

AN INTRODUCTION TO THE NHS END OF LIFE CARE PROGRAMME

Claire Henry, Pam Fenner

There are approximately 500,000 deaths a year in England. When asked where they want to die, the response of most people is that they want to die at home. In 2003, the Department of Health published *Building on the Best: Choice, Responsiveness and Equity in the NHS*. The strategies outlined in this document have aimed to offer patients more choice in relation to their health needs. This includes improving the quality of care at the end of life. The NHS End of Life Care Programme was established to achieve this aim. Health and social care staff are being provided with practical solutions on how they can improve end-of-life care for their patients. This article will outline the work of the Programme and highlight how it is supporting patients at the end of their lives. *Declaration of interests: The NHS End of Life Care Programme is funded by the Department of Health*

KEY WORDS

End of life care
Nursing role
Patient choice

More than half a million people die in England and Wales every year; five deaths in every six are of people aged 65 years or older (Office for National Statistics, 2004) and one in five take place in a care home (Higginson, 2003). All professionals will be involved in the care of dying people. Although death is inevitable, this does not mean that health and social care professionals can simply leave nature to take its course — that would be a failure of care. It is essential that dying people's needs and symptoms are managed effectively.

Death should be made as 'good' as possible. This is important for all concerned — the patient who is dying,

Claire Henry is National Programme Director and Pam Fenner is Project Lead, NHS End of Life Care Programme. Email: information@eolc.nhs.uk

the loved ones they leave behind and the health and social care practitioners.

End-of-life care requires an active, compassionate approach that treats, comforts and supports individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices. It encompasses support for families and friends up to and including the period of bereavement (Ross et al, 2000a,b). All care staff should be ready to listen to people nearing the end of life, address their needs if possible and seek expert help where extra skill or knowledge is required.

The NHS End of Life Care Programme

The NHS End of Life Care (EoLC) Programme has been implemented in response to the content of *Building on the Best: Choice, Responsiveness and Equity in the NHS* (Department of Health, 2003). The objectives of the EoLC Programme are listed in *Table 1*.

The experience of the EoLC Programme is a key contributor to the Department of Health-led national End of Life Care Strategy. This Strategy aims to ensure that high-quality care is provided at the end of life for all

patients, irrespective of diagnosis, and will cover care given in hospitals, care homes and the community. It will continue to build on previous initiatives, such as the very successful programme to train district nurses in palliative care (Addington Hall et al, 2006), as well as the EoLC Programme in skilling up general health and social care staff.

The EoLC Programme provides training in the principles of palliative care for general staff across primary, acute and community settings. Central to this training is the dissemination of three key tools, which were endorsed by the National Institute for Clinical Excellence (2004). These are the Gold Standards Framework, the Liverpool Care Pathway and Preferred Place of Care. Other tools have been developed locally. The Programme has also included work on advance care planning.

Gold Standards Framework

The Gold Standards Framework (GSF) is concerned with community palliative care. It has, for more than 6 years, been helping to improve care for patients nearing the end of their lives in the community. It is now being used by about a third of primary health care teams across the UK. The GSF is a practice-based system that aims to

improve the organisation, quality of care, communication and proactive planning for people in the last stages of life living in the community, so that more people will live and die well in their preferred environment. For more information visit the GSF website at www.goldstandardsframework.nhs.uk.

The Liverpool Care Pathway for the Dying Patient

The Liverpool Care Pathway for the Dying Patient (LCP) is a tool that was developed to incorporate the best practice of hospice care into care for people in hospital and other settings. It provides a framework for the care of patients in the last days or hours of life once a diagnosis is made that a person is dying. The LCP involves promoting good communication with the patient and family, anticipatory planning, including psychosocial and spiritual needs, symptom control (e.g. pain, agitation and respiratory tract secretions) and care after death. The LCP has accompanying symptom control guidelines and information leaflets for relatives. For more information visit the LCP website at http://www.mcpcil.org.uk/liverpool_care_pathway.

Preferred Place of Care

The Preferred Place of Care (PPC) plan is a document that patients keep and take with them if they receive care in different places. It has space for the patients' thoughts about their care and the choices they would like to make, including saying where they ideally would like to be when they die. Information about the family can also be recorded so that any new care staff

can read about the people close to the patient and what matters to them. If anything changes, this can be written in the plan so that it stays up to date. It is never too early to start a PPC plan. This is currently being revised to take account of the Mental Capacity Act 2005. For more information visit the PPC website at <http://www.cancerlancashire.org.uk/ppc.html>.

Pertinent issues relating to the organisation of end-of-life care that have emerged following the establishment of the EoLC Programme are as follows:

- ▶▶ Implementation of local resuscitation policies
- ▶▶ The development of local protocols and training for nurses and paramedics in verification of death
- ▶▶ Education of staff, especially at induction, and ongoing training
- ▶▶ Understanding the implications of cultural and language diversity of both staff and patients
- ▶▶ The need to manage co-morbidity effectively
- ▶▶ Recognising different patterns of dying, e.g. cancer, organ systems failure, frailty and decline (Lynn and Adamson, 2003).

These are likely to vary across England, depending on how services have been developed in the past.

Key achievements of the EoLC Programme

The increased adoption of the above end-of-life care tools across the country demonstrates the potential effect of the Programme to improve patient care and the patient's experience. In

conjunction with the implementation of the tools, other examples of good practice have been developed (Table 2).

Care homes

In recognising that 20% of deaths occur in the 20,000 care homes within England (Higginson, 2003), the EoLC Programme has initiated a care homes sub-group that has focused on developing specific resources for this setting. All tools are currently being adapted. In July 2006, 3% of care homes were involved which compares to 0.3% at the start of the Programme in June 2005. To support this development, an *Introductory Guide to End of Life Care in Care Homes* has been published (NHS End of Life Care Programme and National Council for Palliative Care, 2006). Future publications include a good practice guide for care home staff (anticipated publication June 2007).

Advance care planning

Advance care planning (ACP) is a core component of the EoLC Programme. Guidance for health and social care professionals with regard to the implementation of an advance care plan has been published and is available on the website (www.endoflifecare.nhs.uk).

ACP is a process of discussion between an individual and his/her care providers, irrespective of discipline. If the person wishes, his/her family and friends may be included in the discussion. With the person's agreement, this discussion is documented, regularly reviewed and communicated to key persons involved in the person's care. An ACP discussion might include the following issues: individual concerns (social, cultural or spiritual); important values of personal goals for care; understanding of the illness and prognosis; and preferences for types of care or treatment that may be beneficial in the future and whether these are available.

The difference between ACP and care planning in general is that the process of ACP will usually take place in the context of an anticipated deterioration in the individual's condition in the future, with attendant

Table 1

Objectives of the NHS End of Life Care Programme

Greater choice for patients, irrespective of their diagnosis, with regard to where they wish to live and die

A decrease in the numbers of emergency admissions of patients to hospitals when they have expressly wished to die at home

A decrease in the number of patients transferred from a care home to a hospital in the last week of life

loss of capacity to make decisions and/or ability to communicate wishes to others. (Advance decisions are replacing living wills and directives.) Under the Mental Capacity Act 2005, individuals can continue decision-making about their care should they lack capacity in the future. In this context, the outcome of ACP may be the completion of a statement of wishes and preferences or an advance decision. This whole process is voluntary. Alternatively, people may decide to appoint a person ('lasting power of attorney') to represent them and take decisions on their behalf if they subsequently lose capacity. The National Council for Palliative Care has published detailed guidance about the Mental Capacity Act 2005. For more information please refer to www.ncpc.org.uk.

Evaluation of the EoLC Programme

Evaluation is vital to ensure that lessons are learnt. Currently, the Sue Ryder Centre for Palliative and End of Life Studies, Nottingham University, is undertaking a formal evaluation of the Programme. A National Care of the Dying Audit in Hospitals (based on the LCP) is also underway. This is being led by the Marie Curie Palliative Care Institute in Liverpool, in collaboration with the Royal College of Physicians' Clinical Effectiveness and

Evaluations Unit, London. The findings are expected to be published in November 2007.

In addition, an after-death analysis tool for the GSF has been developed which enables teams to review the last 10 deaths in a GP practice. This will include aspects such as supportive care registers, multidisciplinary meetings, advance care planning discussion, handover forms, and services provided to the patient. This is undertaken before and after practices implement the GSF.

The University of Lancaster has evaluated the first 100 PPC records. Seventy-two per cent of patients expressed the wish to die at home and 67% did die at home. Thirty per cent of those assessed died within a week of assessment, 68% within a month and 81% within 2 months. Discussion about choice at the end of life, personal wishes concerning place of care and death, and issues of access to services have far-reaching implications for health care providers and models of palliative care. PPC provides health care professionals, patients and carers with an adaptable tool that could promote patient choice and preferences. Further studies are required to identify whether and how PPC might facilitate patients' preferences for home death.

Barriers to implementation

Barriers to the implementation of the tools described in this article are:

- ▶▶ Lack of leadership
- ▶▶ The work is seen as an isolated project
- ▶▶ Infrastructures are not in place
- ▶▶ The effect elsewhere in the system is not considered
- ▶▶ Insufficient training
- ▶▶ Perceived time constraints
- ▶▶ The improvement is not in the direction of the organisation's goals
- ▶▶ Lack of planning and ownership
- ▶▶ Lack of performance management
- ▶▶ Not seen as a priority.

How should nurses start to consider end-of-life care in their area?

It is hoped that by sharing what is happening across the country, readers will start to think about what is going on in their locality with regard to end-of-life care provision. It would be useful for nurses to consider the following issues in relation to their patients:

- ▶▶ How many deaths do you have each year?
- ▶▶ What are the main disease groups amongst them?
- ▶▶ Do you have care plans that include care at the end of life stating patients' wishes and preferences?
- ▶▶ Do you recognise when patients are nearing the end of their lives?
- ▶▶ How comfortable/confident are you in raising the issue of death and dying?
- ▶▶ Do you talk with patients about where they would like to live and die?
- ▶▶ How many GP practices do you work/liase with?
- ▶▶ What links do you have with social care and specialist palliative care such as a link Macmillan nurse?
- ▶▶ Have any of the EoLC tools been implemented in other organisations within your geographical location, e.g. GP practices, acute trusts, community hospitals, hospices and care homes?
- ▶▶ Do you know what the priorities of your commissioners are and whether there is an overall palliative care/end-of-life care strategy?

Table 2

Locally developed examples of good practice in end-of-life care

Locally agreed protocols between ambulance trusts and the various care settings. This enables patients to be transferred at agreed times, preferably in the morning, to allow patients time to settle in and professionals to rectify any issues

Do-not-attempt resuscitation policies across care settings

Rapid discharge policies for patients who wish to die at home

Nurse verification of death, which allows a more timely response to families' needs, especially in the community, thus helping to reduce anxiety

'Just-in-case boxes' containing medication that may be needed in the community to help support patients at home and prevent admission to acute care

Guidance prognostic indicators for GPs: these have been developed by the central Gold Standards Framework team and are designed to help GPs identify when a patient is in the last year of life

Key Points

- ▶ All health professionals and care staff will be involved in the care of dying people and therefore need to acquire the requisite skills.
- ▶ The NHS End of Life Care Programme was established to improve the end-of-life care of all patients, irrespective of diagnosis.
- ▶ It is hoped that through the Programme more patients will be given greater choice with regard to where they will die, and that there will be a decrease in the number of adults dying in hospitals.
- ▶ The three tools that are integral to the NHS End of Life Care Programme are: the Liverpool Care Pathway, the Gold Standards Framework and Preferred Place of Care.

Once you have considered these questions use your findings to plan any future service development with your local team (you may wish to involve your local commissioners). Each strategic health authority will have a nominated lead for the EoLC Programme. To find out about your local link for end-of-life care email information@eolc.nhs.uk.

Next steps

The EoLC Programme is continuing to work with strategic health authority nurse directors and local champions to integrate the tools within the EoLC Programme into mainstream care. This includes developing practical solutions for sustainability, including primary care trusts' commissioning arrangements to ensure that end-of-life care is included.

Further details

Readers may be interested to note that a number of publications have been produced which include a first-year progress report, an introductory guide for facilitators and managers to improving end-of-life care, advance care

planning, newsletters on a quarterly basis and a website containing helpful information to improve end-of-life care. If you have issues or solutions you would like to share, the NHS End of Life Care Programme would like to hear from you. **EOLC**

Contact details

NHS End of Life Care Programme,
3rd Floor, St John's House, East Street,
Leicester LE1 6NB
Office Tel: 01162225103
Fax: 01162225101
Email: information@eolc.nhs.uk
Web: www.endoflifecare.nhs.uk

References

Addington Hall J, Shipman C, Burt J, Ream E, Beynon T, Richardson A (2006) *Evaluation of the Education and Support Programme for District and Community Nurses in the Principles and Practice of Palliative Care*. King's College London, University of London

Department of Health (2003) *Building on the Best: Choice, Responsiveness and Equity in the NHS*. Department of Health, London

Higginson I (2003) *Priorities for End of Life Care in England, Wales and Scotland*. National Council for Palliative Care, London

Lynn J, Adamson DM (2003) *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. RAND Cooperation, Santa Monica, CA

National Institute for Clinical Excellence (2004) *Improving Supportive and Palliative Care for Adults with Cancer*. NICE, London

NHS End of Life Care Programme, National Council for Palliative Care (2006) *Introductory Guide to End of Life Care in Care Homes*. <http://www.endoflifecare.nhs.uk/eolc> (last accessed 23 February 2007)

Office for National Statistics (2004) *Mortality Statistics: General (Series DH1)*. National Statistics Online. <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=620> (last accessed 23 February 2007)

Ross M, Fisher R, MacLean MJ (2000a) *A Guide to End of Life Care for Seniors*. Health Canada, Ottawa

Ross M, Fisher R, MacLean MJ (2000b) End-of-life care for seniors: the development of a national guide. *Journal of Palliative Care* 16(4): 47–53

Useful sources of information

Age Concern: www.ageconcern.org.uk; Tel: 0208 765 7200

Commission for Social Care Inspection (CSCI): www.csci.org.uk; Tel: 0207 979 2000

Counsel and Care: www.counselandcare.org.uk; Tel: 0207 241 8555

Department of Health cancer and end-of-life information: www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer

Healthcare Commission: www.healthcarecommission.org.uk; Tel: 0207 448 9200

Help the Aged: www.helptheaged.org.uk; Tel: 0207 238 1114

Help the Hospices: www.helpthehospices.org.uk; Tel: 0207 520 8200

Hospice Information: www.hospiceinformation.info; Tel: 0207 520 8232

Houses of Parliament and Health Select Committee Inquiry into Palliative Care: www.publications.parliament.uk/pa/cm/cmhealth.htm

Marie Curie Cancer Care: www.mariecurie.org.uk; Tel: 0207 599 7777

Mental Health Foundation and copies of *Dying Matters: A Workbook for People with Learning Disabilities*: www.mentalhealth.org.uk; Tel: 0207 803 1101

The Alzheimer's Society: www.alzheimers.org.uk; Tel: 0207 306 0606

The National Council for Palliative Care: www.ncpc.org.uk; Tel: 020 7697 1520

The Princess Royal Trust for Carers: www.carers.org; Tel: 0207 480 7788