Public Health approaches to end of life care: An overview

Nicola Bowtell
Why is a public health approach to end of life care important?
467,095 deaths per year in England – almost equivalent to the population of Somerset.
Trends in deaths in England, 1940 to 2036


Projections-ONS Subnational Population Projections with Components of Change (Births, Deaths and Migration) for Regions and Local Authorities in England: Table 5 www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/componentsofchangesbirthsdeathsandmigrationforregionsandlocalauthoritiesinenglandtable5
Numbers and percentages of deaths in England, 1963 and 2014

<table>
<thead>
<tr>
<th></th>
<th>1963</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Number of deaths</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 and over</td>
<td>182,748</td>
<td>215,117</td>
</tr>
<tr>
<td>85 and over</td>
<td>25,723</td>
<td>50,550</td>
</tr>
<tr>
<td>Percentage of deaths</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65 and over</td>
<td>62</td>
<td>77</td>
</tr>
<tr>
<td>85 and over</td>
<td>9</td>
<td>18</td>
</tr>
</tbody>
</table>

Source: NEoLCIN; PHDS, derived from ONS Mortality
Ageing population: Percentage of older people in the UK 1985, 2010, 2035

Next 20 years number of people:

- >85 in England will double
- >100 will quadruple

Now “aged society”

By 2035 “super-aged society”

Source: Office for National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency
Number of people estimated to require end of life care

Source: Etkind SN et. al. - How many people will need palliative care in 2040? Past trends, future projections and implications for services - BMC Medicine201715:102
Older people and living alone: % of usually resident population living alone by age group, 2011
Older person health and caring

Activity limiting long-term health problem or disability in the household population

<table>
<thead>
<tr>
<th></th>
<th>Under 65</th>
<th>65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>11%</td>
<td>52%</td>
</tr>
<tr>
<td>Fall from</td>
<td>12%</td>
<td>Rise from</td>
</tr>
<tr>
<td>2001</td>
<td></td>
<td>50%</td>
</tr>
</tbody>
</table>

There has been a corresponding increase in the older population providing unpaid care.

Hours of unpaid care provided per week: age 65+

<table>
<thead>
<tr>
<th></th>
<th>1 - 19 hours</th>
<th>20 - 49 hours</th>
<th>50+ hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Office for National Statistics
Many people want to die at home

- Majority of people want to die at home (82%)
- Home and Hospice - 94% believed they died in the right place
- Hospital – 73% believed they died in the right place

Source: ONS Voices Survey 2015
Variation in the proportion of people that died at home by CCG (2015)
Variation in the proportion of people that died at home by CCG (2015)

<table>
<thead>
<tr>
<th>Year</th>
<th>Max - Min</th>
<th>95th - 5th Percentile</th>
<th>75th - 25th Percentile</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>2006</td>
<td>11.9</td>
<td>6.6</td>
<td>2.5</td>
<td>18.9</td>
</tr>
<tr>
<td>2007</td>
<td>11.0</td>
<td>7.3</td>
<td>2.9</td>
<td>19.3</td>
</tr>
<tr>
<td>2008</td>
<td>10.8</td>
<td>6.8</td>
<td>2.8</td>
<td>19.7</td>
</tr>
<tr>
<td>2009</td>
<td>11.0</td>
<td>7.0</td>
<td>3.1</td>
<td>20.2</td>
</tr>
<tr>
<td>2010</td>
<td>12.6</td>
<td>6.9</td>
<td>3.1</td>
<td>20.7</td>
</tr>
<tr>
<td>2011</td>
<td>14.4</td>
<td>8.0</td>
<td>2.7</td>
<td>20.7</td>
</tr>
<tr>
<td>2012</td>
<td>11.8</td>
<td>7.3</td>
<td>3.2</td>
<td>22.0</td>
</tr>
<tr>
<td>2013</td>
<td>12.8</td>
<td>7.5</td>
<td>3.0</td>
<td>22.2</td>
</tr>
<tr>
<td>2014</td>
<td>14.7</td>
<td>8.2</td>
<td>3.1</td>
<td>22.4</td>
</tr>
<tr>
<td>2015</td>
<td>11.9</td>
<td>7.9</td>
<td>3.0</td>
<td>22.6</td>
</tr>
</tbody>
</table>

- **Max - Min (Range)**: WIDENING Not Significant
- **95th - 5th Percentile**: WIDENING Significant
- **75th - 25th Percentile**: WIDENING Not Significant
- **Median**: INCREASING Significant
Factors associated with place of death

Factors related to illness
- Non-solid tumours: Hospital
- Long length of disease: Home
- Low functional status: Home

Individual factors
- Demographic variables:
  - Good social conditions: Home
  - Ethnic minorities: Hospital

- Personal variables:
  - Personal preferences: Home

Health care input
- Use of home care: Home
- Intensity of home care: Home
- Availability of inpatient beds: Hospital
- Previous admission to hospital: Hospital
- Rural environment: Home
- Areas with greater hospital provision: Hospital

Social support
- Living with relatives: Home
- Extended family support: Home
- Being married: Home
- Caregivers’ preferences: Home

Macrosocial factors
- Historical trends: Home

Source: adapted from Gomes & Higginson (8).
Public Health approaches to end of life care: An overview
What is a new public health approach to end of life care?

• Goes by many names…
  • Community engagement, participation, development
  • Health promotion
  • Community capacity building
  • Social network approaches
  • Compassionate Communities
The principles of a new public health approach

Built on the Ottawa Charter for Health Promotion (1986) and the Alma Ata Declaration for Primary Health Care (1978)
The public health vision for end of life care

Service-orientated approach

• Palliative/hospice services extended into the community
  - Dependent on provider
  - Focus on professionals

Public health approach

• Engaged and developed communities able to provide community led care
• Utilisation of community networks and assets
The role of public health approaches

Public health approaches expand the reach and effectiveness of care into the community.

- Provide better and more holistic end of life care.
- Enable people to remain in community setting if they prefer.
- Reduce pressures in acute services.
The case for adopting a public health focus

• Prevention approach adopted for other issues but not EOLC

• Many prefer to remain in the community as long as possible

• Professional care is episodic; everyday care goes beyond this

• Need a social framework for a holistic approach to EOLC
The case for adopting a public health focus

- Need to address grief and loss which is also part of EOLC
- Need to go beyond illness bound view to include carers etc.
- Economic argument – burden on acute services can be eased
- EOLC is for the well and the ill; it is everyone’s responsibility
Community engagement and end-of-life care

• Kellehear first described the ‘public health approach to end of life care’ (1999)

• Aligned the two apparently paradoxical disciplines

Compassionate Communities are community development initiatives that actively involve citizens in their own end-of-life care

Build partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them with professional care
The Charter and Toolkit

• The Dying Well Community Charter
  • NCPC
  • Engagement with NHS England, hospices, charities and Royal Colleges

• Public Health Approaches to End of Life: A Toolkit
  • Allan Kellehear

http://www.ncpc.org.uk/communitycharter
Dying Well Community Charter

• Published by NCPC 2014
• Public Health approach to end of life care
• Set of commitments for individuals, organisations, and local communities.

• Five principles of care and support:
  • Recognition and respect
  • Communicate
  • Involvement
  • Support
  • Help us plan
Dying Well Community Charter Pathfinders Project

• Public Health Approach
  Pioneering the Dying Well Community Charter

• PHE commissioned Evaluation

• 8 Pathfinders
Pathfinders: Methodology

Eight Pathfinders
Birmingham
Cheshire
Dorset
Hackney
Hull and East
Riding of Yorkshire
Lancashire
Liverpool
North Somerset
Pathfinders: Lessons learnt

• Enthusiasm high
• Community engagement understood
• Variable knowledge and understanding of community development
• Work best when they are owned by the community
• Keep it simple there isn’t a one size fits all
National Palliative and End of Life Care Partnership

Six ambitions to bring that vision about

01. Each person is seen as an individual
02. Each person gets fair access to care
03. Maximising comfort and wellbeing
04. Care is coordinated
05. All staff are prepared to care
06. Each community is prepared to help

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk
Introducing Ambition Six

Each community is prepared to help

The building blocks for achieving our ambition

Compassionate and resilient communities
Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Public awareness
Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.

Practical support
Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.

Volunteers
To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk
Conclusion

• Approximately 500,000 die each year in England
• This is expected to rise
• Most people would prefer to die at home
• Many of these will die in hospital without a clinical need
• There are pressures on social care and variation in the availability of 24/7 palliative care services in England
• Public health approaches to end of life care should improve the quality of care of end of life care for many and may relieve pressure on services
Thank you