

# Reading list

**End of life care**

**December 2014**

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Further copies of this reading list can be downloaded from <http://www.kingsfund.org.uk/readinglists>

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## Contact details

Information Centre  
The King's Fund  
11-13 Cavendish Square  
LONDON  
W1G 0AN

Tel: 020 7307 2568

Email: [library@kingsfund.org.uk](mailto:library@kingsfund.org.uk)

Twitter: [https://twitter.com/kingsfund\\_lib](https://twitter.com/kingsfund_lib)

Website: <http://www.kingsfund.org.uk/library>

## BOOKS/REPORTS

Taylor, Karen

Deloitte Centre for Health Solutions

### **Transforming care at the end-of-life : dying well matters.**

London : Deloitte, 2014

*Web publication*

This report finds that at least £4.5 billion is spent each year in England caring for those at the end of their lives. Analysis of national reviews and audits over the past 18 months highlights shortcomings and concerns about the large degree of variation in services across the country.

<https://www2.deloitte.com/content/dam/Deloitte/uk/Documents/life-sciences-health-care/transforming-care-at-the-end-of-life.pdf>

Great Britain. Department of Health. NHS Medical Directorate. End of Life Care  
**National Survey of Bereaved People (VOICES) by NHS Area Team (England) : 2011-12.**

Statistical Bulletin ; 6 March 2014

Newport : ONS, 2012

*Web publication*

[http://www.ons.gov.uk/ons/dcp171778\\_355031.pdf](http://www.ons.gov.uk/ons/dcp171778_355031.pdf)

Leadership Alliance for the Care of Dying People

### **One chance to get it right : improving people's experience of care in the last few days and hours of life.**

London : LACDP, 2014

*Web publication*

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/323188/One\\_chance\\_to\\_get\\_it\\_right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)

Associated documentation:

<https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Marie Curie Cancer Care

### **Difficult conversations with dying people and their families.**

London : Marie Curie Cancer Centre, 2014

*Web publication*

This survey of over 1,000 GPs reveals that terminally ill people are not getting access to the right care when they need it. The report highlights issues surrounding round-the-clock care with families reporting having to case after prescriptions, nurses waiting hours for vital drugs to arrive, and locums unable to prescribe.

<http://blog.mariecurie.org.uk/wp-content/uploads/2014/03/S691-Difficult-Conversations-report.pdf>

National Council for Palliative Care

### **Life after death : six steps to improve support in bereavement.**

London : NCPC, 2014

*Web publication*

[http://dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL\(1\).pdf](http://dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf)

National Council for Palliative Care

### **NCPC specialist palliative care (SPC) workforce survey 2013 [and] SPC longitudinal survey of English strategic clinical networks.**

London : NCPC, 2014

*Web publication*

[http://www.ncpc.org.uk/sites/default/files/NCPC\\_SPC\\_Workforce\\_Survey\\_2013.pdf](http://www.ncpc.org.uk/sites/default/files/NCPC_SPC_Workforce_Survey_2013.pdf)

National Council for Palliative Care

### **National survey of patient activity data for specialist palliative care services : MDS full report for the year 2012-2013.**

London : NCPC, 2014

*Web publication*

<http://www.endoflifecare-intelligence.org.uk/view?rid=803>

Georghiou, Theo and Bardsley, Martin

Nuffield Trust

### **Exploring the cost of care at the end of life.**

London : Nuffield Trust, 2014

*Web publication*

[http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end\\_of\\_life\\_care.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf)

Associated documentation:

<http://www.nuffieldtrust.org.uk/media-centre/press-releases/further-evidence-cost-end-life-care-outside-hospital-%E2%80%93-new-nuffield-trus>

Office for National Statistics

**National Bereavement Survey (VOICES), 2013.**

Statistical bulletin ; 10 July 2014

London : ONS, 2014

*Web publication*

[http://www.ons.gov.uk/ons/dcp171778\\_370472.pdf](http://www.ons.gov.uk/ons/dcp171778_370472.pdf)

Associated documentation:

<http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2013/index.html>

Public Health England

**Patterns of end of life care in England, 2008 to 2010 : analysis of the National End of Life Care Intelligence Network local authority profiles by PHE region and centre.**

London : PHE, 2014

*Web publication*

<http://www.endoflifecare-intelligence.org.uk/view?rid=789>

Associated documentation:

[http://www.endoflifecare-intelligence.org.uk/resources/publications/patterns\\_in\\_eolc](http://www.endoflifecare-intelligence.org.uk/resources/publications/patterns_in_eolc)

ISBN: 1860165344

Royal College of Physicians and Marie Curie Palliative Care Institute

**National care of the dying audit for hospitals, England : national report, May 2014.**

London : RCP, 2014

*Web publication*

[https://www.rcplondon.ac.uk/sites/default/files/ncdah\\_national\\_report.pdf](https://www.rcplondon.ac.uk/sites/default/files/ncdah_national_report.pdf)

Executive summary: [https://www.rcplondon.ac.uk/sites/default/files/ncdah\\_exec\\_summary.pdf](https://www.rcplondon.ac.uk/sites/default/files/ncdah_exec_summary.pdf)

Associated documentation:

<https://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

ISBN: 9780992827700

Connor, Stephen R. and Sepulveda Bermedo, Maria Cecilia

Worldwide Palliative Care Alliance and World Health Organization

**Global atlas of palliative care at the end of life.**

London : Worldwide Palliative Care Alliance, 2014

*Web publication*

[http://www.who.int/nmh/Global\\_Atlas\\_of\\_Palliative\\_Care.pdf](http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf)

Tickell, Clare, Chair

Commission into the Future of Hospice Care

**Future ambitions for hospice care : our mission and our opportunity.**

[London] : Help the Hospices, 2013

*HOQHC (Com)*

The final report of the Commission into the Future of Hospice Care.

<http://www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care/commission-resources>

Commission into the Future of Hospice Care:

<http://www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care>

Compassion in Dying

**Divided in dying.**

London : Compassion in Dying, 2013

*Web publication*

This report highlights the key findings from a survey of the general public on the recording of end-of-life treatment and care wishes. It also draws on people's individual experiences of their loved one's end of life and makes recommendations for practice.

<http://www.compassionindying.org.uk/sites/default/files/2013-08-01%20-%20Divided%20in%20Dying%20-%20Final.pdf>

Wood, Claudia and Salter, Jo

Demos

**A time and a place : what people want at the end of life.**

Sudbury : Sue Ryder, 2013

*Web publication*

<http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isnt-working/~ /media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx>

Paget, Ally and Wood, Claudia  
Demos

**Ways and means.**

London : Demos, 2013

*Web publication*

This report reveals that the likelihood of what can be described as a 'good death' - one where the wishes of the patient and their family are met - can be significantly affected by where people live, their ethnicity and previous contact with social care. But the most critical factor is early diagnosis and timely initiation of support.

[http://www.demos.co.uk/files/Ways\\_and\\_Means\\_-\\_web.pdf?1371658165](http://www.demos.co.uk/files/Ways_and_Means_-_web.pdf?1371658165)

Neuberger, Julia, Baroness Neuberger, Chair  
Independent Review of the Liverpool Care Pathway

**More care, less pathway : a review of the Liverpool Care Pathway.**

London : DH, 2013

*HOQHC (Neu)*

This report sets out recommendations regarding the Liverpool Care Pathway and end of life care following an independent review of the LCP chaired by Baroness Julia Neuberger. The recommendations include: phasing out the LCP and replacing it with an individual end of life care plan; a general principle that a patient should only be placed on the LCP or a similar approach by a senior responsible clinician in consultation with the healthcare team; unless there is a very good reason, a decision to withdraw or not to start a life-prolonging treatment should not be taken during any 'out of hours' period; an urgent call for the Nursing and Midwifery Council to issue guidance on end of life care; an end to incentive payments for use of the LCP and similar approaches; and a new system-wide approach to improving the quality of care for the dying.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf)

Associated documentation:

<https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Thiel, Veronika, et al.  
The King's Fund

**Midhurst Macmillan Community Specialist Palliative Care Service : delivering end-of-life care in the community.**

London : The King's Fund, 2013

*Web publication*

[http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/midhurst-macmillan-coordinated-care-case-study-kings-fund-aug13.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/midhurst-macmillan-coordinated-care-case-study-kings-fund-aug13.pdf)

Co-ordinated care for people with complex chronic conditions project page:

<http://www.kingsfund.org.uk/projects/co-ordinated-care-people-complex-chronic-conditions>

Leadership Alliance for the Care of Dying People

**Engagement with patients, families, carers and professionals : proposed advice for health and social care practitioners involved in looking after people in the last days of life.**

[Redditch] : NHS England, 2013

*Web publication*

<http://www.england.nhs.uk/wp-content/uploads/2013/12/lacdp-engage.pdf>

Associated documentation:

[https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage/consult\\_view](https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage/consult_view)

Macmillan Cancer Support

**Time to choose : making choice at the end of life a reality.**

London : Macmillan Cancer Support, 2013

<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/TimeToChoose.pdf>

Marie Curie Cancer Care

**Death and dying : understanding the data.**

London : Marie Curie Cancer Care, 2013

*Web publication*

[http://www.mariecurie.org.uk/Documents/press-and-media/R018\\_P110-MC-Atlas-Report\\_V13\\_SD.pdf](http://www.mariecurie.org.uk/Documents/press-and-media/R018_P110-MC-Atlas-Report_V13_SD.pdf)

Associated documentation:

<http://www.mariecurie.org.uk/en-GB/Policy/Campaigns/Improving-end-of-life-care/>

Lindsey, K.  
National End of Life Care Programme  
**End of life care co-ordination : core content : standard specification.**  
National Information Standard ; ISB 1580 (Amd 16/2013)  
Leicester : NEOFPC, 2013  
<http://www.isb.nhs.uk/documents/isb-1580/amd-16-2013/1580162013spec2.pdf>  
*Web publication*

Addington-Hall, Julia, et al.  
National Institute for Health Research  
**Variations in out of hours end of life care provision across primary care organisations in England and Scotland.**  
SDO project ; 08/1813/259 (February 2013)  
Southampton : NIHR, 2013  
[http://www.netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1813-259\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-259_V01.pdf)  
Executive summary: [http://www.netscc.ac.uk/hsdr/files/project/SDO\\_ES\\_08-1813-259\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_ES_08-1813-259_V01.pdf)  
Associated documentation: <http://www.nets.nihr.ac.uk/projects/hsdr/081813259>  
*Web publication*

Mason, B., et al.  
National Institute for Health Research  
**Co-ordination of care for people at risk of dying in the next 12 months : a multi-site prospective study and consensus seeking exercise.**  
SDO Project ; 08/1813/258  
Southampton : NIHR, 2013  
[http://www.netscc.ac.uk/hsdr/files/project/SDO\\_FR\\_08-1813-258\\_V01.pdf](http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1813-258_V01.pdf)  
Associated documentation: <http://www.nets.nihr.ac.uk/projects/hsdr/081813258>  
*Web publication*

ISBN: 9781908874153  
NHS National End of Life Care Programme and National Council for Palliative Care  
**Advance decisions to refuse treatment : a guide for health and social care professionals.**  
[London] : NEOFPC, 2013  
<http://www.ncpc.org.uk/sites/default/files/ADRT%20books.pdf>  
*Web publication*

NHS England  
National Council for Palliative Care  
**Guidance for doctors and nurses caring for people in the last days of life.**  
Gateway number : 00264 (16 July 2013).  
[London] : NCPC, 2013  
<http://www.ncpc.org.uk/publication/guidance-doctors-and-nurses-caring-people-last-days-life>  
*Web publication*

NHS Improving Quality and Association of Directors of Adult Social Services  
**Sharing successful strategies for implementing 'Supporting people to live and die well: a framework for social care at the end of life.' : a progress report on implementing the end of life care Social Care Framework 2010 by local authority adult social care departments in England.**  
[London] : NHSIQ, 2013  
<http://www.nhsiq.nhs.uk/download.ashx?mid=8501&nid=8502>  
*Web publication*

Public Health England. National End of Life Care Intelligence Network (NEoLCIN)  
**What we know now 2013 : new information collated by the National End of Life Care Intelligence Network.**  
London : Public Health England, 2013  
<http://www.endoflifecare-intelligence.org.uk/view?rid=771>  
*Web publication*

Thomas, Keri and Paynton, David  
Royal College of General Practitioners  
**RCGP commissioning guidance in end of life care.**  
London : RCGP, 2013  
[http://www.rcgp.org.uk/news/~/\\_media/Files/CIRC/EOLC/RCGP-EOLC-Guidelines-Apr-2013.ashx](http://www.rcgp.org.uk/news/~/_media/Files/CIRC/EOLC/RCGP-EOLC-Guidelines-Apr-2013.ashx)  
*Web publication*

Social Care Institute for Excellence  
Care Provider Alliance  
**Phasing out of Liverpool Care Pathway : briefing for social care providers.**  
London : SCIE, 2013  
[http://www.scie.org.uk/adults/endoflifecare/files/briefinglcpjuly2013.pdf?dm\\_i=405,1OPLY,2QSPZ8,67AS3,1](http://www.scie.org.uk/adults/endoflifecare/files/briefinglcpjuly2013.pdf?dm_i=405,1OPLY,2QSPZ8,67AS3,1)  
*Web publication*

Rutter, Deborah and Holmes, Pamela  
Social Care Institute for Excellence

**Dying well at home : the case for integrated working.**

SCIE Guide ; 48

London : SCIE, 2013

*Web publication*

[http://www.scie.org.uk/publications/guides/guide48/?dm\\_i=405,1HOHE,2QSPZ8,52ET3,1](http://www.scie.org.uk/publications/guides/guide48/?dm_i=405,1HOHE,2QSPZ8,52ET3,1)

Together For Short Lives

**Commissioning children's palliative care : a guide for clinical commissioning groups (CCGs).**

Bristol : Together For Short Lives, 2013

*Web publication*

[http://www.togetherforshortlives.org.uk/assets/0000/8448/Together\\_for\\_Short\\_Lives\\_clinical\\_commissioning\\_group\\_guidance.pdf](http://www.togetherforshortlives.org.uk/assets/0000/8448/Together_for_Short_Lives_clinical_commissioning_group_guidance.pdf)

Hughes-Hallett, Thomas, et al.

World Innovation Summit for Health

**Dying healed : transforming end-of-life care through innovation.**

[Doha] : WISH, 2013

*Web publication*

<http://www.wish-qatar.org/app/media/386>

Associated documentation:

<http://www3.imperial.ac.uk/global-health-innovation/globalhealthpolicysummit/wish/forumreports>

Alzheimer's Society

**My life until the end : dying well with dementia.**

London : Alzheimer's Society, 2012

*Web publication*

<http://www.alzheimers.org.uk/site/scripts/download.php?fileID=1537>

Association for Palliative Medicine of Great Britain and Ireland, et al.

**Commissioning guidance for specialist palliative care : helping to deliver commissioning objectives.**

Southampton : Association for Palliative Medicine, 2012

*Web publication*

<http://www.apmonline.org/documents/135764105191600.pdf>

ISBN: 9780199599400

Cohen, Joachim and Deliens, Luc, editors

**A public health perspective on end of life care**

Oxford : Oxford University Press, 2012

*HOQHC (Coh)*

Diabetes UK and NHS Diabetes

**End of life diabetes care : full strategy document commissioned by Diabetes UK.**

Newcastle upon Tyne : NHS Diabetes, 2013

*Web publication*

2nd edition

[http://www.diabetes.org.uk/upload/Position%20statements/End-of-life-care\\_strategy\\_Doc111113.pdf](http://www.diabetes.org.uk/upload/Position%20statements/End-of-life-care_strategy_Doc111113.pdf)

Associated documentation:

[http://www.diabetes.org.uk/About\\_us/What-we-say/Improving-diabetes-healthcare/End-of-Life-Care/](http://www.diabetes.org.uk/About_us/What-we-say/Improving-diabetes-healthcare/End-of-Life-Care/)

ISBN: 9780470656143

Grinyer, Anne

**Palliative and end of life care for children and young people : home, hospice and hospital.**

Chichester : Wiley-Blackwell, 2012

*HOQHC: QG (Gri)*

Housing 21

**The Dementia Voice Nurse Service pilot : overview of findings and learning from the evaluation of the two year pilot programme : December 2008 – December 2010.**

[Beaconsfield] : Housing 21, 2012

*Web publication*

[http://www.housing21.co.uk/index.php/download\\_file/view/735/](http://www.housing21.co.uk/index.php/download_file/view/735/)

ISBN: 9780853284444

Goodman, Claire, et al.

London School of Economics and Political Science. NIHR School for Social Care Research

**End of life care.**

Methods review ; 12

London : NIHR, 2012

*Web publication*

[http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR-Methods-Review\\_12\\_web.pdf](http://www2.lse.ac.uk/LSEHealthAndSocialCare/pdf/SSCR-Methods-Review_12_web.pdf)

Lucas, Lauren

Local Government Information Unit

**A good death : the role of the local authority in end of life care.**

London : LGiU, 2012

<http://www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf>

Marie Curie Cancer Centre

**Don't let me down : ensuring a good transition for young people with palliative care needs.**

London : Marie Curie Cancer Centre, 2012

*Web publication*

<http://www.mariecurie.org.uk/Documents/press-and-media/News-Comment/Dont-Let-Me-Down.pdf>

Marie Curie Cancer Care

**Committed to carers : supporting carers of people at the end of life.**

London : Marie Curie Cancer Care, 2012

*Web publication*

<http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/commissioning-services/committed-to-care-Mar-12.pdf>

Marie Curie Cancer Care

**Understanding the cost of end life care in different settings.**

London : Marie Curie Cancer Care, 2012

*Web publication*

<http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/commissioning-services/understanding-cost-end-life-care-different-settings.pdf>

Calanzani, Natalia, et al.

Marie Curie Cancer Centre, et al.

**Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK : demographic profile and the current state of palliative and end of life care provision.**

London : Marie Curie Cancer Centre, 2012

*Web publication*

<http://www.mariecurie.org.uk/Documents/WHO-WE-ARE/Diversity/Palliative%20care%20BAME%20report%20June%202013.pdf>

NHS National End of Life Care Programme and Institute of Healthcare Management

**An evaluation of the Route to Success resources, related tools and frameworks covering disease specific areas : heart failure; advanced kidney disease; dementia; and long term neurological conditions.**

London : NEoLCP, 2012

*Web publication*

[http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/144153EoLC\\_IHM\\_RtS\\_Evaluation\\_Report.pdf](http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/144153EoLC_IHM_RtS_Evaluation_Report.pdf)

NHS National End of Life Care Programme

**Reviewing end of life care costing information to inform the QIPP End of Life Care workstream.**

[Leicester] : NEoLCP, 2012

*Web publication*

[http://thewholesystem.co.uk/wp-content/uploads/2014/07/EoLC\\_QIPP\\_Costings\\_Report.pdf](http://thewholesystem.co.uk/wp-content/uploads/2014/07/EoLC_QIPP_Costings_Report.pdf)

ISBN: 9781908874313

NHS National End of Life Care Programme

**Commissioning person centred end of life care : a toolkit for health and social care professionals.**

[London] : NEoLCP, 2012

*Web publication*

<http://www.nhs.uk/download.ashx?mid=8628&nid=8627>



National Council for Palliative Care

**What about end of life care? : mapping England's health and wellbeing boards' vision for dying people.**

London : NCPC, 2012

*Web publication*

<http://www.ncpc.org.uk/sites/default/files/NCPC%20Mapping%20EOLC%20Health%20and%20Wellbeing%20strategy%20briefing%20October2012.pdf>

Toolkit: <http://www.ncpc.org.uk/freedownloads?keys=toolkit>

ISBN: 9781898915898

National Council for Palliative Care

**Open to all? : meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life.**

London : NCPC, 2011

*HOQHC (Nat)*

ISBN: 9780957022423

National End of Life Care Intelligence Network

**What do we know now that we didn't know a year ago? : new intelligence on end of life care in England.**

Leicester : NEoLCIN, 2012

*Web publication*

<http://www.endoflifecare-intelligence.org.uk/view.aspx?rid=464>

ISBN: 9780957022416

Effiong, Kufre, et al.

National End of Life Care Intelligence Network

**Deaths from liver disease : implications for end of life care in England.**

Leicester : NEoLCIN, 2012

*Web publication*

<http://www.endoflifecare-intelligence.org.uk/view.aspx?rid=276>

ISBN: 9781908874306

National End of Life Care Programme

**The route to success in end of life care : achieving quality for social work.**

[Leicester] : NEoLCIN, 2012

*Web publication*

<http://www.nhs.uk/nhsq.nhs.uk/download.ashx?mid=8190&nid=8189>

ISBN: 9780956922595

National End of Life Care Intelligence Network

**Deprivation and death : variation in place and cause of death.**

Leicester : NEoLCIN, 2012

*Web publication*

<http://www.endoflifecare-intelligence.org.uk/view?rid=254>

ISBN: 9781908874290

National End of Life Care Programme

**The route to success in end of life care : achieving quality for lesbian, gay, bisexual and transgender people.**

[Leicester] : NEoLCIN, 2012

*Web publication*

[http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/139519EoLC\\_LGBT\\_Route\\_to\\_Success\\_web\\_.pdf](http://socialwelfare.bl.uk/subject-areas/services-activity/health-services/nhsnationalendoflifecareprogramme/139519EoLC_LGBT_Route_to_Success_web_.pdf)

National End of Life Care Programme

**Critical success factors that enable individuals to die in their preferred place of death.**

Leicester : NEoLCP, 2012

*Web publication*

[http://webarchive.nationalarchives.gov.uk/20121115173345/http://endoflifecareforadults.nhs.uk/assets/downloads/EoLC\\_CSF\\_Report\\_for\\_Publication\\_2.pdf](http://webarchive.nationalarchives.gov.uk/20121115173345/http://endoflifecareforadults.nhs.uk/assets/downloads/EoLC_CSF_Report_for_Publication_2.pdf)

National End of Life Care Programme

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## JOURNAL ARTICLES

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**Improving end-of-life care for people with dementia.**

*Nursing Standard 2014; 28 (48): 37-43 (30 August 2014)*

Nurses caring for older patients across diverse settings will provide care for people with dementia approaching the end of their lives. Demographic changes mean that the number of people dying with dementia will increase, however nurses and other healthcare professionals may be unprepared to meet their needs. Factors that are essential to provide compassionate and dignified end of life care for people with dementia include effective communication with those with cognitive impairment and an awareness of likely causes of anxiety, fear and resistance to care when carrying out interventions. Accurate assessment and pain relief are required to ensure good end of life care. Knowledge of challenging and complex issues around maintenance of nutrition and hydration requirements, and communication skills to discuss the issues with families and carers are also required. [Abstract]

Wye, Lesley, et al.

**What works in 'real life' to facilitate home deaths and fewer hospital admissions for those at end of life? : results from a realist evaluation of new palliative care services in two English counties.**

*BMC Palliative Care 2014; 13 (37): (28 July 2014)*

BACKGROUND: We evaluated end of life care services in two English counties including: coordination centres, telephone advice line, 'Discharge in Reach' nurses, a specialist community personal care team and community nurse educators. Elsewhere, we published findings detailing high family carer satisfaction and fewer hospital admissions, Accident and Emergency attendances and hospital deaths for service users compared to controls. The aim of this paper is to discuss what contributed to those outcomes. METHODS: Using realist evaluation, data collection included documentation (e.g. referral databases), 15 observations of services and interviews with 43 family carers and 105 professionals. Data were analysed using framework analysis, applying realist evaluation concepts. Findings were discussed at successive team meetings and further data was collected until team consensus was reached. RESULTS: Services 'worked' primarily for those with cancer with 'fast track' funding who were close to death. Factors contributing to success included services staffed with experienced palliative care professionals with dedicated (and sufficient) time for difficult conversations with family carers, patients and/or clinical colleagues about death and the practicalities of caring for the dying. Using their formal and informal knowledge of the local healthcare system, they accessed community resources to support homecare and delivered excellent services. This engendered confidence and reassurance for staff, family carers and patients, possibly contributing to less hospital admissions and A&E attendances and more home deaths. CONCLUSIONS: With demand for 24-hour end of life care growing and care provision fragmented across health and social care boundaries, services like these that cut across organisational sectors may become more important. They offer an overview to help navigate those desiring a home death through the system. [Abstract]

<http://www.biomedcentral.com/1472-684X/13/37>

Davies, Nathan, et al.

**Barriers to the provision of high-quality palliative care for people with dementia in England : a qualitative study of professionals' experiences.**

*Health and Social Care 2014; 22 (4): 386-385 (July 2014)*

Approaches to palliative care that were originally developed for people with cancer are now being adopted for people with dementia, as a response to many reports of poor-quality care for people with dementia at the end of life. This study explored perceived barriers to the delivery of high-quality palliative care for people with dementia using semi-structured interviews. Recordings were transcribed verbatim and analysed using thematic analysis with an inductive approach and a coding strategy. To improve the trustworthiness of the analysis, independent reading and coding of the transcripts were undertaken, followed by discussions among the four researchers to reach agreement and consensus of the themes. Two group interviews (n=7 and n=6), 16 individual interviews and five interviews of pairs of professionals were conducted in 2011/2012 with participants from backgrounds in palliative care, dementia services, palliative care research and policy making. Four themes were identified as barriers to providing high-quality palliative care for people with dementia: (i) ambivalence towards the systematisation of palliative care; (ii) disconnection between services; (iii) different assumptions about training needs; and (iv) negotiation of risk. Understanding these barriers to providing high-quality palliative care for people with dementia could help in the development of a dementia-specific palliative care pathway. [Abstract]

Pal, Laura and Manning, Lisa

**Palliative care for frail older people.**

*Clinical Medicine 2014; 14 (3): 292-295 (June 2014)*

Frailty is a clinical syndrome associated with increased risk of functional disability, dependency, institutionalisation and death. Frailty is a dynamic process, but transition to a level of worse frailty is more common than improvement. The palliative care needs of older people are often under assessed and undertreated. Comprehensive specialist assessment during acute admissions reduces the risk of cognitive or functional decline, and death. Palliative care in the form of anticipatory care planning, consideration of addition to the general practitioner's palliative care register and symptom control should be initiated early, and can include curative treatments, which might improve functioning, and quality of life. [Summary]

Bronnert, Rosie

**Discussing and planning care for people approaching the end of their life.**

*Clinical Medicine 2014; 14 (3): 296-299 (June 2014)*

Timely identification of patients approaching the end of their life is an important skill. Clinical tools can support the identification of such patients. The General Medical Council requires clinicians to consider and act on end-of-life issues in appropriate patients. Sensitive discussions about planning future care can benefit patients and their families and/or carers. Written care plans of shared decision-making with patients and families can support clinicians and others in providing the most appropriate care for patients as they deteriorate and when they are dying. [Abstract]

Trueland, Jennifer

**The Importance of home.**

*Health Service Journal 2014; 124 (6391): 6-7 (21 March 2014 Suppl.)*

Patients want it and the NHS benefits - so how can we move the terminally ill out of hospital? [Introduction]

[http://www.hsj.co.uk/Journals/2014/03/20/g/g/y/HSJ\\_COMMISSIONING\\_140321.pdf](http://www.hsj.co.uk/Journals/2014/03/20/g/g/y/HSJ_COMMISSIONING_140321.pdf)

**'We do more with the same resource'.**

*Health Service Journal 2014; 124 (6391): 8-9 (21 March 2014 Suppl.)*

How services around the country are using training, technology and specialist services to allow more terminally ill patients to be supported at home. [Introduction]

[http://www.hsj.co.uk/Journals/2014/03/20/g/g/y/HSJ\\_COMMISSIONING\\_140321.pdf](http://www.hsj.co.uk/Journals/2014/03/20/g/g/y/HSJ_COMMISSIONING_140321.pdf)

McTague, Laura, et al.

### **An innovative development programme for consultants to improve patient care in the last months of life.**

*Clinical Medicine 2014; 14 (3): 299-302 (June 2014)*

Around half the annual 600,000 deaths in England occur in hospital, with an average of 30 days spent as inpatients during the last year of life, over several admissions. Forty per cent of people who die in hospital may have no medical need to be there and most would not choose to die in hospital if their care could be delivered in an alternative setting. Most people who die in the UK are managed by their general practitioner (GP), together with a range of hospital specialists without referral to specialist palliative care services. Delivering patient-centred care in the last months of life and enabling people to die in a place of their choosing requires individuals and their families to know that they may be approaching the end of life in good time to be involved in decision-making, and for community support to be in place. Honest conversations about limits of medical treatment must be part of routine care if patients are to have time to consider their choices, as outlined in the General Medical Council (GMC) requires behavioural change in healthcare teams, influenced and led by consultants, acknowledging that clinicians are largely trained to cure or extend life. All physicians need to engage deeply in this challenging area of care and make it a routine part of their practice. Developing practice to embrace this requires more than the transfer of knowledge. Senior doctors are accustomed to identifying their own learning needs. Recognising the need to change practice around palliative and end-of-life care (EoLC) may result from personal or professional experiences - good or bad - and the need to deliver enhanced curriculum requirements for trainees under their supervision. A range of learning opportunities is available, including e-learning, and local, regional and national training in EoLC. However, raising the bar in EoLC needs more than knowledge, and one-to-one work with specialist palliative care clinicians is a form of learning that is most highly valued. This may be a powerful way of learning, but is time intensive and palliative care clinicians do not always appreciate the issues in other specialties. This paper reports on an innovative development programme for senior clinicians that was designed and piloted in two trusts. Box 1 lists the questions to ask when evaluating EoLC. [Abstract]

Burbeck, Rachel, et al.

### **Understanding the role of the volunteer in specialist palliative care : a systematic review and thematic synthesis of qualitative studies.**

*BMC Palliative Care 2014; 13 (3): (10 February 2014)*

**BACKGROUND:** Volunteers make a major contribution to palliative patient care, and qualitative studies have been undertaken to explore their involvement. With the aim of making connections between existing studies to derive enhanced meanings, we undertook a systematic review of these qualitative studies including synthesising the findings. We sought to uncover how the role of volunteers with direct contact with patients in specialist palliative care is understood by volunteers, patients, their families, and staff. **METHODS:** We searched for relevant literature that explored the role of the volunteer including electronic citation databases and reference lists of included studies, and also undertook hand-searches of selected journals to find studies which met inclusion criteria. We quality appraised included studies, and synthesised study findings using a novel synthesis method, thematic synthesis. **RESULTS:** We found 12 relevant studies undertaken in both inpatient and home-care settings, with volunteers, volunteer coordinators, patients and families. Studies explored the role of general volunteers as opposed to those offering any professional skills. Three theme clusters were found: the distinctness of the volunteer role, the characteristics of the role, and the volunteer experience of the role. The first answers the question, is there a separate volunteer role? We found that to some extent the role was distinctive. The volunteer may act as a mediator between the patient and the staff. However, we also found some contradictions. Volunteers may take on temporary surrogate family-type relationship roles. They may also take on some of the characteristics of a paid professional. The second cluster helps to describe the essence of the role. Here, we found that the dominant feature was that the role is social in nature. The third helps to explain aspects of the role from the point of view of volunteers themselves. It highlighted that the role is seen by volunteers as flexible, informal and sometimes peripheral. These characteristics some volunteers find stressful. [Abstract]

<http://www.biomedcentral.com/1472-684X/13/3>

### **Gentle Dusk - Future Matters.**

*Inside Palliative Care 2013; 26 18-19 (December 2013)*

Future Matters (a community outreach programme in North London, established by Gentle Dusk) trains volunteers from third sector and community organisations to become Peer Educators in End of Life Care Planning. They are then able to cascade information to members of their local communities and enable and support communities to put their end of life care plans in place. [KJ]

Future Matters <http://www.gentledusk.org.uk/future-matters.html>

Gott, M., et al.

**Transitions to palliative care for older people in acute hospitals : a mixed-methods study.**

*Health Services and Delivery Research* 2013; 1 (1): (November 2013).

This study finds that patients with palliative care needs represent a significant proportion of the hospital inpatient population and that there is a significant gap between NHS policy regarding palliative and end-of-life care management in acute hospitals in England and current practice.

[http://www.journalslibrary.nihr.ac.uk/\\_data/assets/pdf\\_file/0011/94277/FullReport-hsdr01110.pdf](http://www.journalslibrary.nihr.ac.uk/_data/assets/pdf_file/0011/94277/FullReport-hsdr01110.pdf)

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Duffin, Christian

**Liverpool Care Pathway : dying to know what will happen next.**

*Nursing Standard* 2013; 28 (9): 14-15 (30 October 2013)

Nurse consultants in palliative care have told *Nursing Standard* that increasing numbers of terminally ill patients are dying painful or undignified deaths. [Summary]

Beland, P.

**Implications for carers of terminally ill patients dying at home.**

*Nursing Standard* 2013; 28 (3): 40-45 (18 September 2013)

Most terminally ill patients will express a wish to die at home. To achieve this, patients must rely on the support of family carers, who may experience emotional and health difficulties in providing such care, both before and after the death. Healthcare professionals can help to relieve the burden on family carers, and there is guidance available to direct GPs and other community healthcare professionals on providing good anticipatory palliative care for patients, and support for carers. This will increase the likelihood that patients at the end of life will achieve a 'good death', and family members will have a positive experience of care giving. [Introduction]

Wynne, L.

**Spiritual care at the end of life.**

*Nursing Standard* 2013; 28 (2): 41-45 (11 September 2013)

With increasing focus on providing spiritual care at the end of life, healthcare professionals and those involved in policy development are questioning how to make a "good" death the expectation, rather than the exception. However, there is a lack of awareness of the importance of spirituality to patients' lives, and how good spiritual care can enhance quality of life and improve patient outcomes. This article examines the role of spirituality in palliative care, focusing on spiritual assessment, communication and compassion in nursing. The article attempts to provide a working definition of spirituality, focusing on who should provide spiritual care and the difficulties in meeting the spiritual needs of individuals at the end of life. Strategies to promote the spiritual wellbeing of the patient are discussed. [Abstract]

Iliffe, Steve, et al.

**Modelling the landscape of palliative care for people with dementia : a European mixed methods study.**

*BMC Palliative Care* 2013; 12 (30): (12 August 2013)

**BACKGROUND:** Palliative care for people with dementia is often sub-optimal. This is partly because of the challenging nature of dementia itself, and partly because of system failings that are particularly salient in primary care and community services. There is a need to systematize palliative care for people with dementia, to clarify where changes in practice could be made. To develop a model of palliative care for people with dementia that captures commonalities and differences across Europe, a technology development approach was adopted, using mixed methods including 1) critical synthesis of the research literature and policy documents, 2) interviews with national experts in policy, service organisation, service delivery, patient and carer interests, and research in palliative care, and 3) nominal groups of researchers tasked with synthesising data and modelling palliative care. **DISCUSSION:** A generic model of palliative care, into which quality indicators can be embedded. The proposed model includes features deemed important for the systematisation of palliative care for people with dementia. These are: the division of labour amongst practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between disease-modifying treatment and palliative care and between palliative and end-of-life care; and the process of bereavement. **SUMMARY:** The co-design approach to developing a generic model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines. This model will be explored further in the intervention phase of the IMPACT project. [Abstract]

<http://www.biomedcentral.com/1472-684X/12/30>

Henry, Claire and Hayes, Anita

**Providing high-quality end-of-life care universally.**

*Nursing Times 2013; 109 (33): 16-18 (21 August 2013)*

The National End of Life Care Programme was launched in November 2004, and has been instrumental in delivering the Department of Health's (2008) End-of-Life Care Strategy and the National Institute of Health and Clinical Excellence's (2011) Quality Standard for End of Life Care for Adults. End-of-life care now sits within NHS Improving Quality. In this article we discuss an overview of the programme's successes, challenges and priorities for the future. [Abstract]

<http://www.nursingtimes.net/Journals/2013/08/16/j/o/a/210813-Providing-high-quality-end-of-life-care-universally.pdf>

Bakhai, Khyati, et al.

**Electronic coordination of palliative care and its effect on primary and community care.**

*BMJ 2013; 347 (7920): GP6 (10 August 2013 Suppl.)*

To respond better to patients' wishes, palliative care must be efficiently and effectively coordinated across hospital, primary, and community care. Khyati Bakhai and colleagues look at the implications of an electronic care coordination system for patients and staff workloads. [Introduction]

[http://careers.bmj.com/careers/advice/view-article.html?id=20013923&utm\\_source=feedburner&utm\\_medium=feed&utm\\_campaign=Feed%3A+careers%2Frecent+\(Latest+from+BMJ+careers\)](http://careers.bmj.com/careers/advice/view-article.html?id=20013923&utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+careers%2Frecent+(Latest+from+BMJ+careers))

Collis, Emily

**Care of the dying patient in the community.**

*BMJ 2013; 347 (7915): 27-30 (6 July 2013)*

Most people report a preference to die at home. To support this preference, doctors in all settings need to identify relevant patients early. Anticipatory care planning should include discussion and documentation of patient preferences, anticipatory prescribing, and completion of a do not attempt cardiopulmonary resuscitation order. General practitioners have a key role, in both homes and care homes, before and after death. Good communication and effective coordination of care 24 hours a day are essential to prevent unwanted and unnecessary hospital admissions towards the end of life. [Summary]

Van Beek, Karen, et al.

**Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group) : a descriptive study.**

*BMC Health Services Research 2013; 13 (275): (17 July 2013)*

**BACKGROUND:** According to EU policy, anyone in need of palliative care should be able to have access to it. It is therefore important to investigate which palliative care topics are subject to legislation and regulations in Europe and how these are implemented in (national) health care plans. This paper aims to deliver a structured overview of the legislation, existing regulations and the different health care policies regarding palliative care in seven European countries. **METHODS:** In 2008 an inventory of the organisation of palliative care was developed by the researchers of the Europall project. Included were two open questions about legislation, regulations, and health policy in palliative care. This questionnaire was completed using palliative care experts selected from Belgium, England, France, Germany, the Netherlands, Poland and Spain. Additionally, (grey) literature on palliative care health policy and regulations from the participating countries was collected to complete the inventory. Comparative analysis of country specific information was performed afterwards. **RESULTS:** In all countries palliative care regulations and policies existed (either in laws, royal decrees, or national policies). An explicit right to palliative care was mentioned in the Belgium, French and German law. In addition, access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. Also, all countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, opioids and the role of volunteers. **CONCLUSIONS:** Although all included European countries have policies on palliative care, countries largely differ in the presence of legislation and regulations on palliative care as well as the included topics. European healthcare policy recommendations should support palliative care access across Europe. [Abstract]

<http://www.biomedcentral.com/1472-6963/13/275>



Dean, Erin

**Lessons in delivering good care.**

*Nursing Standard 2013; 44 (44): 16-18 (3 July 2013)*

Education is at the heart of St Christopher's Hospice's mission to make palliative care widely available - it is now one of the largest providers of end of life care education. Its approach influenced Mid Staffs public inquiry chair Robert Francis's recommendations on nurse training. [Summary]

Smith, Randall

**Death and dying in residential care : a matter of concern.**

*Quality in Ageing and Older Adults 2013; 14 (3): 205 - 217*

**PURPOSE:** The purpose of this paper is to trace the history of official policy on the regulation of care homes in respect of end of life care and to contrast this with the results of research on this important theme, not least in terms of what is required to support care home staff in relation to dying residents and their relatives. A central concern is to argue for the open recognition that care homes now cater primarily for frail people towards the end of their lives. Good end of life care and a good death could become a positive "selling point". The author concludes that the system of regulation has broadly failed to address a good death or good end of life care in a residential home. Death talk should no longer need to be avoided in care homes. The research suggests that appropriate support for care home staff in relation to dying residents needs careful identification and investment. A cultural shift is required. **DESIGN/METHODOLOGY/APPROACH:** Following a review of policy documents on regulation and standards of care in residential homes and a subsequent review of the research literature on death and dying in care homes, the paper illuminates the contrast between the ambitious aims in policy documents with very varied practice in everyday care of frail residents. **FINDINGS:** The recent systems of regulation have broadly failed to address a good death or good end of life care in residential homes. Open acknowledgement of death and dying should not be avoided in care homes. Appropriate support for care home staff in relation to dying residents needs careful identification and investment. **ORIGINALITY/VALUE:** The focus of this paper is to contrast official policy with everyday practice. Whilst policy documents suggest recognition of the importance of dignity and respect from dying residents, the research literature indicates great variation in the practice of everyday care. [Abstract]

Mooney, Helen

**How to find the way home.**

*Health Service Journal 2013; 123 (6354): 10-11 (7 June 2013 Suppl.)*

Helen Mooney on addressing the 40 per cent of patients who die in hospital with no medical need to be there. [Introduction]

[http://www.hsj.co.uk/Journals/2013/06/06/f/s/x/HSJ\\_COMMISSIONINGSUPP\\_130607.pdf](http://www.hsj.co.uk/Journals/2013/06/06/f/s/x/HSJ_COMMISSIONINGSUPP_130607.pdf)

**Where they want to be.**

*Health Service Journal 2013; 123 (6354): 12-13 (7 June 2013 Suppl.)*

How partnership working across the country is helping to fulfil patients' wishes to die at home. [Introduction]

[http://www.hsj.co.uk/Journals/2013/06/06/f/s/x/HSJ\\_COMMISSIONINGSUPP\\_130607.pdf](http://www.hsj.co.uk/Journals/2013/06/06/f/s/x/HSJ_COMMISSIONINGSUPP_130607.pdf)

Sleeman, Katherine E. and Collis, Emily

**Caring for a dying patient in hospital.**

*BMJ 2013; 346 (7905): 33-37 (27 April 2013)*

Junior doctors are often required to care for dying patients. Early recognition of dying facilitates meeting patients' and relatives' preferences for end of life care. Communications is the cornerstone of good end of life care. The principles of end of life prescribing are: to stop non-essential drugs; convert essential drugs to the subcutaneous route; and use anticipatory prescribing. [Summary]

Moberly, Tom

**Expanding GPs' role in end of life care.**

*BMJ 2013; 346 (346): GP4 (20 April 2013)*

Provision of end of life care in general practice is widening. Tom Moberly looks at how this is helping general practitioners improve the last years of life for terminally ill patients. [Introduction]

Chinthapalli, Krishna

**The Liverpool care pathway : what do specialists think?**

*BMJ 2013; 346 (7897): 18-19 (2 March 2013)*

Use of the Liverpool care pathway for end of life care has been heavily criticised in the media. The BMJ and Channel 4's Dispatches asked doctors for their views. [Introduction]

Watts, Tessa

**End-of-life care pathways and nursing : a literature review.**

*Journal of Nursing Management 2013; 21 (1): 47-57 (January 2013)*

AIM: To identify and discuss the current state of knowledge about end-of-life care (EOLC) pathways in relation to nursing. BACKGROUND CARE: Enhancing EOLC has become a central concern in governments' health policies worldwide. End-of-life care pathways have been championed as complex interventions to enhance the quality of end-of-life care. However, concerns have been expressed regarding their purpose, initiation and use. EVALUATION: A range of published literature was used to examine EOLC pathways in relation to nursing. KEY ISSUES: Three main themes emerged: nursing's contribution to the evolution of EOLC pathways, implementing EOLC pathways and the influence of EOLC pathways on nursing practice. CONCLUSIONS: End-of-life care pathways are to be welcomed as a means by which the quality of EOLC might be enhanced. However, the state of knowledge about EOLC pathways, their development, implementation and influence on families and professional practice is in its infancy. IMPLICATIONS FOR NURSING MANAGEMENT: End-of-life care pathways are championed as a means by which the quality of EOLC, for dying people and their families might be enhanced. However, as concerns regarding the quality of EOLC persist, nursing management has a crucial role in driving forward and supporting EOLC pathway development, implementation and evaluation. [Abstract]

Trueland, Jennifer

**Stay on the right path.**

*Nursing Standard 2012; 27 (15): 18-20 (12 December 2012)*

Public criticism of the Liverpool Care Pathway has left many patients and relatives suspicious of the framework, which was developed in the 1990s to improve care in the final hours or days of life. Here, nurses explain the benefits of the approach and warn against turning back the clock. [Summary]

O'Dowd, Adrian

**Liverpool care pathway : doctors speak out.**

*BMJ 2012; 345 (7883): 20-21 (17 November 2012)*

Adrian O'Dowd assesses the professional reaction to media criticism of a pathway used to guide end of life care. [Introduction]

Henry, Claire and Hayes, Anita

**The National End of Life Care Programme.**

*British Journal of Healthcare Management 2012; 18 (11): 568-574 (November 2012)*

In 2008 the Department of Health published a national end of life care strategy for England, the first of its kind in the world (Department of Health, 2008). The strategy acknowledged that despite examples of excellent care, many people do not die in their preferred setting or after being involved in planning their care. Despite surveys consistently indicating that most would prefer to die at home or in a community setting such as a hospice (Cicely Saunders International, 2011), in 2005, 58 per cent of deaths took place in hospital. The strategy also acknowledged that many people experience unnecessary pain and other symptoms and referred to 'distressing reports of people not being treated with dignity and respect'. The low priority accorded end of life care (EoLC) by both the NHS and social care, partly due to a societal reluctance to discuss death and dying, has led to wide variations in standards. The absence of a co-ordinated, person-centred approach to EoLC also imposes avoidable costs on the NHS. This article examines the National End of Life Care Programme's key role in promoting and supporting the changes that can deliver the improvements in care and productivity outlined in the strategy. We have approached this by working with partners to achieve whole system transformational change. Both our approach and the resources we have developed complement the recently-published NHS Change Model. [Abstract]

Addicott, Rachel  
The King's Fund

**Delivering better end-of-life care in England : barriers to access for patients with a non-cancer diagnosis.**

*Health Economics, Policy and Law* 2012; 7 (4): 441-454 (October 2012)

The End of Life Care Strategy (Department of Health, 2008) radically raised the profile of end-of-life care in England, signalling the need for development in planning and delivery, to ensure that individuals are able to exercise genuine choice in how and where they are cared for and die. Research has indicated that there have been continuing difficulties in access to high-quality and appropriate support at the end of life, particularly for patients with a diagnosis other than cancer. This article uses research findings from three case studies of end-of-life care delivery in England to highlight some of the barriers that continue to exist, and understand these challenges in more depth. Access to high-quality and appropriate end-of-life care has been a challenge for all patients nearing the end of life. However, the findings from this research indicate that there are several interrelated reasons why access to end-of-life care services can be more difficult for patients with a non-cancer diagnosis. These issues relate to differences in disease trajectories and subsequent care planning, which are further entrenched by existing funding arrangements. [Abstract]

Pender, Sue and Pearce, Fiona

**End of life care community services.**

*Journal of Community Nursing* 2012; 26 (5): 4-6 (September 2012)

Caring for people approaching the end stages of their lives can be a challenging yet immensely rewarding area in which to work. Front line staff, such as nurses and therapists, are the visible face of care provision; however, the organisation and co-ordination of service provision from support and administrative staff can have a tangible impact upon the quality of service provision received by the patients and their families. This article aims to give a brief outline of how one community healthcare organisation developed a system and associated process to provide a single point of referral for end of life care from a range of community nursing services. [Abstract]

Smith, Sue et al.

**Involving families in end of life care.**

*Nursing Management* 2012; 19 (4): 16-22 (July 2012)

The authors outline the benefits of an initiative piloted at North Tees and Hartlepool NHS Foundation Trust. Family members of people at the end of their lives are asked to fill in diaries to provide feedback about care, and the information is used to address issues raised. The data and comments are collated, audited and fed back to clinical staff and managers across the trust to benchmark patient-reported outcome measures and quality markers for achieving a 'good death'. The term 'family' refers here to family, friends, carers and significant others who are present at the bedside of patients who are dying in hospital and who are on the Liverpool Care Pathway. [Abstract]

Gandy, Rob

**Young carers and end of life services.**

*British Journal of Healthcare Management* 2012; 18 (6): 298-306 (June 2012)

In 2009, the NHS National Centre for Involvement and Liverpool Primary Care Trust undertook a national pilot project to establish how best to undertake patient and public involvement in respect of end of life (EOL) services. This article describes the outcomes from its sub-project which focused on young carers. It is projected that there are substantial numbers of young carers in the UK, at any one point in time, supporting their (grand)parents, or other adult family members, during their terminal illness. Interviews with young carers were conducted to gain understanding of their experiences of EOL service delivery by carers and professionals, and what support they felt they needed themselves. It was found that young carers were often inadvertently marginalised and at times felt 'invisible' to those providing care to the patient. Young carers require the same consistent, accurate and honest information as adult carers. Carers and professionals need to talk and listen to them, and to recognise the importance of the whole family, in the care of the patient. Local young carers' services can provide support and information, but there are many organisations that could also provide greater support including schools, social services, and health professionals. [Abstract]

Harrison, Nadine, et al.

**Are UK primary care teams formally identifying patients for palliative care before they die?**

*British Journal of General Practice 2012; 62 (598): 250-251 (May 2012)*

**Background** The palliative care approach has the potential to improve care for patients with progressive life-threatening illnesses from the time of diagnosis. Policy and clinical directives in the UK advocate early identification. **Aim** To determine the extent to which practices identify patients for palliative care, including factors influencing early identification and possible effects on place of death. **Design and setting** Qualitative and quantitative data were collected from six general practices from three Scottish NHS boards and analysed. **Method** Records of patients who had died in the previous 6 months were analysed and interviews with practice staff (n = 21) and with patients currently on the practice palliative care register and bereaved relatives (n = 14) were conducted. In addition, a practice meeting was observed. **Results** In total, 29% of patients who died were recorded as being on the practice palliative care register before death. Two-thirds of patients with cancer were recorded on the register, but for those with non-malignant conditions only around 20% had any palliative care documented. This was a result of GPs not finding the current guidelines useful and being reluctant to discuss palliative care overtly with patients early in their illness. Palliative care services and documentation were geared towards patients with cancer. More district nurses than GPs saw the benefits of inclusion on the palliative care register. Only 25% of patients on the register died in hospital. **Conclusion** Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care approach before they die. Those identified are more likely to benefit from coordinated care and may be more likely to die at home. [Abstract]

Milligan, Stuart

**Optimising palliative and end of life care in hospital.**

*Nursing Standard 2012; 26 (41): 48-56 (13 June 2012)*

The acute hospital setting is increasingly regarded as an important area for the delivery of palliative care. A significant number of patients with advanced, life-limiting illness have a range of palliative care needs, some of which can be met by ward staff, but others may require additional, specialist input. Several factors have the potential to limit the palliative care patients in hospital receive, not least of these being disagreement about when and how the transition to palliative care should take place. In practice, however, palliative care can readily be delivered in conjunction with active disease management. [Abstract]

Gardiner, Clare, et al.

**Factors supporting good partnership working between generalist and specialist palliative care services : a systematic review.**

*British Journal of General Practice 2012; 62 (598): 252-253 (May 2012)*

**BACKGROUND:** The care that most people receive at the end of their lives is provided not by specialist palliative care professionals but by generalists such as GPs, district nurses and others who have not undertaken specialist training in palliative care. A key focus of recent UK policy is improving partnership working across the spectrum of palliative care provision. However there is little evidence to suggest factors which support collaborative working between specialist and generalist palliative care providers **AIM:** To explore factors that support partnership working between specialist and generalist palliative care providers. **DESIGN:** Systematic review. **METHOD:** A systematic review of studies relating to partnership working between specialist and generalist palliative care providers was undertaken. Six electronic databases were searched for papers published up until January 2011. **RESULTS:** Of the 159 articles initially identified, 22 papers met the criteria for inclusion. Factors supporting good partnership working included: good communication between providers; clear definition of roles and responsibilities; opportunities for shared learning and education; appropriate and timely access to specialist palliative care services; and coordinated care. **CONCLUSION:** Multiple examples exist of good partnership working between specialist and generalist providers; however, there is little consistency regarding how models of collaborative working are developed, and which models are most effective. Little is known about the direct impact of collaborative working on patient outcomes. Further research is required to gain the direct perspectives of health professionals and patients regarding collaborative working in palliative care, and to develop appropriate and cost-effective models for partnership working. [Abstract]

Smith, Joanne and Brown, Trish

**The assistant practitioner in palliative and end of life care.**

*Journal of Community Nursing 2012; 26 (3): 19-20 (May 2012)*

The importance of a well trained workforce to support the needs of those approaching the end of their life and the needs of their carers is readily acknowledged, yet relatively few healthcare professionals are specifically trained to manage palliative and end of life care. Access to suitable education is often patchy and many health and social care providers have difficulty accessing relevant education and training. This paper reflects on a Palliative and End of Life project for assistant practitioners being delivered in the North West of England. [Abstract]

Iley, K

**Improving palliative care for patients with COPD.**

*Nursing Standard 2012; 26 (37): 40-46 (16 May 2012)*

Chronic obstructive pulmonary disease (COPD) is a progressive condition characterised by reduced inspiratory and expiratory capacity of the lungs. COPD is not fully reversible and is a common cause of death in the UK. It is difficult to predict when a patient with COPD has end-stage disease and requires palliative care. Patients with COPD are less likely to receive palliative care than those with cancer. The need to discuss treatment options, palliative care and end of life care with these patients is important, although it is acknowledged that these discussions can be difficult for patients and healthcare professionals. [Abstract]

Gandy, Robert, et al.

**Using care profiles to commission end-of-life services.**

*Primary Health Care Research and Development 2012; 13 (2): 106-119 (April 2012)*

AIM: In early 2010, Liverpool Primary Care Trust (PCT) undertook a project to establish whether a care profiles methodology could be used to commission end-of-life (EoL) services. The Department of Health (DH) originally used them for a variety of services in the 1990s. The project sought to adapt the original care profiles structure for commissioning purposes, and produce a series of care profiles that would cover the full EoL care pathway. BACKGROUND: The DH required PCTs in England to undertake local reviews of EoL services ahead of its publication of the National EoL Strategy in 2008. Related cross-sector work in Liverpool highlighted the need for a means of specifically commissioning EoL services. It was contended that care profiles offered the opportunity to set service requirements in respect of skill mix, delivery, quality and outcomes for each stage of the EoL pathway, which could be costed subsequently. METHODS: An iterative approach was adopted involving workshops and consensus, based on action learning events, which incorporated and adapted past approaches for developing care profiles. Four half-day workshops were held, each targeting one EoL stage, with the outputs evaluated by an external reference group. A full cross-section of commissioning, provider and service user interests were involved. FINDINGS: The project was successful, with its recommendations subsequently used to commission EoL services across Liverpool. It was concluded that the basic service requirements for EoL care are the same, irrespective of the related disease. The strength of care profiles is their simplicity and flexibility. They complement and augment integrated care pathways, and by requiring the recording of outcomes throughout the care process, they aid quality and audit processes. They should be transferable to other conditions, with benchmarking enabling improved efficiency. They represent the type of clinically relevant and detailed vehicle essential for clinical commissioning groups. [Abstract]

Gambles, Maureen, et al.

**Development and implementation of the Rapid Discharge Pathway Version 12 to enable imminently dying patients to die in the place of their choice.**

*International Journal of Care Pathways 2012; 16 (1): 14-18 (March 2012)*

This study reports on the further development and implementation of a Rapid Discharge Home to Die Care Pathway (RDP Version 12). A rapid discharge pathway (RDP) was originally developed by members of the Hospital Specialist Palliative Care Team at the Royal Liverpool and Broadgreen University Hospitals NHS Trust in response to an identified clinical need to enable imminently dying patients to die in their place of choice when a clinical situation has changed rapidly and there has been an urgent request for a patient to die at home. The initial development and early evaluation, along with an example of the pathway itself, was published in 2004. The current study reports specifically on the subsequent development of the pathway that occurred alongside that of the generic Version 12 of the Liverpool Care Pathway for the Dying Patient published in December 2009. The study outlines the process of development and implementation of the RDP Version 12; patient scenario and a completed example are included to further illustrate the circumstances in which it can be used and the resultant process. [Summary]

Cowey, Eileen

**End of life care for patients following acute stroke.**

*Nursing Standard 2012; 26 (27): 42-46 (7 March 2012)*

End of life care is an important aspect of acute stroke nursing because stroke mortality rates remain high, despite advances in care. There is a national drive to improve the quality of end of life care in all clinical areas, including for stroke patients. Patients who have had a stroke should not be excluded from acute stroke care at the end of life. Stroke care should incorporate multidisciplinary working, anticipatory care planning and prescribing, and effective communication with patients and families. The use of end of life care pathways is widely recommended as best practice. Palliative care specialists may provide support where patients' needs are complex, while decisions to withhold cardiopulmonary resuscitation should be avoided immediately following stroke. Spiritual care extends beyond religious care and is the responsibility of the multidisciplinary team. Although more research is required about stroke care at the end of life, providing high-quality, patient-centred services for patients who have had a stroke and their families during this time is achievable. [Abstract]

Lawrence, Vanessa, et al.

**Dying well with dementia : qualitative examination of end-of-life care.**

*British Journal of Psychiatry 2011; 199 (5): 417-422 (November 2011)*

BACKGROUND: People with dementia often die badly, receiving end-of-life care of poorer quality than that given to those who are cognitively intact. AIMS: To define good end-of-life care for people with dementia and identify how it can be delivered across care settings in the UK. METHOD: In-depth interviews were conducted with 27 bereaved family carers and 23 care professionals recruited from the community, care homes, general hospitals and continuing care units. Data were analysed using the constant comparison method. RESULTS: The data highlighted the challenge and imperative of 'dementia-proofing' end-of-life care for people with dementia. This requires using dementia expertise to meet physical care needs, going beyond task-focused care and prioritising planning and communication with families. CONCLUSIONS: The quality of end-of-life care exists on a continuum across care settings. Together, the data reveal key elements of good end-of-life care and that staff education, supervision and specialist input can enable its provision. [Abstract]

Warren, Tracey, et al.

**Developing an end-of-life benchmark in acute care.**

*Nursing Times 2011; 107 (43): 15-17 (1 November 2011)*

Nottingham University Hospitals used the Essence of Care Benchmarking programme to review and improve end-of-life care. The trust developed and implemented its own end-of-life benchmark. This provided a baseline of existing practice and led to greater awareness of standards of best practice in all clinical areas. Nottingham University Hospitals used the Essence of Care Benchmarking programme to review and improve end-of-life care. The trust developed and implemented its own end-of-life benchmark. This provided a baseline of existing practice and led to greater awareness of standards of best practice in all clinical areas. [Abstract]

Hurst, Keith and Roberts, Dai

**How do UK end of life services compare?**

*Nursing Standard 2011; 26 (7): 14 (19 October 2011)*

There are two main end of life inpatient care providers in the UK, NHS palliative care wards and hospices. Both aim to improve the quality of life for patients who are seriously ill. The Datawatch compares palliative care and hospice ward structures, processes and outcomes and finds that hospices provide, by far, the best care. [Introduction]

Conroy, Simon

**End-of-life decisions in acute hospitals.**

*Clinical Medicine 2011; 11 (4): 364-365 (August 2011)*

Despite policy exhortations, practice experience is that ACP [advance care planning] is a relatively low volume affair, practised by enthusiasts, and has yet to fully attract the widespread support seen, for example, for the LCP [Liverpool Care Pathway]. No doubt future efforts will be directed at better understanding the 'who, how, where and when' of ACP in the UK. [Conclusion]

Evans, Natalie, et al.

**Appraisal of literature reviews on end-of-life care for minority ethnic groups in the UK and a critical comparison with policy recommendations from the UK end-of-life care strategy.**

*BMC Health Service Research 2011; 11 (141): (June 2011)*

BACKGROUND: Evidence of low end-of-life (EoL) care service use by minority ethnic groups in the UK has given rise to a body of research and a number of reviews of the literature. This article aims to review and evaluate literature reviews on minority ethnic groups and EoL care in the UK and assess their suitability as an evidence base for policy. METHODS: Systematic review. Searches were carried out in thirteen electronic databases, eight journals, reference lists, and grey literature. Reviews were included if they concerned minority ethnic groups and EoL care in the UK. Reviews were graded for quality and key themes identified. RESULTS: Thirteen reviews (2001-2009) met inclusion criteria. Seven took a systematic approach, of which four scored highly for methodological quality (a mean score of six, median seven). The majority of systematic reviews were therefore of a reasonable methodological quality. Most reviews were restricted by ethnic group, aspect of EoL care, or were broader reviews which reported relevant findings. Six key themes were identified. CONCLUSIONS: A number of reviews were systematic and scored highly for methodological quality. These reviews provide a good reflection of the primary evidence and could be used to inform policy. The complexity and inter-relatedness of factors leading to low service use was recognised and reflected in reviews' recommendations for service improvement. Recommendations made in the UK End-of-Life Care Strategy were limited in comparison, and the Strategy's evidence base concerning minority ethnic groups was found to be narrow. Future policy should be embedded strongly in the evidence base to reflect the current literature and minimise bias. [Abstract]

<http://www.biomedcentral.com/1472-6963/11/141>

Munro, Robert

**Present at the end.**

*Nursing Standard 2011; 25 (42): 18-19 (22 June 2011)*

Having time to sit with dying patients would be every nurse's ideal, but in reality that is often not possible. One trust has found a different method of support [using a 'dignity volunteers' scheme]. [Summary]

Reynolds, J. and Croft, Sue

**Applying the Preferred Priorities for Care document in practice.**

*Nursing Standard 2011; 25 (36): 35-42 (11 May 2011)*

Patient choice and control should be central to the delivery of high-quality, end of life care. Advance care planning (ACP) is a process through which a patient's choices and preferences for care can be discussed and documented. It also enables patients to express what they would want to happen to them in the event that they lose capacity to make decisions. This article focuses on the use of the patient-held Preferred Priorities for Care (PPC) document, an example of an ACP tool. This article aims to provide a greater understanding of the PPC document as an end of life care tool and increase practitioners' knowledge, confidence and competence in undertaking ACP conversations with patients and their carers. Four case studies are provided to link theory to practice. [Abstract]

Newbury, Jenny

**The drama of end of life care at home.**

*Nursing Times 2011; 107 (11): 20-23 (22 March 2011)*

BACKGROUND: Many terminally ill patients want to die at home. Family carers are fundamental to achieving this, but often feel anxious and unprepared for the role. Supporting them is vital in palliative care. AIM: To explore the experiences of carers of patients dying at home, in particular their expectations and preparedness for the dying process. METHOD: The study followed a qualitative approach. In-depth, semi-structured interviews with 15 carers were carried out. RESULTS: Carers experienced uncertainty and felt unrehearsed for their role. They were reluctant to seek information to give them a script for their performance because it was too painful to contemplate the patient's death. The carers needed the direction of health and social care professionals, and the help of paid carers, but experiences of these services varied. [Abstract]

Gott, Merryn, et al.

**Transitions to palliative care in acute hospitals in England : qualitative study.**

*BMJ 2011; 342 (7802): 856 (16 April 2011)*

This is a summary of a paper that was published on [bmj.com](http://bmj.com) as BMJ 2011;342:d1773.

**OBJECTIVE:** To explore how transitions to a palliative care approach are perceived to be managed in acute hospital settings in England. **DESIGN:** Qualitative study. **SETTING:** Secondary or primary care settings in two contrasting areas of England. **PARTICIPANTS:** 58 health professionals involved in the provision of palliative care in secondary or primary care. **RESULTS:** Participants identified that a structured transition to a palliative care approach of the type advocated in UK policy guidance is seldom evident in acute hospital settings. In particular they reported that prognosis is not routinely discussed with inpatients. Achieving consensus among the clinical team about transition to palliative care was seen as fundamental to the transition being effected; however, this was thought to be insufficiently achieved in practice. Secondary care professionals reported that discussions about adopting a palliative care approach to patient management were not often held with patients; primary care professionals confirmed that patients were often discharged from hospital with "false hope" of cure because this information had not been conveyed. Key barriers to ensuring a smooth transition to palliative care included the difficulty of 'standing back' in an acute hospital situation, professional hierarchies that limited the ability of junior medical and nursing staff to input into decisions on care, and poor communication. **CONCLUSION:** Significant barriers to implementing a policy of structured transitions to palliative care in acute hospitals were identified by health professionals in both primary and secondary care. These need to be addressed if current UK policy on management of palliative care in acute hospitals is to be established. [Abstract]

<http://www.bmj.com/content/342/bmj.d1773.full>

Richards, Suzanne H., et al.

**The experiences and needs of people seeking palliative health care out-of-hours : a qualitative study**

*Primary Health Care Research and Development 2011; 12 (2): 165-178 (April 2011)*

**AIM:** To explore the experiences of people with advanced cancer and/or their caregivers accessing out-of-hours care. **BACKGROUND:** The organisation and delivery of out-of-hours in the United Kingdom has undergone major reforms over the past three decades culminating in the new General Medical Service contract in 2004. There are concerns around continuity of care for patients with complex needs under the new arrangements. **DESIGN:** A qualitative interview study was undertaken recruiting patients from two primary care trusts in Southwest England. Semi-structured interviews were conducted with 28 people with advanced cancer and/or their caregivers who had recently requested out-of-hours care. Interviews were recorded, transcribed and analysed thematically. **FINDINGS:** Two main themes were identified including the legitimacy of seeking help and continuities of care. Most participants were reluctant to seek help, finding it difficult to decide whether their needs were sufficient to contact services. The degree to which services legitimised participants' requests mediated their experiences. Distress arose when services were dismissive of their needs, whereas respondents were appreciative of clinicians who provided them with reassurance. Participants reported a lack of relational and informational continuity of care. Consulting with an unfamiliar clinician out-of-hours raised doubts in some participants' minds about the quality of care. Some participants recounted episodes in which there were problems with pain management. While the themes suggest that the delivery of out-of-hours care as a whole was not always perfect, around-the-clock access to professional sources of support and reassurance was highly valued. However, the transfer of information to out-of-hours providers remains a key challenge; participants did not understand why out-of-hours providers could not access more information on their medical histories given the level of computerisation within the National Health Service. The findings highlight the need to improve continuity between in-hours and out-of-hours services for patients with complex needs. [Abstract]

Reid, Megan, et al.

**Breaking news of death to relatives.**

*Nursing Times 2011; 107 (5): 12-15 (8 February 2011)*

Breaking news of death can have a significant impact on bereaved relatives if it is not carried out appropriately. This article explores best practice on breaking news of death, and discusses why it is so important for nurses to get it right. [Abstract]



Costantini, Massimo, et al.

**The effectiveness of the Liverpool care pathway in improving end of life care for dying cancer patients in hospital : a cluster randomised trial.**

*BMC Health Services Research 2011; 11 (13): (24 January 2011)*

**BACKGROUND:** Most cancer patients still die in hospital, mainly in medical wards. Many studies in different countries have shown the poor quality of end-of-life care delivery in hospitals. The Program 'Liverpool Care Pathway for the dying patient' (LCP), developed in the UK to transfer the hospice model of care into hospitals and other care settings, is a complex intervention to improve the quality of end-of-life care. The results from qualitative and quantitative studies suggest that the LCP Program can improve significantly the quality of end-of-life care delivery in hospitals, but no randomised trial has been conducted till now. **METHODS AND DESIGN:** This is a randomized cluster trial, stratified by regions and matched for assessment period. Pairs of eligible medical wards from different hospitals will be randomized to receive the LCP-I Program or no intervention until the end of the trial. The LCP-I Program will be implemented by a Palliative Care Unit. The assessment of the end-points will be performed for all cancer deaths occurred in the six months after the end of the LCP-I implementation in the experimental wards and, in the same period of time, in the matched control wards. The primary end-point is the overall quality of end-of-life care provided on the ward to dying cancer patients and their families, assessed using the Global Scale of the Italian version of the Toolkit 'After-death Bereaved Family Member Interview'. **DISCUSSION:** This study can be interpreted as a Phase III trial according to the Medical Research Council Framework. In this study, the effectiveness of a fully defined intervention is assessed by comparing the distribution of the endpoints in the experimental and in the control arm. [Abstract]

<http://www.biomedcentral.com/1472-6963/11/13>

Addicott, Rachael

The King's Fund

**Full interaction at the end of life.**

*Health Service Journal 2011; 121 (6241): 24-25 (27 January 2011)*

End of life care must remain multidisciplinary despite financial constraints, argues Rachael Addicott. [Introduction]

Boyd, Kirsty and Murray, Scott A.

**Recognising and managing key transitions in end of life care.**

*BMJ 2010; 341 (7774): 649-652 (25 September 2010)*

Prognostic paralysis may delay a change in gear for too long. Being alert to the possibility that a patient might benefit from supportive and palliative care is central to delivering better end of life care. [Introduction]

Ellershaw, John, et al.

**Achieving a good death for all.**

*BMJ 2010; 341 (7774): 656-658 (25 September 2010)*

A good death for all is now recognised as a priority at societal and political levels. To achieve this goal we need a fundamental shift of emphasis: to train and educate healthcare professionals; to ensure rigorous assessment of new end of life care services that aim to improve quality and choice; and to explore best use of resources. [Introduction]

Sartori, Penny

**Understanding the subjective experiences and needs of patients as they approach death.**

*Nursing Times 2010; (106): (37): 14-16 (21 September 2010)*

When patients are approaching the end of life their spiritual as well as physical needs should be considered. This article considers how nurses can best support patients who are dying and work to ensure they experience a peaceful transition to death. Attending to their spiritual needs is shown to be of utmost importance; the near death and end of life experiences that some patients may have are also taken into consideration. [Abstract]

Lawton, Catherine

**Developing a nurse led hospice outpatient clinic to improve palliative care services.**

*Nursing Times 2010; 106 (34): 18-20 (31 August 2010)*

A team of palliative care clinical nurse specialists at the Phyllis Tuckwell Hospice in Farnham, Surrey, set up a hospice based outpatient clinic to improve services for patients with cancer. This article examines how the team used clinical audit, a staff questionnaire and patient feedback to evaluate the service and make recommendations for the future development of the clinic. [Abstract]

Emanuel, Linda and Glasser Scandrett, Karen

**Decisions at the end of life: have we come of age?**

*BMC Medicine 2010; 8 (57): (8 October 2010)*

Decision making is a complex process and it is particularly challenging to make decisions with, or for, patients who are near the end of their life. Some of those challenges will not be resolved - due to our human inability to foresee the future precisely and the human proclivity to change stated preferences when faced with reality. Other challenges of the decision-making process are manageable. This commentary offers a set of approaches which may lead to progress in this field. One clearly desirable approach can and should be used more often than it is: the routine inclusion of discussions about the goals of care and documentation with all patients who have a poor prognosis. The match between a patient's goals and the care received should be the gold standard for quality palliative care. Planning for future situations is necessary but hard. In order to achieve efficient elicitation and documentation of advance care planning, research is needed on each individual's thresholds for transitioning from curative to palliative intent and on the trajectory of changed preferences when illness occurs. Another clearly desirable approach is the documentation and use of community preferences, so that proxies making decisions without guidance from the patient can at least know what the majority of people considering similar situations chose to do. Part of the challenge of achieving 'quality dying' may have to do with the still current (mainly Western) tendency to a death-denying culture and the inability of dying people to enter into the dying role. Awareness of the tasks of the dying role and the provision of time and space for those tasks during the delivery of medical care is essential. Medicine needs to continue to enhance the existential maturity of our profession, our patients and the cultures in which we practice. This state of mind should provide for decisions made with a more settled acceptance of mortality and with more awareness of the necessary connection to our survivors and next generation that mortality creates. Specific interventions, such as Dignity Therapy and advance care planning, may aid this state of mind. [Abstract]

<http://www.biomedcentral.com/1741-7015/8/57>

Pitt, Vern

**The mourning after.**

*Community Care 2010; (1825): 28-29 (1 July 2010)*

A specialist bereavement service in Hertfordshire helps people with learning disabilities deal with loss and trains social care staff on how best to support clients. [Introduction]

<http://www.communitycare.co.uk/2010/06/25/bereavement-service-for-people-with-learning-disabilities/#.Us7QwPRdWck>

Pati, Anita

**Looking from the outside in.**

*Nursing Standard 2010; 24 (47): 20-21 (28 July 2010)*

A housing and care provider [Housing 21] for older people has taken the unusual step of employing a nurse to manage end of life care. [Summary]

Pugh, Edwin J., et al.

**Offering spiritual support to dying patients and their families through a chaplaincy service.**

*Nursing Times 2010; 106 (28): 18-20 (20 July 2010)*

Despite its importance in end of life care, spiritual care is currently poorly addressed. This article presents the results of an innovative service in which nurses notify hospital chaplains of all patients placed on the Liverpool Care Pathway (LCP) and the chaplains then visit to offer spiritual support to both patients and their carers. Nurses reported that the service was not only valuable for patients and their families but also for themselves and the whole clinical team. All nurses said they wanted the service to continue. [Abstract]

Rosenberg, J. P. And Yates, P. M.

**Health promotion in palliative care : the case for conceptual congruence.**

*Critical Public Health 2010; 20 (2): 201-210 (June 2010)*

This article provides a critical review of the literature relevant to the conceptual foundations of health promoting palliative care. It explores the separate emergence and evolution of palliative care and health promotion as distinct concerns in health care, and reviews the early considerations given to their potential convergence. Finally, this article examines the proposal of health promoting palliative care as a specific approach to providing end of life care through a social model of palliative care. Research is needed to explore the impact for communities, health care services and policy when such an approach is implemented within palliative care organisations. [Abstract]

Carlson, Glenn

**Do end of life care pathways improve symptoms and quality of life for patients and families?**

*Nursing Times 2010; 106 (24): 16 (22 June 2010)*

End of life care pathways standardise care of the dying. This Cochrane review explored whether following them ensures patients receive comfort or dignity. [Introduction]

*End-of-life care pathways for improving outcomes in caring for the dying.:*

<http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD008006/frame.html>

Detering, Karen, et al.

**The impact of advance care planning on end of life care in elderly patients : randomised controlled trial.**

*BMJ 2010; 340 (7751): 847 (17 April 2010)*

A coordinated, systematic model of patient centred advance care planning using non-medical advance care planning facilitators assists in identifying and respecting patient's wishes about end of life care, improves such care from the perspective of the patient and the family, and diminishes the likelihood of stress, anxiety, and depression in surviving relatives. 1 fig. 4 tables 50 refs. [Summary]

<http://www.bmj.com/content/340/bmj.c1345.full>

Slater, Lyndsey

**Palliative care :do all patients now have a choice about where they die?**

*Nursing Times 2010; 106 (7): 20-22 (23 February 2010)*

Modern day palliative care has developed over the past 40 years and many government policies have been produced to support development of services. Guidance sets out the aims and objectives for delivering palliative care, which are that every person with a life threatening illness has the right to receive appropriate palliative care wherever they are. This article explores whether people do have a real choice about the care they receive and where that care is delivered. 29 refs. [Introduction]

## WEB RESOURCES

### **Choice at End of Life**

King's Fund and Marie Curie Cancer Care project (completed October 2010)

<http://www.kingsfund.org.uk/projects/choice-end-life-marie-curie>

### **Dying Matters**

<http://www.dyingmatters.org/>

### **End of life**

Social Care Institute for Excellence

<http://www.scie.org.uk/adults/endoflifecare/index.asp#>

### **ELCQuA End of Life Care Quality Assessment Tool**

<http://www.elcqua.nhs.uk/> (Registration required to use this tool)

### **End of life care for adults quality standard**

National Institute for Health and Clinical Excellence (NICE)

<http://guidance.nice.org.uk/QS13>

### **Gold Standards Framework**

A systematic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers

<http://www.goldstandardsframework.org.uk/>

### **Hospice UK**

<http://www.hospiceuk.org/>

### **Improving care for people at the end of their life**

Department of Health

<https://www.gov.uk/government/policies/improving-care-for-people-at-the-end-of-their-life>

### **International Observatory on End of Life Care**

Lancaster University. School of Health & Medicine

<http://www.lancs.ac.uk/shm/research/ioelc/index.php>

### **Marie Curie Cancer Care - commissioners and referrers**

<http://www.mariecurie.org.uk/en-GB/Commissioners-and-referrers/>

- **Marie Curie End of Life Care Atlas**  
<http://www.mariecurie.org.uk/atlas>

### **Marie Curie Palliative Care Institute Liverpool**

<http://www.mcpcil.org.uk>

### **National Council for Palliative Care**

[includes extensive links to other related sites]

<http://www.ncpc.org.uk/>

### **National End of Life Care Intelligence Network**

Public Health England

<http://www.endoflifecare-intelligence.org.uk/>

- **End of Life Care Profiles**  
<http://www.endoflifecare-intelligence.org.uk/profiles.aspx>
- **Publications**  
<http://www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx>
- **Tools**  
<http://www.endoflifecare-intelligence.org.uk/resources/tools/default.aspx>

### **Omega**

<http://www.omega.uk.net/>

### **Together for Short Lives**

<http://www.togetherforshortlives.org.uk/>