**The high impact actions for nursing and midwifery 6: where to die when the time comes**

**Keywords** High impact actions | End of life care | Palliative care

The quality of end of life care varies significantly. A challenge is to enable people to die in their place of choice and avoid inappropriate admission to hospital.

Although around half of the 500,000 deaths in England each year occur in acute hospitals, research suggests that 40% of those who die in hospital have no medical need to be there (National Audit Office, 2008). This is inappropriate for patients and their families and around half of all complaints made to acute trusts relate to an aspect of end of life care.

At the same time, deaths that occur in hospital unnecessarily are costly to the NHS. Palliative care hospital bed days are far more expensive than home care.

Economic modelling for the NAO by Hatziandreou et al (2008) estimated hospital care costs £222 per day, compared with £28 per day for care provided in the community (the patient’s own home or a nursing home).

Clearly, the care for avoiding inappropriate admissions to hospital at the end of life is compelling both for patients and their families and for the NHS.

**WHAT CAN NURSES DO?**

Preparation is the key to getting end of life care right. By identifying people who are nearing the end of life, nurses can help to unblock the end of life pathway and ensure that people are not hospitalised needlessly or receive inappropriate care.

When people die in hospital despite having a preference to die at home and no medical need to be there, and that 55% of people with cancer would prefer to die at home while only around 25% do so.

Death remains a subject that people find difficult to talk about. However, unless healthcare professionals discuss the way they care for people who are dying, the NHS will not improve the experience of patients and their families at this important time – and the quality of end of life care.

The Gold Standards Framework (2004) stated that many people who are nearing the end of life would prefer to die at home. Community Palliative Care Institute Liverpool and Royal College of Physicians (2007) noted that 55% of people with cancer would prefer to die at home but, in fact, only around 23% do so.

**The case studies featured in this article include people with long term conditions and dementia who are nearing the end of their life.**

**CASE STUDY 1: A COMMUNITY MATRON FOR SUPPORTIVE AND PALLIATIVE CARE**

Community Health Oxfordshire worked with Sue Ryder Care and community matron services that provide specialist palliative care outside the NHS, to develop a specialist community midwife role to provide supportive and palliative care.

The new role was piloted in 2006 and jointly funded by Sue Ryder and the primary care trust. It was deemed successful and the role was made permanent in 2009.

The community matron has a unique role within end of life care. Responsibilities include prescribing medications, providing frontline clinical care, offering expertise and education, and working in partnership with a range of organisations.

Lisa Clement, who was appointed to the role, had experienced the frustrations of providing end of life care in the home at first hand in her former position as district nurse. She now helps to bridge the divide between NHS services and those traditionally provided by the local hospice.

Ms Clement has an active clinical caseload covering South Oxfordshire; she also works in an advisory capacity in the north of the county and provides strategic advice within the local PCT. Her role also entails reviewing existing services and identifying areas for improvement.

There is a special relationship between the community midwife and the local hospice and she is able to liaise with consultants there for advice and support whenever she needs it.

Ms Clement is a member of the end of life group for Oxfordshire and is part of the strategic health authority’s clinical leader’s network, focusing on dementia. She has been instrumental in designing a formal scoring tool to assess patients with dementia more accurately.

**Impact of the initiative**

Fifty nine out of 51 people under the community matron’s care died in the place of their choice.

Her work has helped to reduce inappropriate hospital admissions for patients at the end of life and, during her first year, she prevented 25 admissions with a caseload of 90 patients. This saved an estimated £41,000.

The trust is now agreeing a model for extending those services, which may develop the role of community nursing staff in end of life care.

**CASE STUDY 2: INTEGRATED END OF LIFE CARE**

NHS Leeds Community Healthcare has 500 district nurses covering a city with a population of 750,000. Two local hospices provide end of life care.

The trust recognised that the existing care pathway for people at the end of life was inconsistent and varied according to the patient’s location and the expertise available from the community nursing team.

It designed a framework that clearly outlines the responsibilities of district nurses and joint care management in caring for patients at the end of their lives. Once the framework had been agreed, all staff with a clinical caseload received training in how to deliver the new way of working.

The end of life pathway begins once a patient has received a prognosis. A district nurse contacts the patient to discuss the range of interventions and support available. Discussions take place about the preferred place of death and DNACPR orders, and preparations are made, including the prescription of anticipatory drugs.

The main focus of the framework is to avoid unnecessary hospital admissions and ensure people can die where they want to.

The idea is that district nurses can anticipate and prevent crises occurring. The framework also helps them to plan their workload more effectively around the needs of dying people.

The district nurses are supported by the complex and palliative continuing care service (CAPCCS), a joint initiative between Marie Curie Cancer Care and NHS Leeds that provides pallial care and support for people who are dying. This support could range from simply sitting with someone who lives alone to keep them company, through to practical tasks like doing the laundry or making a cup of tea.

**Impact of the initiative**

More than 80% of patients are now achieving their wish to die at home. There has been a significant improvement in the prescription of anticipatory medicines and use of the Leeds Care of the Dying pathway.

The CAPCCS teams provide 1,500 contacts each month in support of district nursing and the sitting service provides 5,000 nights of one to one care in a year. CAPCCS has achieved a 9% reduction in admission to hospital due to improved symptom control at home.

It has a high level of job satisfaction and staff turnover is low.

**CASE STUDY 3: PATIENTS WHO WANT TO DIE AT HOME ANTICIPATORY DRUGS**

Sara Crook, a district nurse, undertook an audit to find out what was happening in the community around end of life care. It uncovered a range of problems, including poor documentation, poor recording of DNACPR and patients not identified as being in the end of life phase. However, there were also areas of good practice with the community nursing teams, with 31 practices developing their services in line with the Gold Standards Framework for 2007.

In light of this audit, the trust developed new documentation to standardise the approach to end of life care. Once documented, this became the way of working, the trust introduced other improvements, including:

- A ‘just in case’ box containing anticipatory drugs for common side effects, such as pain, nausea and respiratory problems;
- A comfort box, containing regularly used items such as, such as continent products, mouth care and a life-style pressure relieving mattress that can be used on the patient’s own bed. Additional items can be added to suit the individual patient’s needs;
- A purpose designed in-trainer site for palliative care;
- Patient/carer information leaflets addressing practical issues at the end of life.

**Impact of the initiative**

The just in case box has dramatically reduced the number of calls for crisis medication to ease side effects. Now, district nurses can administer drugs within 30 minutes, instead of several hours.

The number of patients identified as being in the end of life phase has increased and the trust now documents DNACPR orders and the preferred place of death.

Community nurses looked after almost 600 patients at the end of life in 2009. The target is to increase this by 50% in 2010.

A life book has been developed for patients using the Gold Standards Framework. This provides information about care, as well as more personal, reflective information.

**REFERENCES**


NICE guidance on supportive and palliative care at the end of life. *www.goldstandardsframework.nhs.uk*

The National Audit Office, 2008. This is inappropriate for the patient’s own bed. Additional items can be added to suit the individual patient’s needs.

- A purpose designed in-trainer site for palliative care;
- Patient/carer information leaflets addressing practical issues at the end of life.

**Impact of the initiative**

The just in case box has dramatically reduced the number of calls for crisis medication to ease side effects. Now, district nurses can administer drugs within 30 minutes, instead of several hours.

The number of patients identified as being in the end of life phase has increased and the trust now documents DNACPR orders and the preferred place of death.

Community nurses looked after almost 600 patients at the end of life in 2009. The target is to increase this by 50% in 2010.

A life book has been developed for patients using the Gold Standards Framework. This provides information about care, as well as more personal, reflective information.

- A purpose designed in-trainer site for palliative care;
- Patient/carer information leaflets addressing practical issues at the end of life.

**Impact of the initiative**

The just in case box has dramatically reduced the number of calls for crisis medication to ease side effects. Now, district nurses can administer drugs within 30 minutes, instead of several hours.

The number of patients identified as being in the end of life phase has increased and the trust now documents DNACPR orders and the preferred place of death.

Community nurses looked after almost 600 patients at the end of life in 2009. The target is to increase this by 50% in 2010.

A life book has been developed for patients using the Gold Standards Framework. This provides information about care, as well as more personal, reflective information.

- A purpose designed in-trainer site for palliative care;
- Patient/carer information leaflets addressing practical issues at the end of life.