

North Yorkshire Scrutiny of Health Committee Meeting
2nd September 2016

JSNA 'Deep Dive' Report: End of Life Care

Dr Victoria Turner (Public Health Registrar)

Why is End of Life Care so important?

“[My husband] was a quiet man who didn’t argue and accepted what was going on because he had no choice. It wasn’t his choice, it was everybody else’s choice really.”

“It was one of the most wonderful experiences of my life, because my dad died in his own bed, in his own home, with people he loved and who loved him around him. He died with a smile on his face.”

Quotes from “A Different Ending: Addressing inequalities in end of life care”
(Care Quality Commission, 2016)

Introduction

‘Dying Well’ is one of the five key themes for the Joint Health & Wellbeing Strategy 2015-20.

- Purpose of report: **combine national guidance with local data to inform local commissioning priorities**
- UK EoLC comparatively good, but improvements needed (out of hours, communication).
- National direction changing, with shift towards community services



What is end of life care?

GMC: approaching end of life when **likely to die in the next 12 months**. This includes people whose death is imminent, and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

What are the key issues?

JWBS 2015-2020 aim: to enable more people approaching the end of life to be **cared for and to die in their place of choosing**, enabling the **delivery of the best possible standard of care in all end of life settings**.

- To do this, need to address:
 - **Discussions around dying**
 - **Access for all**
 - **The importance of coordination**
 - **Training**

What commissioning priorities are recommended?

Recommendations for commissioners are based around 7 key themes:

- **Access at all times for all people**
- **Integration with other existing/planned services**
- **Staff training**
- **Preferred place of death**
- **Community engagement**
- **Appropriate level of care**
- **Support for carers and relatives**

Who is at risk and why?

1% of population die each year. Not all will have been identified on an EoLC register.

CQC report on 'addressing inequalities in EoLC':

- People with conditions other than cancer
- Older people
- People with dementia
- BME groups
- LGBT
- Learning disabilities, mental health
- Homeless, gypsies and travellers
- Those in secure/detained settings

What is the level of need in the population?

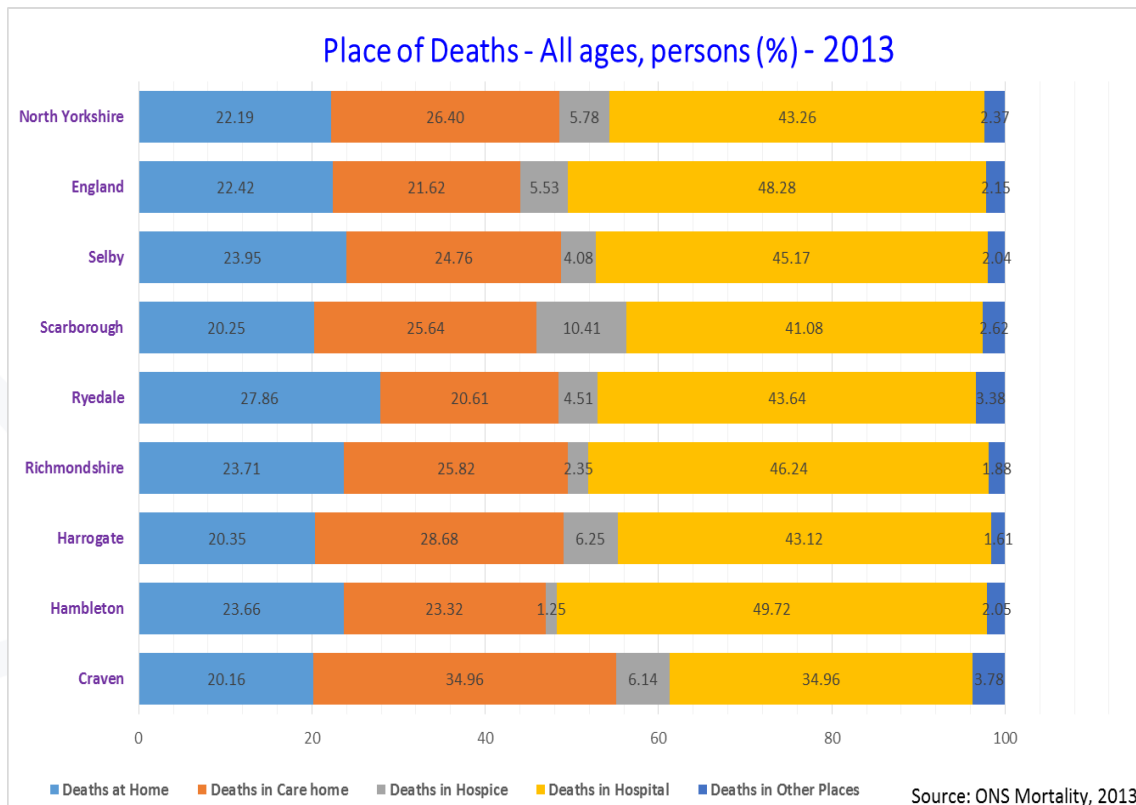
- 6,197 deaths in NY (2013)

- 22.2% at home
- 26.4% in care home
- 5.8% in hospice
- 43.3% in hospital

- Main causes of death:

- CVD (31.18%)
- Cancer (27.91%)
- Respiratory disease (15.03%)

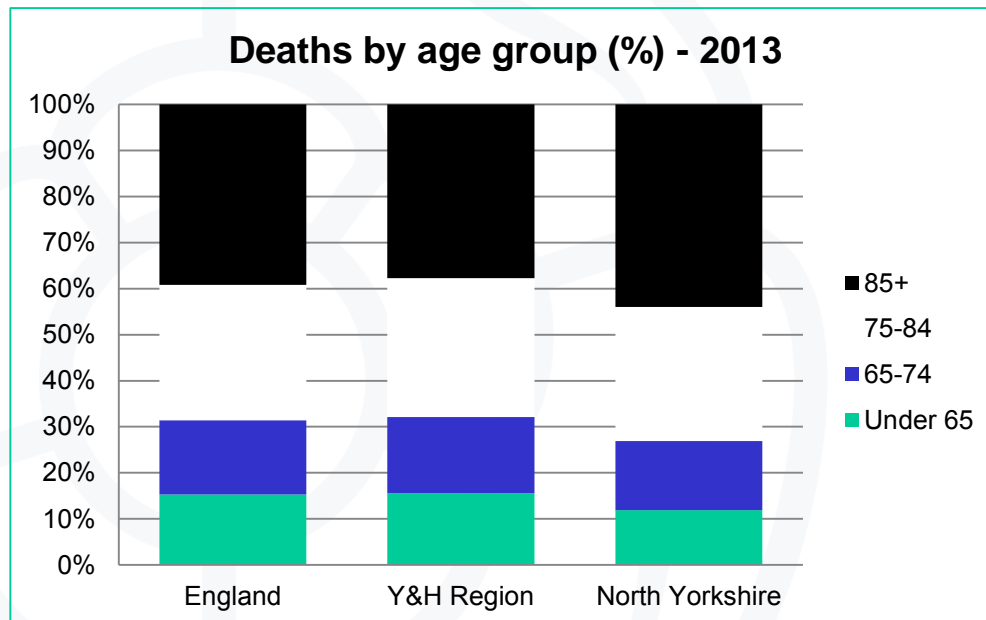
- Some variation in location of death, both between districts and by cause



What is the projected level of need?

NY population to increase by 12,000 by 2020

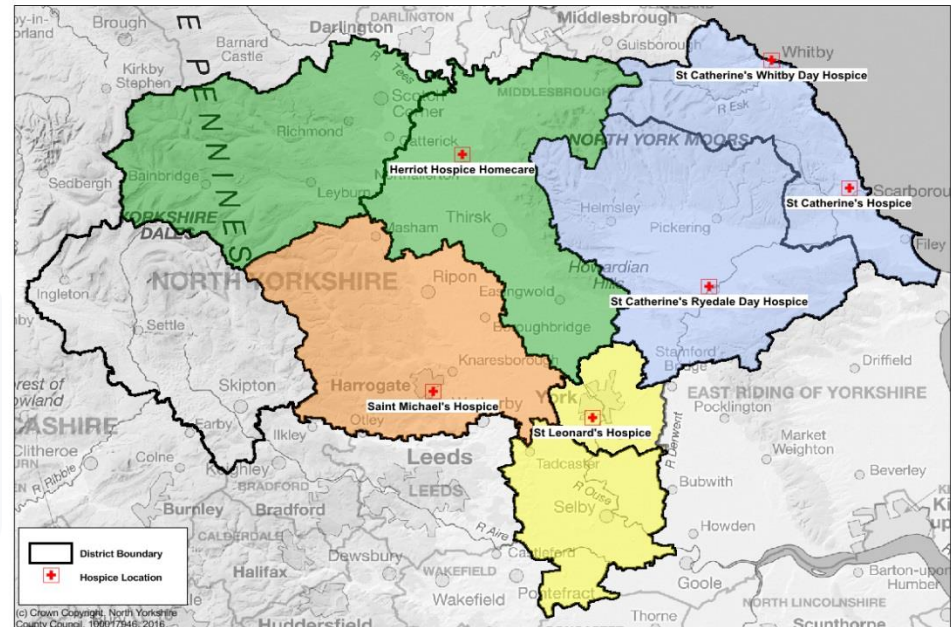
- **Already have elderly population**
- **Increasing proportion will be over 65 by 2020**
- **Greater care needs**



What services are currently provided?

Information in main report and appendices on:

- **Local partnerships**
 - Children and young people
- **Hospital services (inpatient and outpatient)**
- **Nursing services**
 - Care homes
 - Domicillary care
- **Hospices**
- **Other voluntary sector**



What needs might be unmet?

Local areas of unmet need largely reflect national areas of unmet need.

- **Access to preferred place of dying**
- **Integration of EoLC into all care pathways**
- **Co-ordinated IT system**
- **Access to inpatient hospice facilities**
- **Training**
- **Out of hours access**

Evidence for effective intervention?

NICE National Institute for Health and Care Excellence

NICE guideline

Care of dying adults in the last days of life

NICE guideline
Published: 16 December 2015
nice.org.uk/guidance/ng31

Office for National Statistics

Statistical bulletin

National Survey of Bereaved People (VOICES): England, 2015

Quality of care delivered in the last 3 months of life for adults who died in England.

Contact: Helen R Colvin elcol@ons.gov.uk Release date: 22 April 2016 Next release: To be announced

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9. Dignity and respect in the last 3 months of life
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Housing LIN
Connecting people, ideas and resources

Practice Briefing

End of Life Care: Helping people to be cared for and die at home

"A few conclusions become clear when we understand this; that our most cruel failure in how we treat the sick and the aged is the failure to recognize that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."
- Atul Gawande, *Being Mortal: Medicine and What Matters in the End*

"End of Life Care does not start with palliative care. It starts with community."
- Julian Abel, *Life & Death Matters*

This briefing is for people working in housing, public health, care and support. Recognising a gap in information on this topic, Public Health England commissioned the Housing LIN (Learning and Improvement Network), the leading voice of expert advice and support in the field of housing, care and support services, to produce this briefing.

Drawing on the Housing LIN's knowledge of the sector and with input from its network members, it looks at the importance of end of life care delivered at home, describing the context, inequalities in end of life care, and examples of good or emerging practice. It is intended to be a practical guide for those working in mainstream and/or specialist housing, care and support, and public health to understand their respective roles, and how they may work with each other.

NHS
Public Health England
Improving Quality

Protecting and improving the nation's health

National End of Life Care Intelligence Network


Palliative care co-ordination: core content

Implementation guidance

National Information Standard SC011580

REPORT

On the brink
The future of end of life care



The End of Life Care Coalition

Cheshire Eastern Cheshire hospice WE ARE PALLIATIVE MIND THE NATIONAL COUNCIL FOR PALLIATIVE CARE Sireo Project

What's important to me.
A Review of Choice in End of Life Care

EXECUTIVE SUMMARY

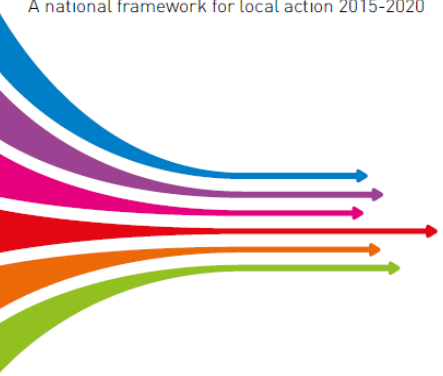


Published by **The Choice in End of Life Care Programme Board**

February 2015

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

CareQuality Commission

A different ending
Addressing inequalities in end of life care

Overview report



MAY 2016

Additional needs assessment required?

Data often not held in single accessible location, but by multiple partners:

- **Information on staff training**
- **How many people needing EoLC are identified on a suitable register?**
- **Information on patient experience**
- **Information on preferred place of death**
- **Detailed funding arrangements**
- **Cost-effectiveness**

Next steps

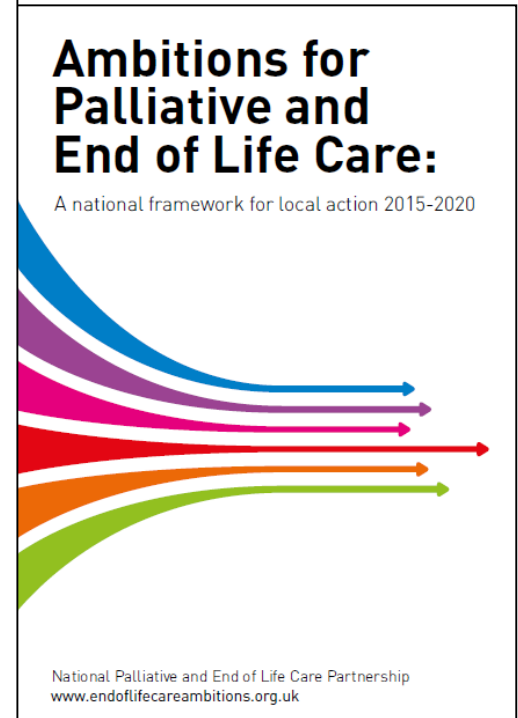
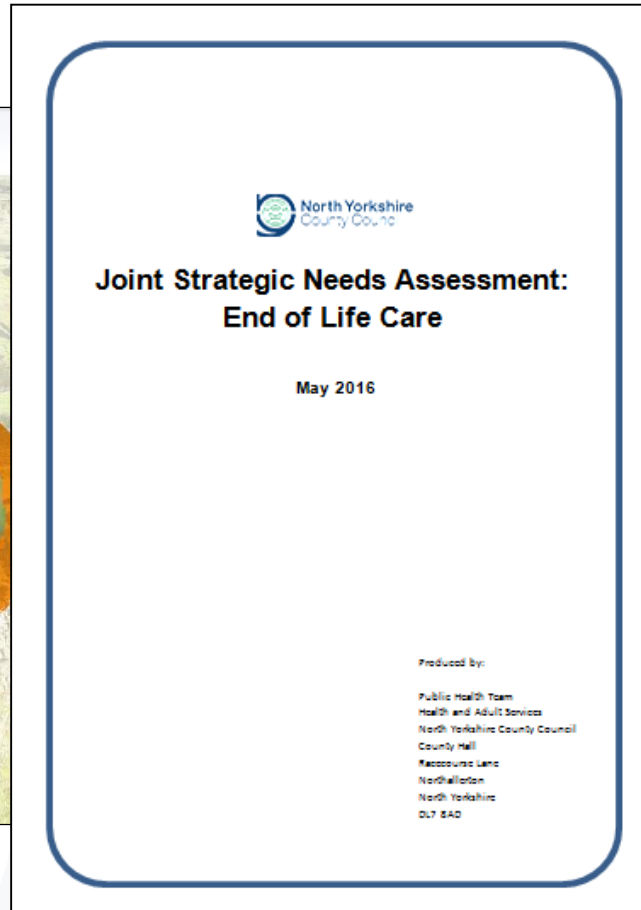
- Health and Wellbeing Board appointing a **theme sponsor** for 'Dying Well' (Joint Health and Wellbeing Strategy 2015-2020)
- Commissioners to consider **reviewing current and prospective EoLC services** in light of report findings
- Commissioners to consider **using (and expanding) existing networks** of end of life care professionals to help achieve recommendations
- Commissioners and NYCC Public Health Team to review the **PHE health economics report** on EoLC (end of June 2016)

Stakeholders consulted:

- North Yorkshire County Council Public Health Team
- Harrogate & Rural District Clinical Commissioning Group
- Scarborough & Ryedale Clinical Commissioning Group
- Partnership Commissioning Unit
- Public Health England: Health Economics team
- Dr Mike Brookes, GP (Reeth Medical Centre) & RCGP/Marie Curie Palliative and End of Life Clinical Support Fellow
- Age UK North Yorkshire

Input also received from colleagues at Martin House Children's Hospice and the University of York.

Questions?



Dying Well: Executive Summary

Almost everyone will experience end of life care at some point during their lives. Many of us will be involved in caring for someone who is dying, often a close friend or relative. Some of us will be involved in a professional manner, looking after dying people as part of our role in health or social care, or other professions such as lawyers or religious leaders. Most of us will also need end of life care as individuals, regardless of what our eventual cause of death might be.

The difference good end of life care makes to both dying individuals and their families cannot be underestimated. Each death is personal; the memories of every death remain with the people involved long after a loved one has passed away. The final thing we can do for the people we care for is to make sure they receive the best possible care at the end of their lives. However, a deep-seated unwillingness to talk about death across society has meant that discovering the needs of dying people, and then trying to translate these needs into practice, has not been an easy process. The North Yorkshire Health and Wellbeing Board has recognised the importance of improving care at the end of life by including 'Dying Well' as one of the five key themes for the [Joint Health & Wellbeing Strategy 2015-20](#).

What is end of life care?

The General Medical Council definition of 'end of life' says that people are 'approaching end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

End of life care involves any care that is provided when a patient has reached this terminal stage. This includes the palliative management of pain and other symptoms, and also the provision of psychological, social, spiritual and practical support. The range of health and social support needed highlights the importance of an integrated service model for end of life care.

National Context

The UK population is steadily ageing, and deaths in England and Wales are expected to rise by 17% between 2012 and 2030. Currently just over 1% of people in the UK die every year; in 2014 there were 501,424 deaths registered in England and Wales (ONS, 2015). North Yorkshire already has a population with a significant proportion of elderly residents - end of life care is therefore a very important issue for many residents and their families.

The UK provides comparatively good end of life care overall (2015 Quality of Life Index), but some areas, such as communication and access to out of hours services, need improvement. A recent estimate suggested that of the approximately 355,000 people needing palliative care services every year, around 92,000 people were still not being reached. 70% of carers report that those they care for do not get all the support they need.

The majority of costs from end of life care currently come from hospital admissions, averaging £4500 per person. It is estimated that providing better care in the community will reduce unnecessary hospital admissions, with potential savings estimated around £500 per person (Nuffield Trust, 2014). The overall financial cost of end of life care is not currently known, as care is provided by many different people across a range of different settings. A review of the economics of end of life care by Public Health England is due to be released in June 2016.

Key issues

Discussions about dying: The persisting view of death as a 'taboo subject' by patients, families and medical practitioners means that the wishes of the dying person are often missed, leading to inappropriate care being given in the wrong locations. Most people still die in hospitals, despite the most common preference being to die at home. In North Yorkshire 43% of deaths occurred in hospital (2013), which is lower than the national average but still does not reflect expected patient wishes.

Access for all: Although many people receive very good end of life care, it is still not available to everyone. Access to care can be affected by where people live, the type of illness they have, age and deprivation level. End of life care is well-integrated into some care pathways (particularly for cancer), but not for others such as dementia. In addition, not all people have out of hours access to end of life care services. Across the country only 11% of hospital inpatients have 24/7 access to a specialist palliative care teams, and not all people in the community have 24/7 access to advice and key therapies such as analgesia.

Co-ordinating services: Good quality end of life care can only be achieved if there is a co-ordinated approach between service providers, including electronic communications systems (EPaCCS). People needing end of life care often have complex health and social care needs, and will therefore come into contact with a range of services including primary care, secondary care, emergency services, social services, housing services and voluntary sector organisations. Good communication is needed to make sure that individuals access the right services at the right time, in order to prevent unnecessary duplication of services or inappropriate treatment.

Training: All people involved in end of life care (both palliative care specialists and non-specialists such as GPs, community nurses and social workers) need suitable training, including how to identify and manage people at the end of life, and also relevant communication skills for discussing end of life issues with patients and their families.

Holistic care:

End of life care encompasses more than just health needs. Dying well is likely to also require social care, spiritual care, legal assistance, general wellbeing advice and emotional support both for the dying and for their families.

Areas for improvement

End of life care services in North Yorkshire can be improved by focusing on seven key areas:

1. **Access at all times for all people:** ensuring all people with end of life care needs can access the correct treatment and advice 24/7
2. **Integration with other existing/planned services:** ensuring end of life care is integrated into pathways for all conditions, not just cancer care; improving IT systems to enable better sharing of information between services and avoid service duplication that wastes resources
3. **Staff training:** training for both generalists and specialists involved in end of life care, including how to both identify and manage end of life patients
4. **Preferred place of death:** all patients should be given to opportunity to express their preferred place of death, and enabled to die there wherever possible
5. **Community engagement:** voluntary sector organisations and community initiatives should be utilised where appropriate to support end of life care services
6. **Appropriate level of care:** treatment should be focused on symptom relief in order to maximise remaining quality of life; patients should have an agreed

ceiling of care to prevent unnecessary interventions that risk causing harm with no curative benefit

7. **Support for carers and relatives:** end of life care should extend to the carers and families of those who are dying, and should include bereavement support after a death. This should link to the North Yorkshire carer's strategy (currently under development)

Links

Ambitions for Palliative and End of Life Care: a national framework for local action 2015-2020

<http://endoflifecareambitions.org.uk/>

Guide for commissioners on end of life care for adults

NICE commissioning guidelines [CMG42], December 2011

<https://www.nice.org.uk/guidance/cm42>

Care Quality Commission: 'A different ending: End of life care review'

Addressing inequalities in end of life care

<http://www.cqc.org.uk/content/different-ending-end-life-care-review>

On the Brink: The Future of End of Life Care

Report by the End of Life Care Coalition

<http://endoflifecampaign.org/wp-content/uploads/2016/02/End-of-Life-Report-WEB.pdf>

Nuffield Trust: Exploring cost of care at the end of life

Providing a best estimate of current costs, and comparing to Marie Curie community model

http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf

North Yorkshire JSNA: End of Life Care [full report]

<http://hub.datanorthyorkshire.org/dataset/jsna-data>

North Yorkshire Health Joint Health and Wellbeing Strategy 2015-2020

<http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=21125&p=0>