Supporting people to live and die well:

a framework for social care at the end of life

A summary
Introduction

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. The new 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

The framework, developed by the former National End of Life Care Programme now NHS Improving Quality, 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 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 the impact of re-ablement and personalisation
• Reflect end of life needs in local authority and commissioners 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

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

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.

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.

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.

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.

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.

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.

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

For further information on 'Supporting people to live and die well: a framework for social care at end of life', access the following link:- http://www.nhsiq.nhs.uk/improvement-programmes/long-term-conditions-and-integrated-care/end-of-life-care/facilitators-and-champions-network.aspx

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