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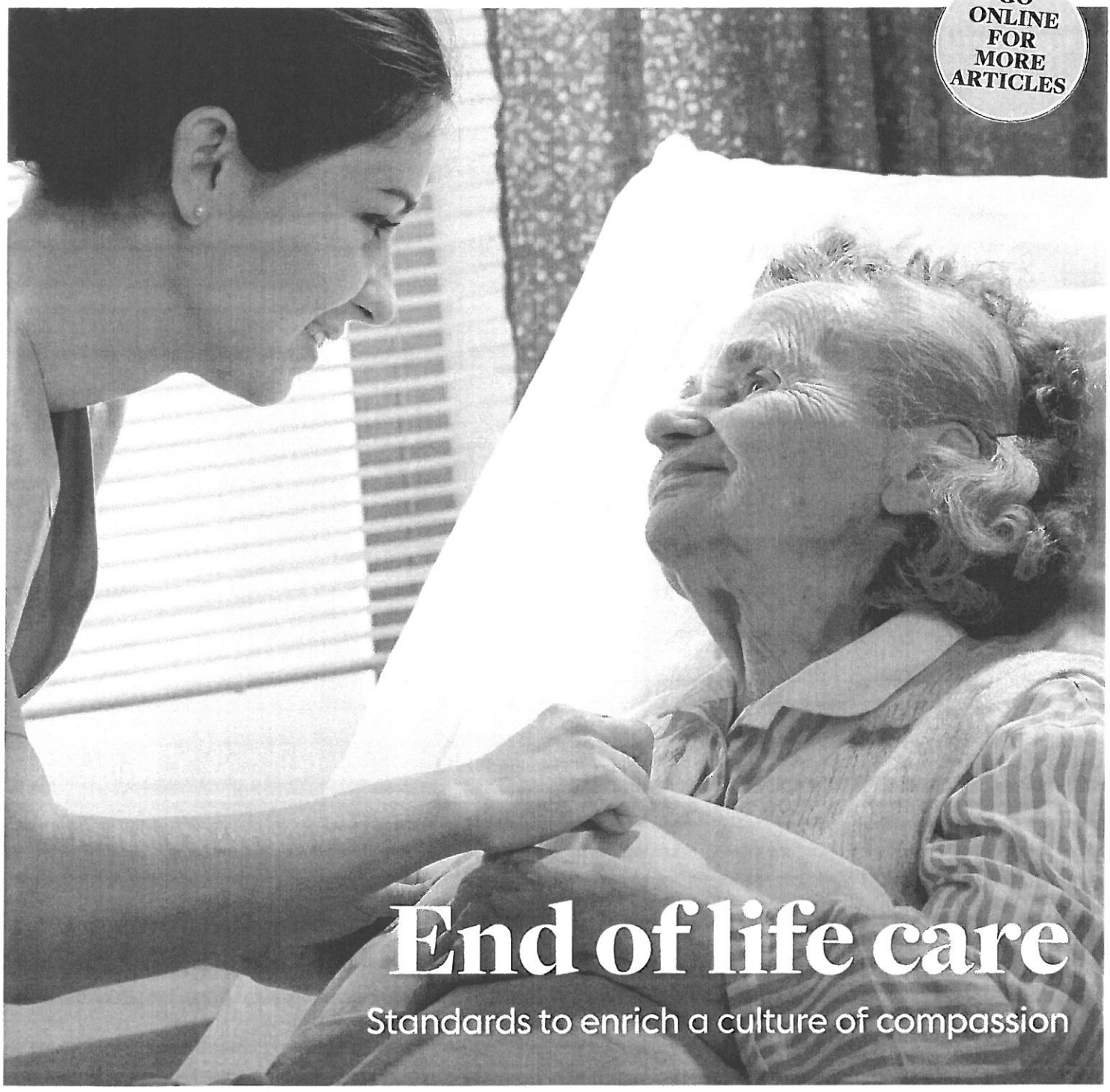

End of life care

Standards to enrich a culture of compassion

END OF LIFE CARE

Using the Gold Standards Framework to deliver good end of life care

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Abstract

The aims of excellent end of life care (EOLC) and nursing are at the heart of healthcare. Chelsea and Westminster Hospital NHS Foundation Trust, a multi-site London teaching care provider, recognises and values the importance of good EOLC, and the quality of EOLC is used as one of the key metrics in assessing the quality of patient and family care across the trust.

The principles of EOLC, including those enshrined in the Gold Standards Framework (GSF), are closely aligned with the trust's core values. Each member of staff is encouraged and supported, through the GSF process, to recognise and respond as befits their role in implementing the principles of EOLC, agreed by staff, and by patients and their relatives.

This article describes the experience of, and collaboration between, trust staff and members of the GSF team, who have worked together for the past 18 months, and how this work has placed EOLC at the heart of patient care and staff recruitment. This collaboration has helped to enrich the culture of compassion and care that the trust aims to deliver, and to focus on providing person-centred care.

Keywords

end of life care, Gold Standards Framework, nursing management, person-centred care

Background

German philosopher Martin Heidegger wrote that every human being is moving towards their own death. Rather than seeing this as negative, Heidegger suggested that, if we acknowledge this reality, it sets us free to live life as we truly want to. For many nurses and nurse leaders, Heidegger's call to live life to the full is the inspiration for delivering patient-centred nursing care.

Chelsea and Westminster Hospital NHS Foundation Trust is a large London teaching care provider with multiple sites and cares for adults and children who require specialist and non-specialist care.

As part of its extensive range of other patient-centred services, the trust has one of the largest HIV and sexual health services in the UK, a large maternity unit and a children's hospital. While most patients return home, some are moving towards the end of their lives and may die while in the hospital, or return home to do so.

The trust recognises the importance of good end of life care (EOLC), and uses the quality of EOLC to measure delivery of good patient care, in agreement with the governors and local clinical commissioning groups. The delivery of consistently good EOLC, 24 hours a day, seven days a week, can be achieved only if clinical and non-clinical staff recognise their roles in this task. The trust, led by nursing, has recognised that the principles of EOLC can help enrich its culture of compassion and care, and attract nursing staff who embrace the same values.

EOLC has been defined as care that helps all those with advanced, progressive, incurable illness to live as well as possible until the day they die (General Medical Council (GMC) 2010). Unfortunately, we have become a death-denying society, sheltered by lack of exposure to, avoidance of and the over-medicalisation and specialisation of caring for those who are dying.

In reality, caring for people moving towards the end of life is a human task built on sensitivity and humility, coupled with good symptom management, which are core values of nursing.

In 2014, the trust made the following commitments to all adults and children moving towards the end of their lives:

» When you are moving towards the end of life, we will support you and your family sensitively to ensure your needs and wishes are met, and enable you to die in your preferred place of care.

» When you are approaching the end of your life, we will offer you the opportunity to be involved in your care planning. This includes an assessment of your needs and preferences, and an agreed set of actions reflecting these choices.
» We will work to ensure that you and your family receive excellent care in accordance with your wishes, at all times of the day and night. We will work with our community partners to ensure this happens.
» We will monitor how we are doing by talking to you and your family, taking part in national surveys, and by immediately addressing any concerns.
» The trust will offer you personalised care based on your wishes and needs. This includes attending to your physical, social, emotional, spiritual and religious needs.
» We recognise the importance of your family, friends and support network, and that they have the right to have their own needs assessed and reviewed, and to have a carer's plan.
» To care for you and your family, we will ensure that all staff and volunteers working in the trust are aware of the issues surrounding care at the end of life, particularly the importance of excellence in communicating.
» We will participate in research to improve patient and family care at the end of life.

To support all staff to deliver these commitments, the trust, guided by the EOLC steering group, wanted to build on its EOLC strategy. It therefore approached the Gold Standards Framework (GSF) Centre in End of Life Care team, based in the West Midlands, for support in using the GSF to bring together, and build on, all aspects of the trust's EOLC strategy.

National context of end of life care

About half a million people, roughly 1% of the population, die in the UK every year, and one person dies about every minute. Just over 100 years ago most people in the UK died from infection, accident and trauma, and childbirth, many had short trajectories of illness and most died in their fifties. This is still the case in many developing countries. Now most people in the UK die from frailty, dementia, comorbidities, heart disease, chronic obstructive pulmonary disease and cancer, and there is a consequent shift in lifespan, with an increasing number of people over 85.

In the developed world, with changing demographics, we face a different kind of challenge. More people are living longer with serious, incapacitating conditions, more are nearing the final year or so of their lives and in 2015, for the first time for many years, the death rate started to rise (Office for National Statistics 2015). This presents new challenges of meeting demand with inadequate resources, potential over-use of hospitals and over-medicalisation, and inadequate focus on early detection, prevention and support in the community to prevent expensive and avoidable hospitalisation (Macdonald and Loder 2015). The healthcare system is still unprepared for this change, and nowhere more so than in hospitals.

Despite most people expressing a preference to die at home where possible, just less than half still die in hospital, and about half of these could have died at home with more proactive and better supported community care (National Audit Office 2008). Despite the UK being rated top of the world end of life care league table (Economist Intelligence Unit 2015), and improvements since publication of the NHS end of life care programme and strategy (Department of Health 2008) and the Ambitions for Palliative and End of Life Care report (National Palliative and End of Life Care Partnership 2015), care is still often reactive and inadequate (Parliamentary and Health Service Ombudsman 2015).

Poor care of patients in the final days of life has been much cited in the media and national policy, about the withdrawal of the Liverpool Care Pathway (Neuberger 2013) and with a particular focus on inadequate care of dying patients in hospital.

EOLC, defined in national policy terms as care in the final year, rather than the final days, of life (GMC 2010), has received much attention in National Institute for Health and Care Excellence (NICE) guidance (NICE 2015), and from the Care Quality Commission (CQC), and it is now recognised that it is the business of all healthcare professionals and an important part of the work of every member of hospital teams. But is the health service prepared for this challenge, how well are hospital staff trained in this area, and what can be done to develop more proactive, joined-up, person-centred care for people in the last chapter of their lives, to enable them to live and die well in the place and manner of their choice?

End of life care in hospital

Most people have two to three hospital admissions in the final year of life, about 30% of hospital patients at any one time are in their last year of life (Clarke 2014), and an estimated 10% of patients die after admission.

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