End of Life Care

Introduction

Approximately half a million people die each year in England. The number is expected to rise by 17% from 2012 to 2030. The percentage of deaths occurring in the group of people aged 85 years or more of all deaths are expected to rise from 32% in 2003 to 44% in 2030 (NHS England, 2014) About three quarters of deaths are expected, so there is potential to improve the experience of care in the last year and months of life for at least 355,000 people, and those close to them, each year (National Council for Palliative Care, 2012).

An estimated 10-11% of people over 65 years and 25-50% of those over 85 years were frail. Frailty is strongly linked to adverse outcomes, including increased mortality (Social Care Institute for Excellence, 2013).

Around half a million carers provide support to people dying at home of a terminal illness. The costs to family carers may include lost earnings, 24 hour care and physical and mental health consequences, some of which may be permanent (NHS England, 2014) Between 2001 and 2011, the number of unpaid carers has grown by 600,000 (NHS England, 2014)

Death occurs in a wide variety of settings from hospitals, care homes and hospices to the home. The PRISMA survey 2010 indicates that home and hospice are the most preferred place of death (63% and 29% respectively) (Harding, 2010).

What do we know?

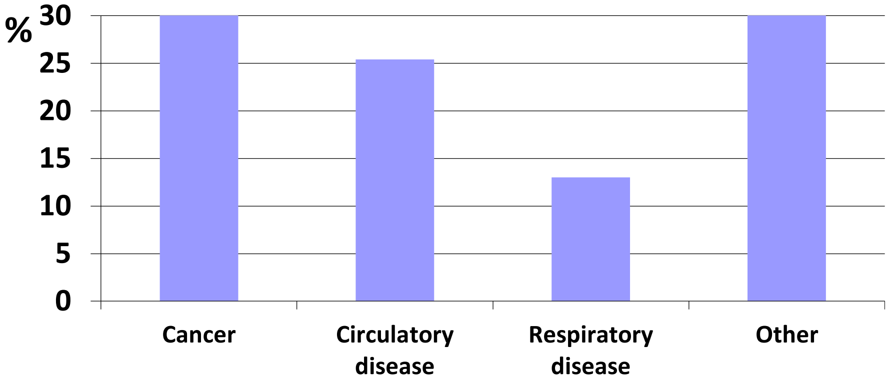
Facts, Figures, Trends

Numbers of people affected by End of Life Care

Local picture

1,330 people died in Bedford Borough, 2013. Figure 1 shows all deaths by disease category in Bedford Borough, 2013. 69% of deaths are from cancer, circulatory and respiratory diseases.

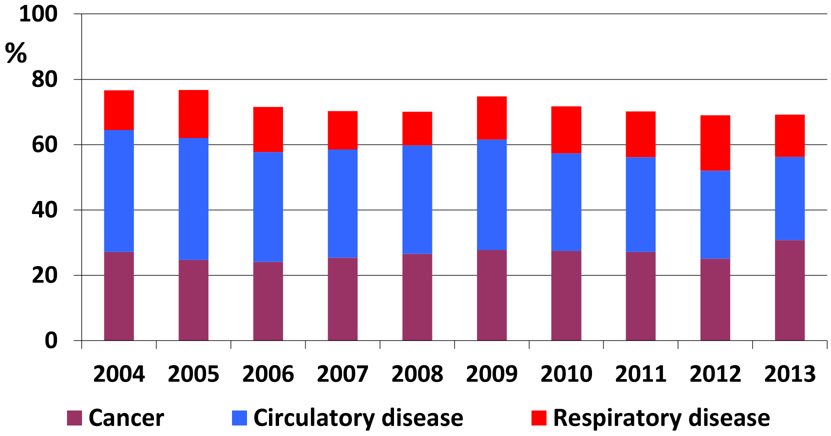
Figure 1 Underlying cause of death in Bedford Borough, all ages 2013



Source: Public Health England

Figure 2 shows a timeline of underlying cause of death in Bedford Borough for all ages due to the three commonest causes of death. Compared with 2004, cancer shows a slow increasing trend, circulatory disease a marked decrease and respiratory disease a roughly steady trend.

Figure 2 Timeline of underlying cause of death in Bedford Borough, all ages



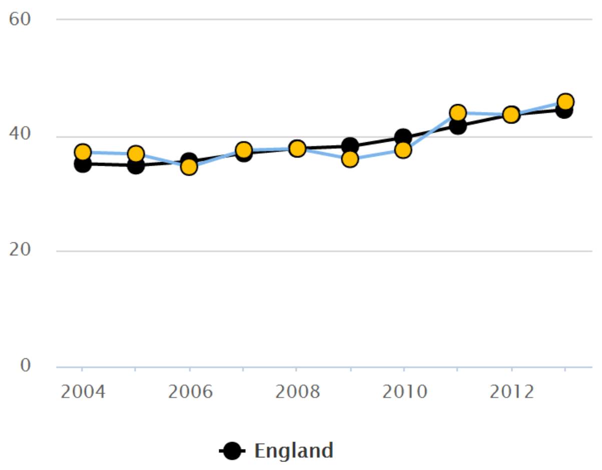
Source: Public Health England

Harm caused and projected future position if no action taken

Public Health England wants to understand the trends and variations in place of death as proxy indicator for quality of end of life care. As such the NHS England has an indicator of the percentage of Deaths in Usual Place of Residence (DiUPR). Figure 3 is the timeline of the number of deaths registered in each area where the place of death is recorded as home, care home or religious establishment. Both Bedford Borough and England were above 40% for the last three years and the proportion is increasing. However, whilst this has been an important driver for improving end of life care at home, the 'place of death' is not necessarily the highest priority for everybody. In a population-based study involving just under 10,000 adults across England, only 34% ranked 'dying in preferred place' as their top care-related priority: the rest were split fairly evenly between the other two options of 'having as much information' as they wanted and 'choosing who makes decisions' about their care.(Gomes, 2011).

Figure 3 Deaths in usual place of residence, Bedford Borough & England

● Lower ● Similar ● Higher compared with England

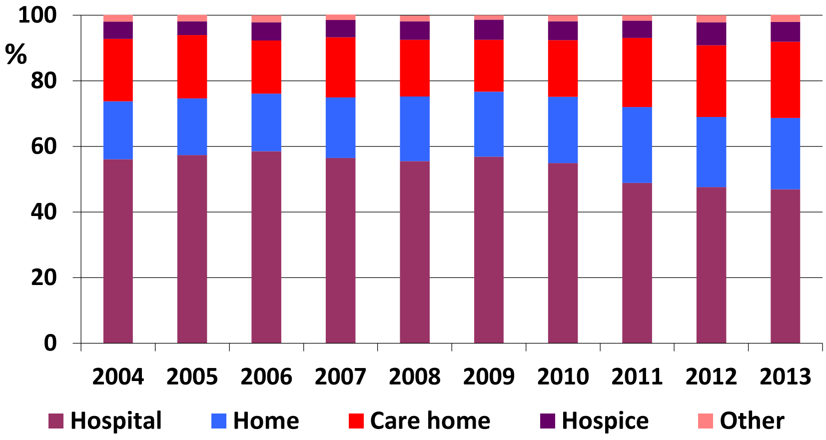


Bedford Borough is in coloured dots

Source: End of Life, NHS England

Figure 4 shows place of death from 2004-2013 in Bedford Borough. Compared to 2004, hospital deaths were decreasing, home deaths were increasing, care home deaths were increasing and hospice death were slightly increasing.

Figure 4 Place of death in Bedford Borough



Source: End of Life, NHS England

Current activity & services

Currently, the Bedfordshire CCG are up-dating the End of Life strategy which was written in 2009 and refreshed in 2011. It should result in a higher proportion of deaths at the usual place of residence.

Bedfordshire Partnership for Excellence in Palliative Support (PEPS)

Sue Ryder provides 24 hour support and co-ordination of palliative care across Bedfordshire for patients, carers and health and social care professionals. The PEPS service offer a single point of contact through their co-ordination centre. The centre's number is given out to patients, their families or carers when the patients are identified as being in the last 12 months of life. All calls are answered by skilled nurses who have access to relevant medical records (SystmOne and Electronic Patient Record). They will then contact the most appropriate service provider.

PEPS works in partnership with many local health and social care partners including nursing teams, hospices, GP's, hospital, voluntary services and ambulance service. They are able to arrange face to face specialist palliative care assessments 24/7 and support and facilitate rapid hospital discharge. On average:

- The co-ordination centre receives more than 1,500 calls per month
- Hospital admissions avoided
- There is an EoLC template for the GP practices in NHS Bedfordshire CCG
- Receive an average of 140 new PEPS referrals each month. Currently there are 1,182 active patients on the register (December 2016)

Future developments include:

- Work with existing providers on a transformation plan to improve end of life services and implement an integrated, coordinated and proactive approach
- Increase community Palliative care Consultant cover
- Recruit additional health care resources into the community
- Fully roll out Advanced Care Planning across health and social care
- Working with health and social care colleagues to improve joint working across end of life

Cancer Support: Specialist Palliative Care Nurse, Bedfordshire

The Specialist Palliative Care team include Clinical Nurse Specialists whose aim is to work in partnership with the primary care team and holds a caseload of those patients with complex specialist palliative care needs. Each patient, over 18y with a life limiting condition and registered with a Bedfordshire GP, will be assessed holistically using an agreed tool at the beginning of their palliative diagnosis and at appropriate points of the care pathway.

The Specialist Palliative Care Physiotherapist's role is to maximise patients' ability to function, promote independence and assist them to adapt to their condition. This is available to patients in North and Mid Beds.

Referral is made to other services and agencies as appropriate and the team will work with the relevant key worker at any given time. The team also work in partnership with Bedfordshire Partnership for Excellence in Palliative Support (PEPS- see above).

The service is delivered across Bedfordshire, aligned with community nursing teams and GP practices, Monday-Friday 9am-5pm and on-call over the weekend. Contact for out of hours specialist assessment and advice is made via PEPS Contact Centre.

Hospices

In total five hospices are commissioned to provide specialist palliative care services across

Bedfordshire (see

Table 1)

Table 1 Hospice services, NHS Bedfordshire CCG

Hospice	In-patient beds	Day hospice	Out-patient
Sue Ryder Care, St Johns Hospice, Moggerhanger	15	Provides treatment only for 4 patients per day, 3 days per week	3 afternoons per week
Keech Hospice, Luton	8	Provides 20 places per day, 4 days per week	
Bedford Day Care Hospice	-	Operates Monday-Friday	
Willen Hospice, Milton Keynes	20	Provides 15 places per day 3 days per week	1 day per week
Garden House Hospice, Letchworth	12	36 places over 3 days per week	3 mornings per week

Source: Bedfordshire CCG

Local Views

The National Survey of Bereaved People (VOICES- Views of Informal Carers - Evaluation of Services) aimed to assess experiences of care in the last three months of life for adults who die in England. 37.6% of carers thought the overall quality of care was outstanding or excellent in NHS Bedfordshire CCG compared with 43.2% in England, 2011/12 (ONS, 2015).

National & Local Strategies (Best Practices)

Scope for improvement

The Leadership Alliance for the Care of Dying People published a document called ‘One Chance to Get it Right’ which articulated a vision of what good care in the last days to hours should look like(Leadership Alliance for the Care of Dying People, 2014). They proposed five Priorities for Care are that when it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

NICE provided 16 Quality Standards in 2011 that is largely an expansion on Only Chance to Get it Right (NICE, 2011).

Ambitions for Palliative and End of Life Care is a national framework for local action 2015-2020 (National Palliative and End of Life Care Partnership, 2015). It reports that too frequently care is poor. With a rapidly ageing society and changing patterns of illness many more people will live with long term conditions. It identifies six ambitions for improving care:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

What is this telling us?

Contribution to inequalities

Inequitable access to consistent, high quality of end of life care for certain groups of people remain:

- Homeless people die at more than three times the rate of aged matched controls in the general population. The average age of death in the UK for single homeless people is between 40 and 44 years (DoH, 2010)
- Amongst the black and minority ethnic population, there is a lower uptake of palliative and end of life care services compared to white/majority groups and evidence of poorer outcomes (Calanzani, 2013)
- People with learning disabilities are less likely to have access to specialist palliative care services, receive inadequate pain control in their final illness and are more likely to have their deaths described as not being planned for, uncoordinated and poorly managed (Bristol University, 2013)
- Approximately one third of people aged over 60 years will die with dementia, many with complex physical and psychological needs. Yet many receive poor quality care towards the end of life (Sampson, 2015)

What are the unmet needs/ service gaps?

BCCG has undertaken a review of its commissioned end of life services and is working with existing providers to implement improvements from April 2017. These will include:

- End of life care in non-cancer patients especially those with dementia, black and minority ethnic population and people with disabilities
- Need for more integrated pathways delivering coordinated care
- Proactive management of end of life service users
- Exploring the ‘Compassionate Cities’ approach to end of life

This chapter links to the following chapter in the JSNA:

References:

NHS England (November 2014). Actions for End of Life Care: 2014-16

National Council for Palliative Care (2012). Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives. http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf [accessed 24/11/15]

Social Care Institute for Excellence. Dying well at home: the case for integrated working: SCIE Guide 48, March 2013. http://www.scie.org.uk/publications/guides/guide48/files/guide48.pdf [accessed 24/11/15]

NHS England’s Commitment to Carers, 2014. http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf [accessed 24/11/15]

Harding R et al (2010). PRISMA: a pan-European coordinating action to advance the science in end-of-life cancer care. *European Journal of Cancer* 2010;46(9):1493-1501

Gomes B, Calanzani, N and Higginson IJ (2011). Local preferences and place of death in regions within England 2010. Cecily Saunders International, London

Sue Ryder http://www.sueryder.org/how-we-help/care-services/PEPS [accessed 25/11/15]

Office for National Statistics

Leadership Alliance for the Care of Dying People: One Chance to Get it Right (2014). https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf [accessed 26/11/15]

NICE Quality Standard for End of Life Care (2011). https://www.nice.org.uk/guidance/qs13 [accessed 26/11/15]

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 National Palliative and End of Life Care Partnership www.endoflifecareambitions.org.uk [accessed 27/11/15]

Office of the Chief Analyst, Department of Health (2010). Healthcare for single Homeless People. http://www.qni.org.uk/docs/healthcare%20for%20single%20homeless%20people%20NHS.pdf [accessed 26/11/15]

Calanzani N et al (2013). Palliative and end of life care for black, Asian and minority ethnic groups in the UK: demographic profile and the current state of palliative and end of life care provision. Public Health England, King's College London and Marie Curie Cancer Care

Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) (2013). http://www.bristol.ac.uk/cipold/fullfinalreport.pdf [accessed 26/11/15]

Sampson EL et al (2011). Improving end-of-life care for people with dementia. *British Journal of Psychiatry*; 199(5): 357-9