



Palliative Care: Summer 2014.

This bulletin covers the key research, news reports and journal articles to appear in the months June – September 2014 in the field of Palliative Care.

In the News

Royal College of General Practitioners report: Doctors told to dispense with confusing medical jargon

[The Guardian – 18 June 2014](#)

A report by the [Royal College of GPs](#) urges the U.K.'s 250,000 medics to avoid the use of words such as "chronic," "palliative" and "hospice," and warns that describing a diagnosis of cancer as "positive" can be misinterpreted as good news. Doctors may fail to realise that they have failed to make themselves understood to the patient and should check they have done so by asking the patient to repeat the information back to them if they are unsure, it recommends. Equally, some patients are too embarrassed to ask doctors questions they want answered because they do not want to reveal their lack of understanding of what they have been told or their poor reading skills. It cites the word "chronic" as an example of where "doctors can unintentionally use words that are un-familiar to their patients, without realising that the meaning is not clear. Some concepts familiar and obvious to doctors may be alien to patients." While doctors use "chronic" to mean persistent or long-term, the word is widely understood to mean "severe," giving rise to a potential confusion.

Reference: '[Health Literacy: Report from an RCGP-led health literacy workshop.](#)' Royal College of General Practitioners, June 2014

Families must get a say on "dying patients" care

[The Daily Mail – 25 June 2014](#)

Families will be given a say over the treatment of patients who are thought to be near death, ministers promised. They said loved ones must be "involved in decisions" in National Health Service hospitals to ensure the "horrific" abuses and "tick-box" culture created by the discredited Liverpool Care Pathway [LCP] never happen again. And hospital managers or doctors who try to cover up the circumstances of a patient's death will be subject to criminal



prosecutions and heavy fines in court. The radical rights for families are part of a new protection package for the dying that ministers say will mean an end to the "protocols and processes" that led to the LCP scandal. New rules for the care of patients thought to be near the end of their lives will forbid hospitals from deciding that someone is dying and then speeding their end by drugging them and removing tubes giving them food and water. Instead, there must be regular reviews of treatment in all cases, dying patients and their families must be kept informed and involved in decisions, and treatment will be "tailored to the individual." Hospitals will be told to appoint independent assessors to decide on complaints in "serious or untoward incidents." The new rules on care for the dying ('Priorities of Care') were announced by Care Minister Norman Lamb.

Note: The 'Priorities of Care' are based on '[One chance to get it right: Improving people's experience of care in the last few days and hours of life](#),' Leadership Alliance for the Care of Dying People, June 2014.

'Legal duty over resuscitation orders.'

[BBC News – 17 June 2014](#)

Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate order on medical notes, the Court of Appeal in England ruled. The issue was raised by a landmark judgement that found doctors at Addenbrooke's Hospital, in Cambridge, had acted unlawfully.

Reform of end-of-life care sought

[The Belfast Telegraph – 4 July 2014](#)

The National Health Service could save tens of millions of pounds each year if more was done to allow cancer patients to die at home instead of in hospital. New estimates from Macmillan Cancer Support suggest the 36,400 patients who died in hospital in 2012, despite saying they would prefer to be in their own homes, cost the NHS £137 million. The report says that had these patients been treated at home by community care teams, spending would have halved.

Reference: '[Can we live with how we're dying? Advancing the case for free social care at the end of life](#).' Macmillan Cancer Support, July 2014.

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Liverpool Care Pathway successor "clarifies GP role," says Royal College of General Practitioners

[GP Online – 26 June 2014](#)

Five new '[Priorities for Care](#)' will restructure the approach to caring for people nearing the end of their life, placing greater emphasis on the wishes of the dying person and communication with their family. The priorities were created by the Leadership Alliance for the Care of Dying People, a coalition of 21 organisations formed in response to a 2013 report on the failings of the Liverpool Care Pathway, led by Baroness Julia Neuberger.

The alliance accepted recommendations for a named GP to take overall responsibility for the care of patients nearing the end of their lives in the community. Dr. Maureen Baker, chairwoman of the Royal College of General Practitioners, one of the Alliance bodies, said: "Today's announcement should provide much-needed clarity for doctors and, most importantly, much-needed reassurance for patients and their families and carers. By setting out clear principles of what is expected, it should increase the confidence of doctors, nurses and other health professionals in confronting sensitive issues around end-of-life care, as well as reducing the potential for confusion or misinterpretation."

The '[Priorities for Care](#)' state that, when it is thought a person may die within the next few days or hours:

- This possibility 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.
- Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- 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.
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

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Dying wishes going unfulfilled

[The Daily Mail – 10 July 2014](#)

Only a third of people nearing the end of their lives who want to die in the comfort of their own homes are able to do so, new figures suggest. Thirty-five per cent of people who expressed a preference to die at home had their wishes fulfilled in 2013, the Office for National Statistics (ONS) said. The ONS's national survey of bereaved people, based on the views of almost 50,000 respondents on the quality of care provided to a friend or relative in the last three months of life in England, also found that quality of care was rated significantly lower for people who died in a hospital, compared to those dying at home, in a hospice or care home. Almost half of those included in the survey died in hospital, which the ONS states "indicates the importance of providing high quality care in this setting." But it said hospitals were still "lagging behind" other care settings.

Reference: [National Survey of Bereaved People \(VOICES\)](#), Office for National Statistics, July 2014.

'Expanding choice and improving the quality of end-of-life care.'

[Department of Health – 1 July 2014](#)

A review has been launched to make sure adults at the end of life, their carers and family have more choice. The review will be undertaken by an independently-led programme board chaired by Claire Henry, Chief Executive of the National Council for Palliative Care (NCPC) which is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland.

The review is a significant milestone in the government's commitment to increasing choice in end of life care and will look at a variety of different aspects including what people want, the support they need and the services required to make choice a reality.

The review will provide advice to government on improving the quality and experience of care for adults at the end of life, their carers and those who are important to them by expanding choice. An independently-led board of experts on end-of-life care will present its findings and advice to government in February 2015.

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[Health groups launch new pathway for terminally ill patients](#)

A [new approach to supporting dying people](#) is being implemented across north east Essex. The 'Individual Care Record for the Last Days of Life' has been adopted by a number of health organisations working in partnership. It has been developed following the withdrawal of the Liverpool Care Pathway, which had been blamed for poor care in a Parliamentary review, and is designed to provide tailored support to terminally ill patients at all times. It is based on five 'Priorities for Care,' created by a national coalition of organisations, and will mean care is focused on dying people's wishes, rather than processes. Priorities for care include guidance about food and drink, stating that patients should be supported to eat and drink for as long as they wish to do so, and also stresses the importance of clear and sensitive communication between staff, the person who is dying, and their family and friends.

[Research](#)

[Exploring the cost of care at the end of life](#)

[The Nuffield Trust - September 2014](#)

This research explores whether reduced hospital activity and costs at the end of life were likely to be offset by increased care costs in other health and social care settings using the Marie Curie home-based palliative care nursing service – the subject of a previous study by the Nuffield Trust. The results suggest that cost savings might be available if community-based support were made more widely available to help people to die in their own homes, where that was their preference. Given the finite resources available for health care, it is important that there is an understanding of the costs of end-of-life care. However, acquiring good-quality data surrounding costs for palliative care is challenging, especially as care services for those at the end of life are fragmented across many different providers.

"This work demonstrates how crucial it is that we develop better ways to understand resource use in everyday care. This would help care services to be responsive to the needs of those near to death, so they can provide support and care in the most appropriate setting for the individual." Theo Georghiou, Senior Research Analyst, Nuffield Trust and report author.



'Results of the National End-of-Life Care Intelligence Network's impact evaluation.'

[Public Health England \(PHE\) – 1 July 2014](#)

The survey asked people to rate the impact the network has made since being commissioned in 2010. Over 50% rated it as having a positive impact across all categories, and only five out of an average of 253 people responded that it had made a negative impact.

[Journal abstracts](#)

What is the incidence of patients with palliative care needs presenting to the emergency department? A critical review.

[PALLIATIVE MEDICINE Online – 12 August 2014](#)

There is an absence of evidence regarding the incidence of patients with palliative care needs presenting to the Emergency Department. Further research needs to be undertaken in this area to ensure both clinicians and policymakers have sufficient information for service provision.

[Palliative care in advanced dementia](#)

[CLINICS IN GERIATRIC MEDICINE Online – 16 June 2014](#)

Because neurodegenerative dementias are progressive and ultimately fatal, a palliative approach focusing on comfort, quality of life, and family support can have benefits for patients, families, and the health system. Elements of a palliative approach include discussion of prognosis and goals of care, completion of advance directives, and a thoughtful approach to common complications of advanced dementia. Physicians caring for patients with dementia should formulate a plan for end-of-life care in partnership with patients, families, and caregivers, and be prepared to manage common symptoms at the end of life in dementia, including pain and delirium.



[Dying well with dementia: Insights from qualitative studies of place of death and advance care planning](#)

[ALZHEIMER'S & DEMENTIA, 2014;10\(4\):225.](#)

People with dementia often die badly, receiving end-of-life care of poorer quality than that given to the cognitively intact. Advanced care planning (ACP) has the potential to improve end-of-life care in dementia. Commonly ACP is completed in the last six months of life, in dementia there may be problems with this as decision-making capacity and ability to communicate necessarily decrease as the disease progresses. Choosing the right time to discuss ACP with people with dementia may be challenging given the duration of the illness may be many years.

[The effect of using high facilitation when implementing the Gold Standards Framework in Care Homes programme: A cluster randomised controlled trial](#)

[PALLIATIVE MEDICINE Online – 18 June 2014](#)

The provision of quality end-of-life care is increasingly on the national agenda in many countries. In the U.K., the Gold Standards Framework for Care Homes programme has been promoted as a national framework for improving end-of-life care. While its implementation is recommended, there are no national guidelines for facilitators to follow to undertake this role. There is a danger that without national guidelines, facilitation of the Gold Standards Framework for Care Homes programme will vary and consequently so will its implementation.

[Trends in death and end-of-life costs in the U.K.](#)

[BRITISH JOURNAL OF HEALTHCARE MANAGEMENT, 2014; 20\(6\):298-299.](#)

From the view-point of health and social care the end of life tends to be the most expensive period in a person's lifetime costs. Acute admissions peak in the last year of life, while social and primary care costs start to rise slightly earlier. It is death (or nearness to death) not age *per se* that drives these costs. Interestingly the funding formula which distributes money to English Clinical Commission groups [CCG] implicitly assumes that age distributions predict death and hence end-of-life costs are assumed to be driven by age. If end-of-life is so important to the overall cost born by each CCG, why are the trends in death so poorly understood and their importance even more poorly communicated?

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[Social media and palliative medicine: A retrospective 2-year analysis of global twitter data to evaluate the use of technology to communicate about issues at the end of life](#)

[BMJ SUPPORTIVE & PALLIATIVE CARE Online – 2 September 2014](#)

A lot of discussion about palliative care is taking place on Twitter, and the majority of this is positive. Social media presents a novel opportunity for engagement and ongoing dialogue with public and professional groups. A total of 683.5K tweets containing a combination of 13 palliative care terms were analysed. The tweet volume for all terms increased by 62.3% between 2011-2012 and 2012-2013. The most popular terms include "end-of-life" and "palliative care." Sentiment was high with 89% of tweets rated more positive than all other tweets sent on Twitter during this period. The term 'Liverpool Care Pathway' experienced the highest percentage increase in tweets reaching a peak in July 2013.

['Needs of people with severe dementia at the end-of-life: A systematic review.'](#)

[JOURNAL OF ALZHEIMER'S DISEASE Online – 4 August 2014](#)

Ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned.

[Using a public health approach to improve end-of-life care: Results and discussion of a health needs assessment undertaken in a large city in northern England](#)

[BMJ SUPPORTIVE & PALLIATIVE CARE Online – 5 September 2014](#)

More people from deprived communities die in hospital. 18% of people who die each year are on a palliative care register, reflecting a lack of recognition and planning for EoLC [end-of-life care] given that 75% of people who die need EoLC. Staff highlighted concerns about capacity of services; pressure on out-of-hospital care; problems at physical and electronic interfaces between services; suboptimal hospital discharge; need for earlier recognition of the EoL stage for patients. Patients and carers stressed the importance of communication, coordination and continuity of care; full involvement in care planning; honesty and support for the bereaved; advocate for patients and families; accessible information; improved urgent care; integrated team working; pain relief, dignity and respect.



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'How hospice staff members prepare family caregivers for the patient's final days of life: An exploratory study.'

[PALLIATIVE MEDICINE Online – 23 September 2014](#)

There is widespread agreement that the families of hospice patients need to be prepared for the final days of life, yet current practices preparing families are not well described. The purpose of the study was to describe how hospice clinicians prepare family for the final days of life, including:

- 1) the content of the preparatory information
- 2) strategies and timing of preparation, and whether the preparation is tailored
- 3) who prepares families

Preparatory messages included information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. Commonly used strategies included listening, engendering trust, repetition, collaboration with other disciplines, and demonstrations.

[Supporting family carers providing end-of-life home care: A qualitative study on the impact of a hospice at home service](#)

[JOURNAL OF CLINICAL NURSING Online – 19 September 2014](#)

It is suggested that the hospice at home aide service is helping patients to remain at home for the last days of their lives and is thus supporting the implementation of the End of Life Care Strategy aim to promote patient choice. Supporting family carers is clearly vital, particularly with an increasing ageing population where carers may have their own health needs. Similarly, for the "sandwich" generation of dual carers and those in employment, consideration needs to be given to what support is appropriate for their needs. An individual package of care based upon ongoing assessment of carers' needs is undoubtedly required. For end-of-life care, this re-assessment is vital, as the caring role changes over the disease trajectory. Adopting the philosophy of recognising family carers as co-workers and supporting them in this role, will help to facilitate carer empowerment and is clearly required if their needs are to be recognised and ultimately met. The policy driver to support patients to be cared for and to die at home, if they so wish, has resulted in the reconfiguration of hospice services.



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The emergence of HAH teams and increased day care interventions have resulted in more options for patients and their families. However, increasing the amount of care that a family member has to provide in these circumstances needs to be adequately supported with the provision of a flexible service tailored to individual needs and delivered by appropriately trained staff.

[Breaking bad news about transitions to dying: A qualitative exploration of the role of the district nurse.](#)

[PALLIATIVE MEDICINE Online – 23 September 2014](#)

While other colleagues can avoid breaking bad news of transition to dying, district nurses have no choice if they are to provide optimal end-of-life care. While ideally placed to carry out this work, it is complex and they are unprepared for it. They urgently need carefully tailored training in this aspect of their work, to enable them to provide optimal end-of-life care. District nurses' role in breaking bad news of transition to dying was challenging, but the conversation was described as essential preparation for a good death. Four main challenges with the conversations were patients' responses to the prognosis (unawareness, denial and anger), timing the conversation, complexities of the home environment and limited preparation in this aspect of their work.

[Interventions to improve hospice and palliative care referral: A systematic review](#)

[JOURNAL OF PALLIATIVE MEDICINE Online – 7 July 2014](#)

Hospice and palliative care are underutilized among patients at the end of their lives despite evidence that they improve patient satisfaction and reduce costs. The authors' search strategy yielded 419 studies, of which only six met their eligibility criteria. Three studies included nursing home populations; one included home care patients, one targeted care managers, and one reported on heart failure patients. Three studies had a cohort design, two were pre-post, and only one was randomized. Two studies evaluated a process to identify eligible subjects. Two evaluated the impact of advance care planning programs and two only provided education. Interventions that only provided education showed a median increase in referral of 5% while interventions that identified hospice candidates showed a median increase in hospice referral of 19.5%. Interventions of different levels of complexity can improve the use of hospice services among subjects with high mortality risk.

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The role and significance of nurses in managing transitions to palliative care

A qualitative study

[BMJ OPEN Online – 30 September 2014](#)

Nurses are generally present, and often influential, in supporting patient and family acceptance of medical futility and in assisting doctors in negotiating referral to palliative care. Yet the specificities of the nursing role and how nurses may contribute to timely and effective referrals is not well understood. This study aimed to systematically explore hospital-based nurses' accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions. Four significant themes emerged:

1. professional dynamics and the roles played by nurses in initiating the transition to palliative care
2. the value of nurses' informal interactions in timely and effective transitions
3. the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility
4. the emotional burden experienced by nurses within this clinical context.

[An ethical defence of The Liverpool Care Pathway](#)

[NURSING TIMES, 2014; 110\(40\):20-21.](#)

Palliative care in the UK has been ranked as the best in the world. However, The Liverpool Care Pathway [LCP] was criticised and phased out. This article looks at the LCP's aims, assesses the problems and how these should be tackled. Many of these problems stemmed not from the LCP itself, but its improper use. Better training on the pathway and on communication with patients and relatives could ensure it is used correctly. The Leadership Alliance for the Care of Dying People (2014) has said it is to replace the LCP with its five Priorities for Care. Its main concern was that the LCP was associated with "standardised treatment and care carried out, irrespective of whether that was right for the particular person." The LACDP has not recommended a single set of support materials, preferring to allow organisations to "work it out for themselves." It therefore seems plausible that, providing they follow the Priorities for Care, using LCP guidance as intended would be largely consistent with providing high-quality end-of-life care.

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Managing end of life medications at home – accounts of bereaved family carers: A qualitative interview study.

[BMJ SUPPORTIVE & PALLIATIVE CARE](#) | Online – 25 September 2014

Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. Key barriers to managing end of life medications at home included: complex regimes; unwanted responsibility in deciding when to use "as needed" medication; disagreements with professional staff, and anxiety about medication errors, especially if perceived to have implications for survival.

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