

# Adults, Health & Public Protection Policy & Scrutiny Committee

<b>Date:</b>	29 March 2017
<b>Classification:</b>	General Release
<b>Title:</b>	<b>UPDATE ON END OF LIFE CARE</b>
<b>Report of:</b>	Liz Bruce-Tri Borough Executive Director of Adult Social Care Services & Jules Martin - Managing Director of Central London Clinical Commissioning Group (CCG)
<b>Cabinet Member Portfolio</b>	Adult Social Services & Health
<b>Wards Involved:</b>	All
<b>Policy Context:</b>	Building Homes and Celebrating Neighbourhoods
<b>Report Author and Contact Details:</b>	Colin Brodie, Public Health Knowledge Manager, cbrodie@westminster.gov.uk Andrew Pike, Assistant Director of Communications, CWHHE CCGs andrew.pike@nw.london.nhs.uk

## 1. Executive Summary

- 1.1 This report summarises the work and findings of the Joint Strategic Needs Assessment (JSNA) on End of Life Care including the recommendations for key partners. The JSNA was presented for discussion and approved by the Westminster Health & Wellbeing Board.
- 1.2 The report also summarises the local direction of travel for End of Life Care in Westminster, and continuing progress made against the JSNA recommendations since publication of the report.

## 2. Key Matters for the Committee's Consideration

- 2.1 The Adults, Health & Public Protection Policy & Scrutiny Committee are invited to consider and endorse the End of Life Care JSNA report and recommendations.
- 2.2 The Adults, Health & Public Protection Policy & Scrutiny Committee are invited to note progress made against the recommendations. The responses will form

the basis of recommendations that will be incorporated into a short report that will be submitted to the relevant Cabinet Member(s) for a response.

### **3. Background**

- 3.1. People approaching the end of their life experience a range of physical symptoms, and emotional and spiritual needs. To manage these issues effectively requires integrated and multidisciplinary working between teams and across sectors regardless of whether the person is in their home, in hospital, a care home, or hospice.
- 3.2. Families and carers of people at end of life also experience a range of challenges and will have their own specific needs which must be addressed before, during and after the person's death
- 3.3. While some people experience good and excellent quality end of life care, many people do not. In order to address this variation and identify local issues for end of life care a request for a JSNA was submitted and approved by the JSNA Steering Group, a sub-group of the Health & Wellbeing Boards, July 2014
- 3.4. The JSNA provides a comprehensive evidence base to inform local strategic and commissioning approaches to end of life care. It draws on a range of information and data, both quantitative and qualitative, including national and local data, policy and strategy, literature, as well as views of patients, service users and the public. It provides an opportunity to understand the whole landscape for people approaching end of life, and their carers' and to highlight areas of improvement to be addressed in joint strategic planning.

### **Joint Strategic Needs Assessment Findings and Recommendations**

#### **3.5. *Tri-borough Population and number of deaths***

The percentage of either gender at all ages over 65 for the three boroughs is significantly low compared with England. The exception is in the Royal Borough of Kensington & Chelsea for those aged 85+ for both genders, with the percentage of women over 85 years close to the England average, but with a significantly higher percentage of males older than 85 years because of the Royal Hospital Chelsea, a home for retired soldiers.

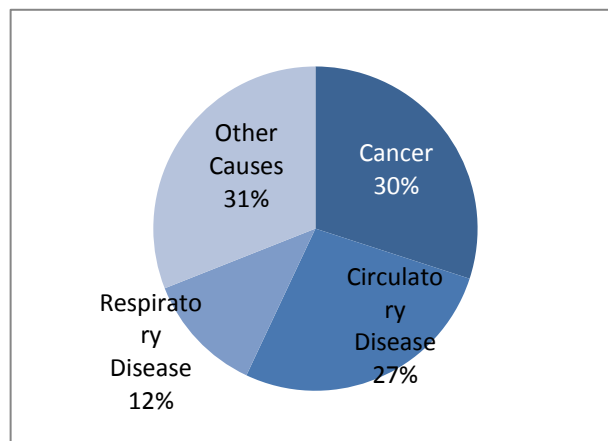
The death rate is low compared to other areas, even when taking into account the age distribution of the population. There have been an average of 2,815 deaths per year between 2006 and 2014. Despite an increasing and aging population the number of deaths has reduced by 19 each year.

The median age at death is 83 years for women and 76 years for men, compared to national figures of 85 for women and 82 for men. Median age at death varies from 66 years in Earl's Court to 88 years in Pembridge.

The number of deaths that occur is not likely to change significantly over the next ten years. This takes into account the small increase in the ageing population predicted by the Office for National Statistics and the expected reduction in death rates.

### 3.6 **Cause of death**

On average there are 844 (30%) deaths per year due to cancer, 768 (27%) due to circulatory disease, 341 (12%) deaths due to respiratory disease and 863 (31%) deaths due to other causes. The percentage of deaths due to cancer is significantly higher in the north of Westminster City Council and is significantly associated with an older median age at death.



Examination of deaths in the three boroughs is complicated by the geography and the different populations of the organisations responsible for providing services. There are a number of different populations to examine: Resident, Registered, Residents who are Registered, and Registered who are not Resident. Additionally, those who die may do so anywhere in the country.

The overarching theme emerging from the JSNA (a joint local authority and Clinical Commissioning Group description of the current and future health and wellbeing needs of its local population, along with the priorities for action) is the need for a whole scale 'culture shift' for all practitioners that may come into contact with dying people, to consider End of Life care as 'everyone's business' and not just a service provided by specialist palliative care.

- 3.7. The recommendations were drawn from the evidence contained in the JSNA and in development with key stakeholders. Many of the recommendations cut across a number of different themes and service areas, and were presented in a format for commissioners to consider whether they are appropriate for local implementation.
- 3.8. Recommendation 1 refers to an ambition for the local delivery of high quality, person- centred end of life care designed to improve the experience of the dying person and their families, carers and friends. Recommendations 2 to 5 describe the culture, governance, processes and systems that need to be in place in order to achieve this ambition

3.9. The detailed recommendations are presented in the End of Life Care JSNA Key Themes document but are also summarised below.

Recommendation	Summary
<p><b>Recommendation 1: Maximise choice, comfort and control through high quality effective care planning and co-ordination</b></p>	<p>Everyone with a life limiting long term condition should have care plans which address their individual needs and preferences, particularly as they approach the last phase of life. Their care must be coordinated, with a clear oversight of the respective roles and responsibilities of all health, social care and third sector service providers.</p>
<p><b>Recommendation 2: Promote end of life care as ‘everybody’s business’ and develop communities which can help support people</b></p>	<p>The overall focus of end of life care must be a community model, with input from specialist services when needed. Local leaders, commissioners, professionals and our populations should generate a culture where talking about and planning for the last phase of life is ‘normal’, and all practitioners are willing and able to give end of life care.</p>
<p><b>Recommendation 3: Identify clear strategic leadership for end of life care across both social care, health and the independent sector</b></p>	<p>A lead organisation should be identified with responsibility for ensuring developments are cohesive. Leadership should reflect a community based model across a range of services, with a clearly articulated end of life care vision and ambitions.</p>
<p><b>Recommendation 4: Develop a coordinated education and training programme for practitioners, the person dying, carers and for family and friends (if they wish)</b></p>	<p>Formal and informal training and education programs for all frontline practitioners needs to be coordinated, systematic, visible and evaluated, in line with good practice guidelines.</p>
<p><b>Recommendation 5: Everyone should have easy access to evidence and information</b></p>	<p>More information needs to be easily available. Accessibility in terms of language, style, culture and ability should be reviewed. Evidence and information must be available to commissioners and providers and used to actively improve services.</p>

#### **4. END OF LIFE CARE IN WESTMINSTER LONDON/CURRENT WORK PROGRAMMES**

##### **4.1. Recommendation 1: Maximise choice, comfort and control through high quality effective care planning and co-ordination.**

Central London CCG utilise the Co-ordinate My Care (CMC) system along with the other 31 CCGs across London to record the care plan of those identified as being at the end of life. The CMC platform has been updated to facilitate the creation and updating of records and the Three Borough End of Life Care Steering Group regularly review the reports and discuss what additional support can be provided to increase the number of patients whose care information is shared on the system.

##### **4.2** Central London Community Healthcare (CLCH) have convened six working groups closely aligned to the recommendations of the JSNA with three groups looking at:

- High quality, relationship centred, compassionate care
- Advance care planning/risk stratification
- Assessment and care planning

The individual working groups report back on the progress of achievement against each of the outcomes, to the newly formed End of Life Care Operational Group.

##### **4.3. Recommendation 2: Promote end of life care as ‘everybody’s business’ and develop communities which can help support people**

Supporting people in the Last Phase of Life (LPOL), has been identified as a priority area in both the Health and Webbing Strategy for Westminster 2017-2022 and the North West London (NWL) Sustainability & Transformation Plan (STP) submitted in October 2016. The shift to consider people in the last phase of life rather than those at the end of life recognises the more gradual functional decline that characterises the progression of various long term conditions and increasing frailty. This reinforces the need to recognise when people are in the last phase of life and to have discussions at an early stage with them and their families regarding their preferences and what support is required. This will allow a shift from an existing hospital- based model of care, often through emergency services, to a new community and person-focused model of delivering care with input from specialists when needed.

##### **4.3** The CCG are also working with the new provider of the Community Independence Service to consider how the service can work alongside local hospices, district and community nursing, primary care practitioners and specialist palliative care teams to provide support to those in the last phase of life.

#### **4.5 Recommendation 3: Identify clear strategic leadership for end of life care across both social care, health and the independent sector**

In the North West London area, a programme of work is being undertaken as part of the STP to improve the quality of care for people who are in their 'last phase of life'. This includes patients in Westminster.

- 4.6 Providers working across Westminster have end of life care strategies with key leaders within the organisations identified and governance mechanisms in place for monitoring progress.
- 4.7 Imperial College Healthcare NHS Trust (ICHT) and Chelsea & Westminster NHS Foundation Trust both have organisational end of life care strategy documents. The CLCH End of Life Care Strategy (2015-2018) was launched in March 2015 and sets out plans to improve end of life care and the experience for people and carers using CLCH services at the end of their lives. This encompasses improving access to end of life care services, improving choice and the coordination of services to reduce inequalities of service provision and increasing the proportion of patients who are cared for and die in their preferred place of care.
- 4.8 The strategy covers generalist and specialist palliative care, including care given in all settings of CLCH (at home, all community based services, in-patient, specialist in-patient palliative care services, day Hospice, specialist community palliative care services, prison health, nursing and residential care).
- 4.9 The Health & Wellbeing Board approved the End of Life Care JSNA at their meeting on 21 January 2016 and agreed to take on a leadership role for End of Life Care, providing a steer for local implementation.
- 4.10 The inpatient and community End of Life Care services are monitored regularly, through a number of quality indicators that include using carer feedback to improve services. In 2017/18 the CCG will build on these indicators by introducing a new Commissioning for Quality & Innovation (CQUIN) to specifically measure carer feedback.

#### **4.10 Recommendation 4: A coordinated education and training program for practitioners, the person dying, carers and for family/friends (if they wish)**

The NWL LPOL programme has identified consistent training and education across the NWL Collaboration of CCGs as one of the six key interventions and discussions have been initiated with HENWL to agree a funding mechanism.

- 4.11 The CLCH EOLC Strategy includes a working group dedicated to training and education which categorises staff groups and supports the delivery of appropriate training in relation to the end of life care components of their jobs.

- 4.12 ICHT and CLCH have delivered end of life care training to staff including difficult conversations training.
- 4.13 The dementia workforce development programme is due to commence in February 2017. It will include a range of modules, including a focus on end of life care and dementia. The modules will include a range of learning approaches including e-learning, workshops, training and a communication strategy.
- 4.14 The module will focus on living well with dementia and supporting a person with dementia to die well, or as they would have wished. It will include exploring advanced decision making, the range of symptoms that a person with dementia may experience at the end of life. It will also include supporting family carers and help them to understand what is happening at the end of life.

**4.15 Recommendation 5: Everyone should have easy access to evidence and information**

One of the interventions which has been recommended and prioritised by the North West London Last Phase of Life programme, is to deliver a telemedicine clinical support facility to help staff in care homes (initially) to be able to access generalist healthcare and end of life care advice and support

- 4.16 The service will be staffed by experienced, clinical professionals who are capable of providing rapid triage and advice / guidance to both clinical and non-clinical staff. Best practice from elsewhere, particularly Airedale - <http://www.health.org.uk/gold-line> - has shown that this model allows professionals and carers to better facilitate the wishes of patients at the end of their life. It also helps support them to enable people to die in their preferred place and can also reduce inappropriate A&E attendance and hospital admissions. Working with Social Finance, we will be looking to implement something similar in our care homes, in the first instance. The next phase of the programme will then be to focus on the CCG's wider cohort of residents, including those people being cared for by district nursing, intermediate care services and by formal and informal carers. One of the interventions which has been recommended and prioritised by the North West London Last Phase of Life programme is to deliver a telemedicine clinical support facility, to help staff in care homes (initially) to be able to access generalist healthcare and end of life care advice and support. The next phase of the programme will then be to focus on the wider cohort of residents, including those people being cared for by district nursing, intermediate care services and by formal and informal carers.
- 4.17 The service will be staffed by experienced clinical professionals who are capable of providing rapid triage and advice / guidance to both clinical and non-clinical staff. Best practice from elsewhere has shown that this model allows professionals and carers to better facilitate the wishes of patients at the end of their life and support them to die in their preferred place, and can also reduce inappropriate A&E attendance and hospital admissions

## **5. CONSULTATION**

- 5.1. A workshop was held at the Black & Minority Ethnic Health Forum in June 2015. Feedback from the workshop was incorporated into the findings, particularly the Policy and Evidence Review (Supplement 2)
- 5.2. A workshop was held at the End of Life Care Steering Group in September 2015 to inform the development of the recommendations. The End of Life Care Steering Group consists of CCG and GP End of Life Care leads as well as community and secondary care providers
- 5.3. CCG and GP End of Life Care leads were interviewed for the JSNA.
- 5.4. The draft JSNA was disseminated to key stakeholders in November 2015, including colleagues in Local Authority, Adult Social Care, CCGs, Central London Community Healthcare, Hospices, Specialist Palliative Care Teams, Healthwatch, and Community and Voluntary organisations. Feedback was collated and reviewed by the Task and Finish Group and informed the final report.

## **6. EQUALITY IMPLICATIONS**

- 6.1. JSNAs must consider the health, wellbeing and social care needs for the local area addressing the whole local population from pre-conception to end of life.
- 6.2. The “local area” is that of the borough, and the population living in or accessing services within the area, and those people residing out of the area for whom CCGs and the local authority are responsible for commissioning services
- 6.3. The “whole local population” includes people in the most vulnerable circumstances or at risk of social exclusion (for example carers, disabled people, offenders, homeless people, people with mental health needs etc.)

## **7. LEGAL IMPLICATIONS**

- 7.1. The JSNA was introduced by the Local Government and Public Involvement in Health Act 2007. Sections 192 and 196 Health and Social Care Act 2012 place the duty to prepare a JSNA equally on local authorities, CCGs and the Health & Wellbeing Boards.
- 7.2. Section 2 Care Act 2014 imposes a duty on local authorities to provide or arrange for the provision of services that contribute towards preventing, delaying or reducing care needs.
- 7.3. Section 3 Care Act 2014 imposed a duty on local authorities to exercise its Care Act functions with a view to ensuring the integration of care and support provision with health provision to promote well-being, contribute to the prevention or delay of care needs and improve the quality of care and support.



- 7.4. JSNAs are a key means whereby local authorities work with CCGs to identify and plan to meet the care and support needs of the local population, contributing to fulfilment of local authority s2 and s3 Care Act duties.

**If you have any queries about this Report or wish to inspect any of the Background Papers please contact Report Author:**

**Andrew Pike [andrew.pike@nw.london.nhs.uk](mailto:andrew.pike@nw.london.nhs.uk)**

**APPENDICES:**

Joint Strategic Needs Assessment - End of Life Care Key Themes Report