NHS England’s National Programme for End of Life Care

Jacquie White
Deputy Director, Long Term Conditions, Older People & End of Life Care

22nd September 2016
Opening thoughts…

“The good physician treats the disease; the great physician treats the patient who has the disease.”

*William Osler - 1800s*

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

*Dame Cicely Saunders (founder of the modern hospice movement)*
Scene setting – what we know
The case for change

1m
People with frailty

10m
People have two or more LTCs

16m
People have one LTC

0.5m
At end of life
The case for change

3.2% of people with LTCs have a care plan

20% / 75% end stage LTC palliative care before dying/cancer patients receiving palliative care before dying

6% / 82% recorded preferences/supported to die in preferred place as a result

75% deaths from non-cancer/long term/frailty conditions
The case for change

- 25% of hospital beds occupied by someone dying
- 4% over 65s in care home with 14% total emergency admissions for over 65s
- Three-fold increase in cost of health care with frailty
- Good community based EoLC could reduce hospital costs by £180 million per year

£180m
1 in 9

caree had emergency care while the carer recovered from illness

1 in 5

received no practical support with caring

Nearly 1 in 2

(46%) said they had fallen ill but just had to continue caring

1.4 million

people providing fifty or more hours of unpaid care per week

£1bn

in Carer’s Allowance goes unclaimed each year
Gaps, System Challenges & Drivers
## For the NHS...

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

- Nobody likes **talking** about death and dying
- Death seen as a **failure of treatment**
- Not just a medical or health issue – also a **social and societal issue**
- Historically, **funding** comes from multiple sources
- Difficult to use conventional **metrics**
- Those who have died unable to report back on their own **experience**
- The strongest lobbyist are those who have had poor experiences with somebody they love
- Need to be able to stand back and make sure that services deliver for **everybody**
How will we meet this challenge?
What will be different?
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.
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
Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what’s possible.
The foundations for the ambitions

<table>
<thead>
<tr>
<th>Personalised care planning</th>
<th>Shared records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and training</td>
<td>24/7 access</td>
</tr>
<tr>
<td>Evidence and information</td>
<td>Involving, supporting and caring for those important to the dying person</td>
</tr>
<tr>
<td>Co-design</td>
<td>Leadership</td>
</tr>
</tbody>
</table>
Each person is seen as an individual
The building blocks for achieving our ambition

<table>
<thead>
<tr>
<th>Honest conversations</th>
<th>Systems for person centred care</th>
<th>Helping people take control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everybody should have the opportunity for honest and well-informed conversations about dying, death and bereavement.</td>
<td>Effective systems need to reach people who are approaching the end of life, and ensure effective assessment, care coordination, care planning and care delivery.</td>
<td>Personal budgets and integrated personalised commissioning are some of the potentially powerful tools for delivering tailored and personal care for many more people.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clear expectations</th>
<th>Access to social care</th>
<th>Integrated care</th>
</tr>
</thead>
<tbody>
<tr>
<td>People should know what they are entitled to expect as they reach the end of their lives.</td>
<td>People must be supported with rapid access to needs-based social care.</td>
<td>End of life care is part of new models of integrated health and social care being promoted across the health and social care system.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Good end of life care includes bereavement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.</td>
</tr>
</tbody>
</table>
Commitment for EoLC

Opportunity and support to:

• Have honest discussions about needs and preferences
• Make informed choices about care, supported by clear and accessible information
• Develop and document personalised care plan
• Share personalised care plan with care professionals
• Involve, to the extent that you wish, family, carers and those important to you
• Know who to contact if you need help and advice at any time
How will NHS England oversee and drive delivery of our EoLC commitments?
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 hospitals and the community**
   To significantly improve the experience of end of life care in hospitals, at home, and in 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

- Published an EoLC commissioning toolkit
- Testing feasibility of Care navigator scheme
- Palliative care clinical data set
- Publishing guidance on using a set of palliative care currencies
- Developing an EoLC Digital Delivery plan
- Personal Health budgets
- Clinical advice hubs
- Published information for commissioners
- Test new community based models
- Launch of community of practice
- Knowledge hub launch
- Clinical network

www.england.nhs.uk
“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!

@jaqwhite1
#A4PCC

england.longtermconditions@nhs.net

www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/