Delivering high quality end of life care for people who have a learning disability

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NHS England

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“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders

The scale of our challenge

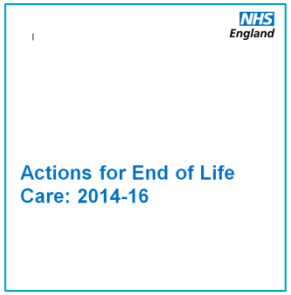
- Size of older population over next 20 years (ONS):
  - Aged 85 or more: from 1.7 to 3.7 million
  - Aged 75-84: from 4.1 to 6.3 million

- Number of deaths registered in England and Wales
  - 2015 - 530,000 (5.6% more than in 2014)
  - Projected 628,659 by 2040

- Projected number needing palliative care (Etkind et al, 2017):
  - Increase by 25 – 42%

The scale of our challenge: inequity

- People with learning disability – 2.5 times more likely to have health problems than other people
- Between 25-40% of people with learning disability also experience mental health problems
- People in lower socio-economic categories experience multi-morbidity at a younger age than those in higher socio-economic categories
- And other inequalities…….cumulative effect



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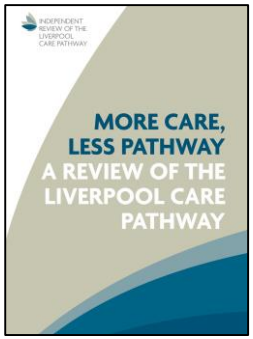

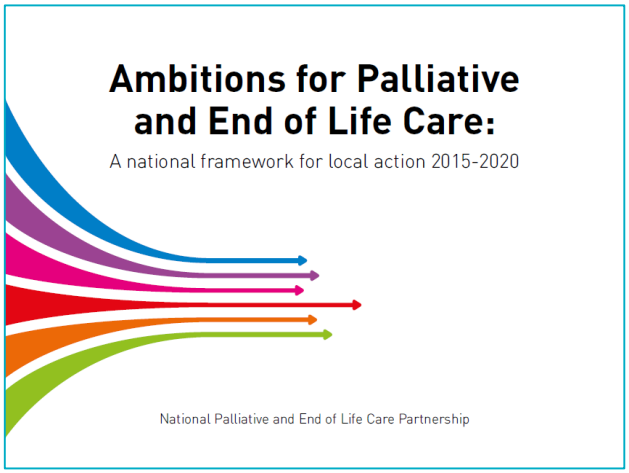

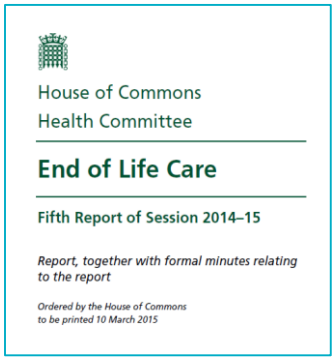

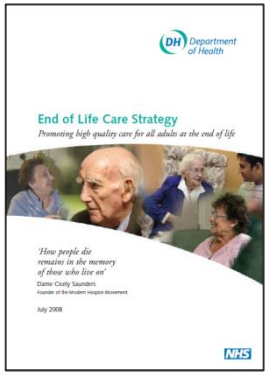

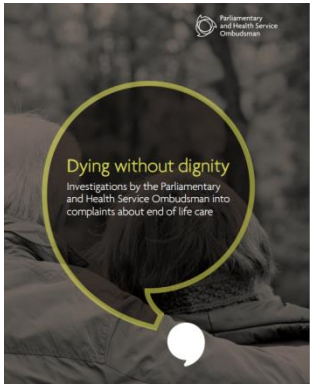

www.england.nhs.uk

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

"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

The foundations for the ambitions

Personalised care planning	Shared records
Education and training	24/7 access
Evidence and information	Involving, supporting and caring for those important to the dying person
Co-design	Leadership

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Maximising comfort and wellbeing

My care is regularly reviewed
and every effort is made for me
to have the support, care and treatment
that might be needed to help me
to be as comfortable
and as free from distress
as possible.

03

Maximising comfort and wellbeing

The building blocks for achieving our ambition

Recognising distress whatever the cause

It is important to recognise all sources of distress quickly, to acknowledge distress and to work with people to assess its extent, its cause and what might be done.

Addressing all forms of distress

The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional, or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the causes.

Skilled assessment & symptom management

Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date.

Specialist palliative care

People approaching the end of life should have access to Specialist Palliative Care when this is needed. This should include a clear understanding of how to access medicines and equipment as part of the rapid response to changing needs.

Priorities for care of the dying person

People approaching death should expect local systems to accord with the priorities identified by the Leadership Alliance for the Care of Dying People.

Rehabilitative palliative care

Maximising the person's independence and social participation to the extent that they wish requires professionals to work with, and support, the person in helping them to achieve their personal goals.

EoL Programme: how it all fits together

6 point commitment

- Honest conversations
- Informed decisions
- Developing personalized care plan
- Sharing plan with professionals
- Involving family to the extent wishes
- Know who to contact

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Unpacking the vision : what does this mean for the person?

1. Condition recognised as advanced or getting worse

2. Personalised planning - leading to coordinated action - is offered for treatment, care and support

3. High quality experience anywhere anytime

Unpacking the vision: what does this mean for the person?

3. High quality experience anywhere anytime
    - Staff who know what they are doing
    - Timely access to medicines, equipment, etc.
    - Feeling safe physically and emotionally
    - Family/those important to me are supported

How do we make this …
… a reality … every time?

Improvements in the quality of care do not occur by chance. They come from the intentional actions of staff equipped with the skills needed to bring about changes in care, directly and constantly supported by leaders at all levels. They do not come free and will require a substantial and sustained commitment of time and resources.

Ham, Berwick & Dixon:
Improving quality in the English NHS
King's Fund, Feb 2016

CIPOLD, LeDeR, Treat Me Well etc

- Learning disability awareness
- Reasonable adjustments
- Communication
- Person centeredness
- See the person not the label - ‘diagnostic overshadowing’
- Active listening
- Advocacy
- Listening, engaging and working with families in partnership
- Understanding MCA
- Co-ordinated care and support

‘Top tip’
Identify and create the reasonable adjustments needed to ensure people with a learning disability can access the end of life care they need

“No jargon please! There’s often a communication breakdown. When you don’t understand everything, you feel out of control.”
GRASSroots group

The Secretary of State - 20 March 2018
7 key principles that will guide the Government's thinking ahead of the social care green paper, to be published later in 2018.

*…**full integration** of health and social care centred around the **person**.*

*…the highest possible **control** given to those receiving support.*

*…I want to turbo-charge progress on **integrated health and care budgets**, making them the norm and not the exception when people need ongoing support.*

*…I can announce new pilots in Gloucestershire, Lincolnshire and Nottinghamshire which will mean that over the next 2 years every single person accessing adult social care will be given a **joint health and social care assessment** and - critically - a **joint health and care and support plan**, where needed…every single person with a joint care plan will also be offered an **integrated health and care personal budget**.*

*…I can announce that we will be consulting on **Personal Health Budgets**, in order to achieve better integration for those with the greatest ongoing social care needs as well as health needs.*

Personal Health Budget areas

In 2017/18 28,000 people had PHBs (target expansion to 40,000 in 2018/19.

In 2017/18, 2,700 were people with learning disabilities and/or autism.

Continuing Health Care **moving towards PHBs as the default for delivery**	**Mental Health including S117**	**Choice in End of Life Care**	**Looked After Children**	**Wheelchairs and other specialist equipment**
Substance Misuse	**Neurological disability**	**People with a learning disability**	**Integrated Budgets**	**Veterans**

DHSC and NHSE - consultation closed 8th June 2018

Transforming Care and IPC/PHBs

- Integrated Personal Commissioning (IPC) aims to provide a holistic personalised approach for people with more complex needs
- 2018/19 – 22 areas involving 71 CCGs will be delivering IPC. Many will focus on people with a learning disability and/or autism
- Specific project in Greater Manchester - 4 separate council areas – focussed work on adults & CYP on the dynamic risk register at risk of institutionalisation.

  Project is in Phase I, and has been co-produced and co-designed with people and their families.

NHS Mandate 2018-19

Overall 2020 goals:

- Significantly improve patient choice, including in maternity, end-of-life care, elective care and for people with long-term conditions.

2018-19:

- Increase the percentage of people identified as likely to be in their last year of life, so that their End of Life Care can be improved by personalising it according to their needs and preferences.