END-OF-LIFE STRATEGY TO ENSURE QUALITY CARE FOR DYING PATIENTS

The skills and understanding of all nurses need to be developed to improve the patient experience. Ingrid Torjesen examines the government’s long-awaited strategy.

The end-of-life strategy launched this month by the Department of Health outlines how patients should be cared for to ensure they experience a ‘good death’ (DH, 2008). It points out that ‘how we care for the dying is an indicator of how we care for all sick and vulnerable people’.

Many patients end up dying in acute hospitals and may experience care that is far from ideal. Families and carers may not be involved in end-of-life decisions, patients may receive continued treatment when it is not in their best interests and may not be enabled to return home to die if that is their wish. Hospitals often do not recognise that providing care for the dying is one of its core roles, so staff are not trained in this or taught to recognise that death does not always represent a failure in healthcare.

PREPARING FOR DEATH

The strategy aims to change this. Patients need to be assessed in the time prior to their death so their needs and wishes can be ascertained and set out in a care plan.

The overall aim is that better coordination of services, availability of palliative care, fast-response nursing services 24/7 and training for all nursing staff will enable more patients to have the type of death they would choose. This assessment should include the nature of the condition, the patient’s living arrangements, social circumstances, experience of healthcare, approach to life and psychological well-being, mental health status, and cultural, spiritual and religious views. Following a format such as advance care planning can be helpful (NHS, 2006).

The plan will be a statement of the person’s wishes and preferences about the type of care they wish to receive, and possibly an advance decision to refuse specific treatment and/or to appoint an individual to make treatment decisions on their behalf if they are unable to do so for themselves. Some people will not want to confront their own mortality and their choice has to be respected. The care plan should be reviewed by the multidisciplinary team, the patient and carers as the patient’s condition or wishes change. There is never a single right time to initiate discussions about death. Sometimes a patient may bring it up but often it takes a health professional such as a district nurse to recognise it might be time. The Prognostic Indicator Guidance (NHS, 2006) developed as part of the Gold Standards Framework outlines triggers – for example when the answer is ‘no’ to: ‘Would I be surprised if the person in front of me was to die in the next six months or year?’ and ‘Is the patient likely to be aware of this?’.

Clinicians should also consider the likelihood of a death occurring when they assess a new hospital admission. In many cases the patient’s GP is the most appropriate person to lead discussions, as they will know the patient and be aware of medical history and social circumstances. However, hospital clinicians and senior staff in care homes may also be appropriate.

COORDINATED CARE

The care plan should be available to all relevant services, including out-of-hours and emergency services, to ensure care is in accordance with the plan from all of these at all times of day and night.

Coordination of the relevant services is a major activity and lack of it can lead to a person dying in a place not of their choosing. It is therefore important that responsibility falls on a team and not on an individual nurse. Some PCTs have dedicated coordination...
centres through the Marie Curie Cancer Care Delivering Choice Programme.

The strategy (DH, 2008) recommends PCTs create registers of people approaching the end of life, so they can receive priority care. GP practice registers have already been developed under the Quality and Outcomes Framework but are not accessible outside primary care.

Entry to PCT-wide registers would be based on agreed criteria and subject to consent of patients, who would then have access to a 24-hour telephone helpline, rapid response services in the community for nursing and/or specialist palliative care, and ensure that wishes regarding resuscitation and place of death are known to all relevant services.

The strategy emphasises that PCTs must make medical, nursing and personal care and carers’ support services available in the community 24/7, including in care homes, sheltered and extra care housing. Such 24/7 services can avoid unnecessary emergency admissions to hospital and enable more people to die in the place of their choice, and will be delivered by nurses with specialised training.

THE MOMENT OF DEATH

Signs that a patient may be nearing the end include becoming more withdrawn, slipping in and out of consciousness, avoiding food and only taking small amounts of fluid. It is vital nurses recognise this and take action to ensure the patient’s wishes are followed, and relatives and carers are consulted.

Good end-of-life care does not stop at the point of death. All nursing staff need to be familiar with good practice for the care and viewing of the body and be responsive to carer and family wishes, cultural and spiritual needs.

A key element of this is timely verification and certification of death because funeral directors cannot remove the body from a home until the death has been verified. While a doctor is legally required to complete documentation for certification, local policies have been developed to allow nurses to verify death in a patient who had previously been diagnosed with a long-term condition and entered the terminal phase.

Following a death, nurses should alert other staff involved in the care of that patient so records can be updated to prevent distressing NHS correspondence being sent.

TRAINING IN END-OF-LIFE CARE

End-of-life care needs to be embedded in nurse training at all stages – in induction programmes, continuing professional development and appraisal systems.

Palliative care nurse specialists, rapid response nurses and link nurses will need the highest level of competencies in communication, assessment, advance care planning and symptom management. However the group with the greatest training needs are nurses who come into contact with dying patients regularly, although it is not a core part of their role.

Palliative and terminal care represents 8% of a district nurse’s caseload but takes up 40% of their time (Audit Commission, 1999), yet many have received little or no post-registration education in this area. Others with training needs include community matrons, emergency nurses and most nurses in acute care. All should have high level communication skills and at least know how to undertake a comprehensive assessment of the needs and preferences of the patient.

There is currently no explicit statement relating to competency in end-of-life care in the NMC’s Standards of Proficiency for Pre-registration Nursing Education (NMC, 2004). However, new standards to be published in September 2009 are expected to address this.

In addition, the DH’s consultation in Towards a Framework for Post Registration Nursing Careers (DH, 2007) emphasised that although expertise in the provision of end-of-life care will be included in the long-term conditions pathways, in future all nurses will receive training in end-of-life care as part of their continued professional development.

REFERENCES


Nursing and Midwifery Council (2004) Standards of Proficiency for Pre-registration Nursing Education. London: NMC

KEY ELEMENTS OF AN END-OF-LIFE CARE PATHWAY

Step 1: Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

Step 2: Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carer

Step 3: Coordination of care for individual patients
- Strategic coordination
- Coordinating of individual patient care
- Rapid response services

Step 4: Delivery of high quality services
- High-quality care provision in all settings
- Acute hospitals, community, care homes, hospices, prisons, secure hospitals, hostels
- Ambulance services

Step 5: Care in the last days of life
- Identifying the dying phase
- Reviewing needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6: Care after death
- Recognition that end-of-life care does not stop at the point of death
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family

Source: DH (2008)