Health Committee investigation

End of Life care in London

The Health Committee is using its meeting on 20 October 2015 to investigate end of life care (EOLC) in London. The scope and terms of reference for the investigation have been agreed by the Chair in consultation with the Deputy Chair.

Terms of reference

The terms of reference for the investigation are:

- To examine the challenges facing older people living alone in accessing appropriate end of life care in London; and
- To identify and make recommendations on what can be done to reduce inequity in end of life care options for older people in London

Scope

The purpose of this review is for the Committee to understand the challenges people face in accessing good quality end of life care and securing the care options of their choice, and to examine how EOLC options can be improved for Londoners.

The investigation will seek to have an impact by:

- Examining in public, with key stakeholders, the barriers to accessing quality end of life care in London;
- Raising awareness of issues faced by people coming to the end of life in London; and
- Identifying ways in which the Mayor, working with health and social care partners, could help improve the situation, in line with his statutory duty to promote the reduction of health inequalities in London.

National research[1] has identified that there may be specific challenges around end of life for certain demographic groups within the population, namely:

- People living alone, especially the 'oldest old' (85+)
- People from BAME communities
- People from deprived backgrounds
- People with a diagnosis other than cancer
- Other groups of people who may have specific needs, such as people with mental health needs, people with learning disabilities, people who identify as LGBT, people who are homeless, prisoners, travellers and gypsies

We propose to focus the investigation specifically on the first of these groups (people living alone, especially the oldest old) with reference to issues facing people in the

[1] http://www.cqc.org.uk/content/themed-review-end-life-care

remaining categories. There appear to be some potential gaps in the research particularly for people living alone and the oldest old. We will look at specific factors to establish what challenges are faced by people living alone and coming to the end of life, including community support, place of death, place of care, and access to appropriate services.

This investigation will be of particular relevance to the second core objective of the Mayor's Health Inequalities Strategy; to '*Improve access to high quality health and social care services particularly for Londoners who have poor health outcomes.*[2]

Background

Defining end of life care

End of life care (EOLC) is the care experienced by people who have an incurable illness and are approaching death. Good EOLC enables people to live in as much comfort as possible until they die, and to make choices about their care and their death. It includes providing support that meets the needs of both the person who is dying and the people close to them, and includes management of symptoms, as well as provision of psychological, social, spiritual and practical support. There is evidence of considerable variation in the quality of end of life care that people receive, both across services, geographically and between different groups of people.[3]

End of Life Care covers the care received by people who are likely to die in the next 12 months, as well as care in the last days and hours of life, and care after death, including bereavement support for families and loved ones.

Living alone in London

ONS census data (2011) indicates that 32 per cent of London households are single occupancy i.e. living alone, of which around 30 per cent are people aged over 65. This equates roughly to around 3 per cent of London's population or just under 300,000 people. Nationally, those aged 65 and over living alone were more likely to be women: 63% of those aged 65 to 74 were women, and 76% of those aged 85 and over. This is likely to relate mainly to women living longer than men.[4] Research indicates that people who live alone are less likely to die at home than those who have a spouse[5].

Factors affecting end of life care options

Diagnosis

Where people die currently depends largely on their health condition. A recent report by the London School of Economics found that people with terminal diseases other than cancer (for example, dementia, COPD, motor neurone disease) experience greater challenges in accessing palliative and end of life care services than those with a cancer diagnosis.[6]

[2] The London Health Inequalities Strategy 2010
[3] http://www.cqc.org.uk/content/themed-review-end-life-care
[4] http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/do-the-demographic-and-socio-economic-characteristics-of-those-living-alone-in-england-and-wales-differ-from-the-general-population-/sty-living-alone-in-the-uk.html
[5] http://www.scie.org.uk/publications/guides/guide48/choosingtodieathome.asp
[6]Equity in the provision o palliative and end of life care in the UK (LSE 2015)

Co-morbidity
One in three people over 65 will die with dementia (but not necessarily of dementia). Around one in three people living with dementia in the UK live alone[7]. This means that many people who are receiving end of life care for other conditions, such as cancer, will also be experiencing dementia. This can cause additional challenges to ensuring that they receive good quality care.

Cultural preferences
Death and dying are culturally sensitive issues. Different groups within the population may have different requirements and choices. Discussion of death and dying is considered taboo in some communities, which can make it challenging for patients, care providers and families to communicate effectively about their wishes and the best options for people reaching the end of life.

Patient access to services
Research from the Pan London End of Life Alliance shows that seven out of 10 people would prefer to die at home, but in reality only around three in 10 patients in London do – the lowest proportion nationally.[8] Many health and social care challenges exist in supporting people's wishes to be cared for and die in their preferred place of residence, and this is particularly evident across London:

- The number of people dying in hospital is 5% higher than the national average
- London also has the highest average length of hospital stay for people with a terminal illness compared to other regions in England[9]

There is evidence that some boroughs and CCGs prioritise end of life services more than others. A 2014 national review by the National Council for Palliative Care indicated that not all local authorities had incorporated end of life care services in their current health and wellbeing strategies[10]. The study found that of 36 local authorities in England that do not directly or indirectly consider end of life strategies for their residents, 11 were in London.[11]

Changes to national guidance
The draft NICE guideline, which has been published for consultation, follows the abolition of the Liverpool Care Pathway, a protocol for looking after people at the end of their life. This was phased out last year after a government-commissioned review found serious failings in how the pathway was being implemented. The NICE guideline begins to provide some guidance around clinical care in the last days of life in its place.

[7] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=550
[8] https://www.mariecurie.org.uk/commissioning-our-services/partnerships-innovations/strategic/pan-london-end-of-life-alliance
[9] https://www.mariecurie.org.uk/commissioning-our-services/partnerships-innovations/strategic/pan-london-end-of-life-alliance
[10] http://www.ncpc.org.uk/sites/default/files/HWBs_Report.pdf
[11] Brent, Camden, City of London, Enfield, Hackney. Hammersmith & Fulham, Kensington &Chelsea, Lambeth, Lewisham, Sutton and Wandsworth.

Five new[12] Priorities for Care have been set out by the Care Quality Commission as the basis for caring for someone at the end of their life. The new approach recognises that in many cases, enabling the individual to plan for death should start well before a person reaches the end of their life.

The new Priorities for Care are intended to ensure that:

- The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.
- Sensitive communication takes place between staff and the person who is dying and those important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care.
- The people important to the dying person are listened to and their needs are respected.
- Care is tailored to the individual and delivered with compassion – with an individual care plan in place.

The Care Quality Commission is due to publish the findings of its thematic review into inequalities and variations in end of life care by January 2016.

Role of the Mayor
The Mayor has a statutory duty to publish a Health Inequalities Strategy identifying *"major health issues where there are health inequalities between persons living in Greater London"* and *"specify priorities for reducing (them)"*.[13] Equitable access to high quality health and social care services is one of five high-level objectives set out in the Strategy, published in April 2010.

Methodology

Key questions
A call for written views and evidence will be launched as part of the investigation. Key questions include:

- What are the main challenges for ensuring good quality end of life care for older Londoners who live alone?
- What additional challenges are faced by other groups, such as people from BAME communities?
- What healthcare and social support is needed to ensure that more people die in their place of choice?
- How is the quality and availability of end of life care affected by the diagnosis received?

[12] Published May 2015
[13] Part 4, Section 22 Greater London Authority Act 2007

- How well equipped are London's health and social care providers to deal with a rising and ageing population?
- How can the Mayor support better end of life care for all Londoners?

Possible guests

The Committee will hold one public meeting with invited stakeholders, including:

- Pan London End of Life Alliance/Marie Curie
- Dying Matters (advocacy body)
- Age UK
- Public Health England
- Service providers including hospitals, hospices and care homes
- Royal College of Nursing (palliative care nurses)

The Committee could also prospectively arrange a site visit to an end of life care provider.

Potential outputs

The Committee could consider publishing a short issues paper or slide-pack highlighting its key findings.