9. End of life care

Why is this issue important?

End of life care services support those with advanced, progressive, incurable illness to live as well as possible until they die. They also enable people to choose their preferred place of death. The provision of end of life care services has become increasingly complex as people are living longer with multiple conditions.

Surveys of the public have shown that the first preference for most people in the UK (56-74 %) would be to die at home, although as people become sicker and approach death this proportion may decline, as they want access to more extensive support, such as hospice care.1

The Department of Health End of Life Care strategy (2008) seeks to enable people to die at the place of their choice; raise the profile of end of life care in the NHS and local authority; and enable discussions about preferred place of death to take place between families and friends.

Key outcomes

- Improving the experience of care for people at the end of their lives (NHS Outcomes Framework)

The National Dementia Strategy 2009 has a related objective of improving end of life care for people with dementia. (See Dementia section)

Impact in Brighton & Hove

Between 2008 and 2010 there were 2,159 deaths from causes which would have fulfilled the criteria for end of life care (cancer, respiratory, cardiovascular disease & other main cause of death). This is based on a crude death rate for persons as a percentage of the average annual number. This represented a crude death rate of 0.8%, lower than the England average of 0.9%.3 suggesting a lower per capita demand for end of life services. This would reflect the younger age profile of the city.

During this period, 48% of total deaths in Brighton and Hove occurred in hospital, whilst 41% occurred in the usual place of residence (including care homes). Whilst Brighton & Hove are performing slightly better than the England average (54% of deaths fulfilling the criteria for end of life care occurring in hospital and 38% in the usual place of residence), England performance is poor. The England target is for 70% of all deaths to occur at the usual place of residence.

<table>
<thead>
<tr>
<th>Table 1: Place of death for deaths fulfilling the criteria for end of life care, 2008 to 2010</th>
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</thead>
<tbody>
<tr>
<td><strong>No of deaths in Brighton &amp; Hove</strong></td>
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<tr>
<td>---------------------------------</td>
</tr>
<tr>
<td>Hospital</td>
</tr>
<tr>
<td>Own residence</td>
</tr>
<tr>
<td>Care home</td>
</tr>
<tr>
<td>Hospice</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

Source: Office for National Statistics. Mortality data 2008 to 2010

There is no local data on preferred place of death for end of life patients apart from the 200 patients on the Palliative Care Local Enhanced Services Register in 2011/12. Of these 175 (87.5%) had their preferred place of death recorded and 81% died in their preferred place.

The financial spend per year on existing end of life care services is £3,792,843.2 In 2010/11 total spend on hospice services per death was £731 and end of life care per death was £1,234.3

Where we are doing well

The End of Life Care Profile for Brighton & Hove (Table 1) shows a higher proportion of people are dying in their own residence (22%) than in the South East (19%) or England (20%). A lower proportion of people are dying in hospital in Brighton & Hove (48% for 2008 to 2010) compared with the South East (51%) and England (54%).4

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1 Department of Health. End of Life Care Strategy. 2nd annual report. 2010.
A new Palliative Care Partnership (PCP) service model has been introduced in 2013, between Sussex Community NHS Trust Community Palliative Care Team, and The Martlets Hospice at Home Team; to provide a seamless end of life care pathway for palliative and end of life care patients. This provides a more joined up service with a single point of access telephone hub, seven day a week visiting and 24 hours Consultant telephone advice.

A framework for assessing the quality of end of life care in care homes with nursing has been developed in partnership with the council.

Following a survey of learning disability services, joint work has been progressing on reviewing the end of life care pathway for people with learning disabilities. Toolkits are being developed for learning disability social care providers and for specialist palliative care services.

A professional network for end of life care and learning disabilities launches in Brighton & Hove in September 2013.

Brighton & Hove is included in the Pan Sussex Integrated End of Life Dementia Pathway. This aims to improve the end of life care for people with dementia, and enable more to die in their preferred place of death; increase advance care planning for people with dementia; and increase practitioners knowledge and skills about end of life dementia care.

Local inequalities

Socio-economic deprivation is a major determinant of where, when and how people die. Nationally people living in the most deprived quintile (the poorest 20% of areas) are more likely to die in hospital (61%) than any other quintile (54-58%). People living in the most deprived quintile (11%) are less likely to die in care or nursing homes than any other quintile (16-20%).

In Brighton & Hove, between 2008 and 2010, East locality had the highest proportion of deaths in hospital (47%), West had the highest proportion in care or nursing homes (23%), Central had the highest proportion of deaths at home (31%) and East had the highest proportion of deaths in other communal establishment or hospice (10%).

**Figure 1: Place of death by Brighton & Hove Clinical Commissioning Group locality, 2008-2010**

![Graph showing place of death by locality.]

Source: Office for National Statistics. Mortality data 2008 to 2010

Nearly half of hospital deaths are of 65-84 year olds (47%) and the majority of people dying in care or nursing homes are aged 85 years or over (67%).

**Figure 2: Place of death by age in Brighton & Hove Clinical Commissioning Groups, 2008-10**

![Graph showing place of death by age.]

Source: Office for National Statistics. Mortality data 2008 to 2010

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9. End of life care

A higher proportion of men die at home or elsewhere than women (35%) and slightly more men die in hospital (45%). A higher proportion of women die in a care or nursing home (24%) than men. This is likely to be a result of women living longer than men.

Between 2008 and 2010 a higher proportion of people with respiratory conditions died in hospital than with other conditions (Table 2). Cancer patients were more likely to die in a hospice.

<table>
<thead>
<tr>
<th>Table 2: Place of death for deaths fulfilling the criteria for end of life care by cause of death, 2008-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of death</td>
</tr>
<tr>
<td>Hospital</td>
</tr>
<tr>
<td>Own residence</td>
</tr>
<tr>
<td>Care home</td>
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<td>Hospice</td>
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Source: ONS mortality data 2008-10

Predicted future need

It is projected that the average number of deaths per year will have decreased very slightly by 2035, to an estimated average of 2,000.6 As more people live longer demands on end of life services are expected to increase.

What we don’t know

We do not know what the preferred place of death is for Brighton & Hove residents.

There is no data available on sexual orientation, ethnicity, gender reassignment or other protected characteristic groups.

Key evidence and policy

Key evidence and policy can be found in the Department of Health national End of Life Care Strategy 2008.


Brighton & Hove JSNA 2013


Sixteen NICE Quality Statements set out the standard of care to be provided in end of life care. http://www.nice.org.uk/media/EE7/57/EoLCFinalQS.pdf

Recommended future local priorities

1. To continue the development of Electronic Palliative Care Coordination System for the sharing of electronic information on end of life care.

2. Work to increase the number of end of life care patients on GP registers.

3. Roll out of Bereavement Support


5. Train SECAmb staff to treat people in the preferred place of care.

Key links to other sections

- Adults with physical disabilities or sensory impairments
- Adults with learning disabilities
- Carers
- Older people – Social care
- Coronary heart disease
- Respiratory disease
- Cancer
- Stroke
- Dementia

Further information

End of Life Care Network http://www.endoflifecare-intelligence.org.uk/home.aspx

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