PUBLIC HEALTH & PALLIATIVE CARE: a brief overview

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Public health

“The art and science of preventing disease, prolonging life and promoting health through the organised efforts of society”

WHO, Lord Acheson, 1988
Palliative Care

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

WHO 2002
Why should palliative care be a public health issue?

• Aging population
• Changing patterns of disease
• Changing social structure
• Inequity of access
  • Cancer vs non-cancer illnesses
  • Vulnerable groups

The bigger picture ...

- Each year, an estimated **40 million** people are in need of palliative care, 78% of them live in low- and middle-income countries.
- Worldwide, only about **14%** people who need palliative care actually receive it.
- Lack of training and awareness of palliative care among health professionals is a major barrier to improving access.
- The global need for palliative care will continue to grow due to the rising burden of noncommunicable diseases and aging populations.

http://www.who.int/mediacentre/factsheets/fs402/en/
Closer to home...

Based on mortality statistics for England and Wales from 2006 – 2014, by 2040...

- 160,000 more people will need palliative care
- annual deaths are projected to rise by 25.4%
- the number of people requiring palliative care could increase by 42.4% (161,842 more people/year)
- dementia and cancer will be the main drivers of increased need

The 10 Essential Public Health Operations
Public Health England's National End of Life Care Intelligence Network (EOLC) aims to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to adults approaching the end of life. This intelligence will help drive improvements in the quality and productivity of services.

Resources

- [Data and statistics](#) on end of life care by Local Authority and Primary Care Trust in England, broken down by age, gender, place of death and cause of death.

- [Resources](#) including data and analytical tools, information on research, links to publications and other useful sources of information.

Data sources

- Guidance on key health, social care and related [data sources](#) in the field.

Advice and information

- Where to go for [advice and information](#) for patients, carers and relatives.

**EPHO 1. Surveillance of population health and well-being**

National End of Life Care Intelligence Network

http://www.endoflifecare-intelligence.org.uk/home
Health promotion is the process of enabling people to increase control over, and to improve their health

WHO Ottawa Health Charter for Health Promotion 1986
EPHO 4 . Health Promoting Palliative Care : the five principles

1. Enhance a sense of control and support for those living with a life limiting illness.
2. Encourage interpersonal reorientation i.e. to assist, facilitate and enable those living with a life limiting illness to adjust to some lifestyle changes.
3. Build public policies that support dying, death, loss and grief.
4. Reorientate palliative care services, by linking with public health colleagues, utilising education opportunities, research activity, community and policy development.
5. Alter community attitudes to health, death, dying and loss.

Professor Allan Kellehear
Health Promoting Palliative Care
Oxford University Press (1999)
Targets for HPPC

- **Social:**
  - sexuality,
  - work,
  - friendships,
  - recreation,
  - legacy,
  - hobbies,
  - discrimination & stigma,
  - staying ‘normal’

- **Physical:**
  - treatments are for disease and symptoms: anything for physical health and well-being needs?

- **Psychological:**
  - anxiety,
  - depression,
  - loss & grief,
  - despair,
  - Anger

- **Spiritual:**
  - meanings of survival and suffering,
  - religious belief,
  - reunion/reconciliation

Source: Dr Bruce Rumbold, La Trobe University Palliative Care Unit
Wirral End of Life Care Charter
Care, kindness and understanding

You May Expect:

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<th>Support by skilled and knowledgeable staff that recognises your situation &amp; who work together to co-ordinate &amp; manage your care.</th>
<th>With your permission that plans, if you have made any, are shared with those involved in your care, so that your wishes may be fulfilled.</th>
<th>That, if you wish, those who are important to you are involved in decisions about your care &amp; treatment.</th>
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<td>Care which includes what you eat &amp; drink, control with your symptoms, and support with your emotional, social, cultural, and spiritual needs.</td>
<td>Regular reviews of your individual care plans that will meet your needs and include decisions &amp; actions that are made to best fit your wishes.</td>
<td>The possibility that you may die within the next few days or hours is communicated clearly &amp; sensitively, to you &amp; those who are important to you.</td>
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<td>The support of trained staff, who will help you to think &amp; plan ahead, if you want, to discuss your preferences &amp; wishes for your care.</td>
<td>Support to help keep your independence as long as possible by caring staff respecting your dignity &amp; sense of control throughout your illness.</td>
<td>The needs of your family &amp; others important to you are respected &amp; met, as far as possible.</td>
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<td>That you, &amp; others important to you, will be treated with compassion &amp; respect towards the end of your life.</td>
<td>That your body will be treated with dignity &amp; respect after your death.</td>
<td>That during your illness &amp; after your death, those important to you, receive practical, emotional &amp; spiritual support.</td>
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End of life care:
- Is the total care of a person with an advanced, progressive, incurable illness or frailty;
- Is not just about dying;
- May last a few days, or for months or years;
- Begins when, and continues as long as, it is needed.
EPHO 9. Advocacy, communication and social mobilisation for health

“Dying should not be left to the experts…”
The Conversation Project

HAVE YOU HAD THE CONVERSATION?

Help get it out in the open. When it comes to end of life, I want mine to be...

Share how you want to live the end of your life.

749 people have spoken, join them.

WHAT it’s all about

Hear from co-founder Ellen Goodman about what The Conversation Project is, what we’re asking people to do and why she got involved.

WHY it’s important

60% of people say that making sure their family is not burdened by tough decisions is “extremely important”

56% have not communicated their end-of-life wishes

One conversation can make all the difference.

Sources: Survey of Californians by the California HealthCare Foundation (2012)

HOW to get started

Explore our Starter Kit for tools and tips to help you have the conversation.

EXPLORE STARTER KIT

Everyone has a story

Source: http://theconversationproject.org/
National End of Life Care Strategy

Key elements:

- **Societal level:** Actions to raise awareness of death and dying and to change attitudes.

- **Individual level:** Integrated service delivery based around a care pathway.

- **Infrastructure:** Workforce development, measurement, research, funding, national policy support.
Should we be focusing on preferred place of death if ultimately we are unable to guarantee this?
Question

A 90-year old woman died of dementia. According to the National End of Life Care Intelligence Network (2010), what statement best describes recent trends in place of death for people with dementia compared with the general UK population?

A: more likely to die at home
B: more likely to die in a care home
C: more likely to die in a community hospital
D: more likely to die in a hospice
E: more likely to die in an acute hospital
Answer

- B: more likely to die in a care home
Significant difference in distribution of place of death for patients dying with Alzheimer’s disease, dementia or senility compared with the general population aged 75 and over.

- 58.4% (general population) vs 32% (Alzheimer’s disease, dementia or senility) died in hospital.
- 10% (general population) vs 28% (Alzheimer’s disease, dementia or senility) died in old people’s homes.
- 12.1% (general population) vs 31% (Alzheimer’s disease, dementia or senility) died in NH.
- Relatively small percentages die in their own home or hospices.

Figure 7: Place of death distribution for males aged 65+ with underlying cause of death of Alzheimer’s disease, dementia or senility, England, 2007 to 2009

Males

Source: Office for National Statistics, annual mortality extracts

Figure 8: Place of death distribution for females aged 65+ with underlying cause of death of Alzheimer’s disease, dementia or senility, England, 2007 to 2009

Females

Source: Office for National Statistics, annual mortality extracts
National End of Life Care Intelligence Network
What we know now 2014
Key findings

- Proportion of people dying at home or in care homes continues to increase.
- Patients are more likely to die in their place of preference if:
  - They have an EPaCCs record
  - They are receiving palliative care services e.g. H@H, GSF
- 2 in 5 people with dementia die in hospital
- Factors most important to people at EOL were
  - Effective symptom management
  - Being surrounded by loved ones
  - Dignity
- More GPs are having conversations with people about their EOLC wishes
FURTHER READING
Compassionate Communities

- Work of Allan Kellehear
- Community development to provide care (in its broadest sense) to those community members who are living with life limiting illness or dying.

Asset Based Community Development

- Developed in Chicago
- Builds community capacity
- Glass Half Full approach to health
- Influenced Obama’s run to the White House
DISCUSSION

1. Individualisation of care vs collective care

1. “Nanny State”

2. Resource allocation and choice… PPC?