England highest
% deaths in hospital	56.3%	48.7%	36.9%	67.4%
% deaths in own home	22.7%	23.0%	18.5%	29.7%
% deaths in hospice	4.1%	5.8%	0.1%	11.7%
% deaths in care home	14.2%	20.0%	5.8%	32.8%

Source: End of Life care Profiles 2014¹¹

In Barking and Dagenham around 70.8% of all deaths in 2014 were the result of cancer, circulatory diseases and respiratory diseases. With active case finding and good disease management the majority of these deaths could be anticipated and the end of life adequately planned for. While 25.2% of people with cancer and 24.3% of people with circulatory disease died at home, only 14.2% of people with respiratory disease did so, and only 15.8% of cancer deaths were in a hospice (virtually no deaths from circulatory disease or respiratory disease occur in a hospice, which primarily provide care for cancer patients).

People need to be identified at an appropriate stage in their final illness so they can be placed on the supportive palliative care register and appropriately managed in primary care. Identification of palliative care patients is an area of concern nationally, and much still needs to be done to ensure people are identified in time to receive appropriate care (Table 7.29.4). The proportion of people identified in primary care in Barking in Dagenham as having palliative needs has continued to increase, but not at the same rate as the average of other practices in England. The number of people who should be on the register is estimated to be seven fold the current size.

Figure 7.29.4: People identified to be in need of palliative care compared with those identified in London and England

	2011/12		2012/13		2013/14		2014/15	
	Register Count	Prevalence						
Barking & Dagenham	204	0.10	212	0.10	238	0.12	239	0.12
London	13,868	0.15	15,487	0.17	17,054	0.19	21733	0.24
England	113,105	0.20	130,233	0.23	152,099	0.27	177,329	0.31

Source: NHS Comparator and QOF¹²

End of life for adults

Social Care Institute for Excellence produced dying well at home: the case for integrated working which defines the social care standards in end of life care¹³ and the National Institute for Health and Clinical Excellence, NICE produced a quality standard in 2011¹⁴ which defines clinical best practice for adult End of Life Care. These documents provide specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care.

This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.

Inequalities in end of life care

In general, it is known that inequalities exist in access to high quality and appropriate end of life care services. Examples include ethnic and religious differentials in accessing hospice care. It is also known that access to spiritual and bereavement services is more likely to favour people with good social and community networks and affiliations to organisations offering that kind of support. Detailed work is needed to understand the local position on these aspects of inequality.

Current service provision

General palliative care is provided through a variety of professionals in the community such as practice nurses, physiotherapists, or district nurses who can help patients approaching end of life to manage their symptoms or signpost and refer

¹² Quality Outcomes Framework Prevalence, achievements and exceptions at CCG level "Palliative Care" <http://digital.nhs.uk/catalogue/PUB18887> [Accessed 19 August 2016]

¹³ <http://www.scie.org.uk/publications/guides/guide48/files/guide48.pdf>

¹⁴ <https://www.nice.org.uk/guidance/qs13>

them to more specialist services if required. It has been a significant challenge trying to increase the number of GPs in the borough that are signed up to the Gold Standards Framework (GSF)¹⁵ for identification and management of patients approaching the end of life.

As a gold standard GPs should hold a palliative care register and have regular multidisciplinary meetings to discuss patients on the register but these registers are over-represented with cancer patients and meetings do not always take place. The borough has also tried to adopt and implement the Dying Matters 1% campaign and the prognostic indicator, with limited success. The majority of patients seen by the hospital palliative care team continue to be cancer patients.

Community specialist palliative care in Barking and Dagenham is provided through a contract with St Francis Hospice. The hospice has:

- 18 inpatient beds and a day hospice.
- Outpatient services including Hospice at Home team, medical outpatient support and the provision of community equipment.
- Bereavement counseling and support is provided for adults and children whose loved one is/was under any hospice service.
- 24/7 advice, support and visiting from a multidisciplinary community palliative care team.
- Telephone helpline (the Triage service) to ensure rapid assessment of patients referred, and ongoing patient and professional support.
- They also provide a good service to care homes in the borough. We have two care homes compliant with GSF requirements.

Evidence is needed of service quality based on patient reported outcomes and on equity of service reflecting the diversity of the local population. In particular the service should demonstrate evidence of equal opportunity of access to people from different socio-economic, religious and ethnic groups or sexual preferences. Hospital specialist palliative care is provided through Barking Havering and Redbridge University Hospitals NHS Trust (BHRUT). BHRUT Palliative Care Team consists of a consultant, a specialist registrar, lead nurse, clinical nurse specialists and a social worker. It works closely with a wider team including physiotherapy and occupational therapists, chaplaincy, psychologists, community palliative care colleagues and the local hospice. They meet as a multidisciplinary team once a week to discuss all new referrals. Their expertise covers the areas of complex symptom control (pain management, nausea and vomiting, and breathlessness), social issues and psychological and spiritual support. Out of hours care is provided in the community through the Partnership of East London Co-operatives (PELC). PELC provides urgent and emergency unscheduled care when the GP surgery is closed. The hospital palliative care team also has an

¹⁵ <http://www.goldstandardsframework.org.uk/>

out of hours care service which has palliative medicine consultants providing advice to teams within BHRUT caring for patients with specialist palliative care needs. This is a telephone based service that does not provide face to face assessment of patients. District and community nurses also provide an out of hours service. Pharmacy also provides an out of hours pharmacy rota with an on call rota for advising GPs on palliative care medicines.

Gaps in delivery

Availability of good quality, locally accessible and affordable hospice care for Barking and Dagenham residents is vital. There is good 24/7 provision of specialist palliative care advice and support into the community. The challenge is in recognition by referrers of when a referral would be valuable, particularly for people with advanced illness other than cancer.

Identification of patients in primary care is poor in some areas of the borough as evidenced by the low level of recording of palliative care patients on the palliative care registers. If palliative care patients are not identified in time for their care needs to be anticipated and managed by a multi-disciplinary team, their needs and preference cannot be met.

We know that cultural taboos exist in talking about death and dying meaning that patients and carers are not adequately prepared for terminal care and death when it happens. A report commissioned by the North East London Cancer Network through the 'People's Platform' surveyed various people across the sector to gather their views on end of life care. Though small in size, the qualitative study found increasing levels of interest and engagement around end of life care issues and across a number of diverse communities.

Family support is available through St Francis Hospice and BHRUT, but there is no specifically commissioned bereavement support service to support families who do not fall into either of these two services – this would be the majority of bereavements.

Recommendations for Commissioners

The current end of life care mapping exercise and strategy review should be used to inform end of life needs to be commissioned. Four elements should be embedded throughout the commissioning process; information for patients and carers, spiritual care service, support for carers, and social care.

Using the necessary levers, commissioners should ensure that providers are compliant with national guidance and recommendations on best practice in order to ensure optimum care including the Gold Standards Framework (GSF) for identification and management of patients approaching the end of life.

Commissioners should ensure equitable, consistent and sustainable access to end of life care services including the provision of out of hours care to support patients and carers to be cared for and to die in a place of their choice.

The borough will need to commission a locality wide electronic palliative care register. Such a system would ease coordination of care for end of life care patients round the clock and communication between various services.

NHS Barking and Dagenham Clinical Commissioning Group should work with St Francis Hospice to provide planning certainty.

NHS Barking and Dagenham Clinical Commissioning Group should work with St Francis Hospice to jointly plan for palliative care needs in the borough.

NHS Barking and Dagenham Clinical Commissioning Group should work with St Francis Hospice to provide planning certainty. The wishes of people approaching end of life are not always conveyed to those who need to know. Commissioning a locality wide electronic palliative care register helps with care planning and coordination of care for identified palliative care patients.

A systematic means of assessing and addressing training and education needs of health and social care staff at all levels needs to be developed, both in primary and secondary care and also specialist palliative care staff.

A specific bereavement service that will address needs of family and carers who are not accessing services from BHRUT or St Francis Hospice should be commissioned. This would be in line with best practice and national end of life care service pathway.

Promotional activities and materials to break taboos about death and dying should be produced with an aim to 'normalise' death and increase awareness of existing supportive and specialist palliative care services.