National End of Life Care programme - overview

Professor Bee Wee
National Clinical Director for End of Life Care
NHS England

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By 2020.... “significantly improve patient choice at end of life... including ensuring an increase in the number of people able to die in the place of their choice, including at home.”

Government’s Mandate to NHS England 2016-17
## The scale of the challenge

<table>
<thead>
<tr>
<th>Gap</th>
<th>Challenge/Driver</th>
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| Health and well-being      | • Behaviour change: how can the NHS work differently?  
• Empowering patients / public  
• Engaging communities – developing partnerships |
| Care and quality           | • Variations in outcomes  
• Reshape care delivery, e.g. new care models  
• Use of innovation and new technologies |
| Funding                    | • Relentless pressure on services  
• Estimated funding gap of £30 billion by 2020/21  
• Local Authorities under even greater pressures  
• Driving efficiency  
• Local leadership |
The scale of our challenge

- England and Wales:
  - almost 530,000 deaths in 2015 (501,000 in 2014)

- WHO projections for Euro region:
  - NCD: from 7.9 million to 8.3 million deaths/year by 2030

- Scottish study – over **1 in 4** of hospital inpatients were dead within 12 months; a third of these died during index admission

- **75%** of deaths are from non-cancer/long term/frailty conditions
And…

- The larger the number of co-morbidities a patient has, the lower their quality of life

- Dying with dementia report (PHE):
  - age > 65 years: 58% die in care homes; < 10% at home
  - 38% have respiratory comorbidity
  - 36% have circulatory disease

- Increasing evidence on over-treatment and harm

- Early and timely recognition of, and response to, palliative care needs improves care and potentially reduces costs
And for End of Life Care in particular:

- Nobody likes talking about death and dying
- Death often seen as a failure of treatment
- Not just a medical or health issue – also a social and societal issue – deeply personal

- Difficult to use conventional metrics
- Those who have died unable to report back on their own experience
- Need to be able to stand back and make sure that services deliver for **everybody**
How will we meet this challenge?
What needs to be different?

Personalised Health and Care 2020
Using Data and Technology to Transform Outcomes for Patients and Citizens
A Framework for Action

NHS England

www.england.nhs.uk
• Operational Planning and Contracting Guidance 2017-19:

• 9 areas of ‘must do’s’ – e.g.

• Implement the Urgent and Emergency Care Review, ensuring a 24/7 integrated care service for physical and mental health is implemented by March 2020 in each STP footprint, including a clinical hub that supports NHS 111, 999 and out-of-hours calls.

• Deliver a reduction in the proportion of ambulance 999 calls that result in avoidable transportation to an A&E department.
Sustainability and Transformation Plans

“It’s really easy agreeing in principle. It’s really easy in terms of direction of travel……but it’s when you actually bring it down to, well, this means choices. This means decisions. This means choice of where you actually spend or don’t spend. It means curtailing some services in order to actually develop others. That’s where it…or decisions between organisational interests, that’s where the difficulty is.”
Ambitions for Palliative and End of Life Care:
A national framework for local action 2015-2020

National Palliative and End of Life Care Partnership
Working with our Partners
(27 of them in fact!)

Association for Palliative Medicine; Association of Ambulance Chief Executives;
Association of Directors of Adult Social Services;
Association of Palliative Care Social Workers; Care Quality Commission;
College of Health Care Chaplains; General Medical Council;
Health Education England; Hospice UK;
Macmillan Cancer Support; Marie Curie;
Motor Neurone Disease Association; National Bereavement Alliance;
National Care Forum; National Council for Palliative Care;
National Palliative Care Nurse Consultants Group; National Voices;
NHS England; NHS Improving Quality;
Patients Association; Public Health England;
Royal College of General Practitioners;
Royal College of Nursing; Royal College of Physicians;
Social Care Institute for Excellence;
Sue Ryder and
Together for Short Live
Vision for Palliative and EoLC

“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).”

‘Every Moment Counts’ National Voices, National Council for Palliative Care and NHS England.

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

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## The foundations for the ambitions

<table>
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<th>Personalised care planning</th>
<th>Shared records</th>
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<td>Education and training</td>
<td>24/7 access</td>
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<tr>
<td>Evidence and information</td>
<td>Involving, supporting and caring for those important to the dying person</td>
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<tr>
<td>Co-design</td>
<td>Leadership</td>
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National Palliative and End of Life Care Partnership
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How will NHS England oversee and support delivery and improvements in EoLC?
National EoLC Programme Board

- Chaired by Sir Bruce Keogh
- Objectives:
  - NHSE Mandate
  - Choice Review response
  - Ambitions
- Assurance mechanism for Minister and DH
- Meets every 2 months
- Membership – NHS England Directors, ALBs, DH, social care, Ambitions Partnership reps
NHS England workstreams

1. **Enhancing physical and mental wellbeing of the individual**
   - To optimise the person’s mental and physical wellbeing so that they can ‘live as well as they wish’ until they die
   - To optimise support for their families, carers and those important to them to maximise their wellbeing before and after the person’s death

2. **Transforming experience of End of Life Care in the community and in hospitals**
   To significantly improve the experience of end of life care at home, and in hospitals, care homes, hospices and other institutions

3. **Commissioning quality services that are accessible to all when needed**
   To support commissioners and service providers to design and implement models of care which promote integration and care that feels coordinated to those using, and delivering, end of life care services
Programme Highlights

- Empowerment video
- Care coordinator models and systems
- Personal Health budgets
- Knowledge hub launch

- Developing an EoLC Digital Delivery plan
- EPaCCS implementation
- Focus on different care settings
- Launch of community of practice for EoLC in secure and detained settings

- Published an EoLC commissioning toolkit
- Published information for commissioners: specialist level palliative care
- Palliative care currencies, and Palliative care clinical data set
- Ambitions Framework: Self-assessment tool

www.england.nhs.uk
Lasting thought…

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders
(founder of the modern hospice movement)
Thank you for listening!

Commitment

england.endoflifecare@nhs.net