DELIVERING BETTER CARE AT END OF LIFE

The next steps

Report from the Sir Roger Bannister Health Summit,
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TheKing'sFund>

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Foreword

Just over a year ago, in July 2008, the Department of Health published a strategy for improving the care of patients at the end of life. It was a far-sighted move and for the first time it set out a vision for what the NHS in England was expected to provide for its most vulnerable patients. It was recognition too that the business of health care tends to concentrate on making people better and too often regards death as a failure. There was an acceptance that in this area, to put it gently, care and treatment was not always as good as it could be.

As the strategy itself acknowledged, though, this was just the start. Death and dying remain taboo subjects and there are plenty of other priorities occupying the minds of politicians, managers and clinicians. This is likely to be even more the case over the next few years when budgets tighten and local systems respond to a host of immediate pressures to save money. The risk is that the strategy becomes no more than a great vision, that the world moves on and the brief moment when end-of-life care became the focus of attention passes.

The Sir Roger Bannister Summit held at Leeds Castle in November 2009 was one of a number of initiatives to make sure that end-of-life care remained at the centre of policy and practice and that the efforts to implement the strategy were given focus and direction. This report sets out the ten critical actions which those attending the summit felt were vital next steps in taking this work forward.

The summit was attended by senior policy-makers, clinicians, academics, managers and carers from statutory, third and private sectors. There was universal support for the strategy and a determination to do everything possible to maintain the profile of end-of-life care and bring about significant improvements on the ground. It was accepted that this would require changes in attitude as well as in organisation and practice. There was concern that the momentum could be lost, but also excitement at what was possible and a belief that the economic as well as the moral case could be made for better care. The way we care for those at the end of life defines the nature of the health and social care system we provide – and in a sense defines our society and its values.

The King's Fund is enormously grateful to all those who took part with such enthusiasm and commitment and who contributed to this report – the insights are theirs, the mistakes are ours. We also wish to pay thanks to the Leeds Castle Foundation for their generosity in hosting the summit and to the staff for their professionalism and support.

We very much hope that this report will be a useful document, one that helps policy-makers to look again at the levers that will help create new and more effective models of care and the incentives to drive reform. Just as important, we want it to be used by commissioners and providers, by managers, doctors and nurses as well as by patient and carer groups and everyone interested in seeing that every patient at the end of life has the best possible care and support. The task ahead is considerable but levels of awareness are increasing and that is an important first step.

Niall Dickson
December 2009

Introduction

In 2008 the government published the national End of Life Care Strategy for England (Department of Health 2008a). It is an ambitious document, which aims to bring about a step change in access to high-quality care for everyone approaching the end of life, wherever they are being cared for. It also seeks to ensure that patients can exercise meaningful choice about where they are cared for and where they die.

Shortly after the publication of the strategy, the government published *End of Life Care Strategy: Quality markers and measures for end of life care* (Department of Health 2009). End-of-life issues were also prominent in Lord Darzi's review of the National Health Service and in the strategic health authority (SHA) plans that accompanied it (Department of Health 2008b). These developments, combined with efforts to raise public awareness, have significantly increased the profile of end-of-life care in England.

Despite this, there are significant challenges in implementing the strategy. First, there is a marked reluctance in our society to talk about death and dying. Second, the strategy is being implemented just as the number of deaths is predicted to rise, putting additional pressure on those who deliver services. Third, health spending is likely to be tight over the next few years while at the same time the demands of the population for care at the end of life are likely to change.

Death and dying are often seen as the 'last taboos', and this reluctance to discuss death, dying and end-of-life care reduces the likelihood that patients and their carers will be able to have open and honest communication with professionals about their prognosis, care preferences and options for the future. A recent poll of GPs by The King's Fund (The King's Fund 2009a) found that family doctors were often reluctant to consider their own end-of-life needs. These GPs also recognised that such reluctance could affect how they related to patients and how they dealt with death, dying and end-of-life care.

The End of Life Care Strategy recognises the need to shift public perceptions, and the Department of Health has asked the National Council for Palliative Care to take this forward. The council has established the Dying Matters Coalition, which aims to raise awareness and change behaviours to make dying well a normal part of living well.

Research undertaken by Barbara Gomes and Professor Irene Higginson suggests that the annual number of deaths is expected to rise by 17 per cent between 2012 and 2030. People will increasingly die at an older age, with the percentage of deaths among those aged 85 and over expected to rise from 32 per cent in 2003 to 44 per cent in 2030. Those who die at an older age are more likely to be suffering from complex multiple morbidities, and addressing the issues this raises will be a major challenge for both commissioners and providers of care. Although much has been made of the ageing population, the additional deaths and the major impact of co-morbidities has not been fully appreciated in long-term policy planning or economic forecasting.

Offering patients the choice of where they would like to receive end-of-life care is an important feature of the national strategy. Research shows that approximately two-thirds of people would prefer to die at home, yet the percentage of deaths at home fell from

31 per cent in 1974 to 18 per cent in 2003 and has fallen at a higher rate for those aged 65 and over, for women, and for patients with non-malignant conditions (Gomes and Higginson 2008). There is significant and as yet unexplained geographical variation in the rates of deaths at home, but overall forecasts project that if recent trends continue, then by 2030 fewer than 1 in 10 people will die at home.

These projections underline the urgent need for planning to accommodate a large increase in demand for end-of-life care. From 2012 onwards, there will be a need for a substantial increase in either inpatient facilities or community services. Much of this will need to be provided without considerable additional investment.

After significant real growth in NHS funding this century (averaging nearly 7 per cent per year in England up to 2010/11), future prospects are challenging. Research by The King's Fund and the Institute of Fiscal Studies mapped out three possible scenarios for future funding (Appleby *et al* 2009). Under the less optimistic one the gap between what the system needs and what it will receive could be up to £30 billion, or 30 per cent of the budget. Even the most optimistic scenario suggests that productivity would need to increase by around 3.4 per cent per year for six years to compensate for the gap in funding.

Policy choices have to be made over public spending, and the current state of public finances means that these will involve difficult trade-offs. A significant barrier to making sensible decisions in this area is the lack of knowledge about what is currently spent on end-of-life care, as identified by the National Audit Office (2008). Evidence from Canada suggests that between 18 and 22 per cent of health care costs are associated with end-of-life care (Fassbender *et al* 2009) and it is likely that the proportions in England will be similar.

It is clear then that those tasked with implementing the end-of-life strategy face significant challenges. To help with this, The King's Fund organised a summit, bringing together a wide range of individuals with responsibilities in this area, including those responsible for devising the strategy, other senior policy-makers, clinicians, managers, officials and academics. The aim was to build on the national strategy, consider whether key actions could be identified to take forward its implementation, and to inform future policy changes. A list of participants appears in the Appendix (*see* p 48).

The summit considered papers from clinicians, managers and academics. These are reproduced here, and followed by a report of the subsequent debate. This identified ten critical actions to help the successful implementation of the national strategy. We very much hope that commissioners, clinicians, managers and policy-makers will act on this report by using the recommendations in future care planning and delivery for patients who are nearing the end of life.

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PART 1
PAPERS FROM THE SUMMIT

1 Challenges for progress on the End of Life Care Strategy: The agenda for 2010

Dr Rachael Addicott, Senior Research Fellow, The King's Fund

The End of Life Care Strategy (Department of Health 2008a) has radically raised the profile of end-of-life care in the United Kingdom, prompting considerable deliberation on the need for service improvements in the organisation and delivery of end-of-life care, to ensure high quality and equitable care for patients approaching the end of life. The aim of the strategy is to provide a step change in access to high-quality care for all people approaching the end of life, in all care settings, to ensure that patients can exercise meaningful choice in where they are cared for and where they die.

The issue of preferences has largely driven the development of end-of-life care policy, at both a local and national level. Research suggests that the majority of individuals would prefer to die at home, while in reality far fewer achieve this preference (Higginson 2003). Aware of this variance, a great deal of policy and literature has sought to ensure that end-of-life care services are appropriately configured and delivered to ensure that a greater number of people can be cared for in the place of their choice (often assumed to be home). Consequently, much literature and policy has attempted to identify gaps in existing service provision, and to make recommendations on how services should be developed to better meet people's preferences.

Building on existing research and evidence of good practice in end-of-life care, the End of Life Care Strategy (Department of Health 2008a) adopts a whole-systems approach by outlining an end-of-life care pathway, which is intended to guide both the commissioning of end-of-life care, and its delivery. The impact of cultural barriers in end-of-life care is acknowledged in the strategy – death and dying are not openly discussed in society. Health and social care professionals can find it similarly difficult to initiate discussions with patients about end-of-life care, and in some instances death may be perceived as a failure. As the strategy rightly suggests, this cultural barrier prohibits effective care planning, and consequently the potential for people to exercise choice as they approach the end of life.

The strategy is reasonably specific about the services and mechanisms that are required to be in place to support people at each stage of the pathway. These include, for example, development of an agreed care plan subject to regular review, availability of rapid response services, and use of the Liverpool Care Pathway (or equivalent) to organise care in the last days of life. The strategy additionally recommends that significant workforce developments will be required to enable and support professionals in delivering the improvements it outlines, particularly in identifying and discussing with patients their needs and preferences in relation to end-of-life care. Emphasis is given to generalist staff, for whom end-of-life care is only a small aspect of their work. Co-ordination is also a key theme of the strategy, both at a service level, and also in terms of ensuring strategic co-ordination across organisational boundaries.

The End of Life Care Strategy recognises the inequalities that exist in access to end-of-life care, notably for patients with a non-cancer diagnosis. It is built on a range of existing

evidence, including policy documents and national standards. Clearly, end-of-life care policy had developed within the context of wider health and social care policy. Hence, the strategy is clearly aligned with the quality agenda prevalent particularly in *High Quality Care for All* (Darzi 2008), and the world class commissioning vision (Department of Health 2008b).

The King's Fund's research in end-of-life care has highlighted some of the continuing challenges in the provision of high-quality care. Primarily these challenges have fallen into two broad themes.

- **Identification of end-of-life care needs.** Findings have demonstrated that disease trajectories are often unpredictable, and it can be difficult for clinicians to identify when a patient is nearing end of life. Such difficulties may be more pronounced for the generalist workforce, who have less experience with specific disease areas and prognostic indicators. If professionals feel unable to make (and communicate) a confident prognosis about when a patient is nearing the end of their life, they may refrain from making onward referrals to end-of-life care support, for fear of the resource and cost implications that may consequently arise.

- **Communicating with patients and care planning.** Interestingly, while some of our research findings demonstrated that clinicians do feel able to identify the point at which patients are nearing the end of life, some clinicians then fail to subsequently discuss that prognosis with a patient. This tendency would have an impact upon access to supportive services, which are reliant on clinical staff initiating conversations with patients regarding their prognosis and care preferences. Research findings suggest that some clinicians may refrain from initiating these sorts of conversations with their patients because they are simply 'difficult conversations to have'. Further, some clinicians involved in the research expressed anxiety about having discussions with patients about their preferences, as they were unsure whether they would be able to support patients in meeting these preferences given current resource constraints.

As there is limited interaction between specialist and generalist teams, knowledge and experience regarding prognostic indicators is not routinely shared. Generalist staff in particular have difficulties in identifying when patients would be regarded as nearing the end of life. As such, access to end-of-life care services is offered quite late in the patient journey.

Provision of equitable and comprehensive end-of-life care requires the support of a multitude of both generalist and specialist service providers. It is fundamental that these providers are supported to communicate and co-ordinate care on an ongoing basis, to ensure streamlined and high-quality end-of-life care for all patients.

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2 Driving improvements in hospice care – beyond the walls

Barbara Monroe, Chief Executive, St Christopher's Hospice, London

Dame Cicely Saunders' founding vision for St Christopher's Hospice recognised from the start that permeating mainstream health care services would be essential. The emphasis was on an adaptable philosophy rather than a building and on the importance of education and research to improve and promote good practice in all settings. The first hospice home care service was established at St Christopher's in 1969 and from its inception provided a 24/7 visiting service, today supporting more than 800 patients in their own homes.

The rapid adoption of the holistic hospice model has been remarkable. However, complaints about the care of the dying persist and it is clear that current approaches are insufficient to meet the widely acclaimed aims of the first national End of Life Care Strategy. Demographic and disease-related changes, with the additional challenges of an economic recession, mean that need and demand will inevitably outstrip professional and financial resources. Dying won't be got 'right' in and by hospices alone. The drive now must not be so much about improving access to specialist palliative care as about improving wider systems of health and social care for everyone approaching the end of their lives. However, hospices provide a unique repository of expertise that should be utilised, not marginalised.

Proposition 1

Hospices have a responsibility to support the development of a competent and confident generalist health and social care workforce.

Last year St Christopher's trained more than 7,000 health and social care professionals; about half attended courses in our education centre, the remainder joined outreach courses held elsewhere. Too much training effort has been focused on the specialist needs of a few. To redress this we have developed a three-day accredited course for health and social carers, which has now been attended by more than 400 professionals from this workforce, who are most in contact with dying people, yet to date have received almost no training. Supporting the dying is an area of work impacted by the attitudes, culture and personal experiences of paid staff. Face-to-face training opportunities – delivered by those rooted in current clinical care – are vital if practice is to change. It is often professional inhibition and anxiety that prevents the conversations that can help individuals to make informed decisions about their care and record their preferences. More than 300 health care professionals have attended our course on Advanced Care Planning; our Training the Trainers courses promote the approach more widely. Our Advanced Care Plan patient-held booklet, with a tear-out sheet to go in professional notes, is being piloted in GP surgeries and district nurse bases across our catchment area.

There needs to be a sustained focus on getting nursing back on track. Hospices have retained an excellent model of nursing that should be exploited nationally for training purposes. We run a five-day module for teams of senior non-specialist registered nurses from community and acute settings, combining largely experiential classroom learning with a clinical placement with one of our nursing teams. This is followed up with monthly action-learning groups in the participants' own workplace, led by the course facilitator. We believe that team training is vital to achieve culture change and to sustain practice improvement. Interestingly participants universally report having their enthusiasm for nursing rekindled, commenting, 'If we get nursing right we get care of the dying right'. None have seen raw staff numbers as a key inhibitor to positive change. The King's Fund is currently evaluating the model that we would like to see widely replicated by hospices nationally. To support this work we have built on the general principles of the National End of Life Care Programme's (2009) common core competencies and published a set of measurable practice objectives for non-specialist nurses and care staff (St Christopher's Hospice 2009).

Currently one in five people in the United Kingdom dies in residential or nursing care homes. With an ageing population this proportion will increase, yet evidence points to often poor care and inappropriate use of emergency hospital services. Hospices should be in the vanguard of efforts to support improvements in care homes, and with some determined collaboration by national lead bodies including the Care Quality Commission, National Council and Help the Hospices, a nationwide hospice care home support programme could be developed. St Christopher's is the first regional training centre for care homes recognised by the national Gold Standards Framework team. By April 2010 we will have trained 90 London care homes with nursing. Training courses alone will not achieve the necessary culture change, particularly given high staff turnover in inner city areas. Staff need coaching, mentoring and a regular presence over time from someone experienced in palliative care. Hospices are ideally placed to deliver this. We have a research programme examining which model of follow-up best sustains improvements in care. We are also evaluating other models of supporting care homes. We run consultation clinics in some homes, and each care home in our area has a named St Christopher's nurse to encourage care home staff to telephone the 24-hour advice line triaged from our inpatient unit. Many of these developments are jointly funded by the hospice and local primary care trusts (PCTs). We also believe that specialist resources can work harder when shared with other settings. For example, members of our arts and complementary therapy teams are delivering eight-week programmes for groups of elderly residents in care homes. Developments are sustained by teaching simple skills to the staff and by offering a training programme for activity co-ordinators.

Proposition 2

Hospices have a responsibility to deliver cost-effective, high-quality specialist palliative care, easily accessible to those most in need, and to provide a rapid test bed for evaluated service developments.

Hospice teams are comparatively well resourced, offering co-ordinated inputs from multi-professional staff who are accustomed to working together and confident in the field of death and dying. They should focus their direct care packages on the needs of the most complex patient populations; in our experience often those with a combination of difficult symptoms and pre-existing psychological or social vulnerabilities. One of the benefits of hospices' voluntary status is a lack of bureaucracy and short lines of communication, which means that ideas can be brought from concept to practice very rapidly. Service developments must be evaluated and hospices have a responsibility (seldom fulfilled at present) to test their viability in other settings to ensure they are

capable of wider cost-effective applicability. This imperative means the development of long-term relationships between the NHS, academic centres and hospices. These are more likely to be sustained if hospices form larger groupings. We recently completed a three-year research programme, funded by The King's Fund, into the end-of-life care needs of individuals with dementia in one PCT in our catchment area. We are confident that the model improves the care generalists deliver and is cost-effective. Only 8 per cent of the patients from the programme died in a hospital setting. We are now about to replicate the model across six London PCTs to test its wider applicability.

Hospices have rightly been challenged to deliver to a constituency beyond their own, inevitably small, patient numbers. To do so they must create more formal partnerships and consider mergers. Size is essential to reduce back office costs and to offer sensible standard contracts to commissioners for direct care services, clinical support of others and education. When we merged with another local hospice last year, shared support and clinical resources led to a 25 per cent reduction in its cost base. Specialist staff should be shared between voluntary and NHS providers, improving skill development and avoiding professional isolation. Only larger services can sustain required levels of continuity of community delivery and 24-hour visiting services at a cost that is viable in both economic and human terms. Hospice inpatient units can act as an effective triage for a wide range of out-of-hours enquiries from numerous generalist providers. Hospices could be commissioned to manage all community palliative care services in a given area.

Proposition 3

Hospices have a responsibility to use the social capital generated through their strong local community roots to spearhead efforts to change public attitudes and behaviours about dying and bereavement.

We are determined to use our inpatient unit as a flexible hub for community developments and have created an exhibition space, which we share with the local community for concerts, exhibitions and as a meeting space for local voluntary groups. We use the arts in a variety of ways: for example, in one project patient photographs were exhibited at the Dulwich Picture Gallery and in another patients at a local acute hospital and the hospice collaborated to produce giant canvasses now displayed in the main foyer of the hospital. Our schools' project involves 9–10-year-olds and 15–16-year-olds coming to the hospice to talk to patients about what it is like to be dying. Children and patients create artwork or life story performances together and then give a concert at the hospice to which parents are invited, opening the subject of death as a natural part of life to the wider family. A schools' pack is helping others replicate the programme on a national basis (St Christopher's Hospice 2008). The project is now being piloted in care homes. We also use our specialist expertise to provide a south London-wide service for any child bereaved through death; two-thirds of the referrals are for sudden death. Some of the young service users subsequently become peer supporters. Such examples of the extension of specialist expertise to wider community needs are becoming increasingly common in hospices. Hospices can act as a hub for volunteering in their local communities because of their high level of community trust and regard. For example, hospices could sustain and motivate groups of volunteers to work in care homes with training and supervision being provided from the hospice base. Equally, this trust could be used to facilitate the necessary public debate and understanding about the practice and priorities of end-of-life care alongside the availability of increasingly sophisticated and expensive therapies.

Hospices must not shelter beneath their individual identities as local charities. They must rise to the challenge of becoming vehicles for supporting the delivery of good care to dying people everywhere. This will need sustained national leadership. If hospices are

to deliver to their potential in implementing the End of Life Care Strategy, they must embrace the development of nationally agreed models of service delivery and planning, while maintaining their vital local responsiveness. If our aspirations are to be achieved, there must be more effective service integration at all levels and across all settings, and a determination on the part of the Department of Health and local NHS commissioners to find better ways of engaging with hospices and other providers to develop the longer-term relationships necessary for joint service innovation.

(For simplicity practice examples in this paper refer to St Christopher's work. Many hospices are undertaking such initiatives.)

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3 Commissioning end-of-life care: What success looks like

Bob Ricketts, Director of System Management and New Enterprise, Department of Health

Effective commissioning of end-of-life care should start and end with patients and those closest to them. So what should the outcome of world class commissioning be for them?

- personalised care planning, including advance care planning, that takes into account preferences and choices, and is culturally sensitive

- receipt of co-ordinated care and support, including information

- rapid access to specialist advice, clinical assessment, and high-quality care and support in their preferred place for care

- services that treat people as individuals, and with dignity and respect

- services that acknowledge patient and carers as part of the care team

- equality of access

- experience of services of a consistent high quality

- effective processes for the verification and certification of death, and care after death.

Taxpayers also have an interest. They expect end-of-life care services to represent value for money, with appropriate, high-quality care provided efficiently and in the right settings, and a robust measurement and demonstration of the quality and effectiveness of care.

From a broad commissioning perspective, this requires local strategic plans underpinned by robust financial and operational plans that set out how these aims will be achieved and the investment and timescales required. As end-of-life care services will, of necessity, span a range of needs (not solely health-related) and involve a range of potential service providers, strategic planning and service co-ordination needs to be undertaken jointly with partner local authorities, informed by sound joint strategic needs assessment (JSNA) processes.

Specifically, effective commissioning for end-of-life care should include the following key characteristics.

- **Be based on need.** They should draw on comprehensive JSNAs, and be heavily informed by feedback from users and their families. Effective and current user involvement is essential to specifying, procuring and managing contractually responsive, personalised, user-focused services. Third sector organisations – whether as advocates or providers – can give valuable insights into unmet, or partially met, needs.

- **Forecast demand.** This is essential to ensuring that credible, affordable service offers are available to people when they need them. This means – as part of JSNAs and contractual activity planning – being able to assess the probable need for services and key demographic drivers and plan capacity, allowing for the lead times in expanding or developing new community services.

- **Be based on partnership.** PCTs and local authorities should work together as effective strategic commissioners (see above), and commissioners should also develop long-term strategic partnerships with individual providers and networks of providers, including the voluntary sector, to develop sustainable, high-quality services. Integrated care models can work well for end-of-life care. Some of the 16 pilots in the integrated care pilot programme have this as a focus (Department of Health 2009a).

- **Be segmented.** The responsiveness to individual needs will vary by age (for example, the needs of older teenagers differ from those of older people), gender, the condition(s) from which they are suffering, cultural factors (ethnicity, but also life experiences and the extent of familial and social support networks), spiritual/religious beliefs, deprivation and pre-existing vulnerabilities. Commissioners and providers need to understand the needs, wants, aspirations and lifestyles of the people they serve – both individual patients, their families, and the communities within which they live. Social market analysis can play an important role in understanding better the different types of needs to be met, how these are distributed within communities, and appropriate settings for care and support.

- **Promote and assure equality of access.** As well as being sensitive to patients' culture and faith, strategic plans and commissioning strategies need to explicitly address equality of access. Sound equality impact assessments and the robust monitoring of usage and user satisfaction are prerequisites. This is also where close contact with community and advocacy groups is essential.

- **Build from pathway-based specifications.** Commissioners need to specify clearly what needs to be in place to deliver good quality end-of-life care for the populations they serve. A starting point should be the generic pathway in the Department of Health's national End of Life Care Strategy. Build on this by requiring providers to follow and use established systematic frameworks such as the Gold Standards Framework, Preferred Priorities for Care or Liverpool Care Pathway to optimise care delivery.

- **Embed choice.** Commissioning should enable informed choice based on individual need and preference. This means effective engagement of users and those important to them, ensuring that they are aware of the range of services and support that may be available, and that provider staff are trained and resourced to have early and sensitive conversations about death and dying, choice and personalisation.

- **Be serious about paying for quality.** In his speech to The King's Fund in September 2009, the Secretary of State for Health set out his vision of a people-centred NHS, placing quality at the heart of all that it does (Burnham 2009). Key to creating this is creating the right incentives – paying for quality. He said: 'We need to take a fundamental look at how we measure quality and create the right incentives to encourage it. Ara Darzi's *Next Stage Review* identified the common purpose – quality – and it is now time to put real bite behind it. In short, "payment by results" needs to do what it says on the tin – pay more for better patient experiences. Invest soundly in the right services for the best results.' Commissioners need to follow his lead – using appropriate national and local quality markers for end-of-life care (eg, percentage of people who have identified care plans and identified case managers, percentage of people dying on a recognised end-of-life care pathway, percentage of patients dying in their preferred place of care), embedding these in contracts, using commissioning for quality and innovation (CQUIN) to incentivise quality improvement, linking payment to user satisfaction, and – equally importantly – being clear about what constitutes poor service and 'never events' that will attract financial penalties.

- **Robust, focused contract management.** Securing and sustaining quality end-of-life care services requires active and focused contract monitoring management, particularly if commissioners wish to drive-up quality.

- **Shape the structure of supply.** Commissioners need to stimulate and support sustainable sets of providers with the requisite skill sets and resources. This may mean stimulating new partnerships and overcoming barriers to entry. For example, a commissioner may need to encourage existing providers to work together, or enable partnerships with new providers to provide effective home-based end-of-life care. Some existing providers (the local hospice, the foundation trust, community end-of-life teams, Macmillan Cancer Support or Marie Curie Cancer Care, social care) may have some of the necessary skills and resources individually, but they need to be combined in a new way to have best effect.

- **Invest in the right services.** High-quality, personalised end-of-life care should provide better experiences for users and their families, but also represent value for money. There is strong evidence that a lack of prompt access to services in the community leads to people approaching the end of their life being unnecessarily admitted to hospital. The absence of 24-hour response services, timely access to advice and medication, and difficulties of sharing care information with emergency and out-of-hours services, leads to unplanned admissions. To make the right investments, however, requires not just strong JSNA, an understanding of the evidence and best practice, effective capacity planning and so on. It also requires systematic market analysis – understanding the strengths and weaknesses of providers, as well as sound economic appraisal, including understanding the likely impact of service developments on all providers and across the health and social care system.

I have deliberately focused on the strategic commissioning of end-of-life care, but to make good, personalised care a reality requires building capability and aligning incentives and levers at three levels.

- **Patients as commissioners** – particularly as personal budgets develop. Choice-led services required users to be supported and empowered in making choices – this is something we've neglected.

- **Practice-based commissioners** – We need to find better ways of engaging GPs and other primary care staff in the commissioning of end-of-life care.

- **PCT and local authorities as commissioners** –The End of Life Care Strategy highlights the importance of strategic commissioning; for PCTs, world class commissioning development and assurance will be key to building capacity and capability. To help commissioners the Department of Health plans next year to develop and publish a commissioning pack for end-of-life care to help them commission high-quality, pathway-based services.

This will take time, but in the meantime there is no excuse for commissioners and providers not 'getting on with the basics' and ensuring real change is delivered through contracts next year. As an aide memoire, many of these are set out in the guide for transforming end-of-life care, *Transforming Community Services: Ambition, action, achievement* (Department of Health 2009b), which we expect to be embedded in contracts from April 2010.

Important note: the views expressed in this paper are those of the author, rather than a statement of Department of Health policy.

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4 Driving improvements in the community
Delivering end-of-life care: The challenge for providers working together

Dr Cathy Burton, Clinical Champion, Modernisation Initiative End of Life Programme and Macmillan GP Adviser

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End-of-life care encompasses care given in all settings to any adult with advanced incurable illness in the last year(s) of life and includes care given to families and carers before and after the patient's death. The standard of end-of-life care in the community can be very variable.

Challenges

Despite GPs being required to maintain a register of all patients at the end of life under the Quality and Outcomes Framework, the number of patients on GP palliative care registers varies significantly, and there is no evidence to indicate the proportion of patients for whom the end-of-life phase can be identified prospectively. GP registers are more likely to be populated with patients with cancer than with the frail elderly or patients with dementia, which potentially leads to poorer end-of-life care for these latter groups.

Many elderly frail patients and those with dementia are deemed not to have specialist palliative needs, and their care is often provided by generalists. It can be argued that the end-of-life pathway and the needs of the elderly frail, those with multiple co-morbidities and those with dementia, differ from those of patients with cancer or organ failure and good care requires a different approach with these patients.

There is uncertainty and confusion about the definition of palliative and end-of-life care. Clinicians are reluctant to label patients and to switch their mode of thinking from treatment/cure to palliation. There is often a lack of skills and confidence in having discussions with patients and carers about the end-of-life register and what it means. This is compounded by difficulties in providing an accurate prognosis. For some conditions such as the elderly frail or patients with multiple co-morbidities we lack information on the positive predictive values of the triggers used.

There is evidence of poor teamworking in terms of failure to share information and to understand each other's roles and responsibilities. Domiciliary care providers are not normally included in any discussions or involved in teamwork with health care. In addition, a lack of shared understanding between professionals about the meaning of terms such as 'on Gold Standards Framework (GSF)' leads to reluctance to share information.

There is anecdotal evidence that some generalists feel de-skilled and uncomfortable with end-of-life care and that they hand over responsibility for patients at the end of their lives

to specialist palliative care. This trend has been exacerbated by the high priority given to other conditions such as diabetes in the GP Quality and Outcomes Framework and the relatively small numbers of dying patients a GP will treat in a year.

There are also difficulties in diagnosing the dying phase. This uncertainty results in admissions to hospital that are in retrospect deemed to be unnecessary and to the continuation of treatment when it is no longer beneficial to the patient.

There is lack of consistency over what actions should be triggered once a patient is added to a palliative care register. In the absence of good planning and rapidly responsive community services, crises are more likely to result in avoidable and unnecessary admissions.

Solutions

The GSF provides guidance on identification using the surprise question – 'Would you be surprised if this patient were to die in the next 6–12 months?' – supplemented by prognostic indicators. A new focus is needed on standardising practice. Examples include the systematic review of patients on long-term condition registers in Bexley or the use of combined predictive model data in Lambeth to improve identification. If GPs audit their registers regularly, particularly with reference to those patients who died who were not on the register, this will lead over time to improved identification. Secondary care colleagues can support GPs in identifying patients with end-of-life needs.

The result of improved identification will be an extended palliative care register comprising people of differing levels of need. A suggested way of managing an extended list is to use a traffic light system, categorising patients as green, amber or red. Patients then move backwards and forwards between the levels because of dynamic changes in need and there is a need for mechanisms to be in place to identify transition points.

Entry onto the end-of-life register should trigger standardised actions including development of a care plan and identification of a lead professional who will be responsible for ensuring the care plan is acted on by the team looking after the patient, and reviewed at key transition points.

The foundation for teamworking needs to be in developing the generalist role and ensuring GPs and nursing staff are comfortable about, and supported in, providing end-of-life care.

Specialist palliative care has an important role in supporting generalists to become more skilled and confident in managing patients at the end of life. This can be achieved by building on the teamwork that brings GPs, community staff and specialists together in regular GSF meetings.

Multidisciplinary teamworking is a well-established context. At the centre is clarity of purpose, roles and standardised practice.

What this means in an end-of-life community context requires development and exploration. At the heart of our recommended concept is the development and strengthening of the generalist role and responsibility to act as a lead for end-of-life care. The lead or key role may change between district nurse and GP and in exceptional cases pass to specialists, depending on the patient's needs. Carers are co-leaders where possible. A model based on generalists is likely to be the most sustainable model of care.

We need to maximise the potential of social care staff, volunteers, and non-clinical staff as team members and learn from other models such as the Team Around the Child, mental health community teams and commercial examples.

Handovers are part of this model, including out-of-hours services and the supporting information and communication systems that assume the team is not co-located. In this system, the ambulance crew and the hospital provide the back-up care and transfer to different settings (hospice or hospital) if needed or wanted.

The proposed models require a concerted focus on the development of generalists. For GPs, there is a need to strengthen existing levers (local enhanced services, Quality Outcomes Framework) and this should include end-of-life care in the GP contract. The new framework for GP appraisal and revalidation, and end-of-life care inclusion in the core part of the medical curriculum, are other levers.

Commissioners need to ensure staff providing end-of-life care fulfil the necessary competency frameworks and that the role of specialists in supporting the development of generalists is recognised. There is a need to anticipate the potential for an increased number of specialist teams operating within communities that could have roles in end-of-life care. The standardised practice and roles, and the mechanisms to benchmark, need to be commissioned across all providers.

Further areas of research and development include:

- developing benchmarks to allow commissioners to monitor effective registers

- agreeing key performance indictors that monitor teamworking across the different providers (in part these should mitigate against separate budgets)

- understanding the predictive values of prognostic indicators.

Overall there are a number of challenges for providers working together. Some solutions are known and need to be implemented; the suggestions provided here build on these known solutions.

5 The function of quality markers: Measuring impact and outcome

Professor Edwin Pugh, Clinical Lead for End-of-Life Care, North East Strategic Health Authority

Background

The End of Life Care Strategy is about improving the quality of care and experience for all patients at the end of life, and their carers and families, regardless of their condition, setting, or social and personal circumstances.

End-of-life care is now recognised as a priority for care. Quality markers are important to allow objective monitoring, benchmarking and performance review.

Quality markers are aimed at commissioners, providers, strategic health authorities (SHAs) and regulators. They are seen to be a pragmatic first step to help deliver the end-of-life care strategy. They are guidance, not mandatory, and allow objective measuring of care given. In addition they allow comparisons between organisations.

Challenges

A mass of guidance on end-of-life care, including quality markers, has been produced in the last year. It is my impression that the volume and requirements of the national, regional and local documents has seemed relentless and at times overwhelming. Organisational systems and staff capacity to deal with the wealth of instructions and guidance have – in my view – been severely stretched in some places. Changes in NHS structuring and key personnel disrupt and inhibit improvements.

There are recognised to be gaps in the quality markers for certain aspects of care including bereavement and spirituality. It is hoped they will be addressed in the coming year.

It is also recognised that there are too few outcome measures. Those currently recognised include:

- place of death
- audits of care (National Care of the Dying Audit of Hospitals)
- surveys of bereaved relatives (Views Of Informal Carers – Evaluation of Services (VOICES))
- cancer peer review measures.

To ensure backing for the changes required to improve end-of-life care it is important to have clinician backing. This can only be achieved by involving clinicians meaningfully in the commissioning and strategic work.

Solutions

A manageable number of priority quality markers need to be agreed. Within the End of Life Care Strategy 10 quality markers have been highlighted as having the most potential to improve quality of care. It would seem sensible to concentrate on ensuring these receive priority attention. They are:

- having an organisational action plan

- identifying those approaching end of life

- offering those approaching end of life a care plan

- ensuring patient choices are documented and communicated

- ensuring carers' needs are assessed and recorded

- having co-ordinated care across organisations

- having 24/7 services in place

- ensuring workforce development in end-of-life care

- using the Liverpool Care Pathway or equivalent

- monitoring and auditing quality.

For commissioners a manageable number of priority quality markers needs to be agreed for inclusion in service level agreements. In addition a process to review the impact and the compliance of the markers needs to be set up. Providers under contract to the commissioners need to receive adequate resourcing to deliver.

Likewise for providers, a manageable number of priority quality markers needs to be agreed for the organisation, including those specified by commissioners. Organisational ownership is required, appropriate resourcing is needed and results of audit and outcomes should be shared with commissioners.

There may be quality markers that are a requirement of SHAs and regulators. For example, should all hospitals be required to take part in the national audit of the Liverpool Care Pathway?

Objective measures of quality should be seen as a collaborative venture between providers and commissioners. As such, results of audit and monitoring of the markers should be shared and discussed by providers and their commissioners. This will allow joint ownership and common understanding of any issues identified.

Benchmarking of common quality markers between organisations will allow comparisons to be made with the purpose of identifying good practice. Lessons can be learnt to improve practice where needed.

Development and research are needed to produce more outcome markers including meaningful feedback about care from patients and their families and carers.

6 Driving improvements in hospital

Professor JE Ellershaw, Professor of Palliative Medicine at the University of Liverpool

Currently the majority of deaths in England (56 per cent) occur in NHS hospitals and institutions (Office for National Statistics 2007). The changing demographic of our society will lead to an increasingly elderly population with complex problems and a significant impact on acute hospitals. If patients are to be primarily cared for in the community, and we are to meet the choice agenda for more people to die at home, there needs to be a reorganisation of services together with a fundamental shift in the culture of acute hospitals. Key areas of improvement for acute hospitals can be identified linked with the national End of Life Care Strategy (Department of Health 2008).

Discussions as the end of life approaches

It is important that health care professionals and patients have an open, honest dialogue regarding both the management and prognosis of the patient's disease. This discussion can be difficult and must be appropriate to the level of the patient's insight and also their need for information. It is important for health care professionals to identify triggers for discussion and to have the appropriate communication skills to deliver both sensitive information and at times bad news.

Assessment, care planning and review

The requirement for good communication in the hospital sector is vital if the community services are to be enabled to care for the patient appropriately. If the message given in the hospital is not consistent with that of the community it can lead to confusion and ambiguity in care. Key to this is good communication between primary and secondary care. A development that has been led by primary care but is now increasingly being developed and extended into secondary care is that of a supportive care register. Patients with a limited prognosis, often less than one year, are entered onto the register, triggering more frequent discussion and follow-up in the primary care setting (Gold Standards Framework or equivalent). Ideally the supportive care register should be communicated across sectors electronically and can contain elements of advanced care planning such as preferred place of care, the presence or absence of a resuscitation order, current medication and key health care professionals involved in the patient's care.

Co-ordination of care

It is important that there is strategic co-ordination of individual patient care. This means the development of appropriate responsive services. For example:

- a rapid response team that responds to emergencies in a patient's home to avoid inappropriate admissions

- effective discharge planning, co-ordinating both services and equipment effectively in the community, to facilitate the transfer of patients into the community with a corresponding decrease in acute hospital bed days

- the development of a rapid discharge pathway to enable patients who have a prognosis of hours or days to die at home (Department of Health 2008).

Delivery of high-quality services in different settings

The delivery of high-quality, end-of-life care services is necessary across all health care settings if co-ordinated care is to be achieved. A key provider of these services is the ambulance service which should be commissioned for end-of-life care services to avoid unnecessary delays and extended journeys that are inappropriate for the patient's condition.

End-of-life care and specifically care of the dying should be a core skill for hospital health care professionals. However, few have received training at undergraduate or postgraduate level. Repeatedly reports have demonstrated high levels of dissatisfaction and complaints regarding care of the dying in acute hospital settings. If this is to change, then training and education should become mandatory within these care settings with courses tailored to the health care professional's needs.

In every acute hospital there should be a specialist palliative care team that is constituted and delivers a service as identified in National Institute for Health and Clinical Excellence (NICE) guidance (NICE 2004). The team should be efficient, effective, funded appropriately and available 9.00am–5.00pm, 7 days a week. There should be 24-hour access to specialist palliative care advice for the hospital.

Care in the last days of life

Key to delivering good care for the dying is identification of the dying phase, that is, the last hours and days of life. At this point there should be a review of the patient's needs and preference for place of death and support for the carers. Recognition of the patient's wishes should take into account resuscitation and organ donation.

Symptom control and good communication skills are key to good care for the dying. The Liverpool Care Pathway for the Dying Patient (LCP) or equivalent is a programme that translates the key principles of the hospice model of care in the last hours and days of life into general health care settings. The LCP generic document is an integrated care pathway that supports clinicians in making important decisions regarding care for those recognised to be dying. Importantly the LCP programme needs to be reinforced through continuous education and training for doctors, nurses and other health care professionals.

Care after death

It is important for health care professionals to recognise that end-of-life care does not stop at the point of death. Verification and certification of the death should be completed in an appropriate and timely manner and referral to the coroner made, if required. It is paramount that appropriate care and support is given to the carer and family, including emotional and practical bereavement support. Acute hospitals should have services or access to services for bereavement support.
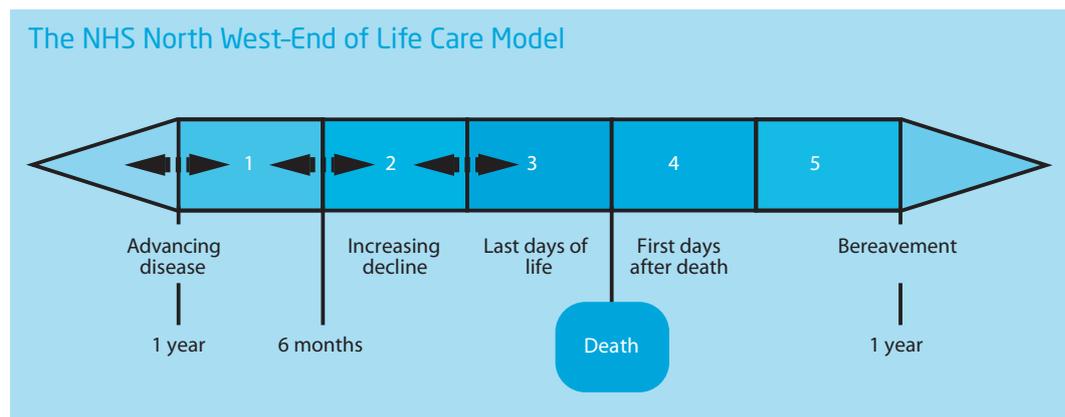
Key organisational levers for change

To enable improvements in end-of-life care every acute hospital needs:

- strong leadership supported by an end-of-life care steering committee, with executive representation, to develop and implement an end-of-life care strategy for the hospital

- mandatory training and education in end-of-life care for the workforce

- to monitor complaints related to end-of-life care and link to a service improvement programme

- involvement in the recently developed national quality markers (Department of Health 2009) together with the *National Care of the Dying Audit – Hospitals* (Marie Curie Palliative Care Institute Liverpool 2009). These are examples of quality improvement programmes that can support the development of end-of-life care services within acute hospitals.

Embedding such processes within the Care Quality Commission inspection could further enhance end-of-life care services in acute hospitals, ensuring a good death is the expected, not the exception, in our society.

Appendix

The NHS North West-End of Life Care Model

| Advancing disease | | Increasing decline | Last days of life | First days after death | Bereavement |

| 1 year | 6 months | | Death | | 1 year |

End-of-life care pathway

Discussions as the end of life approaches

- Open, honest communication

- Identifying triggers for discussion

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences

- Assessing needs of carers

Driving improvements in hospital

- Use of the surprise question

- Communication skills training

- Supportive Care Register communicated across sectors electronically

- Advance Care Planning

Co-ordination of care

- Strategic co-ordination

- Co-ordination of individual patient care

- Rapid response services

- Appropriate responsive services

- Discharge planning, including rapid discharge home to die

- Avoidance of inappropriate admissions

Delivery of high-quality services in different settings

- High-quality care provision in all settings

- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels

- Ambulance services

- Training and education

- Hospital specialist palliative care team which is:

  – efficient

  – effective

  – funded appropriately

  – available 9–5pm, 7 days per week

- 24-hour access to specialist palliative care advice

End-of-life care pathway

Care in the last days of life

- Identification of the dying phase

- Review of needs and preferences for place of death

- Support for both patient and carer

- Recognition of wishes regarding resuscitation and organ donation

Care after death

- Recognition that end-of-life care does not stop at the point of death

- Timely verification and certification of death or referral to coroner

- Care and support of carer and family, including emotional and practical bereavement support

Driving improvements in hospital

- Communication skills training

- Implementation and sustained use of the Liverpool Care Pathway

- Bereavement support

- Access to bereavement services

- Link with map of medicine

Key strategic levers

1. Quality Markers linked with Key Performance Indicators and the Care Quality Commission.

2. Training and education in care of the dying mandatory alongside CPR training.

3. Care of the dying should be incorporated in the clinical governance reporting framework.

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7 Demonstrating the value of new models of care and commissioning

Simon Kirk, Director of Strategy, NHS Sheffield

There is a historic imbalance between the specialist/hospital and generalist/home ends of the end-of-life care spectrum. One of the key roles of commissioners is to reduce avoidable and undesirable variations in care. What should commissioners do to enable them to commission 'a good death' for their populations?

Vision

In a 21st-century advanced industrial or post-industrial culture, the reduction of early avoidable death due, for example, to infectious disease, has been largely successful. Consequently death has arguably become something rarely considered or discussed. Public, patient and professional cultures appear to lack the ability to coherently articulate the meaning of death and dying and consequently what it means to have 'a good death'.

To begin to overcome this, commissioners have a significant role to play in describing a vision for services that could positively contribute to the experience of dying. Components of this vision would include:

- stating a commitment to integrated end-of-life care for all, irrespective of diagnosis

- defining high-quality end-of-life care as something that embeds best practice and is well co-ordinated for individuals

- confirming that end-of-life care should be something beyond the conventional boundaries of health care, something that:

  — is personalised

  — supports patients and their carers

  — meets the needs of individuals not least by enabling the exercise of choice.

Strategy

Analysis of the current situation of end-of-life care is likely to confirm that there is variation in the quantity, quality and accessibility of care services that could deliver the vision. It is proposed that commissioners should examine three particular propositions for the future organisation and delivery of end-of-life care. First, that primary care – notably general practice as care manager and commissioner – has to be central. Second, that workforce development requires attention at the local level because on a 'whole system' basis it is likely to be under-developed. Third, that public discourse needs clarity and openness, otherwise how will we know what people really want?

The commissioning cycle and end-of-life care

The commissioning cycle should by now be well understood. Working through the cycle, with patient and public involvement throughout, broadly requires the following actions when applied to the improvement of end-of-life care:

■ assess need

■ review current provision

■ decide priorities

■ prepare an overall service design

■ consider how to manage demand to ensure appropriate access to care

■ manage performance for quality outcomes.

Every commissioning cycle starts with a coherent analysis of need. The National Health Service is not lacking in national, specialist sector or local analysis with which to stimulate and support debate or from which to extrapolate. The need to undertake significant bespoke programmes of work is likely to be limited. A few recent examples of freely available national work on which commissioners should draw include *Identifying Alternatives to Hospital for People at the End of Life* (Foote *et al* 2008*)*, *The Standards We Expect: Choices for end of life care* (De Montfort University 2008) and *Improving Supportive Palliative Care for Adults with Cancer in Primary Care: A national survey of general practices* (NICE 2003).

More local analyses undertaken by commissioners might include an examination of:

■ the changes needed to support the service shifts necessary to improve the likelihood of death in one's own bed

■ whether there is an appropriate balance of specialist resources available

■ the education, training and development that is required to ensure everyone in the locality has the opportunity of a 'good death'

■ what needs to happen to ensure a co-ordinated journey along high-quality patient pathways, without compromising patient choice

■ the optimum priority order, process, and timescales for commissioning and provision tasks.

In addition, there is increasing interest in, and experience of, the use of social marketing approaches and techniques both to stimulate public and professional debate and to enable commissioners in particular to begin to elicit local public preferences in comparison with national survey data.

The purpose of commissioning should be to help ensure:

■ the explicit commitment of a local system to best practice (defined by evidence-based effectiveness and efficiency)

■ the creation and maintenance of an appropriately skilled workforce

■ the creation of a viable menu of options to make choices possible

■ a system that actually enables and promotes the exercise of choice.

Turning these aspirations into local service reality requires commissioners to undertake some specific actions, to take advantage of changes and developments in the broader non-

specialist, non-end-of life-care environment, to engage with the wider population, and to engage with partners beyond the traditional constituencies.

This is likely to broadly translate into a work programme that challenges commissioners to:

- focus procurement activity on the evidence base (the Gold Standards Framework, Preferred Pathways of Care, and the Liverpool Care Pathway)

- commission a viable menu of options that makes choices available to patients and their families

- take advantage of *Transforming Community Services* (Department of Health 2009) to help reshape the workforce

- test the options and shape public discourse by talking about death, dying, and what constitutes 'a good death'

- explore the potential for personal health budgets as a means of enabling choice, flexibility and perhaps better value for money

- remember and articulate that dying isn't primarily a health service issue, so that joint commissioning with local authorities is explored as well.

Challenges

The challenge for commissioners is to focus on commissioning as much as on procurement and performance management. The challenge for providers is to play their part in reshaping the system rather than primarily in defending their particular sectional interest. The three strategic propositions identified earlier thus translate into three challenges to existing service profiles:

- first, acknowledge and act on the reality that as a fact of life death is the business of primary care

- second, acknowledge that no service provider has or should have a monopoly on death and dying and that this is particularly the case when resources are scarce

- third, commissioners must pursue accountability for the quality of service through, for example, the Gold Standards Framework or through the Commissioning for Quality and Innovation payment framework for the Liverpool Care Pathway.

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8 The End of Life Care Strategy: 16 months on

Professor Mike Richards, National Clinical Director for End of Life Care, Department of Health

Introduction

It is now 16 months since the Department of Health published the End of Life Care Strategy. The strategy aims to bring about a step change in the quality of care provided to people approaching the end of their lives and to their carers and families. The strategy advocates providing greater choice for people approaching the end of life, particularly in relation to receiving care in their preferred location. It was anticipated that full implementation of the strategy might take a decade, but that some progress could and should be made quite quickly.

This paper briefly reviews why a strategy was needed, some key aspects of the strategy, early progress on implementation and the key challenges that will need to be overcome in the next few years.

Why was a strategy needed?

At least five good reasons underpinned the decision to develop a strategy:

- The quality of care in this country for people approaching the end of life and for their families and carers has been variable. There have been some excellent services (eg, in hospices), but large numbers of patients have received sub-optimal care. This has been demonstrated in recent years through reports by the Healthcare Commission and more recently by *Caring to the End*? a report by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD 2009).

- There has been inequality in service provision. Most specialist palliative care services and hospices have tended to focus on the quarter of patients who die from cancer. There have also been geographical variations in access to specialist palliative care.

- Surveys indicate that around 50–70 per cent of people would prefer to die at home and few would choose to die in hospital. In practice more than 50 per cent die in hospital.

- The number of deaths in England will rise substantially over the next 20 years, especially among the very old. We need to plan services for these people now.

- The profile of end-of-life care has historically been very low in the NHS and in social care. This has made it difficult to achieve change.

Key aspects of the strategy

The strategy has three key components, relating to actions that are needed at a societal level, at the level of the individual patient, and to enhance the infrastructure for end-of-life care within health and social care. It is important to emphasise that the strategy has

been developed within the current legal framework, ie, discussions relating to assisted dying are outwith the strategy.

At a societal level a national coalition for end-of-life care, Dying Matters, has been established under the auspices of the National Council for Palliative Care with funding from the Department of Health. More than 1,200 organisations or individuals have so far joined the coalition, with the aims of raising public awareness and changing attitudes towards dying and the care of the dying. A baseline survey to establish current attitudes has already been undertaken.

The strategy recommends a care pathway approach to ensure individuals receive good care. The pathway has six steps and three cross-cutting strands.

- **Step 1** involves identifying patients who are approaching the end of life (possibly within a year or two) and starting a dialogue with the patient about their preferences for care. In practice, this step is often not recognised or acted on by clinicians, thus impairing the prospects of a patient receiving the care they would want and need.

- **Step 2** involves detailed assessment of the patient's needs and wishes in order to develop a care plan with them. Care plans will, of course, need to be reviewed over time as preferences may change.

- **Step 3** relates to co-ordination of care. This has deliberately been included as a step in order that it is not forgotten. People approaching the end of life may need urgent care from a wide variety of providers including GPs, out-of-hours medical services, district nurses, ambulance services, hospitals and specialist palliative care services. Effective and timely communication between these organisations is essential.

- **Step 4** involves the delivery of high-quality care by all of the service providers and in all locations.

- **Step 5** relates to care in the last days of life, when comfort care is of paramount importance along with good communication between health and social care professionals and families.

- **Step 6** relates to care after death, that is, care for the patient's body and their effects and for families and carers.

Across the whole pathway patients may wish for spiritual care. Their families and carers may require support and both patients and carers will need high-quality information.

Early progress on implementation

Although it is only 16 months since publication, very significant steps have been taken on implementation at national, strategic health authority (SHA) and local levels.

Around half of all primary care trusts (PCTs) have identified place of death as one of the eight key indicators (out of a total of around 50) against which they will be performance managed by SHAs. This is almost as many as for indicators of mortality (eg, for heart disease and cancer). This provides encouraging evidence that PCTs are now starting to give some priority to end-of-life care.

All 10 SHAs have continued the good work that was started on end-of-life care as part of Lord Darzi's Next Stage Review (Department of Health 2008). End-of-life care is one of the eight designated clinical pathways. Clinical and managerial leads for end-of-life care have been appointed along with pathway groups. SHAs are responsible for funding the workforce development that formed part of the strategy.

Each SHA has identified particular priority areas for implementation in line with the national strategy. For example the North East SHA is putting a particular emphasis on a public health approach, with a charter for end-of-life care. The East of England SHA has a major initiative to promote choice at the end of life in association with Marie Curie Delivering Choice Programme. The South West SHA is prioritising the development of locality-wide end-of-life care registers. The South Central SHA has developed a cross-organisation Do Not Attempt Resuscitation (DNAR) policy.

At a national level our main objective is to support local implementation. At the Department of Health the End of Life Care policy team is led by Tessa Ing. Alongside this and looking outwards towards the NHS, voluntary and social care services a National End of Life Care Programme is led by Claire Henry. A Department of Health programme board (chaired by Mike Richards) is responsible for overseeing delivery. An external implementation advisory board has been established under the chairmanship of Thomas Hughes-Hallett to provide external support, guidance and challenge to the Department of Health team. Regular meetings are also held with the SHA leads to facilitate cross-boundary support and exchange of ideas.

At a national level several initiatives have been undertaken to support work on individual steps within the care pathway. On Step 1 we are working with specific groups of clinicians (eg, those involved in kidney disease) to tailor the pathway to the likely course of disease for specific patient groups. On Step 2 the national End of Life Care team has developed a simple guide *Planning for Your Future Care* (National Council for Palliative Care 2009), which has been very well received.

On Step 3 the Department of Health is funding eight pilot sites to develop locality-wide, end-of-life care registers. The participants in these pilots have also been brought together to exchange ideas.

One of the key requests from SHA clinical leads around the time of the publication of the strategy was that national standards should be developed for end-of-life care. In response to this, and working closely with the SHA leads, the Department of Health published *Quality Markers and Measures for End of Life Care* (Department of Health 2009).

The Liverpool Care Pathway (LCP) has become well-established as a means of supporting staff to care for patients in the last days of life. Although there has been criticism of the LCP in recent months, we remain committed to this provided that adequate training is given to staff and provided that the decision that a patient is likely to be dying is taken at a sufficiently senior level.

We recognise that relatively little action has been taken at a national level on care after death (Step 6), on support for families and carers (including bereavement care) and on spiritual care. These will be priorities for the coming year.

In relation to infrastructure development the national teams:

- have commissioned a major programme of e-learning modules

- have commissioned pilots of communication skills training specifically related to end-of-life care

- are working on the development of a national end-of-life care intelligence network. This will, among other things, provide better information on the costs and resources used on end-of-life care in health and social care

- are working on the development of a major survey programme which will ask bereaved relatives to provide information on the quality of care received by patients. This will enable us to monitor changes in the quality of care over coming years.

Key challenges

Multiple challenges need to be faced and overcome if the aims of the strategy are to be fully realised. However, I would identify two that have the potential to undermine progress unless successfully handled.

First is the challenge of professional engagement. Hundreds of thousands of NHS and social care staff deal in some way with people at the end of their lives. Many have had little or no training in this area. For many doctors death may be seen as a failure. Encouraging them to see that provision of high-quality end-of-life care is an important and potentially fulfilling role may be difficult, but is vital for the success of the strategy. We will need to work through royal colleges and professional leaders to change attitudes and to ensure that adequate training and support is provided. Regulators will also have an important role to play.

Second is the challenge of the financial downturn. This may be taken as a reason or excuse for inaction by commissioners and providers. We need to develop the evidence base to show that high-quality end-of-life care is highly cost-effective. Evidence to date suggests that shifts of care from hospitals to the community are likely to be broadly cost-neutral. Emerging evidence suggests that the cost of dealing with complaints related to end-of-life care is high. Would it not be better to invest in high-quality care and eliminate the complaints?

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PART 2
SUMMARY OF DISCUSSIONS

Discussion

Ten actions for implementing the National End of Life Care Strategy

1.   Demonstrate the case for change with evidence

There is an urgent need for more evidence, including information on cost-effectiveness and evaluations of new models of care, to give commissioners the confidence to change the way in which services are delivered locally. This will be helped by identifying examples of best practice from both national and international research, as well as from local evidence.

There has been little recognition to date within the health and social care sector of the impact of the projected increase in the number of deaths in England (Gomes and Higginson 2008). Given the challenging economic conditions faced by the NHS, it is possible that there will be little or no further additional spending on end-of-life care over the next several years. Commissioners and providers will therefore need to develop flexible and innovative models of care that are not reliant on additional funding. Commissioners need a more robust evidence base, which can identify high-quality end-of-life care that is also cost-effective.

Commissioners will be reluctant to pay for any additional services, or the redesign of existing services, without evidence that new models are both cost-effective and likely to produce significant improvements in quality. Although there is some data on patterns of death and other descriptive indicators, there is limited evidence on the cost-effectiveness or quality of different models of care to give commissioners the confidence to invest in service redesign.

Developing a good evidence base carries its own challenges, not least the difficulties posed in defining the end-of-life phase. There are further complexities in accessing and linking reliable data from acute, community and social care services. Attempts are being made to more systematically link together datasets of hospital activity (for example, Hospital Episode Statistics) and place of death information (held by the Office for National Statistics), but the result of this work will not be immediately available to commissioners.

While this evidence base is being developed, commissioners will need support and examples of good practice to guide and inform their decisions. In the meantime, there is a need to compile local evidence through audits or service evaluations and to share this with commissioners. In short, commissioners need to make decisions based on what is currently available rather than waiting for a national dataset. The National End of Life Care Programme, for example, has identified case studies from across the country that commissioners and care providers could use as examples of good practice to inform their planning (National End of Life Care Programme 2009).

In addition, the National End of Life Care Intelligence Network may be a useful conduit for gathering such knowledge, and should be able to use the information to identify

examples of good practice and cost-effectiveness and to compare activity and outcomes across different regions. Commissioners should be able to use and add to this body of local intelligence to inform confident decisions.

2. Commission for outcomes

The Department of Health should identify the appropriate levels of commissioning (GP, primary care trust (PCT), supra PCT) for different aspects of end-of-life care. Commissioners should then specify both the outcomes expected and the funding available, creating a conversation at local level with existing and new providers, including those from the independent and third sectors. The aim would be to empower providers to develop innovative solutions within this framework. In this way the focus would be on commissioning quality services that achieve defined outcomes within the available funding rather than finding the cheapest provider.

Commissioning appropriate end-of-life care is complex, and there is a need for greater clarity about the various levels at which it takes place. For example, community nursing and generalist care might be appropriately commissioned by practice-based commissioners or at PCT level, while specialist care may need to be handled across a wider network. The current model for cancer commissioning may be helpful to apply to end-of-life care. Whatever models are adopted they should acknowledge the introduction of personalised care planning and personal budgets, which should provide patients and carers with greater control over the management of their care.

The commissioner's role is to provide leadership to local systems, part of which involves creating a dialogue among local partners. The aims should be to develop a set of defined outcomes for care, and to provide guidance on the available funding. It would then be the responsibility of local providers to develop innovative solutions to deliver those outcomes within the resources available. The national End of Life Care Strategy provides a helpful framework within which commissioners and providers can develop local approaches that appropriately meet the needs across the population. The strategy encourages commissioners to engage in such an integrated model of commissioning and delivery, where all relevant providers are involved in the commissioning process.

There is an urgent need to stimulate, expand and diversify the market of providers, particularly in view of the projected increase in the numbers of people dying (Gomes and Higginson 2008). At the same time, the rise in the public's expectations about the level of care they will receive could be used by commissioners as a useful lever for change, though it will be important not to undermine confidence and trust by raising expectations that cannot be met.

One of the dangers of a tendering process is that it is based on price rather than quality – particularly when resources are limited. However, the ambition must be for commissioners to commission for quality and value rather price, and they should be held to account for how well they commission end-of-life care. There was general agreement that block contracts are not an effective way to manage activity, efficiency or quality in end-of-life care, and providers should be paid on a per case basis, despite the lack of an agreed national tariff.

Measuring outcomes in relation to end-of-life care is complex, as conventional measures such as quality-adjusted life years (QALYs) are not easily applied. However, it is possible to measure satisfaction levels of patients or carers, whether the patient had a care plan, and the extent to which the needs identified in that care plan were met. It is clear that more attention needs to be focused on monitoring the delivery of care to ensure that agreed outcomes are achieved. This issue is also addressed in critical action nine.

One of the obstacles to successful commissioning is the disruption caused to the NHS by administrative reorganisation. It takes time to build relationships and trust, and although the providers of end-of-life care have remained relatively stable, reorganisations among regulators and commissioners have been relatively frequent, causing anxiety and disruption.

However, fundamental change in the way care is organised and delivered is essential – and is what the strategy, and our critical actions, are intended to bring about. We need a solid base of knowledge of 'what works well' at a provider level. As such, building on critical action one, further research is needed to provide commissioners with a robust evidence base. This should include information on the proportion of patients for whom an end-of-life phase can be identified prospectively, and therefore the number for whom end-of-life services need to be commissioned.

3.   Define the local model of care

Patients are likely to experience the best standards of care and support if providers and commissioners work together to: establish the right models of care to meet the identified outcomes for their population; develop examples of good practice; establish clear protocols and ascertain a shared understanding of roles and responsibilities between all those involved in end-of-life care.

Patients who are nearing the end of their life invariably have a range of health and social care needs, which are not adequately met by a single provider.

While there is not – nor should there be – a 'one size fits all' model of joint service provision, whatever is shaped locally should at least have clear objectives with identified outcomes for the needs of the local population. It should bring together the different professionals with clear, agreed and delineated roles and responsibilities. As well as devising local solutions to deliver these outcomes, commissioners and providers will need to consider how the workforce is deployed and where the greatest needs are. These local solutions should be based on available evidence (see critical action one) and informed by examples of best practice.

There was considerable debate about the roles of, and relationships between, specialists and generalists. Almost everyone agreed that both have significant roles to play, but there was less clarity about how to make use of their respective skills. Indeed, the distinction between their roles was felt to be unclear at both national and local level. As a result, there may be misunderstandings between providers about who is providing what, resulting in gaps in the delivery of care.

The appropriate delineation of responsibilities will depend on the current composition of the local workforce (in particular, the availability of a specialist palliative care team). By establishing and agreeing a local model of care, and then delineating responsibilities, providers will be better able to exchange information, manage cases and identify gaps in the provision of care.

Such a co-ordinated model of care delivery is unlikely to form spontaneously where providers have limited history of working together. It is therefore important that those who have a longstanding interest or stake in end-of-life care could be the focus for building a new network.

4.   Identify care pathways and triggers for care

Specialist clinicians in specific diseases should work with their colleagues in palliative and primary care to define care pathways for patients with specific conditions. The aim

should be to improve the identification of patients at the end of life, understand their sometimes complex needs, and put in place appropriate triggers for care. Once patients have been identified, there should be a co-ordinated approach to the management of their care and a documented care plan. Such plans should include an assessment of the needs of their families and carers and arrangements for meeting those needs.

For end-of-life care to be consistent and effective, it is essential to identify when patients are nearing the end of life, though the difficulty in determining prognostic indicators is acknowledged. Specialist palliative care services have traditionally tended to focus on meeting the needs of patients who have cancer and predicting the likely course of the disease is more developed for these patients. However, only a quarter of all deaths are caused by cancer. Disease trajectories for those with long-term conditions, or the frail elderly, are often much less predictable and so it can be difficult to identify when they may be nearing the end of their life. Yet unless a patient is identified as being near the end of life, it will not be possible to establish their needs or to agree comprehensive care plans.

The role of general practice is critical, and more needs to be done to support GPs in identifying patients approaching the end of life. There is wide variation in the number of patients on GP end-of-life registers, which tend to be populated with patients with cancer rather than with the frail elderly or patients with dementia.

It was felt that it would be more helpful if triggers for care could be based on the needs of specific diseases. Having standardised protocols for the care of those patients might encourage clinicians to identify patients who needed to access services. These triggers and protocols should be discussed and agreed among relevant clinical groups and could form the basis for an identified care pathway for disease groups.

While it is important to identify when a patient is nearing the end of life, it is also important to have a system that is sensitive to the needs of the patient at any point in their illness. For example, it may be appropriate for patients with cancer or dementia to have various opportunities to discuss their preferences for care at the end of life from an early stage in their illness. One proposal is to use a 'traffic light' system, whereby patients' needs can be categorised at different times during their illness, for example, as high, moderate or low risk. This focuses on patients' immediate health and social care needs rather than on estimated time until death. A flexible model such as this can promote increased awareness of the end-of-life care needs of patients with long-term conditions or the frail elderly and would be more likely to encourage confident communication between patients and professionals.

It may be possible to encourage better use of end-of-life care registers (such as the Gold Standards Framework) by amending the Quality and Outcomes Framework (QOF) for general practice. Under the current arrangements, QOF rewards the establishment of a register, but not whether a care plan is in place for those on the register, and does not dictate how the information should be monitored or used to improve care. QOF has the potential to be a significant lever for improving care but it needs more sophisticated indicators of quality if it is to be effective.

Once pathways and triggers for care are defined and agreed, all patients identified as being near the end of their life should be able to discuss their prognosis and care needs with an appropriate clinician. There should be a mutually agreed approach to the management of their care and a documented care plan, regularly reviewed by clinicians, the patient and their carers. The plan should include the patient's preferences for care at the end of their life and their preferred place of death and would be used to monitor and manage their needs.

This approach requires effective communication and co-ordination between care providers. However, one identified provider should take overall responsibility for co-

ordinating and delivering that plan and for ensuring that patients' care preferences and needs are met and the needs of families and carers are taken into account.

5. Ensure timely access to care 24 hours a day

Local commissioners should ensure that every patient who is defined as being at the end of life can have access within one hour in whatever setting and whatever time of day or night to a person who is sufficiently trained and can meet their need for urgent care and advice.

The End of Life Care Strategy makes clear that patients who are nearing the end of life and their carers should expect rapid access to specialist advice and assessment at all times. The strategy acknowledges that insufficient access to 24-hour care can result in inappropriate emergency hospital admissions, but there is no published information on how far this access is available.

In many areas specialist staff in particular are available only during office hours from Monday to Friday, with patients receiving a different, and less comprehensive, response out-of-hours. The standard required is that the out-of-hours support should be comparable to that available during traditional office hours. The needs of patients and carers cannot be met in a standard 9–5 model of service delivery. However, not all of these needs will require visits by professionals to patients' homes or specialists available on hospital wards at all times. Sometimes, for example, telephone support will meet patients' needs.

Some areas may be too small to deliver comprehensive specialist nursing and palliative care services round the clock. There may be a need to consider organising care across areas, for example centralising across a county.

The establishment of 24-hour-a-day support for patients nearing the end of life in the community should be equally available for care home residents as for patients who are in their own homes. Specialist palliative care teams, particularly hospice-based providers, have a pivotal role here, though hospices should be commissioned only if they can provide support to local care homes and admissions 24 hours a day.

Community nursing services should also provide this level of care and nurses given the necessary training and support. District nurses, for example, should be trained to administer pain relief via syringe drivers.

Too often, when generalist practitioners are providing out-of-hours care they decide to admit patients to hospital. The challenge is to give these professionals the confidence to manage risk, particularly out-of-hours, and avoid making decisions to admit to hospital if that is not in the patient's interests. A comprehensive care plan that is agreed with the patient, their family and carers is one way of helping to achieve this. It is vital that professional staff have access to this plan – either through an information system or using patient-held records, or both – and also to expert advice and support when they need it.

6. Develop flexible solutions to meet a whole range of needs which include, but are not exclusively, health care solutions

If they are to create flexible and responsive services local commissioners and providers need to ensure that they have in place a range of services to meet social as well as health care needs. These may be delivered by statutory services or the independent or voluntary sectors and by mobilising support from families, neighbours and communities.

'What would it take to help you to die at home?'

Patients who are nearing the end of life are likely to have both health and social care needs and enabling them to die in their own homes will require local services that can respond flexibly and quickly to those needs. It is unlikely that a single provider of local services will have the competence or capacity to meet all these care needs, and it is vital that providers should work closely together to avoid duplication.

Current systems of care assessment and delivery can make responding to simple demands for practical support very complex and time-consuming. We need a system that allows pragmatic solutions to be funded and delivered without unnecessary bureaucracy or multiple assessments: 'good enough' timely care is often what is needed and that will occur only if it is unhindered by bureaucratic processes.

This also links to considerations of risk. As mentioned above, clinicians can find it difficult to talk to patients and their carers about choices and risk. The current system appears to be extremely risk averse, and does not necessarily encourage flexible solutions. For example, a wheelchair can be hired from a pharmacy and arrive in two hours, but without an occupational therapy assessment. Is this an acceptable solution if it allows a patient to be discharged to die in their own home? Or is it acceptable for a patient who is not medically fit for discharge, and indeed never will be, nevertheless to be discharged home swiftly with an appropriate package of support?

The End of Life Care Strategy encourages the development and sharing of innovative solutions to solve local care needs. There are many examples of flexible provision and commissioning across the country (National End of Life Care Programme 2009). Long-term strategic partnerships need to be established between PCTs and care providers to help ensure provision of flexible, sustainable, high-quality services. The advent of personal budgets should also stimulate the demand for flexible and individual solutions to needs.

Much can be learned from the extraordinary success of the hospice movement in this country and its ability to mobilise local support. Marie Curie is experimenting with the use of trained volunteers and others may want to look at their own local models to increase the unpaid workforce in this area. One idea would be to create a neighbourhood team, which might include a retired district nurse, a handyman, and young people to run errands such as shopping or picking up prescriptions. Local hospices, who are trusted in their communities, might act as hubs for this promotion and for mobilisation of community support.

7. Improve care in all settings

Most people want to die in their own bed and it is important to continue the drive to enable more of them to have that choice. At the same time it must be acknowledged that many will still receive care and die appropriately in places such as hospitals and other institutions and it is vital that sufficient attention is paid to improving end-of-life care in those settings. For example, the Department of Health should investigate how quality accounts and the classification of complaints about end-of-life care as critical incidents could be used as levers to monitor performance and drive improvements.

The End of Life Care Strategy aims to increase the percentage of people dying at home or in community settings of their choice – 'in their own bed' is the definition used by NHS Sheffield. This definition takes the emphasis away from traditional conceptualisations of housing, to incorporate care homes and other settings where patients may be living.

However, many people will die appropriately in hospitals. Many deaths occur unexpectedly during active treatment and local audits have shown that only around 60

per cent of those deaths could have been predicted. The National Confidential Enquiry into Patient Outcome and Death (2009) found that only 4.2 per cent of emergency admissions of people who died within four days of admission were inappropriate. Even in countries that have very high proportions of deaths at home such as the Netherlands, more than a third of people still die in hospital (Davies and Higginson 2004). So it needs to be recognised that patients will continue to die in hospitals and other institutions because: that is their preference; they have health care needs that can only be met through acute hospital treatment; their death was not predicted.

With the increase in numbers of people dying, and dying at an older age, we do need to ensure that we do not focus all investment on community provision, but also concentrate on improving end-of-life care in hospitals and other institutional settings.

There is a need in many hospitals to review standards of end-of-life care. This is underlined by the fact that most hospital complaints relate to this area and hospitals spend significant resources investigating and responding to such complaints.

However, hospitals should not be told first that they are not good at end-of-life care and then that they should not be doing it anyway as people should be able to die at home. Caring for patients at the end of their lives is a key issue for hospitals. Patients can be cared for well in hospitals and die well in hospitals, and there is evidence of good practice in areas across the country where services and environments have transformed end-of-life care (The King's Fund 2009b). Reducing variation and consistently improving the provision of end-of-life care in hospitals should be a priority for trust boards.

There is a range of levers that could be used for improving care in hospital settings. In the first instance, poor care at end-of-life should be treated in the same way as any other instance of poor care. For example, failure to provide sufficient pain relief should be treated in the same way as a dosing error, and treated with the same level of seriousness.

The Department of Health should investigate the role of quality accounts in promoting improvement in end-of-life care. Inclusion of end-of-life care in quality accounts could act as a significant lever in driving improvements in hospitals' care planning and delivery. The Care Quality Commission could also focus particular attention on quality of end-of-life care, particularly on efforts to encourage co-ordinated delivery across health and social care.

8.   Improve workforce skills and confidence

Educators and regulators should ensure that there is adequate knowledge of how to care for someone at the end of life, and training in communication skills at undergraduate and post qualification level for any professional who cares for patients at or near the end of life. Apprentice-style learning is likely to be helpful in conjunction with e-learning or campus learning for the development of these skills, and specialist palliative care providers and independent and third sector providers are particularly well placed to provide this training.

The End of Life Care Strategy emphasised the need for improvements in education and training and identified the minimum levels of skills and knowledge that should be held by different professionals (for example specialists, and those frequently and infrequently engaged with patients at the end of life). To achieve this, there is a need for greater commitment from all providers and commissioners to develop and improve workforce skills and confidence.

There is also a need to establish a more sophisticated understanding of how services can provide support for a patient's range of needs and how professionals can be helped to

communicate more effectively. The aspiration must be for professionals to provide the type of care to patients that they would wish for themselves.

Those delivering care should be able to talk to patients and carers about their prognosis, care needs and expectations with sensitivity and compassion, responding to the different needs and wishes of each individual about how much they want to know and when they want to know it. Too often professionals do not have such skills and confidence, and this should be a primary focus of training support and workforce development.

Given the range of individuals involved in the delivery of end-of-life care, innovative models of education will be required. The strategy promotes e-learning as a possible solution for reaching a large workforce, and this will be a significant lever for disseminating information to a large audience. However, developing communication skills in this sensitive area will also require open, face-to-face communication.

One approach would be to adopt an apprenticeship-style model, based on examples of existing programmes such as those co-ordinated through St Christopher's Hospice. This model uses mentors who have experience and knowledge and who can give others the skills and confidence they need. Where the local provision of specialist or dedicated care is not available to provide such support, clusters of organisations could come together to enable and spread this apprenticeship model (see critical action three).

At a national level, the royal medical colleges have a significant role in developing and disseminating good practice. Such protocols could be used to inform undergraduate training, and the General Medical Council could use the forthcoming revalidation procedures to ensure that clinicians are able to demonstrate ongoing competence in such communication skills.

A large proportion of care at the end of life is delivered by unqualified and low-paid staff. Giving them appropriate support and training will be critical if high-quality care is to be uniformly delivered. Again, employers across all the sectors involved in end-of-life care may provide a useful source of expertise and support for these staff.

9.   Ensure manageable and meaningful local measurement

There is currently duplication and confusion within the measures used to assess end-of-life care, many of which focus on processes not outcomes. We recommend using a small number of key performance measures relating to outcomes rather than processes, such as round-the-clock access, whether all patients nearing the end of life have care plans and whether those care plans are adhered to. There should be consistency between monitoring bodies including regulators, the Department of Health, and local commissioners, about the measures used.

The recently published *End of Life Care Strategy: Quality markers and measures for end of life care* (Department of Health 2009) provides a foundation for monitoring whether organisations are delivering on the End of Life Care Strategy. There are concerns about the fact that many of these markers are related to process rather than outcomes. However, the quality markers are continually evolving and should focus increasingly on all parts of the patient pathway, including spirituality and bereavement.

There are real dangers of overload, confusion and duplication when the requirements of the quality markers are combined with the demands of the QOF and quality accounts.

We do need to measure progress at a local level, but there are too many reporting requirements to provide a meaningful picture of progress against the objectives of the strategy. Greater consistency is also required across the different monitoring bodies to ensure that an agreed set of measures is collected systematically.

Instead, it might be better for regions to focus on a limited number of indicators, such as:

- do all patients nearing the end of life have access to care 24 hours a day, 7 days a week?

- do all patients identified as nearing the end of life have a care plan?

- are the preparations and preferences in the care plan adhered to?

These measures could be incorporated into quality accounts and QOF as a means of motivating action and ensuring accountability.

There is considerable lack of clarity on how organisations are held to account for raising the quality of end-of-life care at a local level, and what the implications of poor results might be. Whatever form it takes, reporting on these measures should be publicly available and transparent. Disclosure and sharing of progress should be considered to be developmental rather than punitive and used to motivate organisations to improve the quality of their care and to use examples of good practice from others to inform their own delivery. Accountability and sharing best practice will be critical for raising the standard of end-of-life care across England.

Greater clinical leadership and ownership were considered key for ensuring the backing of these changes and reporting requirements. A process needs to be established by which to review the impact of, and compliance with, the markers.

10. Completing the loop: has the national strategy delivered for patients and carers?

Analysis of the views of patients and their carers is essential for assessing progress in implementing the national strategy. National measures will use existing analytic tools including surveys of bereaved relatives and patient views, the National Voices survey and the National Care of the Dying Audit.

While the implementation of the End of Life Care Strategy and the National Implementation Group have focused on improving the provision of care and on workforce development, there is also a need to do more on care after death – support for families and carers (including bereavement support) – and on spiritual care.

In order to ensure that these emerging priorities, as well as existing ones, are being met, it will be necessary to continue a national review of evidence of patients' and carers' experiences. Completing the circle in this manner will ensure that service redesign and delivery is evidence-based (critical action one), that progress is continually monitored in a meaningful way (critical action nine) and that overall progress is making a real difference for patients and carers.

There may be no need at this stage for further data to be collected. Instead, information that is already available at a national level should be drawn together, considered and shared in order to identify whether the national strategy has delivered for patients and carers. Using nationally available data will ensure that there is consistent measurement across organisations and regions, and will provide the Department of Health with the information to assess whether the strategy has made a difference for patients and carers.

Organisations currently monitor the number of complaints they receive from patients and their carers, and it is reported that a high proportion of these complaints are in relation to care of patients at the end of life. It is proposed that the number of complaints relating to end-of-life care should continue to be monitored, to identify any shifts over time.

However, further consideration should also be given to the nature of these end-of-life care complaints and what they relate to. This will help the Department of Health to identify

improvements in specific areas of care over time, as well as continuing areas that require improvement.

The content of complaints could be monitored through local audit, and quality accounts could be used as a lever for ensuring that providers examine their delivery of end-of-life care (and resultant complaints).

Conclusion

Inadequate care at the end of life should not be acceptable in our society. A patient who is dying should have the best possible experience, be treated as an individual with dignity and respect, be free from pain and other symptoms, and, where possible, be in familiar surroundings with family and friends. A poor experience at the end of life can be devastating for both the patient and their families and friends.

The End of Life Care Strategy remains the guidance for improving end-of-life care services, with a compelling vision for the future. The task now is to address the obstacles and barriers to implementing that strategy; the actions identified at the Leeds Castle summit and set out in this report are intended to provide helpful levers to those making that vision a reality.

Given the rising numbers of deaths and the pressure on funding over the next few years, this is a formidable challenge. But it is no longer acceptable for death to be seen as the last taboo in our society.

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