NHS

National End of Life Care Programme

Improving end of life care

Supporting people to live and die well:

a framework for social care at the end of life

Supporting people to live and die well: a framework for social care at the end of life

Report of the Social Care Advisory Group
of the National End of Life Care Programme

July 2010

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Foreword

In July 2008 the End of Life Care Strategy for England and Wales was published, launching a comprehensive programme to transform the care given to people approaching the end of life, their families and their carers. The National End of Life Care Programme can point to many successes already in changing the culture of dying, and improving the services provided and skills and training of the workforce. Simultaneously, social care is undergoing a transformation. The vision set out in *Putting People First* is for services to work around the people who use them, the social care workforce having at its heart a commitment to work in partnership with service users and their carers, supporting the choices they have made for their care.

We are delighted to commend to you this framework for social care at the end of life. It brings together these two major policy thrusts in an ambitious initiative to enhance the quality of care and support for people who are nearing the end of life. Without the full engagement of social care in end of life care, the support provided for individuals and their families and communities as they approach the end of life will not achieve its full potential. Without recognition in social care services that many people may want to include end of life in their care planning, as well as a commitment to maintain quality of life throughout the end of life, the support that social care workers offer will similarly be less than it could be.

This challenge has been taken up by a senior group of policy-makers, managers, advisors, educators and researchers drawn from all sections of social care, as well as carers. We are grateful to them for the time, energy and commitment they have given to the development of this framework. This report confirms that social care, in all its branches, has a vital role to play in sustaining quality of life for people nearing the end of life and enhancing support for their families. It is now time for everyone concerned with quality of life at the end of life to take this further.

Professor Sir Mike Richards
National Clinical Director,
End of Life Care
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Glen Mason
Director of Social Care
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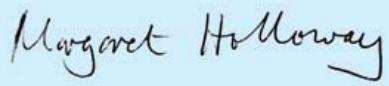
Department of Health

Preface

It is with a great sense of excitement and achievement that we present to you this framework for social care and support at the end of life. As joint social care leads on the National End of Life Care Programme, its development has been a major part of our work and the most encouraging aspect has been the enthusiasm with which this vision has been taken up, extended and endorsed by senior colleagues and leaders across the spectrum of social care. *Supporting people to live and die well* comes to you with the full and ongoing support of the programme's Social Care Advisory Group.

The launch of this framework is only the beginning, however. Achieving quality of life for people at the end of life requires commitment from every social care worker, whatever their role in the mosaic of care in place to support people living in the community. For those people receiving specialist palliative care in a hospital or hospice, the contribution of social care is never to lose sight of the person within their family and community, who is so much more than the 'patient in the bed'. Social care services are being transformed in pursuit of packages of support that are flexible and chosen by the people who use them. Nowhere is the concept of individualised care more applicable than in end of life care services and at no time in life is sensitive, person-centred support from skilled workers more needed.

The challenges are great. Annual numbers of deaths are expected to rise by 17% from 2012 to 2030. If present trends continue, fewer than one in ten of these people will die at home[1]. We will not as a society be able to rise to these challenges unless social care plays its full part. Social care is about supporting people in their daily lives with the choices they make. For some service users that increasingly includes preparing for their death. This is a fact that every frontline social care worker knows intuitively, but they may not always have the confidence to engage with the issues it raises. The framework, and the measures that will be put in place as it is implemented, are intended to provide a supporting structure within which the social care workforce - at all levels - can enhance knowledge and understanding and transform services to support people in the final phase of life. The framework identifies ten objectives, aimed at service development, education, training and support of the workforce, and the enhancement of the evidence base. These are the goals we will be working towards and upon which we will be consulting further as we roll out the framework regionally and nationally. We invite you to join us in this endeavour.



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Social Care Lead
National End of Life Care Programme

[1] Gomez B, Higginson IJ (2009) Where people die (1974-2030): past trends, future projections and implications for care. *Palliative Medicine*, 22:1, 33-41,

Executive Summary

Purpose and scope of this document

Our vision is for every individual and their family to retain their personal dignity, autonomy and choice throughout the care pathway towards the end of their life. To achieve this we need a well-trained and supported workforce, operating in the right kind of commissioning and assessment environment and unconstrained by the traditional boundaries between health and social care.

The Department of Health's End of Life Care Strategy and accompanying implementation programme is intended to change the 'culture' and experience of dying on three different levels: wider society's awareness, service user experience and the professional and service delivery infrastructure. This framework addresses the social care aspect of those changes. It signals a change in the way social care supports people at the end of life.

Context and background

We live in an ageing society with very old age lasting for an extended period of time, often moving imperceptibly into the dying phase. Family structures are increasingly complex, with traditional caring roles sometimes reversed. These are key factors shaping how we should provide end of life services. Social care (including the profession of social work) is well placed to respond to these imperatives.

Nevertheless, barriers remain to ensuring social care can play its full role here. The National Audit Office's 2008 report on end of life care services suggests a need for greater input from social care to address ongoing challenges.

There are also significant opportunities for positive change. The personalisation and re-ablement agendas, for example, can offer a more flexible, integrated and user-led approach to end of life care. The Social Work Reform Board and Qualifications and Credit Framework for social care both present opportunities to embed end of life care skills and competencies within social care.

Key objectives

This framework, developed by the National End of Life Care Programme (NEoLCP) with the involvement of a group of senior professionals and other stakeholders in social care, sets out a direction of travel for social care at end of life. Work is now needed in order to:

- Identify and raise awareness of the role of social care in supporting people at the end of life, among the public, social and health care workforce and management
- Facilitate commissioning and delivery of person-centred, integrated care
- Embed end of life care within commissioning and inspection frameworks and standards for practice
- Strengthen the specialism of palliative care social work
- Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life

- Promote early engagement with end of life care planning that builds on an holistic understanding of wellbeing
- Educate and train social care staff to deliver high quality end of life care
- Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care
- Promote supportive communities through engagement with a wide range of community services
- Work jointly with research commissioners and funders to establish a robust evidence base for good practice in social care at the end of life.

Recommended actions

The framework identifies actions for the NEoLCP and a range of stakeholders in order to:

- Initiate work to embed end of life issues within the public, professional and regulatory/legal domains
- Consult users and carers to identify needs
- Gather and disseminate good practice and evidence, including on the impact of re-ablement and personalisation
- Reflect end of life needs in local authority and primary care trust (PCT) performance indicators and quality markers
- Apply social work and social care assessment models to end of life care and integrate these with specialist health assessments
- Engage with all education and training providers across the social care workforce to influence curricula development and training opportunities
- Further develop the programme's Route to Success series of tools, engaging social care and health care together to address challenges in end of life care, including those associated with hospital discharges
- Establish a network of social care leads and champions across social care
- Encourage local authorities to support community organisations and initiatives in end of life care
- Promote better links between social and health care and other services at local level.

Next steps

This framework is an invitation to the social and health care communities - and other stakeholders - to work with us. We need to improve understanding of what works in practice, to develop new resources and tools and to build a network of champions who can drive forward the necessary changes.

The publication of this document will initiate a programme of stakeholder engagement and consultation at regional and local levels. Evidence of good practice will be gathered and disseminated and test sites established for the development and evaluation of new approaches, culminating in a review and - in due course - publication of a revised framework.

Key messages

1. Social care has a vital role to play in supporting people to live and die well, in the place of their choosing.

2. The social care workforce – from domiciliary care workers to social workers and their managers - may need training and support to recognise the skills they have to facilitate this and to develop further skills.

3. Social care services are undergoing a transformation in the ways in which they are conceived and delivered; social care at the end of life belongs to this agenda for change.

4. Social work education and training are undergoing significant change, and training and skills development for the whole social care workforce is a government priority; education, training and support for the social care workforce in end of life care must be embedded in these wider changes.

5. The personalisation and re-ablement agendas offer significant opportunities for improving the care that individuals and their families receive at the end of life. However, commissioning processes should also take account of the needs of people unable to take full advantage of these approaches.

6. Palliative care social work is an educative and consultative resource for end of life care in mainstream services, as well as making a valuable contribution in specialist settings; strengthening this service offers considerable potential for increasing social care capacity in end of life care.

7. Greater integration is needed across all care and support services, particularly social and health care, to improve the experience of dying for the individual and those around them. This includes tapping potential in the wider community (and other public services) to enhance quality of life at this stage.

8. There needs to be a robust evidence base to support the development of good social care practice in end of life care.

To begin with during the last week of mum's life the professionals - well meaning - suggested hospice care, carers, all sorts, as we were exhausted. Mum said no and we did not want to have to fight for what she wanted: to die at home. The professionals heard and saw what she and we wanted, supported every way they could and mum died at home, with her husband lying next to her, her children by her side and a cat at the end of the bed - each able to say goodbye and they loved her as she died, where she wished and with whom she wished.

This is a moment in time that informs all that I do and motivates me continually to ensure people are afforded the chances and choices they would want at the end of their lives. It is also about the last moments of those who love them and are having to watch them leave. A numbingly awful time, that with thought, care and commitment of all involved, can at least have dignity attached for all.
(Daughter, social worker)

SECTION 1

Context in which the framework has been developed

1.1 The changing demographic and cultural landscape

Changes to the demographic and cultural landscape have ensured that end of life care is afforded central importance in public policy: the fastest-growing population group is people aged over 85. We are seeing a prolonged period at the end of life in which levels of frailty, illness and disease are likely to increase, sometimes shading imperceptibly into the acute dying phase. Thus, quality of life in old age also extends to quality of dying. Services also need to be appropriate to the diverse communities that characterise the UK today.

People with serious illnesses and congenital conditions are living longer, while the numbers of those living with Alzheimer's and other forms of dementia are increasing. 'Survivorship' when living with serious and life limiting illness is an increasingly important dimension to end of life care. However, advances in medical treatments mean that many of these individuals can be cared for and die at home, if the right package of support and care is in place, including out of hours and 24/7 care services.

'Family' in the 21st century is a complex concept: essentially, it can be whatever the individual wants it to be. Family caring roles are varied and traditional roles may be reversed, with, for example, an adolescent caring for a parent or a learning-disabled adult caring for an older relative. For some people with learning disabilities the death of a parent may mean the removal of their primary support. Male carers may find themselves in unfamiliar roles that cut across family and cultural traditions and norms. Service users may give preference to the involvement of same sex partners over close relatives in decision-making processes. Assumptions about support from extended family in black and minority ethnic (BME) communities may be inaccurate in the context of greater social and geographical mobility. These ever-changing dynamics have important implications for the safeguarding agenda and for appropriate provision of care, as well as for older spouses and partners who are involved in care and may have their own social and health care needs.

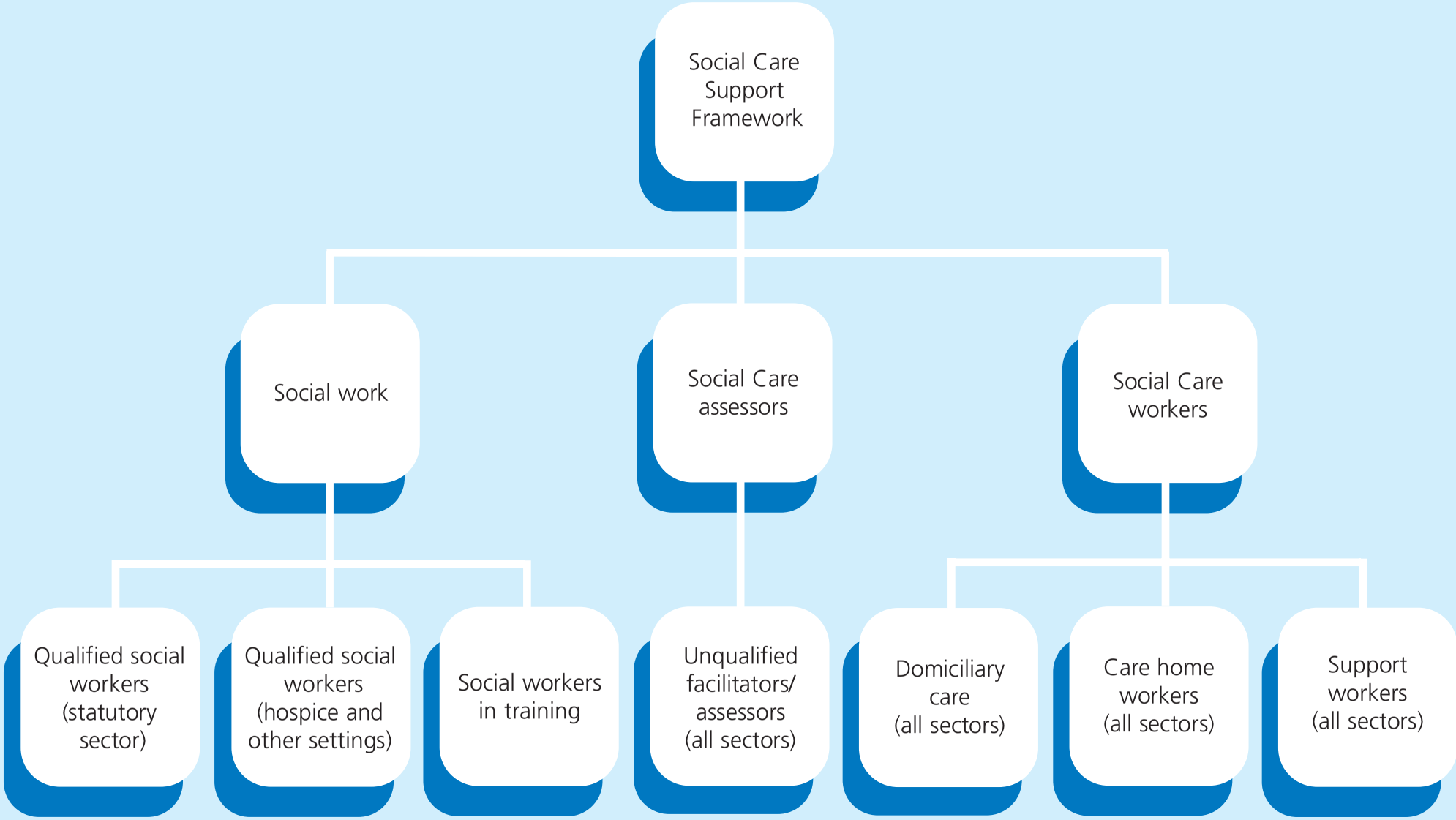
1.2 Policy and workforce change

Social and health care policy is in a phase of rapid and radical change as it pursues government policy of supporting people to remain in their own homes for as long as they might wish. This includes supporting people to live and die in the place of their choice. It is acknowledged, however, that the current system of care and support is unsustainable[2]. Key thrusts in the agenda to transform social support, such as personalisation, re-ablement and workforce development, offer significant opportunities for improving the care that individuals and their families receive at the end of life, through a focus on facilitating autonomy, choice and control.

These policy thrusts have implications for the skills required of the workforce and for the greater integration of roles and services across social and health care and the voluntary sector. Skills development and integration of services are crucial to the delivery of quality care at the end of life and in facilitating individuals choosing their own end of life care pathway. The total adult social care workforce - which includes residential care workers, domiciliary care workers, community workers, day care workers and personal assistants - currently exceeds 1.5 million and has been increasing year on year. This demonstrates the changing profile of the workforce, with increasing numbers employed in the independent sector and through agencies[3]. Many of these have a significant role in supporting people as they approach end of life, in a range of settings (see figure 1).

[2] Department of Health (2009) Shaping the Future of Care Together. Crown, London
[3] Department of Health (2009) Working to Put People First: The Strategy for the Adult Social Care Workforce in England. Crown, London

Figure 1: End of life care and the social care workforce



The launch of this framework takes place in the context of widespread discussion about the roles and skills of the social care workforce, as addressed in the Qualifications Credit Framework (QCF) for social care. The social work profession is also developing the structures and systems to implement the recommendations of the Social Work Reform Board. This review of training and career pathways provides a significant opportunity to improve the holistic support for people at the end of life. Specialist hospice and palliative care social workers have historically made a significant contribution to the multidisciplinary team, but increasingly find themselves limited to the provision of practical resources despite evidence from service users showing appreciation of their wider role[4,5]. Social workers and care managers in mainstream settings often lack confidence to include end of life conversations or planning in their community care assessments and care plans, although (a limited amount of) evidence shows that planning for end of life care at an early stage dramatically increases the likelihood of people's choices being realised[6]. The reviewing of assessments and care packages also offers a clear opportunity to capture changes in needs as they occur and to anticipate the need for end of life care services.

1.3 The End of Life Care Strategy and National End of Life Care Programme

The Department of Health launched its 10-year End of Life Care Strategy[7] in July 2008. The strategy is intended to secure a step-change in the culture and experience of dying at the levels of awareness in wider society; the individual service user/patient experience; and the professional and service delivery infrastructure. The National End of Life Care Programme (NEoLCP) supports its implementation, leading a process of engaging key stakeholders and identifying and promoting good and innovative practice.

In 2009, recognising the fact that the strategy cannot be fully implemented without the active engagement of and input from the social care sector, the programme became the first of its kind within the NHS to appoint two social care leads.

1.4 About this framework

This framework has been developed with the involvement of a group of senior professionals and other stakeholders within social care (see Appendix I for a full list of members of the programme's Social Care Advisory Group) and comes with their full and enthusiastic support. It presents their consensus on what needs to change and how social care needs to develop so that it plays its vital role more effectively in end of life care.

The framework is intended to signal the start of a process of change in how social care engages with, and delivers, end of life care. It is also an invitation to the social and health care communities - and other stakeholders - to work with us to improve understanding of what works in practice, what resources and tools may be available and to help build a network of champions who can drive forward the necessary change.

4 Beresford P, Adshead L, Croft S (2007) Palliative Care, Social Work and Service Users: Making Life Possible. Jessica Kingsley Publishers, London

5 Clausen H, Kendall M, Murray S, Worth A, Boyd K, Benton F (2005) Would Palliative Care Patients Benefit from Social Workers Reatining the Traditional Casework Role rather than Working as Care Managers? A Prospective Serial Qualitative Interview Study. *British Journal of Social Work*, 35:2, 277-285

6 Holloway M (2009) Dying Old in the Twenty-first Century. *International Social Work*, 53:5, 1-13

7 Department of Health (2008) End of Life Care Strategy - promoting high quality care for all adults at the end of life, Crown, London

SECTION 2

A vision for integrated social and health care at the end of life

During my mum's last few days we were not only supported way beyond the [housing association's] brief but my mum was looked after with such sensitivity that it made her passing dignified and peaceful. My gratitude is obviously for my mum's care, but also I feel quite privileged to have been part of such a caring community and would love to think that standard of care could be available to all those who needed it[8]*. (Daughter)*

2.1 Aims and purpose

Our vision is for every individual and their family to retain their personal dignity, autonomy and choice throughout the care pathway towards the end of their life. To achieve this we need a well-trained and supported workforce, operating in the right kind of commissioning and assessment environment and unconstrained by the traditional boundaries between social and health care. Realising this vision is the overall aim of this framework for social care support at the end of life.

In pursuit of this aim, the primary purpose of this framework is to provide a structure that facilitates and promotes:

- The mapping of social care provision in end of life care, identifying good practice, deficits and opportunities
- Stimulation of new developments and initiatives
- Co-ordination of services, including with health care and other care providers, for people at the end of life
- A clear direction for social care support at the end of life that is fully commensurate with the agenda for transforming social care services.

2.2 Opportunities and challenges

Social care is well placed to respond to the demographic and cultural imperatives outlined in Section 1. In particular, social care is often structured around the 'family unit' and is familiar with family-centred models. It is therefore well placed to offer genuinely family-centred services. Social care workers are often highly experienced in assessing the wider needs of individuals and their families in their particular cultural context.

Nevertheless, the findings of the National Audit Office's 2008 report on end of life services[9] suggest a need for greater input from social care in end of life care, specifically to address the following challenges:

- *Place of care*. There is a disparity between preferences expressed by the majority to die at home or in a hospice and the numbers actually dying in hospital (58% of all deaths); in the case of people with dementia, the vast majority die in a care home; the vast majority of deaths from heart disease or pulmonary disease occur in hospital. However, the majority of these will have been admitted from their own home (including a residential care home) in the final week of life.

[8] Comment provided to the National End of Life Care Programme
[9] National Audit Office (2008) End of life Care. National Audit Office, London

I feel that all individuals who looked after my Mother were helpful and supportive. However, I feel that the systems in place and the poor communication between all the services involved failed my Mother. Each organisation that was involved in her care failed her at some level[10]*. (Daughter)*

- *Unnecessary care changes*. A significant proportion of people who die in hospital after being admitted from a care home could have died in their residential or nursing home with better support and advice from care home staff.
- *Inadequate training and skills base.* Only 7% of domiciliary care workers and 5% of care home assistants hold an NVQ level three qualification that includes (optional) training in support for people at the end of life.
- *Poor co-ordination between health and social care services* in planning, delivery and monitoring end of life care.

2.3 Key arenas for change

Key factors identified for successful implementation of the End of Life Care Strategy provide the starting points for engaging social care in addressing these challenges:

- *Strategic commissioning*
- *Care planning*
- *Co-ordinated care*
- *Rapid access to 24/7 care*
- *Delivery of high quality care in all locations*
- *Use of an integrated care pathway*
- *Partnership with and support of carers*
- *Education and training of the workforce.*

The framework and its recommendations are built around these eight factors. However, in order to successfully tackle them and implement this report's recommendations it is vital to raise awareness of the contribution social care already makes (which should be enhanced) to meeting the needs of individuals and their families at the end of life, among the social care workforce, other healthcare workers and the general public.

OBJECTIVE 1
Identify and raise awareness of the role of social care in supporting people at the end of their life among the public, the social and health care workforce and its management

Social care is underpinned by the human rights agenda and thus firmly allied to the Dignity Challenge agenda. Yet the general public is often unaware of the role that social care can play in improving people's experiences of dying, for example through access to domiciliary care services, acting as an intermediary with other services, and facilitating the making and upholding of individual choices. For some people there is also stigma attached to the involvement of social workers and cost implications for using social care services where health provision is free.

[10] Comment posted onto Patient Opinion website (http://www.patientopinion.org.uk)

There is also a low awareness generally among social and health care professionals of the role of social care support at the end of life. Health care workers may be unaware of the role of social work in supporting individuals and may fail to refer appropriately as a result. At the same time, many mainstream social care staff do not perceive end of life care to be within their domain or responsibility. However, the overhaul of social work instigated under the auspices of the Social Work Reform Board, and associated initiatives, offer an opportune time to re-envisage roles and tasks within social care in relation to support at the end of life. These initiatives, from the General Social Care Council (GSCC), include the review of codes of practice for social care workers and employers and of the requirements underpinning the social work degree. A further opportunity arises from the review of social care legislation currently being undertaken by the Law Commission.

The difference [care workers] make is incredible, but as a society we don't value it that much[11]*.(Former carer)*

Joint working in West Essex

A new joint working initiative in West Essex has resulted in much closer partnership working across health and social care in end of life care (EoLC).

The first steps were to ensure that there were social care representatives on the EoLC steering group. This was followed by a new joint communication plan that disseminated all key information for all staff. The third stage was a Preferred Priorities for Care (PPC) event that was attended by a wide range of workers.

Successes:

- EoLC issues were given more weight in the social care agenda and the PPC was incorporated into the revised assessment and review paperwork
- EoLC champions were established in each of the social care teams. Their role is to disseminate information for staff and attend events
- The percentage of PPC completion by social care workers went from 0 per cent to 4 per cent in the first year and continues to grow
- Partnership working has spread throughout frontline staff and management
- The PPC event was 'groundbreaking', in that it was attended by hospital discharge facilitators, ward staff, district nurses, case managers, community psychiatric nurses, learning disability nurses, social workers, community support workers, physiotherapists, occupational therapists and social care managers.

Source: West Essex PCT and Essex County Council Social Care (ECC)

My children regard [the social worker] as being one of the family. That might not be an entirely professional way to regard her, but none the less that's the kind of impact it's had[12]*. (Bereaved husband)*

11 Comment provided to the National Council for Palliative Care

12 Beresford P, Croft S, Adshead L (2008) 'We Don't See Her as a Social Worker': A Service User Case Study of the Importance of the Social Worker's Relationship and Humanity. *British Journal of Social Work* 38:7, 1388-1407

RECOMMENDED ACTIONS

1. The NEoLCP should explore further the possibilities for working with the Dying Matters coalition to raise awareness of - and break down the stigma surrounding - social care at the end of life. This should include ensuring that end of life care issues are raised in wider debates about need and services in society, for example within older people's 'parliaments' and voluntary sector forums.
2. The NEoLCP social care leads should work with professional social work bodies to clarify and articulate the role of social work in end of life care and promote its value; work undertaken by the (American) National Association of Social Workers[13] could be utilised and adapted to the UK context.
3. The NEoLCP should seek to engage with social care umbrella organisations and professional associations (see Appendix II) to clarify and articulate the role of residential and domiciliary care workers, housing and other support workers, occupational therapists (OTs), physiotherapists and nurses in integrated care teams, for example learning disability nurses.
4. The NEoLCP, along with other key stakeholders, should seek to engage the General Social Care Council (GSCC) and other regulatory bodies to emphasise the importance of ensuring that new codes of practice adequately encompass end of life care issues.
5. Representations should be made to the Law Commission's review of social care legislation and the planned commission on long term care to include the implications of end of life care.

[13] http://www.naswdc.org/

SECTION 3

Strategic commissioning for high quality care

3.1 Integrated care

Effective commissioning and delivery of integrated health and social care services are key to achieving high quality care, which addresses the wide-ranging and rapidly shifting needs of the individual and their family/carers at the end of life. In particular, integrated commissioning can help reduce the need for numerous interventions by multiple agencies, which can be disruptive and confusing. Extensive work has been done to test approaches to integrated commissioning and delivery - for example through the Department of Health's Integrated Care Networks[14] - and there are many examples of good practice in joint commissioning and delivery of health and social care. Evaluations show that as well as resulting in better services for individuals, this also often results in efficiency gains.

However, despite recognition of the importance of better integration of social and health care, significant structural barriers remain. Incompatible health and social care IT systems can make communication between the various professionals involved difficult. There can be lack of clarity in roles, for example regarding co-ordinating discharge, or in relation to completing documentation, which can lead to delays.

OBJECTIVE 2
Facilitate commissioning and delivery of person-centred, integrated care

Better information sharing

A digital project called NHSmail, currently being piloted in south London, will enable social care teams to share sensitive information with multidisciplinary colleagues in a secure setting.

NHSmail is a free service, approved for the transmission of patient data between NHSnet account holders.

It will enable staff in a range of social and health care organisations across Lambeth and Southwark to get all the information they need to give patients a high level of end of life care.

The pilot is expected to demonstrate improvements in the speed and quality of patient information flows between different care settings.

Its aim is to support organisations to share information in a timely manner for patients with end of life care needs. The pilot will begin by testing the functionality of the email and fax options. A range of organisations will gradually join in the testing and reach a decision on sharing appropriate documentation. The organisations and services include:

- GP practices
- Community nursing
- Palliative care teams
- Social care hospital discharge teams.

Source: Southwark PCT, June 2010

[14] http://www.dhcarenetworks.org.uk/integration/icn

It was worth getting her back home for that last month because if she'd died in hospital I'd never have forgiven myself. But you need all those things in place - support, friends, family, everything[15]*. (Former carer)*

3.2 Funding arrangements

Funding arrangements for an individual's care are often highly complex; in particular, the differing entitlements of people who are wholly or partly self-funded. Inflexible budgets can result in discontinuity and fragmentation of care. For example, someone with a long-term condition, who has received direct payments or a personal budget to fund their self-directed care, may be unable to retain these arrangements once referred to community health services, which may include palliative care services. Individuals and their families are often left struggling to navigate the system. For people at the end of life, this added burden at a time of emotional turmoil and stress may significantly undermine the quality of care as it is experienced by individuals. On the other hand, self-directed care, in which individuals and their families are supported through information and skilled intervention to make informed choices, can significantly enhance the quality of care experienced.

3.3 Self-directed and person-centred care

Personalisation (understood in its broadest sense of promoting self-directed care and informed choice), use of personal budgets where available, and re-ablement initiatives present an important opportunity to develop flexible, integrated and user-led care packages. This can support individuals in their unique pathway through increasing levels of care. Currently, however, service users are too often directed towards services where current funding is in place rather than the most appropriate care for their needs. Flexibility in funding arrangements can make a significant difference. Skilled social workers and care managers can use an 'envelope of money', or advise carers and service users on the personal budget process, to enable services and support to be adjusted and flexed in line with individual needs and preferences.

The personalisation and re-ablement agendas may also result in significant efficiency gains. Early access to appropriate resources is vital and may prevent more intensive and costly packages of care being required in a crisis. Additionally, when offered choice through personalisation of services, many individuals and carers will opt for more cost-effective interventions. For example, carers may prefer to purchase help with housework to free up their time to care for the family member. Evaluation of re-ablement initiatives also suggests it is possible to achieve significant savings, as well as better quality, more person-centred care. For example, evaluation of projects under the DH Partnerships for Older People Projects (POPPs)[16] suggests that investing early in support for individuals results in savings, in that more intensive care is required later and for a shorter period at the end of life.

The potential for self-directed care at the end of life that might be achieved through personalisation and re-ablement should be recognised. However, there is some way to go in developing a personalised approach to support all groups of people at the end of life, including those with advanced dementia.

15 Comment provided to the National Council for Palliative Care
16 http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm

Putting older people at the centre of services

The Decisions At Life's End (Dale) project in Leicestershire aims to reverse the increasing number of older people dying in hospital as a result of an unscheduled admission. The scheme puts the older person at the centre of services and takes an integrated and holistic approach.
Local teams, consisting of nurses, generic health and social care workers, are integrated within existing intermediate care teams and supported by mainstream services.
A four-phased approach will be implemented over two years in care homes, extra care housing schemes, sheltered housing with wardens and for older people living at home, with carer and/or agency support.

The Dale pathway:

1. Medical assessment is undertaken when death of an older person is predicted.
2. Care at home is requested (or has been stated in a signed directive).
3. Single call made to the DALE service to activate the immediate care required to support both the person and their carer/s at home.
4. Personalised package of care for each person will be co-ordinated by the local district nurse team working closely with the DALE service.
5. Essential medical and care equipment will be delivered within hours.
6. Families or friends can be actively involved in the direct care if they so wish.
7. Continuity is maintained if a person's situation is stable enough to transfer them to mainstream services, for example district nursing teams, hospice at home.

Source: National End of Life Care Programme, May 2010

My mum up till then had been my family carer, and basically my body carer. I was quite a lot of pressure on my mum, so she didn't have time for my brother and sister and other things. So when [the social worker] realized that, she managed to get funding to employ a carer[17]*. (Son, service user)*

We had two lots of carers. The social services carers came in for an hour in the morning and got Mum washed and dressed. The other ones, which we paid for, came in for the rest of the day and sat with Mum, helped her to eat and cooked with her because she'd do things like leave the gas on. The carers were superb. They did over and beyond what they were meant to do. They really worked with each other too. If one was going to be late, they'd ring the others. They were brilliant[18]*. (Daughter of person with dementia)*

17 Beresford P, Croft S, Adshead L (2008) 'We Don't See Her as a Social Worker': A Service User Case Study of the Importance of the Social Worker's Relationship and Humanity. *British Journal of Social Work* 38:7, 1388-1407
18 Comment provided to the National Council for Palliative Care

3.4 Regulation and inspection

There is evidence that complaints relating to end of life care are widespread and can be costly to address. Organisations could learn much from the issues that have arisen from complaints and should routinely seek the views and experiences of service users and their families about end of life care. There is also potential to use the regulation (for example through the Care Quality Commission) and inspection framework to prevent many such complaints, although more evidence is needed on common patterns of complaint and their implications for social care provision. This area also offers a further opportunity for local health and social care organisations to assess how well their services are working together at the point of delivery.

OBJECTIVE 3
Embed end of life care within commissioning and inspection frameworks and standards for practice

Using spot purchasing to avoid a crisis

Macmillan's use of special spot purchasing budgets is enabling people to stay in their homes during periods of crisis that often result in an unwanted emergency hospital admission.

Jan Bolton, Macmillan social care co-ordinator at Northamptonshire Centre for Oncology, used her budget to enable Reuben - an elderly man with health problems who was also caring for his wife - to stay in his own home until he died.

She explains: "Reuben's daughter, Rose, contacted us because she felt at the end of her tether. Reuben had a recurrence of breast cancer and had been told that there could be no more treatment. Rose supported her parents on a twice-weekly basis and they had managed reasonably well until very recently. Reuben's wife, Anna, was physically frail due to Parkinson's disease but was mentally alert and able to organise Reuben and their household. As a team, Reuben and Anna were independent and resourceful. Circumstances changed when Anna had a fall and was admitted to a specialist care centre for a period of rehabilitation."

Reuben was happy for carers to visit him at home but didn't want to go to hospital. Ms Bolton contacted the district nurses, who promptly provided a commode and pressure-relieving mattress, and arranged for a key safe to be fitted because Reuben was unable to get downstairs to let carers into the house. She requested an urgent CHC assessment but was told that due to other commitments this could not be done until the following week.

"At this point I decided to use my budget to pay for a package of care to support Reuben", she says. "Although he was entitled to statutory support I knew that he would be left alone and at risk and that Rose was beside herself with worry and concern. I contacted my preferred agency and they were able to visit that day and start the service the following day. In total I spent £210, which allowed Reuben to remain in his home safely and well cared for in what were to be the last few days of his life."
Source: Macmillan Cancer Support, June 2010

3.5 Care in a crisis

A sudden change in health or other status can be alarming for the individual and their family and can rapidly develop into a crisis requiring emergency intervention, including transfer to acute services. This can be very traumatic for individuals, as well as expensive for the organisations providing services. There is often limited flexibility to purchase services or interventions that might avert the crisis. Better commissioning would enable services to respond to an individual's changing health or other status before the 'crisis' sets in and the individual has to be transferred into acute care. This could include, for example, building flexibility into budgets to enable spot purchasing of services when a crisis is on the horizon. Good practice here needs to be identified and evaluated.

The move to discharge from a community hospital into self-funding nursing care felt rushed. It left no time for adjustment[19]*. (Daughter)*

3.6 Specialist palliative care social work

Palliative care social workers, based in hospices and hospital palliative care units, have a crucial role in ensuring high quality end of life care, both within the specialist setting and within mainstream services. Building on their experience in providing highly skilled support to individuals and their families in the most difficult circumstances, they can provide credible leadership at the local level, educating and supporting social care workers providing end of life care in community settings, spreading good practice and providing expertise on specialist issues (for example on mental capacity and advance care planning). However, current provision is patchy, particularly within hospitals; anecdotal evidence suggests attrition in the service as people resign or retire - a particular problem where there is a single palliative care social worker - with vacant positions remaining unfilled.

OBJECTIVE 4
Strengthen the specialism of palliative care social work

[the palliative care social worker] not only understands the patient, and the partner of the patient, she understands the systems as well... It's obvious to us that she knows her job inside out. And just by the way she comes back at you with an answer and what she's saying, you know she knows what she's talking about and that she knows her job and what is available. And if she's not sure, she'll tell you, but she will find out[20]*. (Husband of a woman receiving palliative care)*

19 Comment provided to the National Council for Palliative Care
20 Beresford P, Croft S, Adshead L (2008) 'We Don't See Her as a Social Worker': A Service User Case Study of the Importance of the Social Worker's Relationship and Humanity. *British Journal of Social Work* 38:7, 1388-1407

RECOMMENDED ACTIONS

1. Existing evidence concerning integrated commissioning and delivery of health and social care should be reviewed and good practice identified and shared.
2. Dedicated shared budgets for end of life care should be explored, including consideration of the point on the care pathway at which these could best serve the needs of people in the end phase of life.
3. Systematic evidence needs to be gathered on the impact of re-ablement, personalisation and early support for people in the end of life phase (and their family/carers) on enhancing the quality of end of life care at the same time as achieving greater efficiencies in care delivery. In particular, consideration should be given to combining individual budgets for social care with personal health budgets to enable individuals to put in place the 'basket' of services and support they need at the end of life; the NEoLCP should link its work to the personal budgets pilots.
4. Examples of good practice in developing community services, and support roles to enable people to be cared for within the community, should be identified and shared; their potential for replication should be explored.
5. Consultation should be undertaken with users/carers to identify common triggers for crisis, needs in the crisis and the responses required from services. In particular, social care should engage with acute health care providers (including in implementing the Programme's *Route to Success* in acute care)[21] to improve how social care and acute care work together to enable people to die in their preferred place of care.
6. There should be streamlined access to continuing healthcare funding, which should be seamless and timely.
7. Local authorities and primary care trusts (PCTs) should identify ways of reflecting end of life care needs in performance indicators and quality markers.
8. PCTs, acute trusts and local authorities should work together on complaints to achieve improvements across end of life care services.
9. Local authorities and PCTs should engage with Care Quality Commission inspection outcomes to measure care home and domiciliary provision for end of life in their localities.
10. The NEoLCP should engage with work already under way under the auspices of the Association of Palliative Care Social Workers and the European Association for Palliative Care to clarify and articulate the contribution of specialist palliative care social work. Particular attention should be paid to potential advisory and consultative roles such as advising on legal constraints and requirements around the Mental Capacity Act.
11. The consultation on the peer review measures for psychological support services provides an opportunity to press for specialist roles such as in palliative care social work.

[21] NEoLCP (2010) The Route to Success in end of life care – achieving quality in acute hospitals. Crown, London www.endoflifecare.nhs.uk/routes_to_success

SECTION 4

Care and support planning

4.1 The end of life care pathway

Six steps have been identified, which together form a pathway through care at the end of life (see figure 2, page 22). Social care has a key role to play at each step within the pathway and in promoting quality of life right up until the point of death. The 'dying phase', using tools such as the Liverpool Care Pathway (LCP), is not identified until Step 5 and indicates that death is anticipated to be imminent. For social care, it may be more useful to think of a 'final phase of life', in which gradually increasing physical deterioration leads to changes in psychological and existential orientation. This has implications for care planning and the timing of discussions identified under Steps 1 and 2 of the care pathway, particularly for people in the frail older ('oldest old') category and those with life-limiting illness.

The pathway through end of life care offers a helpful structure for planning services. However, in reality, it is not a tidy linear progression. People move back and forth, go through 'steps' in a different order, or miss out some stages altogether. There are also many routes into and through social care and the end of life care pathway: many will come to social care via the NHS, as a result of their health needs, or via the voluntary sector. Similarly, services often treat people according to categories, for example a person with a long-term condition such as mental illness, or a person at the end of their life. However the category is often meaningless to the individual, who experiences changing needs over their lifespan - particularly at significant transitions points, such as diagnosis of a progressive disease, or an acute health episode, such as stroke.

An end of life care pathway for all

Three Nottinghamshire PCTs and their local authorities have produced an end of life care pathway for patients and carers across all conditions and settings.

The document contains sections on breaking bad news, advance care planning, information prescriptions and care after death.

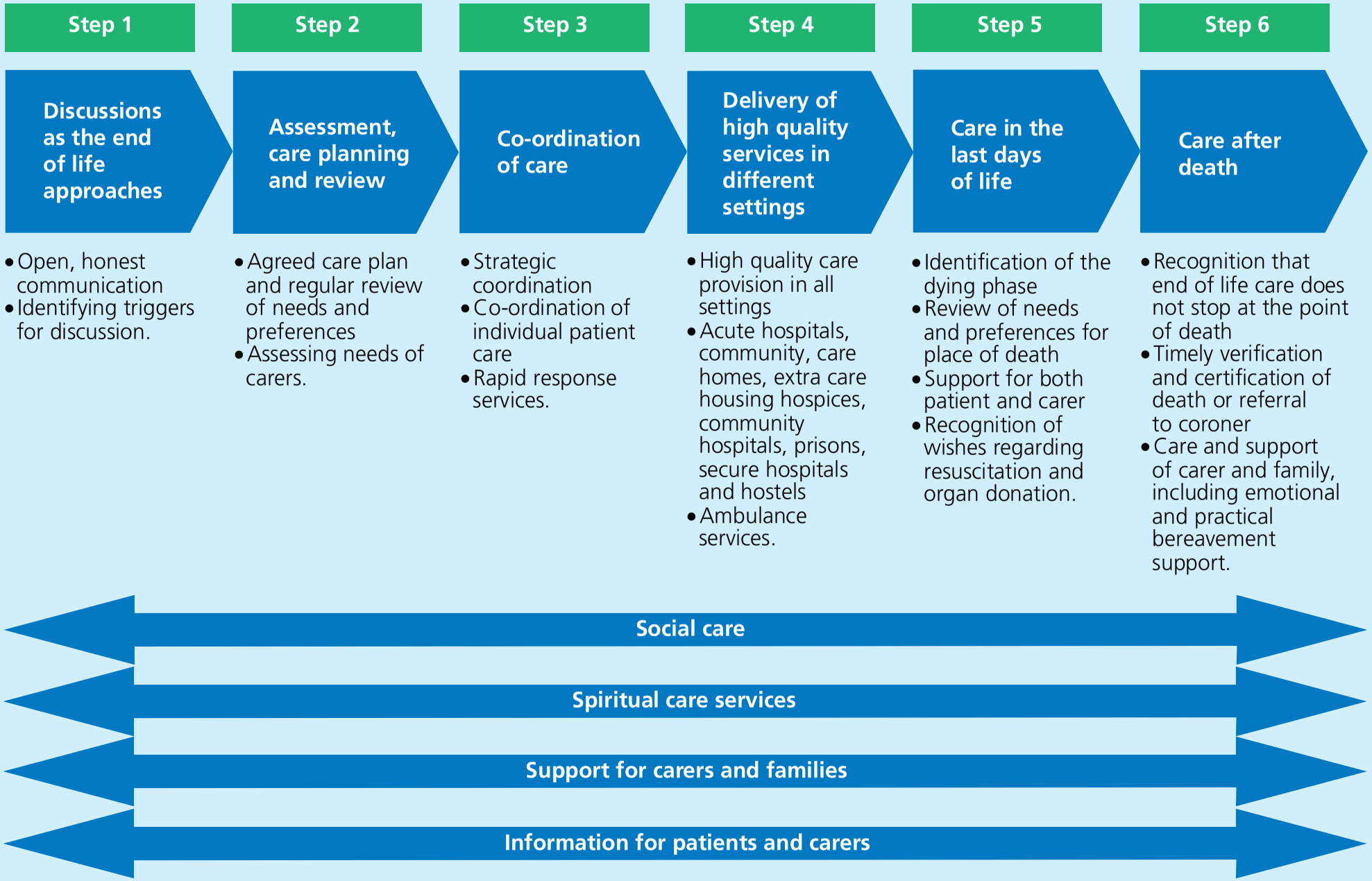
Each PCT is now developing a strategic initiative delivery plan for end of life care to ensure services are commissioned in line with the pathway. Producing the pathway involved a literature search as well as widespread consultations and, finally, a large workshop for all stakeholders including health and social care professionals, the voluntary sector, the chaplaincy, patients and carers.

Source: National End of Life Care Programme, May 2010

[the social worker] always asks what you want to gain today in our meeting…so that you can have the chance to say… You're making a decision of where we are going and that's what I like…[22] *(Woman, service user)*

[22] Beresford P, Croft S, Adshead L (2008) 'We Don't See Her as a Social Worker': A Service User Case Study of the Importance of the Social Worker's Relationship and Humanity. *British Journal of Social Work* 38:7, 1388-1407

Figure 2: End of life care pathway



4.2 Assessment of need

Central to providing quality, holistic care for people at the end of life is ongoing holistic assessment of their needs. This should consider all aspects of their life, extending beyond both the dying person and his or her immediate carer to the wider family, which can include parents of dying adults who are themselves old and frail, children or other dependants. The future care of dependants, in particular, will be of key concern to dying parents and has important implications for the safeguarding agenda.

The role of social care in assessing and meeting the needs of people at the end of life is often narrowly understood (for example limited to assessment for practical resources) by other health care workers. Social workers and other social care professionals are experienced in holistic assessment and have an important contribution to make at different stages in the care pathway. They are also familiar with the process of assessment, monitoring and review of needs.

In practice, many individuals do not receive ongoing holistic assessment of their needs. In the absence of a trigger or requirement to assess, some people receive no or only partial assessment, while others may undergo repeated, unco-ordinated assessments. People at the end of life may require a range of assessments in order to access particular services. However, it is important that unnecessary assessments are avoided at this stage, when both energy and time are limited.

OBJECTIVE 5
Promote understanding and best practice in holistic assessment of individuals, their carers and families at the end of life

The assessment system is often challenging for many service users and their carers to navigate, in particular for continuing healthcare assessment and for people who are self-funding, where there is no appointed care co-ordinator. Advocacy (often provided by the voluntary sector) can be very helpful in supporting people to access the services they need. However, commissioning of these advocacy services can be both complex and patchy.

There are particular issues concerning choice of residential care home for people who self-fund; they (and their families) may not have support to enable them to access and choose the most suitable environment, balancing immediate and longer-term needs. Moreover, although good practice in residential care involves every resident having a regular review of their needs - regardless of their source of funding - practice may be variable. It is crucial that every measure is put in place which enables people to die in their 'home' (including a care home) and avoid unnecessary changes in care setting in the final period of their life.

Assessment has a crucial role to play in crisis management. Social workers are experienced and skilled at carrying out assessments in crisis situations. These can be starting points for planning for future care, including actions to

The professionals involved in her care should have been involved a lot earlier then they would have had a better understanding of how the disease was affecting her quality of life, ability to cope independently and the amount of pain she was experiencing… It seems to me all of the various agencies were not aware of how the illness affected my mother … This meant to me that her treatment was not based around her needs rather what they thought she needed. She stopped being an individual[23]. (Daughter, carer)

[23] Comment posted onto Patient Opinion website (http://www.patientopinion.org.uk)

avoid future 'crisis responses', such as an emergency admission to hospital for a person receiving palliative care in the community, because of illness or accident sustained by the carer at a weekend.

4.3 Care planning for end of life

Social care has an important role to play in linking the holistic assessment of need to a holistic approach to advance care planning. This may include facilitating conversations with other professionals at a time that is right for the individual service user, which may be considerably earlier than envisaged. This might involve a range of social care workers, such as home care assistants and occupational therapists. It may also be appropriate for the 'anticipatory care planning' prompted by a crisis to begin the process of more formal advance care planning. This might involve, for example, emergency duty social work and care management teams liaising with long-term teams to achieve this outcome.

Discharge planning is often problematic for those admitted to hospital in the advanced stages of disease or illness. Inflexible or sparse domiciliary care services and community specialist support can frequently result in people not being transferred back home once the acute health episode has passed. This is compounded by the fact that hospitals are sometimes reluctant to discharge 'ill' people. As a result, more people die in hospital than may be necessary, rather than being transferred back to their preferred place of care.

OBJECTIVE 6
Promote earlier end of life care planning that builds on an holistic understanding of wellbeing

An assessment tool for use in hospices

The Admission Assessment Integrated Care Pathway provides an evidence-based template, which documents patients' demographic information and assesses their holistic needs across the physiological, social, psychological and spiritual domains.

The tool was originally developed by St Ann's Hospice and then disseminated to other hospices through two national study days and a workshop.

One of the main challenges was to persuade separate disciplines to relinquish and share their individual patient assessment processes and documentation.

A comprehensive education and training programme has helped create a sense of ownership within the multidisciplinary team. Over 40 hospices are now using the tool.
Source: National End of Life Care Programme, May 2010

The most outstanding thing that I have come across in palliative care patients is the introduction and power of the PPC - Preferred Priorities of Care[24] pathway…Service users that I have introduced to the PPC have told me how it has been and will be so valuable, in getting their wishes met, and views listened to, at a time when they may no longer have a voice to communicate their wishes and views[25]. (Social care assistant)

Eventually we did talk, luckily the home were very understanding and allowed my daughter in law and I to stay with Ron so we could still provide his intimate care needs but within his room in the home. The rest of the family came every day and we would sit around his bed and talk about times gone past and all of the outrageous things he used to get up to. This was so very important to us to be able to do this[26]. (Woman, wife of a service user)

RECOMMENDED ACTIONS

1. Assessment models from social work practice (needs assessment, carer assessments, family assessments, direct work with children and crisis intervention) should be applied to end of life care and integrated with health assessments (see also *Holistic Common Assessment of supportive and palliative care needs for adults requiring end of life care*[27]). The NEoLCP should promote this sharing of good practice.
2. Social care workers in a range of roles working with older people and people with chronic health problems should receive specific training in anticipatory and advance care planning.
3. Local authorities should include the requirement to review individual residents' needs regularly in contracting and monitoring procedures for all care homes in their area.
4. The NEoLCP should work with social and health care providers to address discharge problems occurring at the interface between acute health care providers and community social support systems, for example through implementation of the programme's *Route to Success* for acute care.

24 NEoLCP (2007) Preferred Priorities for Care, Crown, London http://www.endoflifecareforadults.nhs.uk/publications/ppcform
25 Comment provided to the National Council for Palliative Care
26 Comment provided to Alzheimer's Society
27 NEoLCP (2010) *Holistic Common Assessment of supportive and palliative care needs for adults requiring end of life care*. Crown, London http://www.endoflifecareforadults.nhs.uk/publications/holisticcommonassessment

SECTION 5

Education, training and support of the workforce

5.1 Education and training

Education and training are key to improving end of life care provision and bringing about the required culture change. Many of the preceding recommendations in this report have implications for the development of skills and increasing knowledge in particular aspects of end of life care. However, all social care workers need a broad awareness of end of life care issues so that they are equipped to consider the needs of the person, their family and carers at the end of life.

OBJECTIVE 7
Educate and train social care workers to deliver high quality end of life care

Social care workers already employ interpersonal and communication skills, which are core to end of life care, but conversations about dying are often daunting for untrained staff. Even qualified and experienced social workers who are not specialists in palliative care may not recognise or be confident in the skills they possess. Differences in language and culture may present further obstacles to good communication, as well as additional challenges for training programmes.

However, there is evidence that - whatever their level of qualification or experience - social care workers can gain confidence to discuss issues around death and dying[28]. Communication skills training aimed at end of life conversations is therefore particularly important for all levels of social care worker, including care assistants in domiciliary and care home environments, to develop confidence and refine the skills required to discuss end of life care needs with individuals and their families. Involving users in this kind of training can be very powerful and helps to avoid an overly mechanistic approach.

The NEoLCP's Communications Skills pilots are trialling new approaches across health and social care settings, and producing a range of publications and resources, such as *Developing Skills: Talking about end of life care*, produced jointly with Connected[29]. Bringing social and health care staff together for joint training can be an effective way of breaking down barriers and increasing recognition of each other's roles. However, some 'joint' training programmes are overly focused on medical and nursing roles and require modification to meet the training needs of social care workers.

An e-learning resource - e-End of Life Care for All, (e-ELCA) - has been developed by eLearning for Healthcare (eLfH) in partnership with the Department of Health and the NEoLCP.[30] It aims to offer workers in social care - such as care home assistants, domiciliary care workers and social workers - access to online learning for end of life care. All learning sessions have been written and peer reviewed by clinicians or health and social care experts and practitioners. Access

It's not easy to talk about end of life issues but it's important to do. Now that we've put our affairs in order and talked about what we want, we can "put that in a box" as it were, and get on with living one day at a time, cherishing each day together, as I know it's going to end one day[31]. (Carer of person with COPD)

[28] NEoLCP, Housing 21 (2008) Is it that time already? Crown, London
[29] NEOLCP, Connected (2010) Developing Skills: Talking about end of life care. Crown, London
[30] http://www.e-lfh.org.uk/projects/e-elca/index.html
[31] Comment provided to the National Council for Palliative Care

for social care will be fully available by the end of 2010; eLfH is working with the Social Care Institute for Excellence and Skills for Care in looking at the 130+ sessions to ensure relevance to social care needs and to commission additional social care focused sessions if required.

5.2 End of life care training initiatives

A number of social care initiatives are already under way. End of life care is included in common induction standards for every new member of the social care workforce. However, there is an expectation of a very wide range of knowledge for new starters, so those standards applying to end of life care may not be given prominence. Skills for Health and Skills for Care, in conjunction with the NEoLCP and Department of Health, have produced a guide, which sets out relevant principles and competencies for end of life care[32] and is a helpful resource. The development of the Qualifications Credit Framework (QCF) for the social care workforce at the pre-NVQ4 stage offers an opportunity to include nationally accredited units for end of life care at all levels; end of life care units are currently in preparation for the new Health and Social Care diplomas.

To help plan and target education and training initiatives, greater clarity is needed on existing skill levels and training needs in end of life care across the social care workforce. Some limited audit is under way, for example through the newly qualified social worker (NQSW) pilots, which are informing the development of the Assessed Year in Employment proposed by the Social Work Task Force. The National Minimum Data Set for Social Care generates an annual training needs analysis report. However, without a specific focus on end of life care these will give only a partial picture of skills and training needs. The Association of Palliative Care Social Workers (APCSW) is conducting an ongoing analysis of the roles and skills of specialist palliative care social workers with a view to developing their educative roles.

Staff development consultation programme

NHS West Midlands Workforce Deanery has conducted a wide-ranging consultation to establish the key development needs of everyone involved in end of life care.

There was widespread backing for a region-wide network of end of life care champions. A workforce collaborative group has now been established.

The consultation findings will be used to identify end of life care skills gaps and design new training programmes across a range of organisations.

The project seeks to establish the key workforce development needs and how they could best be met. It also aims to develop a joint understanding of how the draft core principles and competences for end of life care relate to all settings and situations. The extensive consultation included seven workshops working with over 50 contributors from health and social care organisations.

Source: National End of Life Care Programme, May 2010

[32] NEoLCP; Skills for Health, Skills for Care, Department of Heatlh (2009) Common core competences and principles for health and social care workers working with adults at the end of life. Crown, London

5.3 Workforce development and support mechanisms

End of life care is most effective when workers are operating in a supportive environment, which facilitates team discussion and mutual support and also provides a range of staff development opportunities and resources on which to draw - ranging from practice materials and professional updates to expertise on specific issues.

It is particularly important that social care workers are able to refer to other professionals and recognise when to do so, if they cannot themselves meet an individual's needs. Workers in general care settings may sometimes need to access high levels of expertise and specialist skills that are not available within the day-to-day staff team. Cluster models are often very helpful in ensuring that there is specialist expertise available locally when needed.

Good leadership and management are crucial. Problems can emerge if healthcare employers who employ social care professionals have insufficient knowledge of social care practice and professional drivers. Joint social and health care workforce planning can contribute significantly to reducing these problems. Where end of life care leads are in place, they can play a key role in supporting colleagues across social and health care by acting as champions for end of life care, cascading knowledge and resources to colleagues and liaising with policy-makers, service managers and other relevant people, such as Dignity Champions.

OBJECTIVE 8
Create a supportive work environment that enables social care workers to maximise their contribution to quality end of life care

Social workers in education roles

St Christopher's Hospice in London is widely regarded as a centre of excellence in palliative care - in both its services to patients and its wider educational role.

It employs and trains multidisciplinary teams in all aspects of end of life care, offering training in communication skills, cross-cultural practice with families, pain control and specialist children's services.

As well as providing in-house training it also offers:
- Off-site training
- Tailor-made courses for all staff groups
- Practice/service development support: in-house consultancy to develop work in a specific area, for example culturally sensitive practice or care home developments.

Social work is a central discipline at St Christopher's and social workers are involved in training/education as well as providing care for the hospice patients.

At St Christopher's, social work is valued very highly as a profession because social workers have a unique ability to move from practical issues to emotional ones. They are able to support service users in a more holistic way than many other professionals. This is very important in end of life care, and the team believes social work input is needed on any multidisciplinary team working in this area.
Source: St Christopher's Hospice, June 2010

RECOMMENDED ACTIONS

1. There should be engagement with further and higher education providers and the diverse range of independent training organisations to influence the development of curricula and programmes so as to provide a range of opportunities at all levels for social care workers to access education and training in end of life care. This will extend to independent providers of domiciliary care workers or care assistants and carers who work within care home settings as well as the generalised social care workforce. It should include engaging with the Social Work Reform Board and the redevelopment of social worker training at qualifying, post-qualifying and advanced levels; Skills for Care could include a priority target in allocating their Training Strategy Implementation funding.
2. Communications skills training needs to be further developed and rolled out to ensure that all staff are able to initiate conversations with individuals and families about death and dying; learning from the NEoLCP communications projects should be widely disseminated.
3. Consideration should be given to commissioning a comprehensive skills audit to identify gaps in knowledge and skills relating to end of life care across the social care workforce so that action can be taken to address these gaps.
4. The NEoLCP, alongside other key stakeholders, should continue to press for end of life care to be included within the questions set for employers on the National Minimum Data Set for Social Care.
5. The NEoLCP should encourage the development of nationally accredited units for end of life care within the Qualifications and Credit Framework (QCF).
6. The NEoLCP should work with the Association of Palliative Care Social Workers to develop ways in which specialist palliative care social worker educative roles can be developed and social workers facilitated to transfer into the service and/or develop as local champions for end of life care in mainstream services, for example through a mentors network or internships.
7. The NEoLCP should work with the National Skills Academy for Social Care to strengthen professional and practice leadership in end of life care.
8. The NEoLCP should work with stakeholders to encourage uptake of opportunities for online learning through eLearning for Healthcare (eLfH).
9. Integrated workforce planning across the social and health care workforces should be encouraged.
10. The NEoLCP should establish a network of champions for end of life care within social care who can act as drivers for change.

SECTION 6

Service users, carers and the wider community

6.1 Improving the experience of service users and carers

The ultimate aim of achieving the highest quality end of life care - and the role of social care within this - is to improve the experience of dying for the individual and everyone around them. A two-pronged approach, of raising awareness about end of life issues within social care and broadening understanding of social care's remit within the health field, could make a significant contribution to achieving this goal. Social care has longstanding experience and expertise with service users who might particularly benefit: frail older people including those with dementia, lone parents and their children, an adult with learning disabilities or mental health problems, the prison population, people who are homeless.

Social care also has extensive experience of working with carers and carers' groups. The needs of carers should equally be prioritised and may be different from those of service users themselves. Importantly, the overall experiences of those nearing the end of life and their carers could be dramatically improved if social and health care operated in a more integrated way. For this to happen social care's wide-ranging remit needs to be fully appreciated and utilised. The transition from social care to continuing health care may be extremely disruptive, from both a personal care and a financial perspective.

6.2 Other services and the wider community

Social care is predominantly located in community settings; for real improvements in the experiences of dying people and their families to be achieved, there must be partnerships with a wider supportive, 'compassionate' community. The voluntary sector and independent providers have a crucial role to play, particularly in relation to minority or 'hard to reach' groups. The voluntary sector is also the main provider of bereavement support and care. The working relationships between voluntary groups and statutory agencies are better developed at a local level in the social care sector than they are in health. Building on these relationships is essential to improve end of life care for all.

OBJECTIVE 9
Promote supportive communities through engagement with a wide range of community services

We got nothing from the health authorities, you have to go out and find what's available yourself and I would recommend people join as many of these kinds of groups as they can. You never know what you're missing out on both socially and with help and advice. Your world is so limited as a carer, you don't have the freedom just to get up and do things, so it's great for it to be organised for you and you just go along[33]*. (Woman, carer)*

[33] Comment provided to Omega-The national association for end of life care (http://www.omega.uk.net)

Dialogue with diverse communities

Birmingham St Mary's Hospice (BSMH) has started a dialogue with its local BME communities about end of life care.

Feedback has raised the problem of end of life language acting as a barrier to services - even the phrase itself was seen as a barrier. BSMH has recognised the need for greater awareness of and respect for cultural and spiritual issues in palliative care.

Most important of all was the need for meaningful conversations with patients and their families. The hospice is now exploring opportunities for partnership working with local communities to improve this. It is also seeking to identify gaps and make recommendations for future partnerships.

With new funding from the West Midlands Strategic Health Authority the hospice is working to find out what support families, communities and local organisations are already giving to people with life-limiting illnesses in the community. The aim is to develop opportunities for partnership working and provide excellent care for people who want to die in their own homes. It is calling this work 'Compassionate Communities'.

Training is now being offered to end of life care professionals on spiritual, cultural and other issues that may impact on access to services. People from local diverse communities are invited on cultural and spiritual training days to provide insight into the needs of patients from their communities.

The hospice continues to do outreach work to raise awareness of its services among a wide range of service users in Birmingham.

Actions:
- Surveyed local BME communities to establish knowledge and opinion about services
- Launched the Reaching People programme
- Adopted diversity as a priority area in the BSMH three-year strategic plan
- Hosted a conference where people from BME communities and end of life professionals shared a platform to open dialogue around death
- Planning a 'Sharing Care' conference in October 2010, where professionals and community members will explore opportunities for working in partnership
- Offer training on spiritual and cultural issues for health and social care professionals in palliative care. People from diverse communities are invited on these training days to provide insight.

Source: St Mary's Hospice, June 2010

Housing and accommodation issues are very important: if care is better, people will feel able to stay in their preferred place of care as they approach death. If people can stay in their own homes for longer they are likely to retain better quality of life right up until the point of death. Nevertheless, housing is currently often poorly integrated with social and health care. There is good practice to learn from. The Extra Care housing agenda, for example, aims to enable people to care for themselves for longer and to give them better access to the other services they need. This dovetails with the wider social care agenda at end of life.

People nearing the end of life may want to access other local services, such as leisure facilities and adult education, as they continue to pursue life goals. These services may have yet to develop their approach to managing end of life issues.

End of life care in Anchor Homes

Three hundred Anchor Homes staff have been given three days of training in end of life care.

As a result, staff and residents now discuss dying more openly and deaths in the home are handled more positively. Most residents stay in their homes until they die.

A toolkit is being developed to embed this learning and experience within everything that Anchor does.

The training was delivered in conjunction with the International Institute on Health and Ageing.
Source: National End of Life Care Programme, May 2010

Service user forums

Isabel Hospice in Welwyn Garden City has 16 in-patient beds but the team caters for 400 in the community.

Over the last five years Isabel Hospice has developed a consultation system that includes individual patients, family carers, children and service user forums. It examines practice and develops service provision for the future. It is led by a senior palliative care social worker and a senior nurse.

Forum use has increased steadily. Consultation subjects have included information leaflets, policies, catering, staff uniforms and building design. One of the key issues to emerge from patients and family carer feedback is the need for better co-ordination between health and social care.

Patients have also played a significant role in the education of social care workers from the local authority.

The hospice is working with secondary schools in the area to explore issues around care, death and dying, through individualised working programmes.
Source: Isabel Hospice, June 2010

RECOMMENDED ACTIONS

1. End of life care leads and champions in social care should develop links with wider services at the local level, to foster greater awareness and understanding of end of life issues and develop specific initiatives as appropriate.
2. Consultations should take place at national level (using the NEoLCP's user/carer network) and at local levels, with users and carers' organisations, concerning their priorities for end of life care services.
3. Local authorities should foster and support end of life care initiatives from local community organisations, particularly those set up for minority ethnic groups and people who may self-exclude from contact with statutory agencies, for example homeless people.
4. The NEoLCP should consider similarly engaging with organisations for these groups at national level, building on work already under way with homeless organisations and prisons.

SECTION 7

Conclusions and next steps

People approaching the end of their life, and their families, need integrated, holistic services that are flexible enough to meet their changing needs. They also want choice over care at the end of life. For many, this will mean choosing to die at home. Social care support may be one important element that enables them to do so.

Delivering this requires a transformation in service planning and delivery, working across organisational boundaries and in partnership with the individual and their family to ensure care is person-centred. End of life care needs to be 'reframed' for social care commissioners and planners: the concept of 'commissioning for health and wellbeing' needs to be promoted.

The whole social care workforce, including domiciliary and residential care assistants, social workers and other professionals such as occupational therapists and physiotherapists, has a crucial role in supporting individuals, their families and carers at the end of life. To date, a range of challenges and barriers has tended to limit the contribution of social care. Action is now needed to overcome these challenges and barriers to ensure social care fulfils its potential to enhance the support provided for individuals and their families at the end of life.

One urgent issue that has emerged in the development of this framework is the need to strengthen the underpinning evidence base for social care at the end of life. This chimes with the thinking of the National Institute for Health Research (NIHR) School for Social Care Research, which has identified end of life care in its planning for the next round of research commissioning.

OBJECTIVE 10
Work jointly with research commissioners and funders to establish a robust evidence base for good practice in social care support at the end of life

This report has outlined an ambitious vision for change. To achieve this, the publication of this framework will initiate a programme of stakeholder engagement and consultation, evidence gathering, testing of new approaches and evaluation of these, culminating in a review of the framework in 2011.

We envisage that the publication of this first articulation of the framework is only the start of a process of change that will gather momentum as the social care workforce rises to the challenge of supporting people to live, and also to die, well.

Appendix I Membership of the NEoLCP Social Care Advisory Group

Margaret Holloway and Tes Smith	Joint Social Care Leads, National End of Life Care Programme
Cathy Baldwin	Programme Delivery Manager, Alzheimer's Society
Stephen Burke	Chief Executive, Counsel and Care
Jo Cleary	Executive Director for Adult and Community Services, London Borough of Lambeth and Co Chair of the Association of Directors of Adult Social Services (ADASS) Workforce Network
Brian Cox	Head of Leadership and Management, National Skills Academy for Social Care
Owen Davies	Head of Policy and Research, General Social Care Council
Elaine Edgar (observer)	Senior Project Manager, Carers Team, Department of Health
Pam Firth	Isabel Hospice, Head of Family Support and Deputy Director Hospice Services
Glenis Freeman	Cancer and End of Life Care Workforce Lead, Cancer Programme, Department of Health
Jane Gammage	Head of Lifecare, Macmillan Cancer Support
Kim Grove	Head of Resources and Events, UK Home Care Association
Audrey Harmer	National Project Manager, Skills for Care – Project team
Felicity Hearn	Head of Family Support, Sue Ryder Care – Leckhampton Court Hospice; Education and Training Officer for Association of Palliative Care Social Workers
Claire Henry	Director, National End of Life Care Programme
Mary Highe	Commissioning Officer, Norfolk County Council
Philip Hurst	National Development Manager, Age UK
Jeff Jerome	National Director for Social Care Transformation, Department of Health
Sue Johnson	Regional Development Officer, Skills for Care - West Midlands
Martin Knapp	Director, NIHR School for Social Care Research and Professor of Social Policy London School of Economics
Liz Lloyd	Senior Lecturer in Social Gerontology, University of Bristol
Ann Mackay	Director of Policy, English Community Care Association
Dugald Millar	Assistant Director, Joint Commissioning of Adult Services and Partnerships and Director, Joint Commissioning and Partnerships LB Hounslow and NHS Hounslow
Kevin Miller	ADASS Associate, National Council for Palliative Care Trustee
Hilary Mills	Head of Strategic Commissioning, Norfolk Council
Diana Murungu	Specialist Palliative Care and Diversity Social Worker at Birmingham St Mary's Hospice
Rick O'Brien	Head of Branch, Access and Assessment, Wirral Council, Department of Adult Social Services and ADASS End of Life Care Lead
Malcolm Payne	Adviser, Policy and Development, St Christopher's Hospice
Keith Skerman	Management Consultant to the Royal Borough of Windsor and Maidenhead as Head of Adult Services
David Stanley	Chair in Social Care, School of Health, Community and Education Studies, Northumbria University
Amanda Thompsell	Consultant Old Age Psychiatrist and Clinical Champion for the Modernisation Initiative End of Life Care Programme
Jean Tottie	Chair, Uniting Carers – Dementia UK
David Walden	Director of Adult Services and Regional Development, Social Care Institute for Excellence

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Appendix II Useful links

The programme's website lists a range of resources and useful links, including case studies, relating to social care at the end of life. These can be found at http://www.endoflifecareforadults.nhs.uk/care-pathway/socialcare

Alzheimer's Society
http://alzheimers.org.uk

Association of Palliative Care Social Workers
http://www.apcsw.org.uk

British Association of Occupational Therapists and College of Occupational Therapists
http://www.cot.co.uk

Care Quality Commission
http://www.cqc.org.uk

English Community Care Association
http://www.ecca.org.uk

European Association for Palliative Care
http://www.eapcnet.org

General Social Care Council
http://www.gscc.org.uk

Macmillan Cancer Support
http://www.macmillan.org.uk

National Association of Social Workers [USA]
http://www.naswdc.org

National Council for Palliative Care
http://www.ncpc.org.uk/

National Institute for Health Research (NIHR) School for Social Care Research
http://www.nihr.ac.uk/research/Pages/programmes_school_for_social_care_research.aspx

Patient Opinion
http://www.patientopinion.org.uk

St Christopher's Hospice
http://www.stchristophers.org.uk

Skills for Health
http://www.skillsforhealth.org.uk

Skills for Care
http://www.skillsforcare.org.uk

Social Care Institute for Excellence
http://www.scie.org.uk

Social Work Reform Board
http://www.dcsf.gov.uk/swrb

United Kingdom Home Care Association (UKHCA)
http://www.ukhca.co.uk

Glossary

The following glossary sets out definitions for terms used in the framework, gathered from a range of sources. The glossary is a work in progress: usage of these terms varies widely and may change over time. The programme welcomes feedback, comments and suggestions for the glossary via its website.

Advance care planning	The process of identifying future individual wishes and care preferences. This may or may not result in recording these discussions in the form of an Advance Care Plan.
Advocacy	Taking action to help people to say what they want, securing their rights, representing their interests and obtaining services they need. May be provided by a person/organisation independent of the services being provided.
ADASS	The Association of Directors of Adult Social Services (ADASS) represents all the directors of adult social services in England.
BME	Black and minority ethnic
Care pathway	Specifies treatment and care for a given condition based on nationally agreed guidelines, standards and protocols incorporating best practice and evidence-based guidelines. Care pathways, which map out the care journey an individual can expect, are multi-professional; cross-organisational boundaries; and can act as a prompt for care. They provide a consistent standard of documentation that also provides the basis for ongoing audit.
Care Quality Commission	The health and social care regulator for England, aiming to ensure better care for everyone in hospital, in a care home and at home.
Carers	The family or friends who take on, in an unpaid capacity, some or all of the responsibility for the care and support of the individual.
Code of Practice	The Code of Practice for Social Care Workers is a list of statements that describe the standards of professional conduct and practice required of social care workers as they go about their daily work.
Department of Health Integrated Care Networks	These take the lead for the *Putting People First* team in the Department of Health around integration and whole system reform, housing with care, assistive technology and partnership working.
Dignity Challenge	A clear statement, produced by the Department of Health, of what people can expect from a service that respects dignity. It is backed up by a series of 'dignity tests' that can be used to measure how well a service is supporting the dignity of its users.
Direct payments	Cash payments made to individuals who have been assessed as eligible for publicly funded social care support. The cash payments enable individuals to choose the support that best meets their needs and that will achieve agreed outcomes.
Domiciliary care	Care services provided to an individual in their own home by a care worker paid to provide care as part of their employment. Also known as home care.
e-Learning for Healthcare	A programme providing national, quality assured online (eLfH) training content for the healthcare profession.

End of life care	All elements of support to people approaching the end of their lives. In addition to the highly skilled and focused care and support that may be provided by those working as palliative care specialists, all of the other significant support that is given needs to take on a different focus and perspective to accommodate this stage of life. It encompasses the management of all symptoms including pain, and provides psychological, social, spiritual and practical support.
General Social Care Council (GSCC)	The social care workforce regulator in England. It registers social workers and regulates their conduct and training.
Law Commission	The statutory independent body created by the Law Commissions Act 1965 to keep the law under review and to recommend reform where it is needed.
Liverpool Care Pathway (LCP)	An integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life. It is recommended as a best practice model, most recently, by the Department of Health in the UK.
NVQ4	Vocational qualifications on the Qualifications and Credit Framework are new, work-related qualifications. The main focal point of the NVQ Level 4 in Health and Social Care is in management and providing emotional care for clients.
Palliative care	An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Peer review	A group of people from a similar organisation looking at and commenting on an organisation's performance.
Personalisation	Involves putting the outcomes that people want to achieve at the centre of assessment, planning, implementation and reviews. The aim is to promote the individual's wishes about the outcomes they are aiming to achieve, and the solutions that best fit how they want to maximise their independence, promote their dignity and wellbeing. These may include better access to universal services. A second component of personalisation is an emphasis on early intervention and prevention to reduce or delay the need for social care support, and providing information and advice for people who are not eligible for publicly funded social care support.
Personal budgets	Individuals who are eligible to receive publicly funded social care support are allocated an agreed amount of money so that they can direct the funding to meet their needs in ways that best suit them.
Preferred Priorities for Care (PPC)	The PPC document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life.
Qualifications and Credit Framework (QCF)	The QCF is the new framework for creating and accrediting qualifications in England, Wales and Northern Ireland. QCF qualifications are designed with the help of employers so learners can be assured that they are gaining skills that employers are looking for.

Re-ablement	The Department of Health's Care Services Efficiency Delivery (CSED) works with Homecare Re-ablement seeking "to improve choice and quality of life for adults who need care". It offers services for people with poor physical or mental health to help them accommodate their illness by learning or re-learning the skills necessary for daily living.
Safeguarding	A range of activity aimed at upholding an adult's fundamental right to be safe. It is of particular importance for people who, because of their situation or circumstances, are unable to keep themselves safe.
Self-directed care or support	The name given to a way of redesigning the social care system so that the people who get services can take much greater control over them.
Skills for Health	The Sector Skills Council (SSC) for the UK health sector.
Skills for Care	The employer-led authority on the training standards and development needs of nearly one million social care staff in England.
Social care	The boundary of the social care workforce is not easy to define, but broadly it encompasses those who work in public services that are provided, directly or commissioned, by local councils to discharge their personal social services (PSS) responsibilities. The workforce is highly diverse, reaching across the private, voluntary and statutory sectors, dealing with many disadvantaged and dependent people in our society.
Social care workforce	The social care workforce in England comprises over one million people working in people's own homes, care homes, day care, hospitals and in the wider community. An estimated two-thirds of the workforce work for some 25,000 employers in the private and voluntary sectors. The remaining one-third work in the statutory sector, largely for 150 local councils with personal social services responsibilities.
Social work	Social work helps people to live more successfully within their local communities by helping them find solutions to their problems. It also involves engaging not only with clients themselves but their families and friends as well as working closely with other organisations including the police, NHS, schools and probation service. *NB: Definitions for social care and social work vary widely and can be contentious. The definitions for social care, social care workforce and social work are sourced from the Department of Health at:* http://collections.europarchive.org/tna/20100509080731/ http://dh.gov.uk/en/SocialCare/Aboutthedirectorate/DH_080186and: http://www.socialworkcareers.co.uk/qa/general.asp?qn=1
Social Work Reform board	Created to oversee the national reform programme for social work in driving delivery of the recommendations of the Social Work Task Force. This board comprises representatives from social work education, employers, the profession and government.
Survivorship	Living with or beyond cancer
Training Strategy Implementation (TSI) funding	Funding available on an annual basis to support employers, micro-employers and micro-providers with workforce development - building the skills of their employees. The funds are a contribution to the cost of learning and assessment.

Notes

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www.endoflifecareforadults.nhs.uk

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