

# HEALTH AND WELLBEING BOARD

11 FEBRUARY 2014

<b>Title:</b>	<b>End of Life Care Position Statement and Recommendations for Future Focus</b>		
<b>Report of the Integrated Care Sub-group</b>			
<b>Open</b>	<b>For Decision</b>		
<b>Wards Affected: ALL</b>	<b>Key Decision: NO</b>		
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<b>Summary:</b> <p>This paper has received consideration by the HWBB Sub-group 'Taking Integrated Care Forward in Barking and Dagenham' and provides a position statement update on Health and Social Care's provision of End of Life Care (EOLC) in Barking and Dagenham and considers future areas for focus within the coming planning cycle.</p> <p>This report provides an update on the end of life care (EOLC) services in place in Barking and Dagenham. By comparing the current services to the best practice standards set in the Department of Health End of Life strategy (2008), the report highlights the gaps in service provision.</p> <p>The Integrated Care Coalition has agreed that EOLC will be a priority. The Barking and Dagenham, Havering and Redbridge End of Life Subgroup of the Integrated Care Coalition (ICC) will develop proposals for addressing the identified gaps for consideration in the coming planning cycle. It is acknowledged that Redbridge are taking a different route through the Co-ordinate My Care (CMC) pilot.</p> <p>This report draws on both national and local work undertaken within Barking and Dagenham and across outer north east London (ONEL), including:</p> <ul style="list-style-type: none"><li>• Department of Health, End of Life Strategy 2008 (DH 2008)</li><li>• End of Life workshop hosted by Barking and Dagenham Partnership End of Life Care (EOLC) Steering Group 2010</li><li>• The People's Platform report on end of life care in September 2010</li><li>• Dr Sally Hearne End of Life review 2011</li><li>• ONEL End of Life Care Position Paper May 2012</li></ul>			

- Barking and Dagenham Joint Health and Wellbeing Strategy 2012 – 2015
- BHR Integrated Care Strategic Outline Case November 2012

The People's Platform report on end of life care in September 2010 outlined core principles for end of life care:

'End of Life Care must be based on a few basic principles, which all care staff understand and accept... The main concerns were that people wanted to be treated with dignity and respect. Care should be sensitive to religion, culture and sexuality. Staff should make sure they know the patient's cultural background and personal history.'

The People's Platform also highlighted the importance of:

'Greater co-ordination between services is needed, for example having a lead person to join up the relevant services and work with the patient and their family to ensure that both the patient and the support network is given up-to-date information and appropriate services, from housing to medicines to respite care.'

Our primary assertion (and priority) is that people need to be able to choose to die in the setting of their choice and the role of services and support is to enable them to do so. Success in supporting people to remain at home is based upon a number of variables including the potential skill mix from Health and Social Care reducing our reliance upon bed based care- both in relation to acute hospital services and those provided within care homes.

This priority readily accords with one of our proposed priorities for the local plan for the Better Care Fund through the improvement in End of Life Care which enables greater numbers of people to be effectively cared for at home or in the place of their choice and the bringing together of diverse commissioning arrangements to support this. It is also clear that key areas of performance measurement within the Better Care Fund will relate to:

- Reduced usage of acute services
- Improvements in community support
- Reduced usage of care home beds

### **Recommendation(s)**

The Health and Wellbeing Board is recommended to:

- a) Note the position statement and approve the next steps for end of life care as identified throughout the body of the report (listed in Appendix 3 for ease of reference).
- b) Request that the Integrated Care Group develops an action plan to bring back to the Board in March 2014

## 1. Background

- 1.1. Work on improving EOLC services in Barking and Dagenham started in 2009 in response to the Department of Health National End of Life Care Strategy and an EOLC sub-group was established, reporting to the Health and Wellbeing Board. The aim of the group was to oversee the implementation of the National Strategy through coordinating delivery and promoting use of best practice tools and guidance.
- 1.2. Steady progress was made in rolling out key national end of life care tools such as the Gold Standard Framework and Preferred Priorities of Care. Enhancements were made to the district nursing service, community palliative care team. An out of hours service for palliative patients was put in place that allowed patients to continue to be cared for at home being able to receive appropriate interventions as required. This contributed to the objective of reducing the number of patients who die in hospital. In Barking and Dagenham the percentage of deaths at home improved from 17% of all deaths in 2005-06 to 20% of all deaths in 2010-11. Over the same period, the proportion of deaths in hospital fell from 72% to 62% Figure 1)

Fig. 1 - Barking and Dagenham place of death - summary % (Source: ONS PHMF)

	2005/06	2006/07	2007/08	2008/09	2009/10
<b>Home</b>	17.2%	18.3%	17.3%	18.5%	20.1%
<b>Hospital</b>	72.0%	69.4%	69.1%	66.7%	62.8%
<b>Care home</b>	6.4%	7.0%	8.0%	9.8%	13.3%
<b>Hospice</b>	3.4%	4.0%	3.9%	3.5%	2.7%
<b>Other</b>	1.1%	1.3%	1.6%	1.4%	0.9%

- 1.3. In noting the clear progress in the reduction in people dying in hospital we can see alongside this, that there have been some marked increased incidents (doubling) of place of death in care homes this suggests that care homes are increasingly managing the deaths of their residents effectively or conversely, that people are entering care homes and dying shortly after admission – this requires further investigation. We would therefore suggest that our priorities might benefit from being more fully drawn and may include:
  - Helping people to die at home should it be their wish to do so
  - Reductions in people dying in hospital

- Reductions in people dying in care homes who were not previously resident as such six months prior to death.

1.4. An Outer North East London (ONEL) wide steering group was formed in November 2011 consisted of end of life providers and commissioners from Barking and Dagenham, Waltham Forest, Redbridge and Havering health services. The early work of this group included a workshop, where the vision for end of life care was discussed. There was consensus of the vision for end of life care - to provide a co-ordinated and easily navigated end of life service. However at the time there was no clear picture of the EOLC services in place, and so the group commissioned an end of life position paper to summarise the EOLC services, with any gaps when mapped against the Department of health end of life care pathway highlighted.

## **2. Barking and Dagenham End of Life health services**

2.1. There are various methods proposed to calculate the number of deaths which can be predicted and consequently managed - the estimated number for the borough varies between 1030 and 1979 per annum dependant on the prediction tool used.

2.2. Barking and Dagenham has services in place across the EOLC pathway, with specialist palliative care and hospice at home services provided by St Francis Hospice and a bereavement service provided by the third sector as described on the borough's end of life service map.

2.3. The Council commissions a range of services that are contributing to supporting people to remain in their own homes. It is often the case that support is provided to people solely by the Council (or in collaboration with health) where people may die within the first year of services and \ or support commencing. One of the key issues within the system as a whole is the extent to which end of life care is identified at service / support inception. Services commissioned by the Council will include:

- Support at home through the provision of funding for a Personal Assistant.
- Domiciliary or home care.
- Bed based placements.
- Respite services.

2.4. Our work on the Better Care Fund through the development of the two year plan, mapping key services as these are brought together is helping us identify and confirm inputs to End of Life care as a key part of the local service delivery landscape.

2.5. It is clearly the case that existing service providers will, given the nature of their role and the people they are supporting, be involved in caring for people in their end of life. Therefore, support needs to be given to these providers to help improve their capacity, capability and awareness of when to draw in appropriate specialist and / or clinical input where required.

## **3. Improvement Area for End of Life Care**

The Barking and Dagenham end of life service map produced by the ONEL end of life care steering group is provided within Appendix 1: Further information on the gaps identified for improvement after mapping the borough's end of life services against the DH 2008 end of life strategy

This section identifies areas to improve end of life care in the community, care homes and through integrated care. Two funding transfer proposals from Health to Social Care, the Re-ablement allocation and NHS Social Care Section 256 transfer, are being used to improve EOLC, shown below in the next steps boxes.

### 3.1. End of life measures - options

Key metrics, local success measurements and local monitoring arrangements need to be considered for measuring our progress in delivering improvements to end of life care within Barking and Dagenham and to support further steps. There are a number of options which need to be balanced against alignment with other priorities, such as those within the Better Care Fund and that are proportionate. It is suggested that the following metrics could be considered:

Fig. 2 - Potential EOLC Measures

Suggested Measures	Data source
Number of patients on the GP practice end of life register	QOF codes
% of deaths in hospital/ usual place of residence	ONS statistics
Number/% of Service Users on practice / care home end of life registers benchmarked against prevalence in population generally or comparable practices  (This can be benchmarked by list size for GP practice -and /or could just look for growth on current level of performance )	Care home registers (Adult Commissioning contract monitoring)
Number/% of Service Users who have been offered (advanced care plans) ACPs and number of ACPs in place	QOF codes / electronic palliative care registers (CMC)
Number/% of people who died with a recognised end of life status	QOF codes / electronic palliative care register compared to practice list size
Number/% of Service Users dying in place of choice (as specified in ACP).	Electronic palliative care register.
Reduction in emergency admissions which result in death is a measure of success in all settings.	SUS / acute data.
Reduction in excess bed-days.	SUS / acute data.
Being pain free and having condition	Survey of service users / the

managed with medication.	bereaved. Track rate of prescriptions issued.
Loved ones / informal carers experiences to end of life care such as being near friends and family.	Survey for the bereaved which identifies the extent to which people felt supported in their caring role, the cared for was worked with in a way which maximised dignity and respect etc.
Duration by condition and expected life expectancy against setting of care.	Measured against benchmarked stats.
Reductions in people dying in care homes who were not previously resident as such six months prior to death	Sample analysis of cessation of placements within 6 months of start

### 3.2. Proposed priority measures for 2014/15

Whilst the list of potential areas for measurement is wide it is proposed that for 14/15 we focus upon the following:

- Number of service users who have been offered (Advanced Care Plans) ACPs and the number of ACPs in place
- Number of service users dying in the place of their choice
- No of providers participating in EOLC training
- Acknowledging progress in reduced deaths in hospital, consider reductions in deaths of people in bed based services where there entry was less than 6 months prior.

In agreeing the areas of focus for the coming year it is proposed that further work be undertaken to establish baselines, comparative performance and that day to day progress be considered by the Sub-group of the Health and Wellbeing Board.

### 3.3. End of life training programme

Training and support for existing services has been identified as a gap and one where improvement in quality and skills would deliver significant benefits. Following submission of a successful bid, training provision has been secured to cover end of life identification and care planning including carer support and spiritual awareness. The Gold Standards Framework (GSF) is a nationally recognised as the model of best practice for end of life care and St Francis Hospice is an accredited training provider. The following areas have been identified for the provision of focused training support and which will provide optimum benefit across the system.

Securing funds for Gold Standards Framework training enables us to provide training across 80 care homes and 70 domiciliary care providers across Barking, Dagenham, Havering and Redbridge. GP practices in Barking and, Dagenham will benefit from a localised training programme. (Further details of the training approach are provided within Appendix 2).

Initial engagement took place with a range of service providers in Barking and Dagenham at the provider forum on 21 November which provided an opportunity to both brief providers on our objectives and the detail within the training programme; and also to ensure that this is further checked against providers experiences in caring for people, managing and supporting staff and in their interface with other organisations and services. Further engagement with providers is now being completed through various briefings and leafleting. Applications are still being received at the point of writing with those yet to respond with take up of the training places being subject to specific follow up to ensure opportunities and participation are maximised.

### 3.4. **General practice**

People can currently only access 'end of life services' if they are identified as end of life by a clinician; with earlier identification, greater numbers of people would benefit from end of life services and support. There is a clear need for people to be supported by health professionals to have conversations about their end of life preferences, and clinicians need to ensure information on these preferences are shared so they can be followed. GPs have the earliest opportunity to identify end of life patients and are uniquely placed to have a holistic view of the patient's history, aiding identification.

The funding secured to support end of life training for Barking and Dagenham GP practices, will be focused on local priorities. This bid proposes to fund a 6 month contract within Barking and Dagenham to support additional training delivery to GP practices. This training programme will include:

- Promotion of the prognostic indicators and use of the surprise question to increase the number of patients identified as end of life
- Promoting use of the RCGP end of life care charter and the patient charter
- a focus on building on the work of the existing integrated case management service and enhancing this service to delivery further end of life care

#### **Next steps:**

- To deliver the end of life training to GP practices.
- To provide a focus upon identified practices with lower levels of patients on end of life registers to target for support

### 3.5. **Care homes**

The GSF Programme for care homes, supported by the DH 2008 end of life strategy, is a very valuable training programme for care homes. Most care homes have started the training and additional funding will enable homes to be accredited.

#### **Next steps:**

- To utilise bid funding to provide GSF training to care homes. Successful bid details provided within Appendix 2
- Fund EOLC accreditation for care homes from Re-ablement allocations

### 3.6. **Home care agencies/personal assistants**

Increasing numbers of people nationally are receiving care and support in their homes and people using the services appreciate consistency of the people supporting them not least at end of life. With increased training, carers will be more comfortable and skilled in supporting people through end of life and continuity can be maintained. Personal budget holders are also increasingly purchasing personal assistants who may not ordinarily benefit from the training programme agency employed carers are able to access. The council have recruited a PA Coordinator who is developing a training programme linked to an accreditation scheme. A module of the training programme will be EOLC.

**Next steps:**

Develop EOLC training programme for home carers and PAs (NHS Social Care Transfer)

PAs offered opportunity to access places on the domiciliary care provider GSF training.

### 3.7. For informal carers

Carers of Barking and Dagenham (Carers BandD), the council funded carers' support service, offer EOLC training as part of their training programme. There are over 3,000 informal (unpaid) carers in the borough but take-up of EOL training is poor with less than 20 carers going on the training per year. Carers BandD have developed an Ageing Carers programme to support carers through the various challenges of growing old in a caring role. As part of this programme Carers of BandD have included an EOLC training session.

**Next steps:**

Reinvigorate EOL training programme for informal carers to improve the number of informal carers using it (NHS Social Care Transfer)

Encourage Carers in BandD to sign-up to the domiciliary care provider GSF training

### 3.8. Develop and embed end of life provision in Integrated Case Management (ICM) and community rapid response services (CTT)

Historically the Barking and Dagenham ICM service operated with exclusion for 'patients considered to be in the last 3 months of life'. Care co-ordination for end of life patients was undertaken by the patients GP Practice, with a high degree of support from the Community nursing service.

### 3.9. How ICM supports EOLC

Earlier this year it was agreed to expand the scope of Integrated Case Management. The ICM clinical lead agreed to support referrals into ICM for patients considered to be in the last three months of life. These referrals are to be non-disease specific, though this is not always feasible as it is more difficult for clinicians to effectively diagnose patients in the last 3 months of life without a cancer diagnosis.

The ICM multi-disciplinary meetings (MDT) mean clinicians benefit from joint working to support these often complex palliative patients. Where end of life patients are discussed in the ICM MDTs, invitations to meetings should be considered for St Francis hospice clinical staff and the practice nurse. The ICM lead nurse for Barking



and Dagenham has agreed to make use of the 'surprise question' to consider whether end of life care would be appropriate as a standard part of the ICM process. The 'surprise question' is 'whether you would be surprised if the person was to die in the next 12 months'?

Current processes need to be followed to ensure any patients identified as end of life as a part of the ICM service, are communicated to the GP practice for recording on the practice end of life register.

ICM has a vital role to ensure Advanced Care Plans are used. The care plan called 'Thinking Ahead' is based on the GSF guidance and has now been used for three years in the borough. They are completed by the individual if they have capacity. If not district nurses, nurse specialists and St Francis Hospice have supported their completion. Introducing these forms to social care staff can increase the number of plans in use. This is particularly useful for individuals in the early stages of dementia who can have their wishes recorded while they still have capacity. Given the dementia screening programme commencing for over 75s, more and more people will be diagnosed with dementia.

### 3.10. Rapid response - how CTT supports end of life care

The CTT service has been operating since January 2013 and operates a rapid response service from 8am – 8pm. This service could support end of life patients with any unplanned needs, which have not been planned for by community nursing services. This may include issues in the home such as administering IVs, and blocked catheters.

#### **Next steps:**

- CCG to work with the ICM delivery group to implement a plan which embeds the end of life support offered by the ICM service.
- Develop methods to see an increase in the number of advanced care plans in use in the community (NHS Social Care Transfer)

### 3.11. Electronic system to centralise storage of EOLC plans

Health Analytics is used by the Integrated Case Management (ICM) services within Barking and Dagenham, Havering and Redbridge as a care planning tool to support patients with multi co morbidities and complex needs. In the event an ICM patient attends BHRUT AandE, the ICM care plan can be viewed in order that clinical decision making is supported by a comprehensive view of the patients holistic ICM care plan. Health Analytics is also used for management of the continuing health care (CHC) fast track process.

Barking and Dagenham are planning to pilot an extension of the Health Analytics system to support end of life care planning.

Co-ordinate my care (CMC) is a system to provide an electronic way of sharing patient's end of life care plans. CMC was developed in west London by the Royal Marsden hospital. As part of the 111 implementation process in 2012, CMC training was provided to front-line staff in BHR however use of CMC has not progressed in Barking and Dagenham and use across London is variable. The London Borough of Redbridge and Redbridge CCG are planning to pilot CMC.

**Next steps:**

- Barking and Dagenham CCG to plan and implement a pilot of Health Analytics.
- Barking and Dagenham CCG to review the Health Analytics EOLC pilot alongside the Redbridge CMC pilot to decide the way forward.
- Develop methods to see an increase in the number of advanced care plans in use in the community (NHS Social Care Transfer)

**3.12. Improvement to end of life standards within care home contracts**

In addition to the training programme outlined above the following work can take place with care homes:

**3.13. London-wide continuing healthcare procurement (AQP) process**

A procurement process (AQP) is being initiated across London for patients placed into nursing homes as a part of the health fast track continuing healthcare process. As a part of the procurement documentation there is a clear service specification for the provision of end of life care, KPIs and payment arrangements.

The full procurement documentation can be found on the supply 2 health website: <https://www.supply2health.nhs.uk/CP9/Lists/AQPOffers/Attachments/3/Document%201%20AQP%20Qualification%20Information.pdf>

**Next steps:**

It is proposed that the AQP procurement process will be analysed to identify if any aspects of this wider procurement project could be applied to nursing/care home placements through spot purchase agreements

That we review current commissioning arrangements so that alongside training and support to service providers we consider the benefits or otherwise of an additional end of life care premium being paid to reflect the additional inputs required

**3.14. Please don't admit cards**

These cards are carried by residents in care homes to encourage Accident and Emergency staff to treat residents and return them to the care home rather than admit them to hospital, reflecting individual choices and preferences in how and where care is provided.

**Next steps:**

Complete roll out Please Don't Admit Cards in residential care homes and nursing homes (Re-ablement Allocation).

**3.15. Community nursing levels (if GP education results in an increased identification rate)**

As a part of Ernst Young's development of the integrated care strategy, the ONEL end of life steering group recommended district nursing levels be increased in order to support more people to die in their home environment rather than in a hospital.

The proposal outlined an investment (as an 'invest to save') of £440,815 and an expecting savings release from reduced admission rates of £400,000.

**Next steps:**

To be considered through the BCF process and integrated teams.

### 3.16. **Acute response to the independent review of the Liverpool care pathway (LCP)**

Following the release of the report, BHRUT have reviewed the recommendations, and are developing an action plan in response.

The full report can be accessed at this web address:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf)

**Next steps:**

This will be managed as a part of the acute trusts contracting process

## 4. **Summary**

The areas identified for improvement identified within this paper will be reviewed by Barking and Dagenham Clinical Commissioning Group and London Borough of Barking and Dagenham and considered for the coming planning cycle.

## 5. **Mandatory Implications**

### 5.1. **Joint Strategic Needs Assessment**

Barking and Dagenham's updated JSNA outlines:

In Barking and Dagenham the percentage of deaths at home improved from 17% in 2005-06 to 21% in 2009-10. In the same period, the deaths in hospital fell from 72% to 63%. (However deaths in a care home increased from 6% to 13%.) These modest improvements are below the England figures. In Barking and Dagenham around 60% of all deaths in 2007-2009 were the result of cancer, cardiovascular and respiratory diseases. Most deaths could be anticipated and the end of life adequately planned for.

The National Audit Office found that the NHS contracting with hospices on an annual basis, which leads to uncertainty in planning. They recommended that commissioners work with independent hospices to develop three year contracts. A locality wide electronic palliative care register would help with planning and coordination of care.

### 5.2. **Health and Wellbeing Strategy**

Barking and Dagenham Joint Health and Wellbeing strategy includes the following references to end of life care:

Page 7: The majority (around 7 out of 10) of predictable deaths occur in hospital but this is not what local residents want – with around two-thirds wishing to die in their own homes. Much more priority needs to be put into assisting people with severe illnesses to die with dignity and support in their place of choice and in unlocking the obstacles preventing this choice being met. Analysis of sample of people requiring

End of Life identifies that their care and support needs could readily be met in or closer to their own homes rather than in necessarily being admitted into hospital.

Page 8: In line with the Marmot's recommendations we cover the resident population across the life course from pre birth to end of life...

Page 23: There is no avoiding that old age is followed by death, and providing individuals support and dignity in dying is an important part of the health and social care agenda.

Page 24: Priority Area: Improvement and Integration of Services: more older adults who are terminally ill die with dignity in a planned and supported way.

### **5.3. Integration**

End of life care is delivered by multiple providers, and as such effective integration between providers or collaboration, is key to the delivery of seamless end of life care and improved experience of support.

### **5.4. Financial Implications**

There are potential financial implications relating to integrated teams. It is expected that the CCG allocation for 2014/15 will be published in December 2013, as part of the operating plan framework. Through the planning process, resources available to the CCG will be aligned to the areas of greatest strategic and local need. Given the current financial environment the CCG is not expecting that there will be new funding for investment

### **5.5. Legal Implications**

This report contains suggested actions in appendix 3 which do not have legal implications to them. The rest of the report is for noting and does not contain matters for which legal implications arise.

(Implications completed by Chris Pickering, Principal Solicitor)

## **6. Background Papers Used in Preparation of the Report:**

- Department of Health, End of Life Strategy 2008 (DH 2008)
- End of Life workshop hosted by Barking and Dagenham Partnership End of Life Care (EOLC) Steering Group 2010
- The People's Platform report on End of Life Care in September 2010
- Dr Sally Hearne ONEL End of Life Review 2011
- ONEL End of Life Care Position Paper May 2012
- Barking and Dagenham Joint Health and Wellbeing Strategy 2012 – 2015
- BHR Integrated Care Strategic Outline Case November 2012

## **7. List of Appendices**

- APPENDIX 1: End of Life Care Pathway and Local Position

- APPENDIX 2: The Training Bid and Training Content
- APPENDIX 3: Areas for Improvement in End of Life Care - Next Steps