Providing high-quality end-of-life care universally

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- Current literature on end-of-life care
- The elements of the National End of Life Care Programme
- Future plans for palliative care

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Most people who are terminally ill have preferences over how and where they would like to die. Care at the end of life should reflect people’s individual needs.

The National End of Life Care Programme (NEoLCP) has focused on a simple but challenging goal: improving the quality of end-of-life care in all settings, enabling people to live well and die in their preferred place.

Most people would prefer to die where they normally live and this was one of the NEoLCP’s key performance indicators. The number of people dying in hospital is falling (58% in 2005 down to 51% in 2011; Gao, 2013), and the number dying in their own homes has increased. In England, hospital is still the most common place for patients with cancer to die, but an increase in home and hospice deaths since 2005 suggests the NEoLCP has made a difference.

Gao et al (2013) found the increase in the number of people with cancer dying at home or in hospices correlates with the launch of the NEoLCP. Since the launch, almost 63,000 more people have been supported to die where they usually live – at home or in a care home (Gao, 2013).

Although the number of people dying in their own homes is increasing (Fig 1), we should recognise that people dying in their usual place of residence is not an indicator of high-quality care.

Setting clear priorities
When we established the NEoLCP, five key principles underpinned it:
- Evidence – sharing what works in practice by distributing the knowledge base, particularly information on good practice.
- Innovation – where there are gaps in knowledge and practice, proactively supporting individuals and organisations to develop innovative ways of delivering end-of-life care pathways.
- Influence – establishing the right networks and structures to enable a two-way influencing process between the programme and its stakeholders; listening as well as seeking to persuade.
- Enabling – offering a range of support to those working to bring about change, from practical advice to additional resources such as facilitation, opportunities for networking and shared learning, or brokering new relationships.
- Partnership – rather than imposing changes from the centre, establishing mutually beneficial relationships with stakeholders and working through them to implement the National End of Life Care Strategy.

The end-of-life care pathway has been central to achieving the NEoLCP’s goals and is focused on the individual and their needs.

5 key points

1. The number of people dying in hospital fell from 58% in 2005 to 51% in 2011.
2. The Transform Programme improves individual patient experiences and helps make it possible for people to die in the place of their choice.
3. Since the National End of Life Care Programme was launched, almost 63,000 more people have been supported to die where they usually live.
4. Good communication is a fundamental part of treating people with dignity and compassion, whatever stage of life they are at.
5. Facilitating care so people can die in their own homes has the added benefit of significant cost savings.
This approach is based on working in partnership with health and social care staff, providers, commissioners and third-sector organisations across England.

Putting improvement into practice
The care pathway has supported health and social care professionals in actively identifying people nearing the end of life, discussing and recording care preferences, and supporting and coordinating care in the most appropriate setting.

The NEoLCP was aligned with the NHS Quality, Improvement, Innovation and Productivity agenda and included primary, acute and social care. We knew to be effective we had to cover the whole system as the patient experiences it. Programmes were therefore developed to support end-of-life care in both primary and acute settings:

- **Primary care** - The “find your 1%” campaign helps GPs identify patients with less than one year to live and ensure they receive the best possible end-of-life care. It has over 1,000 subscribers and offers tools and training programmes that more than 2,700 GPs and practice staff have used so far. The campaign is now run by the Dying Matters Coalition, which aims to sign up another 1,000 GPs by March 2014 (dyingmatters.org/gp).

- **Acute care** - The Transform Programme for acute hospitals helps staff to identify people approaching the end-of-life phase, ensuring good communication to find out their wishes and plan care accordingly. Sixty trusts are already taking part, sharing learning and innovation across sites.

The Transform Programme encourages the use of existing tools and resources. In particular, five key enablers aim to support the delivery of high-quality, individualised, person-centred end-of-life care:

- Advance care planning;
- Electronic palliative care coordination systems (EPaCCS);
- The AMBER care bundle;
- The rapid-discharge home-to-die pathway;
- The Liverpool Care Pathway: the experience of the programme will contribute to developments following Neuberger’s (2013) independent report on the Liverpool Care Pathway.

Nurses and other professionals have reported that Transform improves individual patient experiences and helps make it possible for people to die in the place of their choice. Hospital trusts have used it to reduce inappropriate interventions and unnecessary hospital admissions. Staff have also benefited from workforce development and training programmes focusing on end-of-life care, including free online learning resources such as e-ELCA.

Involving and listening to service users helped ensure the tools and services we developed met the needs of patients and their families. The results of the Department of Health’s first national survey of bereaved people – VOICES (views of informal carers for the evaluation of services) were published last year (DH, 2012). Families’ and carers’ comments on the quality and coordination of care for people dying at home, in care homes, hospitals and hospices provided valuable feedback and highlighted areas for further improvement.

Making the most of information
One of the key challenges for the NEoLCP was collecting and sharing information. The National End of Life Care Intelligence
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Network (NEoLCIN) played a vital role in pulling together the huge amount of data that many different organisations produce about end of life. The free resource they developed from this data offers users access to key data sources and analysis tools. NEoLCIN, now part of Public Health England, also promotes best practice in data collection, analysis and dissemination.

The NEoLCP was instrumental in the rollout of EPaCCS across England. EPaCCS provide an electronic local record of patients’ end-of-life care preferences that can then, with their consent, be shared across organisations. The systems are being implemented fully or in part in 24 localities, with another 17 planned. The aim is to roll out EPaCCS across England, so all professionals providing end-of-life care are able to share innovation and information.

A recent economic evaluation report on EPaCCS suggests that in each locality where the system is being used, an extra 90 people a year are able to die in their usual place of residence, while significant cost savings are also made (NHS Improving Quality, 2013). As an example, in the south west of England, fewer than 10% of people on EPaCCS die in hospital, and savings from reduced hospital admissions are nearly £48,000 a year (NHS IQ, 2013).

Future plans
On 1 April 2013, NHS IQ was established to bring together the knowledge, expertise and experience of NHS improvement organisations. Elements of the NEoLCP’s work have ended, but the Transform Programme, EPaCCS and the end-of-life care healthcare facilitators and social care champions network continue to work within NHS IQ and other partner organisations.

BOX 1. USEFUL RESOURCES

- Department of Health’s (2008) End of Life Care Strategy
  tinyurl.com/EndofLifeCareAdults
- National Institute for Health and Clinical Excellence’s (2011) Quality Standard for End of Life Care for Adults
  www.guidance.nice.org.uk/ QS13
- National End of Life Care Programme
  www.endoflifecare.nhs.uk
- e-ELCA learning resources
  www.e-lfh.org.uk/projects/end-of-life-care
- National End of Life Care Intelligence Network
  www.endoflifecare-intelligence.org.uk
- NHS Improving Quality
  www.england.nhs.uk/nhsiq

The end-of-life care delivery team will maintain the spread of innovation across health and social care by rolling out Transform and EPaCCS.

The knowledge, tools and skills the end-of-life care sector has around forward planning, crisis prevention and meeting the needs of patients and families can be applied to other areas of care. Having conversations with older people who are frail or individuals with cognitive problems about their wishes is just as important as communicating well with patients who have cancer.

Our new challenge is to support the development of a similar, but much wider, agenda across all aspects of patient care. If health professionals get communication right here, it generally works well across all aspects of patient care. NHS IQ is supporting the Transform Programme and EPaCCS, which are delivering measurable results. Our aim now is to build on the excellent work of nurses and other professionals in delivering high-quality care that helps people to live and die well. NT

References
Department of Health (2008) End of Life Care Strategy: Promoting High Quality Care for Adults at the End of Their Life. London: DH. tinyurl.com/EndofLifeCareAdults