



## Palliative Care: Winter 2014.

*This bulletin covers the key research, news reports and journal articles to appear in the months October 2014 - January 2015 in the field of Palliative Care.*

### In the News

#### Dying Well Community Charter pathfinders announced

[National Council for Palliative Care](#) (NCPC) | Online – 7 January 2015

NCPC and Public Health England (PHE) have announced details of eight Pathfinder communities who are taking up the opportunity to pioneer a public health approach to end of life care in England. The Pathfinder communities were chosen from 23 organisations that expressed an interest, and will be supported and led by local authorities, Clinical Commissioning Groups, Health & Wellbeing Boards, NHS and voluntary sector providers of health and social care. Pathfinders will be implementing the new Dying Well Community Charter and will receive support and resources from the NCPC and PHE to help their local community to work together to improve their response to people who are dying and those who have been bereaved. To help support local good practice, many of the Pathfinders will also support a "buddy" from another area.

The new Charter has been updated from '[What makes a good death? A North East Charter.](#)' It incorporates Priorities for Care that came from the [Leadership Alliance for the Care of Dying People](#) recommendations, as well as work from the Royal College of Nursing and Royal College of General Practitioners' [End-of-Life Care Patient Charter](#).

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#### Revealed: the ten questions patients, carers and professionals most want answered about end of life care.

[Marie Curie Cancer Care](#) has published a report revealing the most important unanswered questions in palliative and end of life care.

The answers raise themes that will be familiar to many people - such as the availability of 24/7 care, improved access to services, training for professionals, advance care planning, and the delivery of care at home.

View the full document, Palliative and end of life care Priority Setting Partnership [here](#)



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## How hospices can save hospitals

Below text is from [The Daily Telegraph](#), 20 January 2015

In January the health select committee began taking evidence for a new inquiry into end-of-life care. This comes after considerable public concern about the quality of care that people receive as they die, and six months after the controversial Liverpool Care Pathway for the terminally ill was officially withdrawn from use in the NHS. The truth is that many frail elderly and terminally ill people are in hospital unnecessarily after being admitted via Accident & Emergency. Often, they would be far better cared for elsewhere. But in many instances, patients head to their local casualty department simply because alternative – and, in many cases, more appropriate – care is not available. NHS community services are in short supply, health care professionals are frequently unaware that other measures, such as hospice care, could help, and planning to discharge patients from hospitals to community services is complex and difficult. This means that of the 500,000 people who die in England each year, about half do so in hospital, even though many have no clinical need to be there and very few want to die there. The vast majority (80%) say that they would like to be cared for and die at home or in a hospice. Since the Sixties, hospices have been at the forefront of providing high-quality care for people approaching the end of life.

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## Caring for People in the Last Days and Hours of Life: National Statement

December 17 2014

In December 2013 the Scottish Government accepted the recommendation that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. This [statement](#) confirms the current position.

Health and Care providers across Scotland are committed to the provision of consistently high quality end of life care for all that reflects the 4 principles set out in the guidance '[Caring for people in the last days and hours of life](#)' published at the end of 2013:

Principle 1: Informative, timely and sensitive communication is an essential component of each individual person's care

Principle 2: Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion

Principle 3: Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible

Principle 4: Consideration is given to the wellbeing of relatives or carers attending the person



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[Wide variation in end of life care at hospitals.](#)

Below text is from [The Daily Telegraph](#), 20 January 2015

Dying patients are receiving "wide variations" of care because of hospitals' failures to replace the controversial Liverpool Care Pathway, the Chief Inspector of Hospitals for the Care Quality Commission, Prof. Sir Mike Richards, has said. Sir Mike said that some hospitals had responded slowly to the withdrawal of the guidance last summer, saying that it had created a "hiatus" in management.

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[Living and Dying with Dementia in England: Barriers to care](#)

[Marie Curie Cancer Care & Alzheimer's Society](#), December 2014.

Dementia sufferers lack proper care because the illness is not recognised as a terminal diagnosis, according to a report from two leading charities. The [report](#) highlights the issues faced by dementia sufferers in the late stages of their lives and the barriers to the high-quality care they require. The report addressed the terminal nature of the illness, calling it "the forgotten aspect of what has been referred to as a silent epidemic." The report adds: "To date much of the focus has been on living well with dementia, with little focus on the experiences of people with dementia nearing the end of their lives".

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[Hardly anyone wants to die in hospital. Let's do something about it U.K.](#)

[The Spectator](#) – 22 November 2014

Of the 500,000 people who die in England each year, about half die in hospital. Many of these people have no clinical need to be there and very few of them want to die in hospital. In fact, 80% of those asked would choose home or a hospice as the place where they'd prefer to spend their last days. It is hardly surprising that most people would opt to die peacefully at home or in the calm environment of a hospice rather than in a busy, often noisy, hospital ward. Indeed there is mounting evidence that the care which a significant number of people receive in hospitals is inadequate.



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[Health Committee announce inquiry into end of life care U.K.](#)

[Health Parliamentary Select Committee](#) 5 November 2014

In June 2014 the Department of Health announced a new approach for those caring for dying people in England during the last days of their life. The approach focuses on achieving five Priorities of Care that should be applied whenever and wherever someone is dying, whether in hospital, a hospice, their own home. The Health Committee has decided to take a broader look at the issue of palliative and end-of-life care. The committee will examine the way that health and social care services, and the voluntary and community sector, support people who are likely to die within 12 months, what opportunities exist for better integration and for improving care quality, and the experience of those caring for people at the end of life. It will review the definitions of, and distinctions between, "palliative" and "end-of-life" care to examine how to provide more effective targeting of resources and management of interventions necessary to bring about service change. The inquiry will examine palliative and end of life care for adults, including the frail elderly, and children and young people.

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## [Research](#)

[Core competencies for palliative care social work in Europe: An EAPC White paper Part 2](#)

[European Journal of Palliative Care](#), 2015;22(1):38-44.

The aim of this White Paper has been to provide an outline of the core competencies expected of social workers in palliative and end-of-life care. The authors sought to situate these within the historical, economic, sociocultural and international contexts of palliative and end-of-life care, and to underpin them with the value base of social work as a professional discipline. Inevitably, our competencies framework needs to fit in a wide range of national contexts and cultures, as well as a multiplicity of health and social care systems in which palliative and end-of-life care may sometimes be at an early developmental stage. This competencies framework may, therefore, need adapting to local need. But the authors would argue that, in essence, this framework embodies the core of what palliative care social workers should aspire to. The next task of the EAPC will be to develop core curricula for the education of social workers in palliative care.



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[Ambulance Data Project for End-of-Life Care U.K.](#)

[National End-of-Life Care Intelligence Network](#) 15 December 2014

The North West and the South East coast ambulance services participated in a joint project with the National End-of-Life Care Intelligence Network to explore collection and use of ambulance data in supporting delivery of end-of-life care. The project examined the information available to ambulance services about people approaching the end of life and the role of ambulance services at this time, including emergency calls and rapid transfers home to die. The report includes recommendations for supporting ambulance professionals in their role which include better identification of the dying patient and unified national ambulance data.

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## [Researchers identify eight signs of impending death in cancer patients](#)

A research team has identified eight highly specific physical and cognitive signs associated with death within three days in cancer patients. Reporting in the journal [Cancer](#), the investigators prospectively observed 357 cancer patients admitted to palliative care units. They determined nonreactive pupils, a decreased response to verbal or visual stimuli, an inability to close eyelids, drooping of the nasolabial fold, hyperextension of the neck, grunting of vocal cords, and upper gastrointestinal bleeding as signs of impending death. "Knowing when death is imminent would provide more information so caregivers can plan appropriately," said David Hui, MD, of The University of Texas MD Anderson Cancer Center in Houston, the study's corresponding author.

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## [Journal abstracts](#)

[Learning about dying, death, and end-of-life planning: Current issues informing future actions](#)

[Journal of Intellectual & Developmental Disability](#) Online – 23 January 2015

Knowing about dying and death is a typical part of lifelong learning, gained through personal experience with the death of loved ones, popular culture, and formal education. Sudden and unexpected death aside, adults in the general community can use this knowledge to plan for the manner of their dying. Such planning might include will making, advance care planning, enduring guardianship, organ donation and, for some, decisions about the where and the how of end-of-life care. People with intellectual disability, however, are not afforded similar opportunities to learn or plan for dying. The aim of this paper is to outline current thinking around the need for people with intellectual disability to learn about and understanding dying and death.



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"You only have one chance to get it right": A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer

[Palliative Medicine Online](#) – 29 January 2015

Participants' experiences of being a caregiver and of professional support were highly varied. The analysis generated 15 themes which were organised into a framework based on Yalom's four "existential conditions": responsibility (e.g., "being the linchpin of care," "you only have one chance to get it right"), isolation (e.g., "being on my own," "being held in mind"), death (e.g., "knowing but not knowing") and meaningfulness (e.g., "giving something back," "acceptance and gratitude"). Healthcare professionals were perceived as influential in both helping and hindering relatives in meeting the challenges they faced.

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Role of the community matron in advance care planning and 'do not attempt CPR' decision-making: a qualitative study

Mandy Kazmierski, Nigel King

[British Journal of Community Nursing](#) Vol 20 No 1 January 2015 p19–24

The community matron (CM) is often the key worker caring for patients with chronic, life-limiting, long-term conditions, but these patients are not always recognised as palliative cases. This study explored the experiences of CMs with regard to advance care planning (ACP) and 'do not attempt cardiopulmonary resuscitation' (DNACPR) decision-making to understand whether or not they felt adequately prepared for this aspect of their role, and why. Qualitative data were generated from six CMs using a broad interpretive phenomenological approach. Face-to-face recorded interviews were analysed using template analysis. The study found that although participants faced complex ethical situations around ACP and DNACPR almost on a daily basis, none had received any formal training despite the emphasis on training in national and local guidelines. Participants often struggled to get their patients accepted on to the Gold Standards Framework. The research found variability and complexity of cases to be the main barriers to clear identification of the palliative phase.

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Difficult Conversations: From Diagnosis to Death

Joel D. Marcus and Frank E. Mott

[The Ochsner Journal](#): Winter 2014, Vol. 14, No. 4, pp. 712-717

Although many published guidelines address difficult communication, communication training is lacking. Consequently, many clinicians may have difficulties with, or in the worst-case scenario,



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avoid delivering bad news and discussing end-of-life treatment. Clinicians also struggle with how to have the last conversation with a patient and how to support patient autonomy when they disagree with a patient's choices. There is a clinical imperative to educate physicians and other healthcare workers on how to effectively deliver information about a patient's health status, diagnostic avenues to be explored, and decisions to be made at critical health junctions. Knowing how to implement the most rudimentary techniques of motivational interviewing, solution-focused brief therapy, and cognitive behavioral therapy can help physicians facilitate conversations of the most difficult type to generate positive change in patients and families and to help them make decisions that minimize end-of-life distress.

## [Current challenges in palliative care provision for heart failure in the U.K. A survey on the perspectives of palliative care professionals](#)

[Openheart Online](#) – 16 January 2015

**Objective:** Palliative care (PC) in heart failure (HF) is beneficial and recommended in international HF guidelines. However, there is a perception that PC is underutilised in HF in the UK. This exploratory study aims to investigate, from a PC perspective, this perceived underutilisation and identify problems with current practice that may impact on the provision of PC in HF throughout the UK.

**Methods:** A prospective survey was electronically sent to PC doctors and nurses via the UK Association for Palliative Medicine and adult PC teams listed in the UK Hospice directory.

**Results:** We received 499 responses (42%—PC consultants). Although PC provision for patients with HF was widespread, burden on PC services was low (47% received less than 10 referrals annually). While PC was acknowledged to have a role in end-stage HF, there were differing views about the optimal model of care. Levels of interdisciplinary collaboration (58%) and mutual education (36%) were low. There were frequent reports that end-of-life matters were not addressed by cardiology prior to PC referral. Moreover, 24% of respondents experienced difficulties with implantable cardioverter defibrillator deactivation.

**Conclusions:** Low HF referrals despite widespread availability of PC services and insufficient efforts by cardiology to address PC issues may contribute to the perception that PC is underutilised in HF. The challenges facing PC and HF identified here need to be further investigated and addressed. These findings will hopefully promote awareness of PC issues in HF and encourage debate on how to improve PC support for this population.



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Doctors' and nurses' views and experience of transferring patients from critical care home to die: A qualitative exploratory study.

[Palliative Medicine Online](#) – 17 December 2014

The practice of transferring critically ill patients home to die is a rare event in the U.K., despite the positive view of health care professionals. Challenges to service provision include patient care needs, uncertain time to death, and the view that transfer to community services is a complex, highly time-dependent undertaking. While there is evidence of this choice being honoured and delivered for some of the critical care population, it remains debatable whether this will become a conventional practice in end of life in this setting.

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[Embracing a broad spirituality in end-of-life discussions and advance care planning](#)

[Journal of Religion and Health Online](#) – 18 December 2014.

A broad view of spirituality is needed, one that may involve traditional religious beliefs, but also includes personal understandings of what is holy or sacred. Embracing this broad practice of spirituality will help both familial and professional caregivers honour an essential aspect of end-of-life discussions and promote greater discernment of the deep meaning in advance care documents.

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[Conducting research interviews with bereaved family carers: When do we ask?](#)

[Journal of Palliative Medicine](#) Online – 17 December 2014

Interviews with bereaved family carers to examine the end-of-life experience of the deceased are important tools for palliative care researchers, but the ethics of approaching the bereaved when they are grieving and vulnerable is often debated. The aim of this study was to explore the insights of bereaved family carers about the most appropriate time to be involved in a research interview about the end of life and death of their family member. Most family carers (86%) [interviewed] feel comfortable being interviewed about the death of their family member within the first 5 months of bereavement, with 43% reporting they could be interviewed within weeks after death. Family carers reported that recall would be better earlier in bereavement and felt it may be helpful to them to talk about their experiences earlier. They said bereaved people should be allowed to decide for themselves when to be involved in an interview. These findings indicate that interviews with the bereaved may be most fruitful for researchers and beneficial to family carers when they are allowed to make the choice about timing for themselves, beginning weeks after the death of their family member.

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[Dying at home: A qualitative study of family carers' views of support provided by GPs community staff](#)

[British Journal of General Practice](#), 2014;64(629):e796-e803.

Dying at home is the preference of many patients with life-limiting illness. This is often not achieved and a key factor is the availability of willing and able family carers. Fifty-nine bereaved family carers were interviewed (54% response rate; 69% female). An overarching theme was of continuity of care that divided into personal, organisational, and informational continuity. Large numbers and changes in care staff diluted personal continuity and failure of the GPs to visit was viewed negatively. Family carers had low expectations of informational continuity, finding information often did not transfer between secondary and primary care and other care agencies. Organisational continuity when present provided comfort and reassurance, and a sense of control. The requirement for continuity in delivering complex end-of-life care has long been acknowledged. Family carers in this study suggested that minimising the number of carers involved in care, increasing or ensuring personal continuity, and maximising the informational and organisational aspects of care could lead to a more positive experience.

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[Factors affecting the successful implementation and sustainability of the Liverpool Care Pathway for dying patients: A realist evaluation](#)

[BMJ Supportive and Palliative Care](#) Online – 7 November 2014

The Liverpool Care Pathway (LCP) for the dying patient was designed to improve end-of-life care in generalist healthcare settings. Controversy has led to its withdrawal in some jurisdictions. The main objective of this research was to identify the influences that facilitated or hindered successful LCP implementation. There is a need to appreciate the organisationally complex nature of intervening to improve end-of-life care. Successful implementation of evidence-based interventions for end-of-life care requires commitment to planning, training and ongoing review that takes account of different perspectives, institutional hierarchies and relationships, and the educational needs of professional disciplines. There is a need also to recognise that medical consultants require particular support in their role as gatekeepers and as a lead communication channel with patients and their relatives.

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## Non-medical prescribing in palliative care: A regional survey

[Palliative Medicine](#) Online December 12, 2014

Background: The United Kingdom is considered to be the world leader in nurse prescribing, no other country having the same extended non-medical prescribing rights. Arguably, this growth has outpaced research to evaluate the benefits, particularly in areas of clinical practice where patients have complex co-morbid conditions such as palliative care. This is the first study of non-medical prescribing in palliative care in almost a decade.

Aim: To explore the current position of nurse prescribing in palliative care and establish the impact on practice of the 2012 legislative changes.

Design: An online survey circulated during May and June 2013.

Participants: Nurse members ( $n = 37$ ) of a regional cancer network palliative care group (61% response rate).

Results: While this survey found non-medical prescribers have embraced the 2012 legislative changes and prescribe a wide range of drugs for cancer pain, we also identified scope to improve the transition from qualified to active non-medical prescriber by reducing the time interval between the two.

Conclusion: To maximise the economic and clinical benefit of non-medical prescribing, the delay between qualifying as a prescriber and becoming an active prescriber needs to be reduced. Nurses who may be considering training to be a non-medical prescriber may be encouraged by the provision of adequate study leave and support to cover clinical work. Further research should explore the patients' perspective of non-medical prescribing.

*This bulletin draws from a number of sources including NHS Networks, the Palliative Care Network Community and the National Palliative Care Council. You are welcome to reuse and share the content of this bulletin, but please acknowledge the TRFT Library and Knowledge Service as originating source.*

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