Implementing the new Actions for End of Life Care 2014-16

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The brief

- Implementing the four interdependent components of the framework
- One chance to get it right: moving forward with the five priorities of care
- *Every moment counts*: incorporating the narrative on end of life care from the person and carer perspective
- Working towards a new end of life care strategy for 2015 and beyond
Overview

How can we improve people’s quality and experience of care?

• Where have we come from?
• Where have we got to?
• What should we do next?
Governments, ministers & organisations change; people’s needs don’t

- More older people
- Living longer; longer ill-health
- More with multiple conditions
- 850,000 with dementia by 2015; 1 million by 2025
- Someone dies every minute
- More will die each year
- Nearly half die in hospital, where they don’t want to be
- 22% die at home (2012)
- Hard to change something we won’t talk about
What people tell us

• We are sick of falling through gaps; we are tired of organisational barriers and boundaries that delay or prevent our access to care.
• We do not accept being discharged from a service into a void
• We want services to be seamless and care to be continuous.

National Voices

The Narrative for person centred coordinated care
Momentous change

Radical change to the NHS landscape
  – new structures
  – new organisations
  – new people
  – new ways of doing things
  – focus shift to outcomes

Growing financial challenge
Fundamentally challenging reports: Francis, Berwick
More Care Less Pathway (Neuberger)
Blows to public confidence and professional morale
Parliament → DH

DH → 10 SHAs

10 SHAs → 152 PCTs

27 clinical networks

Research networks

NHS Trusts

Acute trusts, community services, mental health, Ambulance

NHS Foundation trusts

Acute trusts,

CQC

Local Authorities

Public Health

Public Health Observatories

Monitor

www.ncpc.org.uk
The Liverpool Care Pathway

- Has made a valuable contribution & supported by many clinicians
- BUT...
- “Reports of poor treatment in acute hospitals at night and weekends – uncaring, rushed, and ignorant – abound”
- “Numerous accounts of no access to the palliative care teams outside office hours and at weekends”
- “Poor levels of care and communication”
What went wrong?

- Mainly acute hospitals
- People with conditions other than cancer
- Training & education
- Poor communication
- Language
- Poor care
- Governance
- Evidence
“Ultimately it is the way the LCP has been misused and misunderstood that has led to such great problems, along with it being simply too generic in its approach for the needs of some. Sadly, it is just too late to turn the clock back to get it used properly by everybody. That is why we have recommended phasing out the LCP and replacing it with a more personalised and clinically sensitive approach.”

Baroness Neuberger, 15 July 2013
The Francis Report

"Fundamental rights denied..."

"Appalling and unnecessary suffering..."

"Lack of care, compassion, humanity and leadership..."
What did we know about hospital care?

“The reasonable expectation that an older person or their family may have of dignified, pain-free end of life care in clean surroundings in hospital is not being fulfilled. Instead these accounts present a picture of NHS provision that is failing to meet even the most basic standards of care.”
What were staff saying?

• **Survey of nurses, 2010:**
  - 69% felt they did not have sufficient time/skills to talk to patients about dying

• **Royal College of Physicians survey, 2012**
  - 2/3 had not attended any end of life care training in last 5 years
  - But most self-reported high levels of competence and confidence
VOICES
Dignity & respect in last 2 days of life (2012)

Doctors – all the time
• Hospice – 94%
• Home - 84%
• Care home – 82%
• Hospital – 67%

Nurses – all the time
• Hospice – 93%
• Home - 86%
• Care home – 80%
• Hospital – 63%
Table 13b: Help received in the last 2 days of life: strongly agree / agree by place of death

<table>
<thead>
<tr>
<th></th>
<th>Home</th>
<th>Hospital</th>
<th>Care Home</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal care needs met</td>
<td>83</td>
<td>71</td>
<td>89</td>
<td>96</td>
</tr>
<tr>
<td>Nursing care needs met</td>
<td>82</td>
<td>71</td>
<td>89</td>
<td>95</td>
</tr>
<tr>
<td>Adequate privacy provided</td>
<td>92</td>
<td>72</td>
<td>96</td>
<td>95</td>
</tr>
</tbody>
</table>
“We believe there needs to be a proper National Conversation about dying. Otherwise doctors and nurses are likely to become the whipping-boys for an inadequate understanding of how we face our final days.”

Foreword to “More Care, Less Pathway”
“Many consider death to be the last great taboo in our society and ….most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life.”

End of Life Care Strategy, Department of Health, 2008
After she died, people crossed the street to avoid me, they weren't unkind, just didn't know what to say.
Our greatest fear

How scared are you of the following happening to you?

- Dying in pain 83%
- Dying alone 67%
- Being told you are dying 62%
- Dying in hospital 59%

Compare with:

- Going bankrupt 41%
- Divorce/end of a long-term relationship 39%
- Losing your job 38%

ComRes 2011
What next?

- Recognise
- Communicate
- Involve
- Support
- Plan & Do
- People who are dying and those who are important to them to be central
New guidance

Changes in the last days of life

<table>
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<tr>
<th>Signs that a person may be dying</th>
<th>Should I be worried?</th>
</tr>
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<tr>
<td>The person’s appetite is likely to be very reduced. They may no longer wish to eat or drink anything. This could be because they find the effort of eating or drinking to be too much. But it may also be because they have little or no need or desire for food or drink. Eventually, the person will stop eating and drinking, and will not be able to swallow tablets.</td>
<td>If a person stops eating or drinking because of their reduced appetite, this may be hard to accept, but it is a normal part of the dying process. If they stop drinking their mouth may dry, but this does not always mean they are dehydrated. It is normal for all dying people to stop eating and drinking.</td>
</tr>
</tbody>
</table>

What to expect when someone important to you is dying

A guide for carers, families and friends of dying people
Policy alignment
5 Year Forward View

• No serious mention of EoLC....
• But...
• ...“The right care, at the right time, in the right place”
• ...Work with communities & the voluntary sector
• ...Commitment to carers
• ...7 day service
The Care Act

- Replaces outdated legislation
- Duties to:
  - Provide information & advice
  - Meet the assessed needs of carers
  - Market development: range of local services
- Rights to choice through care plans & personal budgets
“Whilst dying is inevitable, and universal, that is the only certain thing about it. So much else is unpredictable. It is therefore vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives.”
What people told us

What is important to me at the end of my life and after I die?

- Support for my family, carers and those important to me, not just at the end of life but after my death
- Being able to maintain as much of my normal life as possible
- Support for my emotional, physical, social and spiritual needs
- To be as involved as I want in decisions about my care
- Involvement of people important to me in decisions about my care
- To be cared for and die where I would like to be
- The right people having access to my wishes at the right time
- Access to the right services when I need them
What’s important to me:

Recommendations include:
• Roll-out of EPaCCS
• Free and fast social care
• £130 million in next comprehensive spending review
• Community resilience & behaviour change
• Training – needs to be evaluated
A new narrative

Every Moment Counts

A narrative for person centred coordinated care for people near the end of life
Every Moment Counts

**Domains**

- My goals and quality of life and death
- The people who are important to me

Person centred coordinated care near the end of life

“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).”

- Honest discussion and planning
- My physical, emotional, spiritual and practical needs
- Responsive and timely support
Dying Well
Community Charter

“Care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody’s responsibility”
Public Health Approaches to End of Life Care

A Toolkit
8 Pathfinders/Pioneers

- Lancaster (St. John’s Hospice)
- Hull (Dove House Hospice)
- Liverpool (CCGs)
- Cheshire (End of Life Partnership)
- Birmingham (CCGs)
- Weston-super-mare (Weston Hospicecare)
- Hackney (Health and Wellbeing Board)
- Dorset (Conscious Ageing Trust & Compassionate Community)
New Ambitions

• Group of national organisations coming together to produce a new set of shared national ambitions
• Must be ambitious, but achievable
• Will be published in 2015
• 5 Year vision
• Will contain commitments to action
Never again?

Do you want us to let you die? Question nurses on home visits are told to ask elderly patients they have just met

- Patients asked via form if they would agree to a 'do not resuscitate order'
- Elderly are being given questionnaires as part of an NHS England scheme
- Experts fear patients will feel pressured into giving consent to avoid trouble
- Forms sent to GP practices in June, with district nurses visiting patients
- They are targeting the over-75s and patients with long-term conditions

By SOPHIE BORLAND, HEALTH CORRESPONDENT
CREATED: 23:09, 19 August 2014

www.ncpc.org.uk www.dyingmatters.org
Jane Cumming’s response
(20 August 2014)

• Discussions about dying should be part of meaningful relationship that develops between nurse, person & family

• Compassionate care should be at the heart of all conversations and relationships between a nurse and the person involved.

• Poor implementation of a document by individuals is no excuse for causing distress to our most vulnerable people and their families

• A care plan is not a document in itself; it is only as good as the conversations that people, nurses and GPs have together.
Don’t focus on “culture change”…

• Training must lead to changed attitudes, behaviour and practice, and improvements in people’s quality and experience

• So must a “national conversation”

• Focus on the person, not the document

• Make sure people’s wishes and concerns are heard and acted on
Let’s mobilise & work together