

# LONDON ASSEMBLY

Health Committee

## END OF LIFE CARE IN LONDON

*The London Assembly Health Committee has been investigating the quality of care people receive at the end of their lives. This report summarises our key findings and suggests some areas for further investigation.*

# End of life care in London

## Key findings from our investigation

**There is huge variation in the quality of care people receive at the end of their life in London.** Statistically, Londoners receive some of the very best and the very worst end of life care in the country. Overall, London performs poorly in end of life care compared with the national average.

**Access to services is unequal.** Some people are less likely to receive good quality specialist end of life care. Their diagnosis, whether they live alone, their cultural background and sexual orientation all affect the chances of a person receiving the care they need and want.

**Older people struggle to access the care they need, particularly if they live alone.** As the number of older people who live alone grows, this will place further strain on hospital services.

**Fewer than half of London local authorities include end of life care as part of their Health and Wellbeing Strategies.** Without this focus on end of life care provision, services struggle to meet local needs.

**Many people, including medical professionals, find discussions of death and dying very difficult.** But communication between individuals, families, and health and social care providers is an essential part of good end of life care.

## What is end of life care?

A person approaching the end of their life will have a range of needs that can be met by family and friends, and health and social care providers.

The best care will be a package of care measures, tailored for the individual, that could include:

- Managing symptoms, including relief from pain
- Supporting with practical arrangements to reduce anxiety
- Helping to achieve a sense of resolution and peace
- Providing practical support with daily activities such as washing or dressing.

**Expert guests at our meeting in October 2015 made a joint statement setting out their six ambitions for delivering better end of life care:**

- Each person is seen as an individual.
- Each person gets fair access to care.
- Comfort and wellbeing are maximised.
- Care is coordinated.
- All staff are prepared to care.
- Each community is prepared to help.

# End of life care across London

**There are significant variations in the provision of end of life care services across London.** Even where services exist, these cannot be accessed at all times and by all who need them. In the absence of other options, many people will end up in hospital when they neither need or wish to be there.

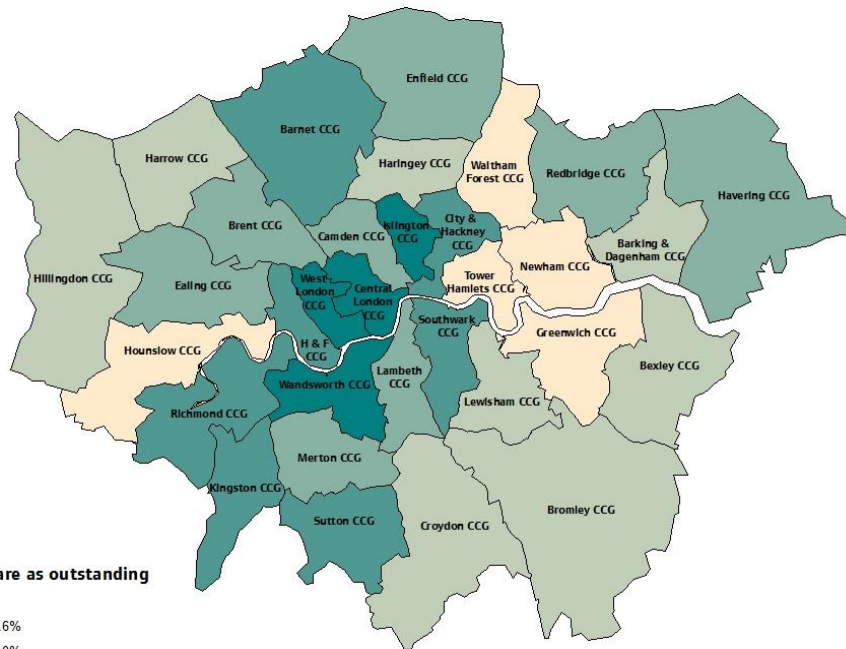
**Only 8 out of 33 London Clinical Commissioning Groups (CCGs) scored above the national average for end of life care quality indicators.**

**London CCG spend varies from £540 to £3,740 per death.**

**70% of London hospitals cannot provide specialist palliative care services seven days a week.**

**One in five community palliative care services is unable to provide out-of-hours services.**

*Figures from the Pan-London End of Life Alliance*



*“Each CCG has an end of life care lead; the challenge is to help them understand what a good death looks like, help them see where they stand on that benchmark, and encourage them to shift the funding.”*

Dr Caroline Stirling,  
Clinical Director for End of Life Care, NHS England (London)

# Access to services

**Evidence shows that certain groups of people are less likely to access specialist end of life care.** Factors include:

**Age:** Older people are less likely to access specialist care. This may be in part because they are unaware of services that are available to them.

**Diagnosis:** The majority of palliative care services in London are geared towards cancer patients. People with other conditions, such as motor neurone disease and chronic obstructive pulmonary disease are less likely to receive specialist care.

**Who you live with:** If a person lives with family or a carer they are more likely to have an advocate for their care and wellbeing, as well as assistance with transport, treatment, organisation and personal care. They are also more likely to discuss their wishes for their end of life care.

**Beliefs:** Some religions and cultures do not believe in predicting death or planning for it. This can make it difficult or impossible to create effective care strategies.

**Deprivation:** The relationship between deprivation and access to health services is complex, but evidence suggests that people in poorer postcodes are less aware of end of life care options and how to access them.

**Health inequalities persist across London. Commissioning the right services will depend on accurately assessing the needs and priorities of local communities, including the marginalised.**

**33% of people who die are over the age of 85, but this group makes up just 15% of hospice users.**

**Only 24% of London patients accessing palliative care have a non-cancer diagnosis.**

**70% of LGBT people surveyed felt isolated from end of life services by the language used.**

*“We know that hospices provide the gold standard for end of life care and deliver high quality care across London, yet...poorer people die in a hospice less frequently than their well-off peers.”*

Dr Jonathan Koffman, Kings College London

*“BAME groups ... face several challenges in relation to end-of-life care including language barriers, cultural differences around talking about the end of life and preparing for death and – for some – low trust in health services leads to them not accessing services and not planning ahead.”*

Compassion in Dying written response

# End of life care for older people

**Older people, and especially the very old, face additional challenges towards the end of life.** Often they have multiple health conditions, and they are more likely to be socially isolated and lonely. This can lead to increasing practical challenges in looking after themselves and managing their conditions.

**Older people are more likely to have multiple health issues.** There are additional challenges to good end of life care when a person has multiple health conditions, such as cancer with dementia. These include predicting when death will occur and ensuring that wishes are established before capacity is lost.

**Suitable housing allows older people to stay at home while they receive end of life care.** But much of London's current housing stock is not fit for this purpose, and with a shortage of hospice and care home places, hospital can be the only remaining option.

**Loneliness can make it harder for older people to get the care they need.** Three in ten people over the age of 80 are lonely.<sup>6</sup> Without supportive networks and relationships, it can be difficult for them to navigate the health and care system or to make their wishes known. Loneliness also increases pressure on local authority services, and can be the tipping point for an individual being referred to adult social care.<sup>7</sup>

**Currently there are around 124,000 people aged 85+ (the 'oldest old') living in London. By 2035 this figure is projected to have more than doubled to around 266,000.<sup>2</sup>**

**75% of people aged 75 or over who live alone are women.<sup>3</sup>**

**Around 10% of London households are occupied by a person aged over 65 who lives alone.<sup>4</sup>**

**1 in 3 people over 65 will die with dementia (but not necessarily of dementia).<sup>5</sup>**

*"Assumptions around older people and the frail elderly need to be challenged: typically, that they are more accepting of their fate and circumstances."*

Dr Jonathan Koffman,  
King's College, London

*"The [people] we have – the majority are over 75 – do not receive any visitors at all, have nobody to get their shopping, nobody to pop in and have a cup of tea with, to share concerns with or any happy memories."*

Deborah Hayes, Age UK

# Talking about end of life care

## **Involving people in decisions about their end of life care options is critical.**

But many people, including medical professionals, find discussions of death and dying very difficult. This needs to change if we are to support people to plan for the end of life.

Effective communication is an important component of good end of life care. Joined-up communication between service providers is vital. But conversations between individuals and their families, and more widely in society, are just as necessary. These conversations need to start early so that individual care plans can be developed, recorded and shared to ensure seamless care.

**Health and care professionals:** We need more skilled staff in all primary care settings (including nursing and care homes) who can initiate sensitive conversations about end of life and establish a trusting relationship to enable further discussion. They should aim to establish preferences and priorities for place and care of death, extent of treatment, and support for those important to the dying person. Ensuring that wishes are recorded and can be shared across care providers and services would greatly improve end of life care.

**Communities:** Increasing public discussions about death and dying, in culturally appropriate ways, can break down the barriers that prevent some people accessing the care that is right for them. Many people do not get the care they want because they do not know who to ask. Local strategies should identify ways to make sure that information reaches people who need it most.

**Mandatory staff training in end of life care is only available in one in five hospital trusts.**

**24% of Londoners have asked a family member about their end of life wishes.**

**71% of Londoners agree that if people became more comfortable discussing dying it would be easier to have end of life wishes met.**

*"It takes communities working together to ensure that people who are dying receive the care and support that is right for them."*

Claire Henry, Chief Executive, National Council for Palliative Care

*"It requires an overt conversation with the patient and their loved ones, saying "We are having this conversation. We have made this decision".*

Dr Caroline Stirling, Clinical Director for End of Life, NHS London

# Next steps

## **We have written to the Mayor urging greater focus on end of life outcomes in developing mayoral policy.**

But much more can be done at a local level to improve end of life care across London. Local authorities are best placed to understand the needs of their local communities. By developing clear strategies and sharing good practice at a local level, more people will receive good end of life care in London.

### **Health and Wellbeing Boards can:**

- **Ensure that end of life care is included in their Health and Wellbeing Strategy.**
- **Work with local partners to raise awareness of the services available in their areas, particularly for marginalised groups.**

### **Health Overview and Scrutiny Committees can:**

- **Examine end of life care in their area or sub-region, to determine whether services are meeting local needs, and how effectively they are engaging with individuals and communities.**

**The evidence base from our investigation is available to support future work at a local level. Please visit**

[www.london.gov.uk/endoflifecare](http://www.london.gov.uk/endoflifecare)

## **How can end of life care in London be improved?**

- **Increase the focus on end of life care in Health and Wellbeing Boards and CCGs.**
- **Provide end of life care training to all social and healthcare staff.**
- **Ensure equitable access in boroughs to community nursing and specialist palliative care.**
- **Highlight the need to shift resources from acute and community providers to manage care out of hospital.**
- **Assess and respond to the need for housing and support for the increasing number of older people in London.**
- **Raise awareness of end of life care options locally.**

*“How we care for people at the end of life is a measure of the compassion of our society. It is vital that here in London we make quality of death, as well as quality of life, the best it can be.”*

Dr Onkar Sahota, Chair of the London Assembly Health Committee



## About the investigation

The Health Committee issued a call for evidence and held a public meeting to discuss end of life care in London. At the meeting, the Committee was joined by a panel of experts:

- Dr Caroline Stirling, Consultant in Palliative Medicine and Interim Clinical Director, End of Life Care, NHS England (London region)
- Claire Henry, Chief Executive, National Council for Palliative Care
- Brian Andrews, Chair, Pan-London End of Life Alliance Lay Representatives Board
- Deborah Hayes, Director of Individual Services, Age UK East London
- Dr Jonathan Koffman, Senior Lecturer in Palliative Care, Kings College London
- Meeta Kathoria, Head of Programmes- Service Development, Marie Curie

The Committee is grateful to our guests and to all the organisations who submitted information to our review and also to John Powell, ADASS National Lead on End of Life Care, for his contributions.

## End notes

1. Unless otherwise stated, figures and statistics in this document are taken from the Pan-London End of Life Alliance written submission to the Health Committee investigation November 2015
2. Office for National Statistics census data 2011
3. Age UK statistics 2015
4. Office for National Statistics census data 2011
5. The Alzheimer's Society 2015
6. Office for National Statistics "Nine things you might not know about older people in the UK" October 2015
7. The Campaign to End Loneliness 2015

## About the Health Committee

The London Assembly Health Committee scrutinises the work of the Mayor and reviews health and wellbeing across London, with a particular focus on public health issues and reviewing progress of the Mayor's Health Inequalities Strategy.

Its members are:

- Dr Onkar Sahota AM (Chair)
- Andrew Boff AM (Deputy Chair)
- Kit Malthouse MP AM
- Murad Qureshi AM
- Valerie Shawcross CBE AM

You can find out more about the work of the committee at

<http://www.london.gov.uk/about-us/london-assembly/health-committee>

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