Enfield Clinical Commissioning Group

Enfield Joint End of Life Strategy 2012 – 2016: Progress update

MEETING:	Health Scrutiny Standing Workstream
DATE:	9th March, 2016
TITLE:	Update on the End of Life Strategy
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Summary

This paper provides details of the progress made to date on the implementation of the above strategy, together with key outcomes produced for residents, and the effectiveness and efficiency of delivery of services associated with this strategy, and the impact on the wider health & social care system.

Good progress is being made on delivering the strategies objectives, with a range of positive outcomes delivered, e.g. increasing the number of people with terminal conditions dying in their preferred place of death.

Despite this progress, key challenges remain, and where progress has been slow, this is often because of the complexities of working in a multi-disciplinary environment and in embedding practise consistently across the Borough. In particular, whilst training delivered to professional groups has been extensive and is ongoing, there remain issues with engagement in primary care in delivering the objectives laid out in the End of Life Strategy; plans have been put in place to appropriately address the underlying issues.

SUPPORTING PAPERS:

Enfield Joint End of Life Care Strategy 2012 – 16

2. RECOMMENDED ACTION:

The Older People and Vulnerable Adults Scrutiny Panel are asked to acknowledge the progress made on the implementation of the End of Life Strategy and its outcomes.

Enfield Joint End of Life Strategy
The strategy is a local response to the recommendations outlined in the End of Life Care Strategy, published in 2012 and was informed by the needs of our population and what we know about current service provision, quality and performance.

The implementation of the Enfield End of Life Care Strategy has been guided by the End of Life Care Steering group. A steering group of key local stakeholders which includes representation from Primary Care, Enfield Carer Centre, Acute Sector, North London Hospice, Adult Social Care, Clinical commissioning group, Voluntary and Community sector. The steering group contributes significantly to the implementation of the strategy. The group reports to the Health and Wellbeing Board.

The Strategy sets out how the NHS, Council and their partners will work to together in Enfield to make sure people:

- Feel able to talk about and prepare for their death, and be able to make decisions about their life, their care and treatment with their families and with professionals;
- Receive consistently high quality care, treatment and help to meet their needs;
- Feel able, with their family, to decide where they wish to die and get the care they need there;
- Feel care and support is provided in a way that respects their dignity and needs;
- Do not suffer from unnecessary pain and suffering;
- If someone close to them is approaching the end of their life, their own needs are understood and help is offered tailored to their needs and preferences.

The Strategy will achieve these goals by improving care to meet national standards for all adults approaching end of life; and developing services to make sure people have choices about their care. Its objectives were based on the National End of Life Strategy:

- *Encourage people to discuss death and dying:* Doing so with their family and friends makes it more likely all of us plan for the end of our life;
- *Identify all people nearing the end of life* is the first step to making sure people's needs are met; sadly not everyone is known to the right services at the right time;
- *Effective Care Planning:* Everyone approaching end of life will need their needs assessed, their wishes discussed and their choices about care recorded in a plan;
- *Co-ordinated care across different organisations* is vital to make sure people have timely access to high-quality services and to manage resources;
- *Develop rapid access to care:* As an individual's condition may change quickly, it is important support is well-organised rapidly, including 24/7 services so more people live and die in the place of their choosing;
- *Ensure services provide consistent, high quality end of life care:* The Gold Standards Framework (GSF) is the national end-of-life care standards and partners are encouraging care organisations to adopt these standards in working with people;
- *Ensure good care in the last days of life:* When an individual reaches this point, It is vital those caring for them recognise this and help make sure death is as pain-free as possible, and they, their family and friends, suffer as little as possible;
- *Involve and support friends and families* as partners in providing care, and involving them in decision-making, whilst recognising they have their own needs;
- *Develop the workforce* to make sure health and social care staff have the necessary knowledge, skills, behaviours and attitudes about end of life care;
- *Develop a robust monitoring and performance framework* to help assess progress in the implementation of this Strategy;
- *Make sure the Strategy represents good value and hospice services are sustainable.*

End-of-life care in Enfield
End of life care is about helping those with advanced and incurable illness to live as well as possible until they die. It helps make sure the care and support of patients and their families are known and met in preparing for, and throughout, their last days and into bereavement. It includes the management of pain and symptoms, as well as psychological, social, spiritual and practical support.

The Strategy aims to improve the care provided at home, acute hospital, care homes, hospice, community hospital and other institutions. Some of the care provided, such as in hospital, care homes or via social workers or home care, is part of the general support provided to vulnerable people. In such cases, it is important staff have the knowledge, skills and attitudes to help people plan, and provide care, for the end of their life in line with national standards.

Other services, such as the support provided in North London Hospice, including its Palliative Care Support Service, or Macmillan Nurses, are more specialist end-of-life (palliative) care. These organisations not only to provide care and support, but also offer best practise advice, training and development about end-of-life to others, such as GPs.

Often, people will receive care and support from a number of specialist and non-specialist organisations, which makes coordinating an individuals' end-of-life care especially important.

Who and how many people might need end-of-life care?
Part of the Strategy promotes people feeling able to talk about and prepare for their death – in this sense, preparing for end-of-life touches us all.

On average, there were 1,900 deaths per year of Enfield residents between 2010 and 2012 – a number decreasing since 2001 as people's life expectancy is increasing - with three-quarters deaths of those aged 70+. The most common cause of death is progressive diseases such as dementia, heart disease or cancer, with these last two conditions the reason for half the deaths in 2009.

Good, well-coordinated end-of-life care tailored to individuals' and families' needs and preferences up to and beyond individuals' last days is crucial in making sure people prepare and live as well as possible in the way they want to.

What progress has been made?

Good progress has been made against the Strategy's objectives since April 2012.

Objective	Progress	Rating
1. Encourage people to discuss death and dying	As part of national Older People's Day, Enfield Council and its partners organised a free event for older people to learn more about the opportunities available in Enfield. Workshops on the above topics was held throughout the day Topics covered were: • Getting ready for winter • Everybody active • Getting involved • Preparing for the future The North London Hospice provides a Sage & Thyme training to professionals. The training guides healthcare professional/care worker to have a difficult conversation with someone who is palliative.	
2. Identify all people nearing end of their life	The CCG is in the process of revising its risk stratification tool to allow for specific types of algorithms for patients with several conditions to be identified. The algorithm will include patients who are palliative. The hospice continues to deliver a GSF Primary Care 'Going for Gold training programme to GPs. The programme will enable GPs improve on earlier identification of people nearing the end of life, having and recording those crucial conversations or 'Advance Care Planning discussions' and enabling better coordination and team working leading to top quality care in alignment with the wishes of patients and their families.	
3. Effective care planning 4. Coordinated care across organisations 7. Good care in last days & after death	Specialist training programmes have been designed and implemented for professionals who are co-ordinating & planning end-of-life care, including training programmes for GPs, community nursing, social workers & hospitals, with input from specialist palliative care consultant. North London Hospice worked with 18 care homes & 4 homecare providers to train staff in the Gold Standard Framework for end-of-life care, including in Advanced Care Planning, CHAT in collaboration with the North London Hospice have a structured formal training programme in place for all groups of professionals dependent on role and grade. CHAT run these sessions all through the year to support the skills and knowledge of developing advanced care plans for residents but also provide practical support to care staff on how to deal with end of life challenges. Enfield is currently working in partnership with North Central London Clinical Commissioning Groups on the development of a shared record. The system will have two functions; a patient held record and interoperability with systems operating across Enfield i.e. GP systems, Acute Trusts, North London Hospice, Mental Health Trust and Adult Social Care.	
5. Develop rapid access to care	A nurse-led Palliative Care Support Service was implemented in Enfield in 2012 to provide support quickly to individuals at crisis and to facilitate hospice/hospital discharge to enable patients to remain in/move to their preferred place of care and death. The scheme has proved very successful in doing so (see next section).	
6. Ensure all services provide high quality end of life care	Roll out of national good practise, the Gold Standard Framework training for health and social care professionals, care homes & domiciliary care, is progressing, with a focus on professional training (see Objective 3).	
9 Develop workforce competencies	As part of its delivery of workforce development to care staff, CHAT in collaboration with the North London Hospice have a structured formal training programme in place for all groups of professionals dependent on role and grade. Training includes: syringe driver training, 'Introduction to Palliative Care' for trained nurses, 'Introduction to Palliative Care' for Health Care Assistants and Support workers, 'Communication and Advanced Care Planning' and 'End of Life Care and	

	Dementia'. These sessions run through the year to support the development of skills and knowledge to put in place advanced care plans for residents but also provide practical support to care staff on how to deal with end of life challenges	
10. Develop a robust monitoring & performance framework	Outcomes-based monitoring framework, including analysis in this document, with further development in 2013/14.	
11. Ensure value for money & sustainability of hospice services	Hospice care provided from St Josephs and Marie Curie now moved to more sustainable contractual arrangements. Funding for North London Hospice increased.	

What has been achieved?
The End of life Care Strategy aims to ensure that we deliver better quality of care and greater choice in End of Life Care. The primary focus is on increasing the number of people who are able to exercise a positive choice about their place of death.

- The North London Hospice provides a service to any patient who has specialist palliative care end of life care needs. All patients have their Preferred place of care discussed and documented and appropriate plans are implemented e.g. Advance Care Plan and DNAR forms in conjunction with the patients GP. This information is stored on our care electronic system;

- The Palliative Care Support Service is now accessible for all patients with a district nurse, enabling the district nurse to have more autonomy and freedom when planning crisis management and end of life care at home. In 2014/15 98% of patients under the care of the Palliative Care Support Service died in their preferred place of death

- The Care Home Assessment Team have proactively supported residents in care homes to have comfortable and dignified deaths in their preferred place and the service has seen a significant success, achieving its aim to support residents to die at their preferred place of death. In 2013/2014 CHAT achieved 95% of deaths in preferred places and in 2014/15 saw an increase of 98%. In 20115/16, to date they have achieved 100%;

- The North London Hospice Enfield Community Specialist Palliative Care team have just introduced Palliative Care outcome tools such as IPOS, Palliative Care Measure, Palliative Care Indicators and the use of the Phasing Tool to identify the level of care patients may need. The outcome tools are revisited at any significant events along the patient's pathway;

- Enfield developed a multi-agency & multi-disciplinary integrated care network. The network establishes an approach to delivering self-management, care and support of older people that is more patient-centered, multi-disciplinary and makes most effective use of existing and new resources to deliver care in the most appropriate clinical setting. With a key element in primary care with the GP as Lead Accountable Professional supported via other health professionals working in the community (Integrated Locality Teams comprising nurses & social care professionals) or in care homes (via nurse-led team working in the Care Homes Assessment Team with specialist skills in end of life);

- The support offered encompasses support for end of life, not just at end of life, but in advanced planning as part of the engagement process; whilst these health professionals working with GPs will be able to bring in specialists, such as hospice staff, in assessments, reviews or care delivery. For example, the care offered for people approaching end of life includes district nurses, but supported through a Hospice run Palliative Care Support Service (PCSS) to help support people out-of-hours at home at short notice to avoid hospital admission;

- In April 2015 Enfield CCG recruited an EOL Macmillan GP to support both primary care and community services in the delivery of End of Life in Enfield. The EOL Macmillan GP is currently working with CPEN and UCL Partners in putting together an EOL training and education package for professionals across primary care and community services.

What is the impact of training on care professionals?
A wide range of training is available about end-of-life care to care professionals, which has improved both the care people receive, e.g. in care homes, and their outcomes through using services such as the Palliative Centre Support Services. Training undertaken includes:

- Ongoing health professional training regarding end-of-life issues, including Advanced Care Planning. Professional practise was improved by palliative care link nurses working between specialist teams and district nurses;
- North London Hospice delivering training on the Gold Standard Framework to staff in 45 care homes and 15 domiciliary home care agencies.
- CHAT ongoing EOL care training across 39 care homes in Enfield; there has been a 25% reduction in falls between 2013/14 & 2014/15; 9% annual reduction in emergency admissions from homes in which CHAT worked over last 2 years. 350+ care home staff was trained in 2013/14 as part of CHAT's coaching/mentoring role, 98% of patients who died did so in preferred placed of death;

How has it made a difference to those approaching the end-of-life or their families?
Improvements have been made in care delivery as a result of the implementation of the EOLC strategy. Some comments of individuals approaching end-of-life or their families can be found below. These comments are typical and underpin the value of the support offered at this time, including the care and consideration given to individuals, but also the choices they felt they had in approaching end of life in a dignified and respectful way.

- A key outcome for the Strategy was to significantly improve the proportion of people who died in a place of their choice, with the overwhelming majority of people saying they want to die outside hospital, and many wanting to die at home. Despite this, two-thirds of people dying in Enfield did so in hospital between 2008 and 2010, with relatively few at home. However, there are promising signs of improvement as a result of initiatives such as Palliative Care Support Service and roll out of professional development have had a significant impact. In 2014/15 98% of patients under the care of the Palliative Care Support Service died in their preferred place of death whilst 91% of people dying who were on district nursing end-of-life caseloads did so at home in 2014/15.

Comment 1:
"*I wanted to thank for your time and effort with Dad over. It is hugely appreciated myself, my family and Dad. I would say that you have been by far the most helpful, transparent, honest and knowledgeable health professional I have come into contact with." – **Relative of home resident***

Comment 2:
*"I avoided a hospital admission and instead got to see a consultant in my care home…I am thankful they supported me to have a voice" – **Care home resident***

What Next?
Good progress has been made with the implementation of the Strategy with many important objectives already delivered. There is still a need to:

- Continue to work with primary care in improving the identification of palliative patients especially non-cancer patients.
- Develop and implement an integrated education for clinical practice staff and specifically targeted educational sessions for HCA/nurses/admin staff
- Progress the Shared Records Project and align with Coordinate My Care system.