

# End of Life Care

## December, 2012

This bi-monthly bulletin covers various aspects of end of life care and should be of interest to staff working in this area. Please see below for a list of contents.

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## Journal Articles

### Advance Directives

Gutierrez, K., M. (2012) **Advance directives in an intensive care unit: experiences and recommendations of critical care nurses and physicians.** Critical Care Nursing Quarterly, 35 (4), 396-409.

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Kwon, S.H., Im, S.H., Cho, K.W., Cho, E., Yoon, S.J. & Oh, S.Y. (2012) **Most Advance Directives Written by Patients With Advanced Cancer or Their Proxies Request Only Minimally Invasive Treatments During End-of-Life Care.** American Journal of Hospice & Palliative Medicine, 29 (8), 622-626.

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Reeves, M.J., Myers, L.J., Williams, L.S., Phipps, M.S. & Bravata, D.M. (2012) **Do-not-resuscitate orders, quality of care, and outcomes in veterans with acute ischemic stroke.** Neurology, 79 (19), 1990-1996.

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Van Oorschot, B., Schuler, M., Simon, A. & Flentje, M. (2012) **Advance directives: Prevalence and attitudes of cancer patients receiving radiotherapy.** Supportive Care in Cancer, 20 (11), 2729-2736.

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Winter, L. & Parks, S.M. (2012) **Acceptors and rejecters of life-sustaining treatment: Differences in advance care planning characteristics.** Journal of Applied Gerontology, 31 (6), 734-742.

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## **Communication, Decision-Making and Support**

Almack, K., Cox, K., Moghaddam, N., Pollock, K. & Seymour, J. (2012) **After you: conversations between patients and healthcare professionals in planning for end of life care.** BMC Palliative Care, 11 (1), 15.

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Barnes, S., Gardiner, C., Gott, M., Payne, S., Chady, B., Small, N., Seamark, D. & Halpin, D. (2012) **Enhancing Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature.** Journal of Pain & Symptom Management, 44 (6), 866-879.

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Barnato, A.E., Tate, J.A., Rodriguez, K.L., Zickmund, S.L. & Arnold, R.M. (2012) **Norms of decision making in the ICU: a case study of two academic medical centers at the extremes of end-of-life treatment intensity.** Intensive care medicine, 38 (11), 1886-1896.

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Carr, D. (2012) **"I don't want to die like that ...": the impact of significant others' death quality on advance care planning.** Gerontologist, 52 (6), 770-781.

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Ha, J.H. & Pai, M. (2012) **Do Personality Traits Moderate the Impact of Care Receipt on End-of-Life Care Planning?.** Gerontologist, 52 (6), 759-769.

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Kerstholt, J., H., Wierings, O., Bart, H. & Frek. (2012) **Increased Empowerment With a Decision Aid for Choosing a Place of Dying.** Journal of Hospice & Palliative Nursing, 14 (7), 484-490.

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Mack, J.W., Cronin, A., Keating, N.L., Taback, N., Huskamp, H.A., Malin, J.L., Earle, C.C. & Weeks, J.C. (2012) **Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study.** Journal of Clinical Oncology, 30 (35), 4387-4395.

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Raijmakers, N.J., van Zuylen, L., Costantini, M., Caraceni, A., Clark, J.B., De Simone, G., Lundquist, G., Voltz, R., Ellershaw, J.E., van der Heide, A. & Opcare9. (2012) **Issues and needs in end-of-life decision making: an international modified Delphi study.** Palliative medicine, 26 (7), 947-953.

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Scott, A., M. & Caughlin, J., P. (2012) **Managing Multiple Goals in Family Discourse About End-of-Life Health Decisions.** Research on aging, 34 (6), 670-691.

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Waldrop, D.P. & Meeker, M.A. (2012) **Communication and advanced care planning in palliative and end-of-life care.** Nursing outlook, 60 (6), 365-369.

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Wender, E. (2012) **Supporting the Family After the Death of a Child.** Pediatrics, 130 (6), 1164-

1169.

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Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E., Osherow, J. & Pao, M. (2012) **Allowing Adolescents and Young Adults to Plan Their End-of-Life Care.** Pediatrics, 130 (5), 897-905.  
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### **Ethics**

Davison, S.N. (2012) **The Ethics of End-of-Life Care for Patients with ESRD.** Clinical Journal of The American Society of Nephrology: CJASN, 7 (12), 2049-2057.  
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### **Euthanasia and Assisted Suicide**

Macleod, S. (2012) **Assisted dying in liberalised jurisdictions and the role of psychiatry: A clinician's view.** Australian & New Zealand Journal of Psychiatry, 46 (10), 936-945.  
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### **Experience of Patients, their Families and Carers**

Aoun, S., O'Connor, M., Skett, K., Deas, K. & Smith, J. (2012) **Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience? A patient perspective.** Health & Social Care in the Community, 20 (6), 599-606.  
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Aschenbrenner, A., P., Winters, J., M. & Belknap, R., Ann. (2012) **Integrative Review: Parent Perspectives on Care of Their Child at the End of Life.** Journal of pediatric nursing, 27 (5), 514-522.  
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Ayalon, L., Bachner, Y.G., Dwolatzky, T. & Heinik, J. (2012) **Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses.** International Psychogeriatrics, 24 (11), 1798-1804.  
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Cataudella, D.A. & Zelcer, S. (2012) **Psychological experiences of children with brain tumors at end of life: Parental perspectives.** Journal of palliative medicine, 15 (11), 1191-1197.  
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Dosser, I. & Kennedy, C. (2012) **Family carers' experiences of support at the end of life: carers' and health professionals' views.** International journal of palliative nursing, 18 (10), 491-497.  
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Ward-Griffin, C., McWilliam, C.L. & Oudshoorn, A. (2012) **Relational Experiences of Family Caregivers Providing Home-Based End-of-Life Care.** *Journal of Family Nursing*, 18 (4), 491-516.  
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### **Grief and Bereavement**

Bateman, S.T., Dixon, R. & Trozzi, M. (2012) **The wrap-up: a unique forum to support pediatric residents when faced with the death of a child.** *Journal of palliative medicine*, 15 (12), 1329-1334.  
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Chi & Tin, A., Fong. (2012) **Beyond Knowledge and Skills: Self-Competence in Working With Death, Dying, and Bereavement.** *Death studies*, 36 (10), 899-913.  
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Lindberg, D. (2012) **When Your Patients Die.** *ONS Connect*, 27 (10), 10-14.  
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Meert, K.L., Templin, T.N., Michelson, K.N., Morrison, W.E., Hackbarth, R., Custer, J.R., Schim, S.M., Briller, S.H. & Thurston, C.S. (2012) **The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit.** *Critical Care Medicine*, 40 (11), 3050-3057.  
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Moss, M.S. & Moss, S.Z. (2012) **Multiple social contexts in qualitative bereavement research.** *Journal of Aging Studies*, 26 (4), 459-466.  
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## **Quality of Care**

Addicott, R. (2012) **Delivering better end-of-life care in England: barriers to access for patients with a non-cancer diagnosis.** Health Economics, Policy & Law, 7 (4), 441-454.  
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Curtis, J.R., Engelberg, R.A., Bensink, M.E. & Ramsey, S.D. (2012) **End-of-life care in the intensive care unit: can we simultaneously increase quality and reduce costs?.** American Journal of Respiratory & Critical Care Medicine, 186 (7), 587-592.  
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Kiely, D.K., Shaffer, M.L. & Mitchell, S.L. (2012) **Scales for the evaluation of end-of-life care in advanced dementia: Sensitivity to change.** Alzheimer Disease and Associated Disorders, 26 (4), 358-363.  
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Scarre, G. (2012) **Can there be a good death?** Journal of evaluation in clinical practice, 18 (5), 1082-1086.  
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## **Research**

Aziz, N.M., Miller, J.L. & Curtis, J.R. (2012) **Palliative and end-of-life care research: Embracing new opportunities.** Nursing outlook, 60 (6), 384-390.  
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Hanratty, B., Lawson, E., Holmes, L., Addington-Hall, J., Arthur, A., Grande, G., Payne, S. & Seymour, J. (2012) **A comparison of strategies to recruit older patients and carers to end-of-life research in primary care.** BMC Health Services Research, 12342.  
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## **Service Design and Management**

Boyd, K. & Murray, S. (2012) **Using end of life care pathways for the last hours or days of life.** BMJ, 345e7718.  
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Chalkidou, K. (2012) **Evidence and values: paying for end-of-life drugs in the British NHS.** Health Economics, Policy & Law, 7 (4), 393-409.  
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Coulourides Kogan, A., Brumley, R., Wilber, K. & Enguidanos, S. (2012) **Physician factors that influence patient referrals to end-of-life care.** American Journal of Managed Care, 18 (11), e3416-e422.  
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Johnston, B., Ostlund, U. & Brown, H. (2012) **Evaluation of the Dignity Care Pathway for community nurses caring for people at the end of life.** International journal of palliative nursing, 18 (10), 483-489.

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Lampert, R. (2012) **Quality of life and end-of-life issues for older patients with implanted cardiac rhythm devices.** Clinics in geriatric medicine, 28 (4), 693-702.

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Limehouse, W.E., Ramana Feeser, V., Bookman, K.J. & Derse, A. (2012) **A model for emergency department end-of-life communications after acute devastating events-part II: Moving from resuscitative to end-of-life or palliative treatment.** Academic Emergency Medicine, 19 (11), 1300-1308.

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Normand, C. (2012) **Setting priorities in and for end-of-life care: challenges in the application of economic evaluation.** Health Economics, Policy & Law, 7 (4), 431-439.

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Silveira, M.J. & Forman, J. (2012) **End-of-life care from the perspective of primary care providers.** Journal of General Internal Medicine, 27 (10), 1287-1293.

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Smith, C., Hough, L., Cheung, C., Millington-Sanders, C., Sutton, E., Ross, J.R., Thick, M. & Riley, J. (2012) **Coordinate My Care: a clinical service that coordinates care, giving patients choice and improving quality of life.** BMJ Supportive & Palliative Care, 2 (4), 301-307.

Watts, T. (2012) **Initiating end-of-life care pathways: a discussion paper.** Journal of advanced nursing, 68 (10), 2359-2370.

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Wiese, M., Stancliffe, R., J., Balandin, S., Howarth, G. & Dew, A. (2012) **End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People with Intellectual Disability in Community Living Services.** Journal of Applied Research in Intellectual Disabilities, 25 (6), 571-583.

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### **Spiritual and Cultural Aspects**

Chang, B., Stein, N., R., Trevino, K., Stewart, M., Hendricks, A. & Skarf, L., M. (2012) **Spiritual Needs and Spiritual Care for Veterans at End of Life and Their Families.** American Journal of



Hospice & Palliative Medicine, 29 (8), 610-617.  
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Karches, K.E., Chung, G.S., Arora, V., Meltzer, D.O. & Curlin, F.A. (2012) **Religiosity, Spirituality, and End-of-Life Planning: A Single-Site Survey of Medical Inpatients.** Journal of Pain & Symptom Management, 44 (6), 843-851.  
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### **Symptom Management**

Bailey, F.A., Williams, B.R., Goode, P.S., Woodby, L.L., Redden, D.T., Johnson II, T.M., Taylor, J.W. & Burgio, K.L. (2012) **Opioid pain medication orders and administration in the last days of life.** Journal of pain and symptom management, 44 (5), 681-691.  
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Thompson, A., J., Silveira, M., J., Vitale, C., A. & Malani, P., N. (2012) **Antimicrobial Use at the End of Life Among Hospitalized Patients With Advanced Cancer.** American Journal of Hospice & Palliative Medicine, 29 (8), 599-603.  
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Wilberg, P., Hjerstad, M.J., Ottesen, S. & Herlofson, B.B. (2012) **Oral health is an important issue in end-of-life cancer care.** Supportive Care in Cancer, 20 (12), 3115-3122.  
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Wilkie, D., J. & Ezenwa, M., O. (2012) **Pain and symptom management in palliative care and at end of life.** Nursing outlook, 60 (6), 357-364.  
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## **Recent Publications**

**A framework for the delivery of palliative care for children and young people in Scotland**  
Scottish Government  
<http://www.scotland.gov.uk/Publications/2012/11/8118/0> (last accessed 20.12.12)

**End of life care following acute stroke**  
NHS QIS and the University of Glasgow  
[http://www.healthcareimprovementscotland.org/our\\_work/cardiovascular\\_disease/programme\\_resources/end\\_of\\_life\\_care\\_after\\_stroke.aspx](http://www.healthcareimprovementscotland.org/our_work/cardiovascular_disease/programme_resources/end_of_life_care_after_stroke.aspx) (last accessed 20.12.12)

**Draft quality indicators for palliative and end of life care**  
Healthcare Improvement Scotland  
[http://www.healthcareimprovementscotland.org/our\\_work/patient\\_experience/palliative\\_care/palliative\\_care\\_indicators.aspx](http://www.healthcareimprovementscotland.org/our_work/patient_experience/palliative_care/palliative_care_indicators.aspx) (last accessed 20.12.12)

**Transforming end of life care in acute hospitals : feedback from a group of pilot site representatives looking at factors that have influenced progress during the first phase**  
National End of Life Care Programme  
[http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC\\_Transform\\_Report\\_Final.pdf](http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Transform_Report_Final.pdf) (last accessed 20.12.12)

**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**  
National End of Life Care Programme / Institute of Healthcare Management  
<http://www.endoflifecareforadults.nhs.uk/publications/ihm-rtS-disease-specific> (last accessed 20.12.12)



## **The impact of Marie Curie Nursing Service on place of death and hospital use at the end of life**

The Nuffield Trust

<http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing> (last accessed 20.12.12)

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

Lauren Lucas, Local Government Information Unit

<http://www.lgiu.org.uk/a-good-death-the-role-of-the-local-authority-in-end-of-life-care/> (last accessed 20.12.12)

## **New Library Books**

Campbell, M. (2012) **Case studies in palliative and end-of-life care.** (Case studies in nursing)  
Wiley Blackwell

Dickinson, G., Leming, M. (2012) **Annual editions : dying, death and bereavement 2013**, 13<sup>th</sup> ed.  
New York : McGraw Hill.

Scottish Partnership for Palliative Care (2011) **A beginner's guide to successful palliative care research.** Edinburgh: Scottish Partnership for Palliative Care

Speck, P. (2006) **Teamwork in palliative care : fulfilling or frustrating?** Oxford: Oxford University Press

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*Journals: Clinical Ethics, Palliative Medicine, BMJ Supportive and Palliative Care*

*Websites: Department of Health, Healthcare Improvement Scotland, End of Life Care for Adults, Scottish Government, The King's Fund*