The community matron’s role in providing end-of-life care

Angela Liddament

The phasing out of the Liverpool Care Pathway and the introduction of the The Leadership Alliance for the Care of Dying People’s (LACDP) five priorities of care has enabled clinicians working in end-of-life care to step back and re-evaluate their practice (LACDP, 2014). The review of end-of-life care services, More Care, Less Pathway (Neuberger, 2013) highlighted areas that needed urgent improvement. These included recognising when a person is dying but understanding the need for ongoing assessment; having a senior named clinician for all patients; and improving the communication skills of all clinicians involved in end-of-life care through the development of educational programmes. Non-malignant diseases are particularly challenging and in these cases it can be hard to recognise when a person is nearing the end of his or her life. Community matrons have their own relationships with the people on their caseload and can often provide untapped expertise and support as their condition deteriorates.

**KEYWORDS:** End-of-life care ■ Community matrons ■ Personalised care-planning

There are few areas in community practice that nurses feel more passionately about than the care of a dying person in his or her own home and it is both a pleasure and a privilege to be part of a very private and emotional time in family life. In 2008, the Department of Health (DH) published the End of Life Care Strategy, which stated that wherever possible, people should be able to spend their final days of life in the place of their choosing. Although this has resulted in a very small increase (from 18.3% in 2004 to 20.8% in 2010), more people are now dying at home rather than in hospital (Collis and Al-Qurainy, 2013).

Due to the funding constraints that have affected the NHS over recent years, community nurses are finding it increasingly challenging to deliver a consistently high level of care (Adamson and Cruickshank, 2013). However, this article aims to illustrate how community matrons and the case management model are having an impact on end-of-life care in the community, especially for people with end-stage long-term conditions.

**PHASING OUT OF THE LIVERPOOL CARE PATHWAY**

Echoing the findings of the Francis Report (www.midsstaffpublicinquiry.com), which highlighted wide-ranging issues with care in Mid-Staffordshire Hospital including poor communication and a lack of compassion among staff, 2013’s More Care, Less Pathway recommended the phasing out of the Liverpool Care Pathway (Ellershaw et al, 2003). Before this, the Liverpool Care Pathway had been seen as the ‘gold standard’ in end-of-life care. Unfortunately, following incidents like those in Mid-Staffordshire Hospital, concerns were raised by families and the media about the inappropriate use of the Pathway, provoking an independent review. The Leadership Alliance for the Care of Dying People (LACDP) was created from a group of 21 institutions such as Public Health England, the RCN and Marie Curie to consider the 44 recommendations of More Care, Less Pathway.

**BACKGROUND — THE LIVERPOOL CARE PATHWAY**

The Liverpool Care Pathway was originally intended to provide a pathway for high-quality, dignified care for dying patients, either in hospital, at home, or in a care home or hospice. Patients were regularly reviewed to check if medication should be stopped and fluids withdrawn once the patient ceased to be able to eat and drink. It was developed at the Royal Liverpool University Hospital and the city’s Marie Curie hospice in the 1990s to provide a uniform model of best practice in end-of-life care. However, the Pathway attracted controversy when it became clear that some patients were put on it without their consent, and/or that their deaths may have been unnecessarily accelerated. In 2013, the document More Care, Less Pathway (www.gov.uk) recommended a raft of measures, including a more individualised approach and that every patient should have a senior member of staff responsible for his or her care.

Source: www.bbc.co.uk/news/health-23698071
Paul, whose wife has cancer

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Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. MAC15512.
Table 1: The LACDP’s five priorities of care for the dying person

<table>
<thead>
<tr>
<th>The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.</th>
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<tr>
<td>Sensitive communication takes place between staff and the dying person, and those identified as important to them.</td>
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<tr>
<td>The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.</td>
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<tr>
<td>The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.</td>
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<tr>
<td>An individual plan of care, which includes food and drink, symptom control, and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.</td>
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The LACDP’s response to the recommendations was published in June 2014 in the paper *One Chance to get it Right* (LACDP, 2014). The Liverpool Care Pathway has now been phased out and been replaced by the LACDP’s five ‘priorities for care of the dying person’ (Table 1).

**Family concerns**

One of the principle concerns raised by the public was the ease that dying relatives could be ‘diagnosed’ as dying and commenced on the Liverpool Care Pathway. It appeared to patients’ families that any grade of medical professional could start the Liverpool Care Pathway, often without informing either the patient or the relatives. Furthermore, once a patient had been started on the pathway, there appeared to be no mechanism for ongoing assessments that would indicate any improvement or reversal in the original decision (Breen, 2013).

One of the recommendations in the LACDP (2014) report called for clear guidance to be issued by the National Institute for Health and Care Excellence (NICE) on the diagnosis of ‘dying’, and who should be ultimately responsible for deciding that a patient is at the end of life. NICE is currently developing new guidelines on the management of end-of-life care for adults, which are due to be published this year, followed by a revision of the Quality Standard on end-of-life care.

In the meantime, the main priority of the LACDP is to focus on clear communication of any decisions and/or actions taken by clinical staff if it is considered a person is nearing the end of life. The LACDP (2014) recommends adopting the approach of focusing on changes in the condition of someone who is likely to be dying rather than diagnosing dying.’

**Recommendation 12 of One Chance to get it Right** clearly states that everyone diagnosed as dying should have an identified responsible clinician accountable for 24-hour care (LACDP, 2014). Clear communication between clinicians, the dying person and his or her family is essential and this communication must be clear with regular opportunities to discuss any uncertainties or concerns.

**DIAGNOSIS**

Community staff have often used the Gold Standards Framework (Thomas, 2003) to identify people thought to be within the last year of life, and then to review them monthly. However, until fairly recently, the Gold Standards Framework primarily identified patients with malignant disease.

Non-malignant disease, including long-term conditions such as heart disease or chronic obstructive pulmonary disease (COPD), is particularly difficult to diagnose in people approaching the final year of their life (Murtagh et al, 2012), particularly as some healthcare professionals may be reluctant to discuss end-of-life issues with non-cancer patients.

Murray et al (2005) identified three different disease trajectories according to diagnosis:
- **Trajectory one:** a short period of evident decline, typically cancer
- **Trajectory two:** long-term limitations with intermittent serious episodes (very typical of chronic heart failure or COPD)
- **Trajectory three:** prolonged dwindling, as often seen in the frail and elderly.

However, because it can be so difficult to predict when a patient with one or more long-term conditions is becoming seriously unwell — partly due to the frequent exacerbations involved in these conditions — the end-of-life care of these patients has often been ‘hit and miss’, resulting in most deaths in these patients taking place in an acute hospital (Murtagh et al, 2012).

The LACDP’s position was that diagnosing a person as ‘dying’ was not always helpful as it did not take into account the uncertainty of their deteriorating condition and the need for ongoing assessment (LACDP, 2014). Even while the Liverpool Care Pathway was still in use, there were concerns about mis-timing its implementation and causing distress to families, which resulted in some clinicians avoiding difficult conversations (Dee and Endacott, 2011). *One Chance to get it Right* (LACDP, 2014) highlights this uncertainty and provides guidance on recognising and communicating clearly when it is thought a person is in the last days or hours of life.

**ROLE OF COMMUNITY NURSES**

Concerns about recognising when a person is dying, the appropriate use of prognostic tools and the identification of a named clinician are important issues that could be managed by senior clinical nurses liaising closely with the patient’s GP. Community matrons are senior clinical nurses who manage a caseload of approximately 50 people with one or more long-term conditions. These people are often nearing the end of life and one of the roles of a community matron is to manage them at home, treating exacerbations promptly to avoid acute hospital admission.

Although it is possible to discharge patients or hand them over to case managers if they become stable and are able to self-manage their long-term conditions, most people stay on a community matron’s caseload until death (DH, 2005). In the author’s experience, case management has developed enormously over the past
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<th></th>
<th>Tin Size (g)</th>
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* MIMS, March 2015; **200ml drinks as per manufacturer dosage instructions.
fiv e years and it is during meetings with GPs that community matrons are able to identify those people nearing the end of life, according to the Gold Standards Framework criteria.

Added to this, the King’s Fund published a report in 2013 introducing a new model of care based on the metaphor of ‘building the house of care’ (Coulter et al, 2013). Encompassing all patients with a long-term condition, the report envisaged an active partnership between patient and clinician, with a personalised care plan at its heart, including:

- Goal-setting
- Action-planning
- Sharing information
- Support
- Long-term decision making.

The aim was for any care plan to be regularly reviewed with decisions able to be changed at any point. Using these personalised care plans has enabled community matrons and GPs to look at advanced care planning as part of a less threatening generalised discussion about the patient’s ongoing care, particularly should he or she require support as a result of becoming very unwell. The proposed integration of social and health care (Goodwin et al, 2012), along with case management, have also played a key role in the introduction of personalised care planning.

**Advanced practice**

As well as running large caseloads, community matrons also act as advanced nurse practitioners with specialist knowledge of long-term conditions, assessment and diagnosis, and independent prescribing, as well as having advanced communication skills.

In addition to these skills, Bowler et al (2009) recognised the importance of palliative care skills for community matrons, acknowledging that because they are key to the treatment of chronically ill patients, they must be able to offer support through to end of life.

Community matrons should also be able to use their advanced communication skills to build strong relationships with patients and their families, which will help them when they come to formulate personalised and advanced care plans. Mutual trust must be established, which will become invaluable as the patient’s condition deteriorates, enabling the community matron to liaise closely with the patient and his or her GP to arrange a smooth transition into end-of-life care.

As highlighted in One Chance to get it Right (LACDP, 2014), recognising when a person is at the end of life is very difficult and cannot be based solely on prognostic tools; nor can it be the responsibility of one clinician. However, developing a trusting relationship with patients will not only allow community matrons to gain a unique insight into their deteriorating conditions; it will also help to engage patients and families in meaningful discussions about future care.

It is important to note that advanced care planning decisions made by people with long-term conditions often change as their health deteriorates. For example, those suffering with end-stage COPD or chronic heart failure frequently develop intractable breathlessness alongside severe anxiety, which they may feel unable to manage at home, especially if they live alone. Although they may have chosen home as their preferred place of care when their advanced decisions were being drawn-up, this can change as frightening and unpleasant symptoms occur. It is in this situation that a community matron is able to support patients and families towards making choices they feel comfortable with, even if it does mean admitting them into secondary, hospice or residential care.

**CONCLUSION**

As modern demands on health care become ever more challenging for healthcare professionals generally, the one area of nursing that must never be compromised is end-of-life care, whether this takes place in a person’s home or in a residential setting.

The unique relationship possible between community matrons and their patients must be recognised and taken advantage of by GPs and other health and social care professionals involved in the care people at the end of life.

Community nurses, and matrons in particular, have a unique set of skills that, if correctly employed, will ensure that the mistakes of the past are never revisited in the future.

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