

Palliative Care bulletin

Winter 2013/2014

Future Ambitions For Hospice Care: Our Mission And Our Opportunity

Inside this issue:

Future ambitions for Hospice care	1
Interim guidance for the care of dying people	2
Dying at home in the UK	3
Dying patients & social care charges	4
Research	5

The aim of the Commission into the Future of Hospice Care is to help hospices look ahead so they can anticipate and meet the changing and growing needs of the communities they serve. This final [report](#) identifies five key steps that hospices should take to ensure that they are fit for the future including strengthening leadership and links with local health and social care systems.

Taking these steps will require action by hospice boards, staff and volunteers as well as organisations supporting hospice care, commissioners, the NHS, national and local government, and academic centres. All play a part in creating the environment in which hospice care can flourish; the report contains recommendations for all of them.

By taking action the Commission believes hospices, their national organisations and others can make a significant contribution to meeting the future palliative and end of life care needs of people living across the United Kingdom.



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Improvements in end of life care

A new [report](#) from Public Health England's National End of Life Care Intelligence Network (NEoLCIN), suggests the proportion of people dying at home or in care homes increased from 38% in 2008 to 44% in 2012. 'What We Know Now' suggests that around 24,000 more people died at home or in care homes in 2012 compared to 4 years ago, reflecting the desires of many people to stay at home to die. However, the report also found there were large variations in the proportion of deaths in hospital between 2009 to 2011. Local authorities with highest and lowest rates ranged from 69% in some areas to 38% in others, although the reasons for this are complex.

Leadership Alliance for the Care of Dying People (LACDP) – interim guidance for clinicians issued

An interim statement has been issued by the LACDP. This is specifically intended for clinicians and health and social care professionals involved in end of life care and provides further guidance and direction in the run up to the Liverpool Care Pathway being phased out by 14 July 2014.

The [statement](#) is published online.

'Interim Guidance: Caring for people in the last days and hours of life,' National Health Service Scotland

In response to recent concerns about use of the Liverpool Care Pathway (LCP), this document sets out clear information on how staff can provide good care for people who are in the last days and hours of their life.

This [document](#) can be used to complement or supplement existing local approaches to providing good end of life care, and should be used to complement any use of the Liverpool Care Pathway prior to the LCP being phased out.

The target audience for this guidance is health and social care staff involved in providing care for people in the last days and hours of life and their families. However, this document is also being made available to members of the public.



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In the news

Dying at home in the U.K.*The Economist—18 January 2014*

Surveys show that over two-thirds of Britons would like to die at home. The National Health Service has calculated that if roughly one more patient per general practitioner died outside hospital each year, it would save £ 180m (\$295m). In 2008 it introduced a broad end-of-life care strategy, which sought to increase awareness of how people die while improving care. Since then the proportion of people dying at home or in care homes (the split is about half-and-half between them) has increased, from 38% to 44%.

TRFT and Hospice staff can make use of a range of library and knowledge services, including:

- Enquiry service
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- Literature searching
- Current awareness information service
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Knowledge.service@rothgen.nhs.uk

'Bereaved workers "need more support," charity says.'*BBC News – 9 January 2014*

A National Council for Palliative Care report says the government should look into the "feasibility" of statutory leave from work after a loved one dies, and it calls on all employers to tell workers what help they are entitled to. A survey commissioned by the charity found 32% of people bereaved in the last five years felt their employer did not treat them with compassion. The report says 87% of people surveyed felt all employers should have a "compassionate employment policy" including paid bereavement leave, flexible working and other support

Full report available here:

['Life after death: six steps to improve support in bereavement'](#)

THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

National Bereavement
Alliance



In the news

'Dying patients should be exempt from social care charges'.*The Guardian - 15 January 2014*

The care bill committee is debating who should be eligible for social care. MPs will also consider whether to add a clause that would enable exemption from social care charges for those at the end of their lives. The amendment would also establish the need for better forward planning about where we would like to die. Most of us would prefer to be at home surrounded by the people we love, yet fewer than 1-in-3 are currently able to do so. Why is it that [89% of those who die in hospital do so following an unplanned admission](#)? In many cases it is because of the sheer exhaustion that comes with providing around-the-clock care.

useful palliative care links

- International Association for Hospice & Palliative Care
- International Palliative Care Resource Centre
- Palliative Care Network Community

Liverpool Care Pathway ban was "scapegoat" warns consultant*The Daily Telegraph - 17 December 2013*

The demise of [The Liverpool Care Pathway](#) [LCP] is a "tragedy" and is equivalent to banning the Highway Code because of bad drivers, a consultant in palliative care has warned. Claud Regnard, a consultant at St Oswald's Hospice in Newcastle, said the guidelines had been made "scapegoat" for sloppy care given by physicians. And he said the failure to implement an alternative would leave bad doctors able to: "continue their poor practice without fear of being discovered for years."

The LCP was designed to provide dignity for those dying with terminal illnesses. But ministers announced this summer that the LCP would be phased out after an independent review uncovered evidence of abuse, including patients being unnecessarily sedated and denied food and water.



Research

Indefinite loss: The experiences of carers of a spouse with cancer

European Journal of Cancer Care: 14 January 2014

This article explores cancer carers' experiences of loss ... [and] ... findings suggest that in addition to conventional and anticipatory grief, many carers experience indefinite loss. Indefinite loss characterised the experiences of spouses [i.e., study participants] caregiving outside of the terminal stage. They experienced the current loss of a taken-for-granted certain future, but the future loss of their spouse remained uncertain. They described a heightened awareness of mortality, and an inability to plan for the future. Losses that are uncertain and potential are largely neglected within the literature.

Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives

Journal of Medical Ethics: 7 February 2014

In W v M, family members made an application to the [U.K.] Court of Protection for withdrawal of artificial nutrition and hydration from a minimally conscious patient. Subsequent scholarly discussion has centred around the ethical adequacy of the judge's decision not to authorise withdrawal. This article brings a different perspective by drawing on interviews with 51 individuals with a relative who is (or was) in a vegetative or minimally conscious state (MCS). Most professional medical ethicists have treated the issue as one of life versus death; by contrast, families – including those who believed that their relative would not have wanted to be kept alive – focused on the manner of the proposed death and were often horrified at the idea of causing death by "starvation and dehydration." The practical consequence of this can be that people in permanent vegetative state (PVS) and MCS are being administered life-prolonging treatments long after their families have come to believe that the patient would rather be dead. The authors suggest that medical ethicists concerned about the rights of people in PVS/MCS need to take this empirical data into account in seeking to apply ethical theories to medico-legal realities.

End-of-life dreams and visions: A longitudinal study of hospice patients' experiences

Journal of Palliative Medicine: 16 October 2013

End-of-life dreams and visions are commonly experienced phenomena during the dying process, characterized by a consistent sense of realism and marked emotional significance. These dreams/visions may be a profound source of potential meaning and comfort for the dying, and therefore warrant clinical attention and further research.

Continuous palliative sedation: Not only a response to physical suffering

Journal of Palliative Medicine: January 2014 - Volume 17 - Issue 1

Together with physical symptoms, psychological and existential suffering may combine to produce a refractory state for which other treatment options than CPS [continuous palliative sedation] were not available or considered inappropriate. A limited life expectancy was by many considered crucial (e.g., to avoid hastening death) and by some less important (e.g., because the patient's suffering was considered to be key). Issues influencing the decision to use CPS related to patient preferences (e.g., dignity, not wanting to experience further suffering) or family issues (impact of suffering on family, family requesting CPS).

The Nurse Practitioner and policy in end-of-life care

Nurse Science Quarterly: January 2014 - Volume 27 - Issue 1

The focus of this column is the interface between policy and end-of-life care, particularly as provided by advanced nurse practitioners. The complexities of end-of-life along with barriers in practice can diminish quality of life for patients and their families. Changes in policy are needed to enable nurse practitioners their full scope of practice in a way that benefits patients and families at end-of-life. Three areas particularly relevant to policy for nursing practitioners and end-of-life care are addressed: scope of practice, reimbursement, and prescribing practices. Other recommendations for policy and end-of-life care are discussed.

Improving the organization of palliative care by implementing quality indicators and national and setting-specific interventions: Study protocol of the IMPACT project

Progress in Palliative Care

There is a wide gap between knowledge about palliative care and its application in everyday clinical practice, affecting many patients in our ageing population. However, changing health care practice is a complex and challenging process. Therefore, the European Union funded Implementation of quality indicators in Palliative Care sTudy (IMPACT) project aims to develop optimal implementation strategies to improve the organization of palliative care for people with cancer or with dementia in Europe.

'Voluntary stopping of eating and drinking at the end of life: A systematic search and review giving insight into an option of hastening death in capacitated adults at the end of life.'

BMC Palliative Care: 2014 - Volume 13 - Issue 1

The terminally ill person's autonomy and control are important in preserving the quality of life in situations of unbearable suffering. Voluntary stopping of eating and drinking at the end of life has been discussed over the past 20 years as one possibility of hastening death. This article presents a systematic search and review' of published literature.

Interventions concerning competence building in community palliative care services: A literature review

Scandinavian Journal of Caring Services: December 2013 - Volume 27 - Issue 4

The review of the literature identified 15 publications which dealt with interventions regarding education and competence building. The publications represent individual studies, only two of which were controlled. All conclude that competence building has a positive effect according to the professionals. It is unknown whether or how patients and relatives feel a positive effect from the interventions just as it is unknown how the development of competencies has actually led to a more developed practice. The effect of local competence building in palliative care in the primary sector is lacking. Methods are needed to further examinations of how a competency has actually led to a more developed practice.

Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers

Dementia: January 2014 - Volume 13 - Issue 1.

The experience of being a carer of a person with dementia at the end of life is expressed in twelve accounts. This is a synthesis of the concerns and challenges for carers at the end of life. These accounts are often insightful and provide several views of carers' and professionals' experience. Having a close relationship as a carer gives a unique and poignant view. What emerges from this review is a range of perspectives that provide contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia and insights drawn from hearing directly from carers may be powerful learning tools.

The development of a 7-day community specialist palliative care service

International Journal of Palliative Nursing: December 2013 - Volume 19 - Issue 12

The author worked as a clinical nurse specialist (CNS) in community palliative care in the Central Lancashire area of England when the CNS service was extended to a 9 a.m. to 5 p.m., 7-day service. A project group was set up to canvas some of the key stakeholders for their views on the extension of the service. The group undertook a literature search, a telephone survey of services in other areas that were providing this level of service, and interviews to ascertain the views of district nurses in the locality of the proposed service extension. The extension of service has long been

advocated and was one of the key recommendations in the U.K. Department of Health's peer review process. Such an extension was implemented following the research phase and was then evaluated by the project lead and the community services manager. The extension was found to be effective in the ongoing monitoring and support of patients. Anecdotally, the CNS team also felt it had been proactive in preventing unnecessary hospital admissions, although this specific aspect is difficult to quantify. This article looks at how the service was developed, how it has evolved over time, and how it works today. Consideration is also given to benefits and limitations.

The Liverpool Care Pathway for the Dying (LCP): Lost in translation and a tale of elephants, men, myopia – and a horse

Palliative Medicine: January 2014 - Volume 28 - Issue 1

To reflect on the eruption of articles, opinions, blogs and counter-blogs about the Liverpool Care Pathway for the Dying (LCP) and Baroness Neuberger's Review feels Sisyphean but necessary. While it is time to move on, in doing so, palliative care must think very deeply about what should change about ourselves. This is not to imply that nothing is being done already, to undermine current initiative where it is to be found, nor to pre-empt the engagement work being undertaken by the Leadership Alliance for the Care of Dying People.

So we intend through hyperbole to catalyse constructive self-examination and criticism. Disagree, of course, but reflect as you do on why that may be.

Metaphorically, it has turned out to be a story about elephants, and in the end, also about a horse. Come the 21st century in the U.K., palliative care was almost mainstream from its birth in the hospice movement. Medicine, generally, was beginning also to assert its clumsy footprint with mixed effect. On the positive side, the specialist palliative medicine training programme had produced a healthy and growing crop of consultants, and many hospitals had palliative care teams.

'Effectiveness of palliative homecare services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: A retrospective cohort study.'

Palliative Medicine: December 2013

This study confirms the effectiveness of palliative home care in enabling patients to spend the final period of their lives at home. The services of a palliative home-care team reduced the consumption of hospital resources. This study also provided evidence of some types of cancer (e.g., hematological cancers and hepatocellular carcinoma) being more likely to require hospitalization, suggesting the need to reconsider the pathways of care for these diseases.

A follow-up bereavement service: "Completing the patient pathway"

Bereavement Care: December 2013 - Volume 32 - Issue 3

The article describes an initiative, The Bereavement Care Follow up Service in Cambridge University Hospitals National Health Service Trust which offers brief intervention and support for relatives following the death of a loved one in hospital.

The service includes sending a letter of condolence, and offering an opportunity to talk to a member of the team involved in the care of their relative. It presents its historical context, its pertinence to grief theory and practice and gives a description and evaluation of the service. The service provides an alternative, less problem-centred pathway to the standard route for those with problems relating to the hospital and gives relatives the opportunity to voice concerns, and to seek information and answers from those best equipped to meet them (experts in clinical and bereavement care).



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