Improving the care of dying patients in hospitals

The National End of Life Care Strategy for England (Department of Health, 2008) was a blueprint for improving the care of all dying people over the next 10 years regardless of diagnosis. The strategy emphasized the importance of improved end of life care provision in acute hospitals as more than half of all deaths take place there. As well as ensuring that those who die in hospital have a good death, the strategy called for improved discharge arrangements and better coordination with a range of community services so that more people can die at home if this is their preferred choice.

The Route to Success in End of Life Care – Achieving Quality in Acute Hospitals was launched last year (National End of Life Care Programme, 2010). The guide aims to provide practical support for NHS managers and clinicians as they seek to meet the needs of end of life care for individuals, when pressure to make best use of resources is increasing. It aims to help trusts reshape how their staff work with each other, their patients, community services and social care partners to meet the agenda of quality, innovation, productivity and prevention. This includes proactive planning to address needs before they become a crisis thus avoiding inappropriate admission to hospital. The guide aims to facilitate fewer people dying in hospital, and fewer and shorter unplanned hospital admissions. Six key levers for rapid progress towards high quality end of life care (National End of Life Care Programme, 2010) have been identified:

1. There should be coordinated care and discharge planning based on assessed need and by working with patients and families, as well as partners in the community and social care
2. Senior clinicians should make treatment decisions close to the patient, intervening early and managing uncertain diagnosis
3. Use recognized tools already developed, such as advance care planning or the Liverpool Care Pathway for the Dying Patient, and train staff in their use
4. There should be strong organizational governance including trust board oversight and senior management engagement
5. There should be training and education as appropriate to each team member's role, with full use of e-learning and more traditional learning methods while addressing staff attitudes towards death and dying
6. There should be access to a hospital specialist palliative care team 7 days a week in line with improving outcomes guidance (National Institute for Clinical Excellence, 2004).

These six key levers can deliver improved outcomes including improving the patient experience and quality of care, enabling people to die in the place of their choice, and helping to manage and reduce unplanned hospital admissions. They also allow the trust to manage its resources effectively including the reduction of inappropriate interventions and the development of a skilled workforce with improved staff morale and retention. They should lead to fewer complaints and improve the reputation of the hospital trust.

The quality agenda

The Care Quality Commission (2010) has included end of life care in its standards and regulations:

- Individuals are assessed (by specialists where appropriate) and involved in planning their care and can make choices, particularly around pain management
- Relevant information is provided
- Unnecessary disruption is minimized
- Individuals can have people present as they die
- Staff are respectful of their privacy, dignity and comfort
- The care plan records post-death wishes, including religious sensitivity.

The variable standards of provision and un-coordinated services were highlighted in the National Audit Office (2008) report. This emphasized how more coordinated work between health and social care, and between acute and community services, could provide improved care. This would enable more people to die in their place of choosing, and save money by reducing emergency hospital admissions and decrease length of hospital stay. In 2009, the National Confidential Enquiry into Patient Outcome and Death review also highlighted the need for improved communication and coordination between and within clinical teams.

In promoting end of life care in acute hospitals, four key areas need to be addressed at the clinical level:

Recognizing end of life

Recognition and discussion of the end of life (timeframe of 12 months) (General Medical Council, 2010) and ensuring that the patient is registered on a supportive or locality register for end of life care facilitates communication between secondary and primary care. It should ensure that the patient's needs are being met in the community, but also that appropriate communication and discussion is undertaken in secondary care. Inclusion of a patient on a register should also improve communication with the family and other services including social care.

Advance care planning

Key to these discussions is the role of advance care planning in end of life care. This offers the opportunity for individuals to discuss with health-care professionals their choices and preferences for care and how they wish to be involved in decision making. Discussions regarding advance care planning require professionals to communicate in a respectful and empathic way. It is important that high quality palliative care is delivered in the acute hospital. This involves a trained generic workforce, together with the additional knowledge and skills of a specialist hospital palliative care team for the more complex patients.

Support systems

Within the Modernisation Initiative End of Life Care Programme the hospital-orientated work has been focusing on systems to support earlier identification of patients, enabling transfer to their preferred place of care and care delivery. The programme has developed the AMBER care bundle for patients who are at risk of dying in the next 1–2 months (Modernisation Initiative End of Life Care Programme, 2009). The care bundle complements the Liverpool Care Pathway for the Dying Patient and other hospital-based initiatives around improving acute care.

AMBER is a care bundle for patients in acute hospitals who are at risk of dying in the next 1–2 months who may still be receiving treatment. It stands for:

- Assessment
- Management
- Best practice
- Engagement of patients and carers
- for patients whose Recovery is uncertain.

A care bundle uses a series of four of five questions to support best practice. The questions can be answered quickly and are based on good evidence or self-evident good practice. It supports clinicians to identify people who may have end of life care needs, helps staff start conversations about dying and gives patients and carers the opportunity to get involved in decisions about care and treatment. Clinicians should undergo appropriate training before implementation of the AMBER care bundle.

Care of the dying in hospital

As over 50% of our society die in acute hospitals, it is important that the care of the dying, and care after death is recognized as a core role for acute hospital trusts with an appropriately trained workforce. The Liverpool Care Pathway for the Dying Patient has now been implemented and is in use in over 80% of acute hospital trusts in England. The Liverpool Care Pathway for the Dying Patient is recognized around the world as a model to support care for patients in the last hours and days of life (Ellershaw and Wilkinson, 2011). It is a tool which guides staff caring for dying patients, to ensure the best possible experience for both the patient and the relatives and carers. Based on a desire to transfer best practice from hospice to hospitals, it is also being used in care homes and the community.

Although the Liverpool Care Pathway for the Dying Patient was originally developed for the care of cancer patients in the acute environment it has been adapted and disseminated across all care settings irrespective of diagnosis. It is important that, once a patient is supported by the Liverpool Care Pathway for the Dying Patient, the multiprofessional team carry out continuous assessment to reflect on and challenge their decisions. It is essential that appropriate training is given to all staff before they use the Liverpool Care Pathway for the Dying Patient in clinical practice.

In order to ensure quality in end of life care in acute hospitals, Commissioning for Quality and Innovation and patient related outcome measures are increasingly being developed. The National Care of the Dying Audit – Hospitals is now in its third round. It is recognized as one of the national audits included in the quality accounts and will be reporting in the autumn of 2011. A survey of bereaved relatives based on the Views of Informal Carers – Evaluation of Services questionnaire will aim to ascertain bereaved relatives' perspectives on the quality of end of life care. These metrics will enable information to be reported at board level within the acute trust to drive continuous quality improvement in end of life care.

Conclusions

With the increasing expertise of our hospices and community services in the delivery of palliative care, acute hospitals need to recognize that end of life care is part of their core business. By working across boundaries and with an adequately trained workforce both excellence in patient care, and choice can be achieved. End of life care is everyone's responsibility. BJHM

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Care Quality Commission (2010) *Guidance about Compliance: Essential standards of quality and safety.* Care Quality Commission

Department of Health (2008) *End of Life Care Strategy – promoting high quality for all adults at the end of life.* Department of Health, London

Ellershaw J, Wilkinson S (2011) *Care of the dying: a pathway to excellence.* 2nd edn. Oxford University Press, Oxford

General Medical Council (2010) *Treatment and Care Towards the End of Life: Good Practice in Decision Making.* General Medical Council, London

Modernisation Initiative End of Life Care Programme (2009) AMBER (Assessment, Management, Best Practice, Engagement for patients whose Recovery is uncertain). www.gsttcharity.org.uk/projects/eolc.html (accessed 25 July 2011)

National Audit Office (2008) *End of Life Care Report 2008.* The Stationery Office, London

National Confidential Enquiry into Patient Outcome and Death (2009) *Caring to the End? A review of the care of patients who died in hospital within four days of admission.* National Confidential Enquiry into Patient Outcome and Death, London

National End of Life Care Programme (2010) *The Route to Success in end of life care – achieving quality in acute hospitals.* National End of Life Care Programme, Leicester

National Institute for Clinical Excellence (2004) *Guidance on Cancer Services - Improving Supportive and Palliative Care for Adults with Cancer. The Manual.* National Institute for Clinical Excellence, London

KEY POINTS

- Over 50% of our society die in hospitals, so care of the dying is a core role for acute hospital trusts.
- Health-care professionals should be appropriately trained to assess and address the needs of palliative care patients.
- Integration of end of life care and locality registers between secondary and primary care will facilitate coordination of care and communication.
- Implementation of frameworks including advance care planning, AMBER and the Liverpool Care Pathway for the Dying Patient will support health-care professionals in improving end of life care for patients and their families.
- End of life care is everybody's responsibility.