

End of Life Care in England

Introduction

Significant developments in end of life care have taken place in England over the last eight years. In 2005, the government at the time undertook a public consultation, *Your Health, Your Care, Your Say*¹, about what people felt were their priorities for the NHS. One of the key themes was making sure that the quality of end of life care was good, wherever people chose to die. This topic was further explored in the White Paper, *Our Health, Our Care, Our Say*². End of life care became a work stream of the NHS Next Stage (Darzi) Review. The outcome of the Darzi review was combined with a piece of work that had already been ongoing, led by Professor Sir Mike Richards, on a wide-ranging consultation with health and social care professionals working in end of life care. The National End of Life Care Strategy was published in 2008³ and the National End of Life Programme, which has overseen the strategy implementation, led by Claire Henry, was formed at the same time. Since then, through a process of engagement in a variety of different areas, we have seen significant changes in where people die. There has been a reversal of the trend of increasing numbers of people dying in hospital, with a reduction nationwide in the percentage of hospital deaths

and increasing proportions of people dying outside of hospital, mainly in care homes and people's own homes⁴.

The programme was founded on a number of basic premises. These are that healthcare professionals should be able to identify those people with chronic illnesses who could be in the last year of life; a health professional who knows the patient well should then begin advance care planning discussions about where the patient would like to die; these wishes then need to be available to the broader health community, using electronic palliative care coordination systems (EPaCCS), initially known as end of life registers, so that when the time came for terminal care, the patient's and family's wishes were known; well coordinated care then means that the patient's wishes can be respected; the quality of care should be excellent and appropriate for end of life care wherever the patient has chosen. National surveys⁵ have shown that the majority of people would like to die at home. In 2005-2007, 58% of people were dying in hospital⁶. Finally, care after death should be sensitive and efficient, with bereavement support available for those who need it. These themes were brought together into a single diagram.

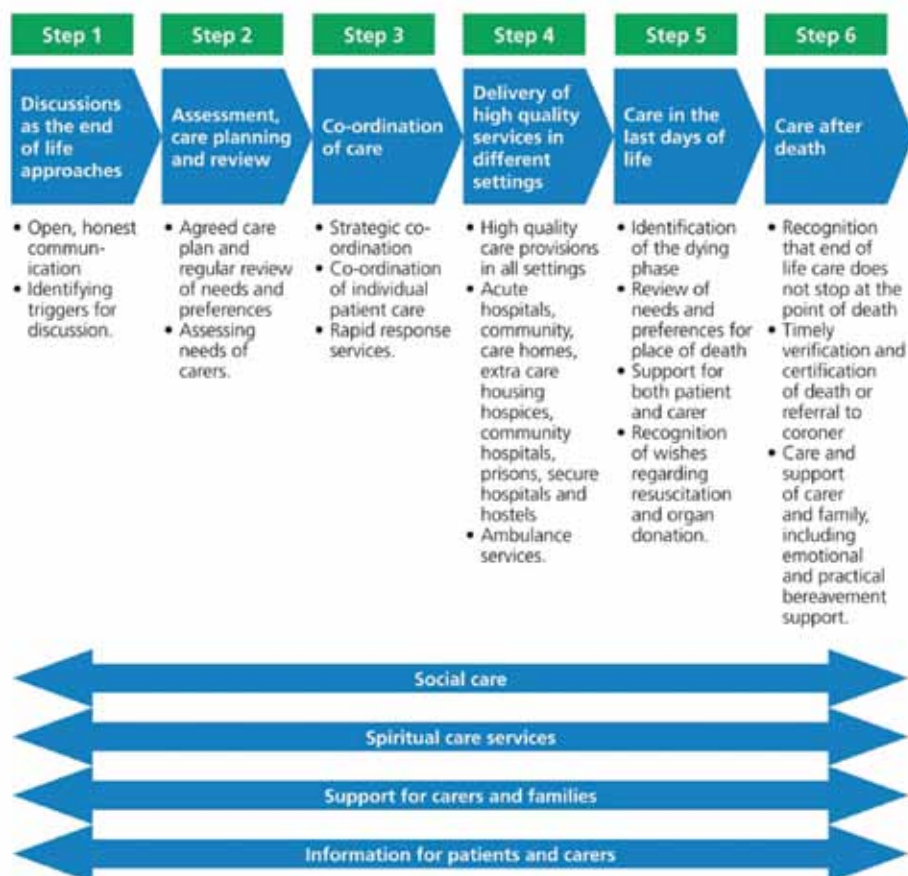


Figure 1. End of Life Pathway (Courtesy of National End of Life Care Programme and adapted from the End of Life Strategy 2008).

These basic premises are common sense and apply to all of us. To quote Benjamin Franklin, 'Nothing is certain except death and taxes'. We are all going to have to face death and we would want the quality of care we receive to be excellent. Not only do we want this for ourselves, we want it for our loved ones. Many of us would like to be able to choose where we die, with the majority of us choosing home. The challenge for the National End of Life Strategy has been turning these common sense and very human principles into practice.

Has the Implementation of the National End of Life Strategy Succeeded?

There is now increasing evidence to show that there is a shift over time in decreasing numbers of people dying in hospital⁷. This change has now been sustained on a year-on-year basis since 2008. It is hard to demonstrate clear causal evidence, from a scientific perspective, that this has been specifically due to the efforts of implementation of the National End of Life Strategy. However, the links between the efforts that have been made, along with new evidence from different components of the strategy, strongly suggest a causal relationship. One of the key markers of change in end of life care has been death in usual place of residence. Care homes are included as well as homes, as many people live in these care homes for significant periods of time. Others may spend their last weeks of life in a nursing home and may choose not to be transferred to hospital for terminal care.

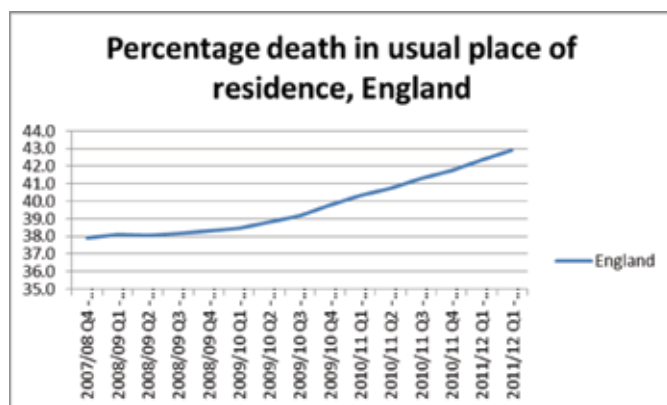


Figure 2. Quarterly percentage deaths in usual place of residence 2007-2012.

These figures indicate that the varieties of interventions that have taken place in end of life care are having an impact on where people die. At the same time, the national VOICES survey of bereaved relatives⁸ has been published, and a baseline has been set to try and gain an insight into the quality of care that has been given. The survey will be repeated on an annual basis. The reports are geographically divided up into cluster clinical commissioning groups. This will help to provide new commissioning bodies and health and wellbeing boards, with both qualitative and quantitative information on end of life care.

How has this change in end of life care taken place? The National End of Life Programme has helped coordinate information on end of life care and has commissioned the National End of Life Intelligence Network to gather together multiple sources of data on end of life care, which has provided a unique insight

into both what has been happening and monitoring of change⁹. The National Programme ran a project to see if EPaCCS were an effective way of coordinating end of life care. Eight pilot sites across the country were involved in this two-year project, with the production of a report which offered great promise for these systems¹⁰. Work is ongoing and the latest figures from a variety of different centres indicate hospital death rates are low for patients who are on an EPaCCS at time of death. These figures are valid for cancer and non-cancer patients with chronic life-limiting disease, including heart failure, COPD and dementia. Some centres have had EPaCCS running for more than two years. We are now starting to see results from various centres with many thousands of patients dying in their place of choice. Data from 3171 patients who died and were on an EPaCCS in the South West has shown an overall hospital death rate of 10% (unpublished). The current national figure is 53%. This data included 990 non-cancer patients. Outcomes of this data are due to be published in early April by the National End of Life Programme in a report on the economic evaluation of EPaCCS.

The financial implications of the shift from hospital death to death in usual place of residence are significant. Estimates of cost vary. Cost of hospital care in the last year of life has been estimated to be £3500¹¹, with a reduction of seven days spent in hospital. Community care has been estimated to be somewhere between £500 and £1500 cheaper than hospital care. There are approximately 600,000 deaths per year in the UK. If the hospital death rate shifts from 53% to 40%, using a figure of £1000 saving per patient, the reduction of cost to the NHS would be £78,000,000.



Over the last year, the Programme has focussed on transforming end of life care in acute hospitals. In the first year, 26 acute hospital trusts were part of the pilot. The focus of this programme has been to encourage the use of five key enablers that are considered to be a fundamental part of end of life care in hospitals. These are: identification of people who could be in the last year of life; use of advance care planning; use of the AMBER care bundle (a decision-making tool for ceiling of care in patients who are deteriorating and have an uncertain outcome, possibly dying within one to two months); rapid discharge home to die pathways; and use of an integrated care pathway for the last 48 to 72 hours of life, such as the Liverpool Care Pathway. A report on the outcome of the first year of the Transform Programme is due to be published in March 2013 and in keeping with other interventions that have taken place in end of life care, the progress made is encouraging.

Practical Implications for Clinicians

There are significant challenges for clinicians to change their practice if end of life care is going to continue to develop. Successful implementation of the end of life strategy involves the whole health community. Developments in each area, including community services, acute trusts, ambulance services, district nursing services, out of hours services and hospices must be linked together and coordinated. This means that clinicians need to think about how their service relates to the broader provision of end of life care. Thus for GPs, overseeing identification of patients who may be in the last year of life, use of advance care planning and EPaCCS, as well as ensuring that end of life drugs are in the home for the final days of a patient's life, are all part of what needs to be done. In the same way, hospital clinicians need to be alert to identifying people who may be in the last year and to work out how they can hand this information on to primary care in an effective way. All clinicians who look after these patients need to develop their communication skills, so that they can work out sensitive ways of engaging in advance care planning discussions with patients and families. Hospital consultants need to be able to oversee this process for their teams, and to be able to participate and communicate what has been done to the broader health community. Particular challenges face those clinicians looking after patients with long-term conditions, including heart failure, COPD, dementia and frailty, as these are the areas where improving care will have the biggest impact moving forwards. Palliative care services have led the way over the last 40 years in looking after cancer patients at end of life. Hospital death rates for non-cancer patients are still high, varying between 60% and 70%. Some centres have hospital cancer death rates of less than 35%. Whether it is possible to achieve the same levels of non-cancer deaths outside of hospital as for cancer remains to be seen, but much of the progress is encouraging and it looks as though a significant shift from where we are now is possible.

What we do know is that if we are going to progress end of life care, clinicians across the whole health community need to be involved. Individual clinicians need to ask themselves, are they aware of what is

happening with end of life care in their locality and how can they participate with their patients? Until we are sure that all of those patients who would like to have had the opportunity to discuss end of life wishes have done so, we will need to continue to redouble our efforts. The changes in end of life care are so widespread that every locality has made some progress, so linking with these efforts will be effective.

What does the Future Hold?

End of life care is part of the NHS mandate¹². It is specifically mentioned as a key area for the NHS Commissioning Board and will be led by Dr Martin McShane as part of domain 2, long-term conditions, as one of the five domains covered by the NHS Commissioning Board. Currently, the National End of Life Programme is ensuring continuity of a successful implementation programme of the National End of Life Strategy by forming transition arrangements over the next year. This will help to ensure that the good work of the programme continues into the new structures of the NHS over the forthcoming years.

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Julian Abel

Julian is a consultant in palliative care at Weston Area Health Trust and Weston Hospicecare. Between 2008 and 2013. He has been part of the Transform Programme for improving end of life care in acute hospitals and works closely with the National

End of Life Care Intelligence Network on a number of projects.
Email: julian.abel@nhs.net