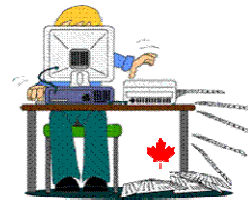


## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

## 3 August Edition | Issue #108



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

Care planning as death approaches: Scroll down to [Specialist Publications](#) and 'The clinical reality of artificial nutrition and hydration for patients at the end of life.'

## Canada

### Home care still the weak link

ONTARIO | *Hamilton Spectator* – 27 July 2009 – The Home First campaign, developed by the Mississauga Halton Community Care Access Centre, attempts to educate health-care consumers about the need for patients who don't need acute-care beds to move from those beds and return home, either receiving home care to make staying home sustainable or while waiting on a long-term care placement. The problem ... was that the execution of the strategy left some families feeling unwelcome and pressured to take frail, elderly patients home, without having adequate resources to provide appropriate care. <http://www.thespec.com/Opinions/article/607225>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | *Winnipeg Sun* – 3 August 2009 – **'Euthanasia debate healthy.'** Like abortion and animal rights, we're never likely to reach a consensus on euthanasia, but it doesn't mean we shouldn't have a debate. The federal Conservatives won't hear of it, but the Quebec government just might, following a draft report from the Quebec College of Physicians saying euthanasia should be considered "appropriate care in certain particular circumstances." The full report will not be released until the fall, but any debate before and after that can only be healthy for Canada. <http://www.winnipegsun.com/comment/editorial/2009/08/03/10346401-sun.html>
- CANWEST NEWS SERVICE | Online article – 15 July 2009 – **'British couple's decision to die together sets dangerous precedent ...'** Critics worry that the ability to easily end a sickly life could become the obligation to do so for those who worry about becoming a burden. Others wondered whether dying alongside a spouse could become an act of romantic valour. "If people feel they would like to stay on, but the balance of burden has tipped too much toward other people – which may be perception rather than reality – then the argument can be made that they may not really so much want to end their life," says Kerry Bowman, University of Toronto Joint Centre for Bioethics. <http://www.calgaryherald.com/news/British+couple+decision+together+sets+dangerous+precedent+critics/1797043/story.html>

## U.S.A.

### **Final rule eases expected blow for hospices**

KANSAS | *Wichita Eagle* – 31 July 2009 – Final regulations from the Centers for Medicare & Medicaid Services will mean a 1.4% increase in payments to hospices serving Medicare beneficiaries for fiscal year 2010. Earlier proposals would have forced them to reduce or eliminate services or limit service areas. <http://www.kansas.com/business/updates/story/912374.html>

Of related interest:

- FLORIDA | Scripps Treasure Coast Newspapers – 29 July 2009 – '**Hospice forced to end adult day program ...**' A five-year-old adult daytime activity program operated by Treasure Coast Hospice will end because of the loss of a grant in 2007, Hospice officials confirmed. <http://www.tcpalm.com/news/2009/jul/29/hospice-forced-to-end-adult-day-program-in/>

### **Hospice chosen for rural palliative care project site**

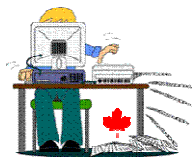
WISCONSIN | *Sheboygan Press* – 29 July 2009 – The Sharon S. Richardson Community Hospice has been selected as a project site for a rural palliative care project, which is being implemented by The Hospice Organization & Palliative Experts (HOPE) of Wisconsin and the University of Wisconsin-Comprehensive Cancer Center. The project's aim is to promote palliative care in rural areas through educational outreach, and programming and working with area physicians. <http://www.sheboyganpress.com/article/20090729/SHE04/907290446/1097>

### **Critics of health reform concerned over government's role in end of life issues**

WASHINGTON DC | FOX News – 28 July 2009 – The White House says opponents of the president's health care reform effort are misrepresenting parts of the House and Senate legislation. At a town hall meeting at the AARP (American Association of Retired Persons) headquarters in Washington, President Obama answered a woman in North Carolina, who asked if it was true "that everyone that's Medicare age will be visited and told they have to decide how they wish to die." The president ... suggested the idea is to expand the use of living wills. Critics have concerns the Medicare reimbursement could involve the government in end of life issues. <http://www.foxnews.com/politics/2009/07/28/critics-health-reform-concerned-governments-role-end-life-issues/>

- AMERICAN ACADEMY OF HOSPICE & PALLIATIVE MEDICINE | Advocacy Alert – accessed 30 July 2009 – '**Help correct misinformation ...**' The Affordable Health Choices Act contains a provision that would provide coverage under Medicare for people to talk to their doctor about their wishes and care preferences at the end of life. This has prompted some groups to falsely claim care planning consultations include "euthanasia," that physicians would be required to "recommend a method for death." <http://campaign.constantcontact.com/render?v=001wOJf7Zsc3-hqCAma2RxyoaGBHYhzo9Ar17AjqTlpUsOFCm9HbFKwjPmGrAay0JHtAzjrT4AgrZfpf3UAxnm1UGCl-Njw5aVKCF6xcLPK-Qc%3D>

### **Barry R. Ashpole**



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops for frontline care providers.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.S. NEWS & WORLD REPORT | Online report – 30 July 2009 – **'Euthanasia, palliative care work in unison in Belgium.'** Study data showed assisted dying is rarely performed in Belgium and "it would be a mistake to suggest that these findings dispel concerns about euthanasia or that they support including euthanasia within palliative care," said Ira Byock, director of a palliative medicine at Dartmouth-Hitchcock Medical Center, in an accompanying editorial (to the published study).<sup>1</sup>  
<http://health.usnews.com/articles/health/healthday/2009/07/30/euthanasia-palliative-care-work-in-unison-in.html>
- 1. Scroll down to **Specialist Publications** and *British Medical Journal* (dated 30 July 2009), **'Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium.'**
- CATHOLIC LEAGUE FOR RELIGIOUS & CIVIL RIGHTS | Press release – 29 July 2009 – **'Euthanasia and health care reform.'** There is language in the bill that implies that the federal government may become involved in euthanasia. Catholic League staff sought clarification (among members of the House of Representatives). No one with whom we spoke said the government is entering the business of euthanasia. But this is not enough. We need to know what is meant by: "An explanation by the practitioner of the continuum of end-of-life services and supports available ..." (and) "The Secretary shall publish in the Federal Register proposed quality measures on end of life care and advanced care planning ..." <http://www.standardnewswire.com/news/964944373.html>
- OREGON | FOX News – 28 July 2009 – **'Oregon offers terminal patients doctor-assisted suicide instead of medical care.'** Some terminally ill patients in Oregon ... were denied treatment and offered doctor-assisted suicide instead, a proposal some experts have called a "chilling" corruption of medical ethics. <http://www.foxnews.com/story/0,2933,392962,00.html>

## International

### Naomi House children's hospice seeks judicial review of compensation decision

U.K. | *The News* (Portsmouth) – 3 August 2009 – The owners of Naomi House children's hospice have written to (Prime Minister) Gordon Brown and sent an order for a judicial review into the government's handling of compensation for (£6 million) lost (in 2008) in (an) Icelandic bank crash.  
<http://www.portsmouth.co.uk/newshome/Naomi-House-children39s-hospice-seeks.5516119.jp>

### Hospice staff forced to turn away (families)

AUSTRALIA | *Sunshine Coast Daily* – 29 July 2009 – The most heartbreaking part of the job for staff at the Cittamani Hospice Service (in Palmwoods, Queensland) is turning away families from the care it was built to provide. But, this has become a regrettably regular process as nurses are forced to turn away up to 25 families a month through a severe lack of funds.  
<http://www.thedaily.com.au/news/2009/jul/29/hospice-staff-forced-turn-away-cittamani/>

Of related interest:

- PALLIATIVE CARE AUSTRALIA | Press release – 24 July 2009 – **'Reform to be informed by national end-of-life framework.'** The organization is to convene a national forum to oversee the development of a National End-of-Life Framework for the Future ... to inform policy and service development to ensure that the needs of people who are dying and their families are met.  
<http://pallcare.org.au/Portals/46/Reform%20to%20be%20informed%20by%20national%20end%20of%20life%20framework%20-%20PCA%20media%20release.pdf>

## **'Doctors are expected to prolong life, but it is not an obligation'**

U.K. | *The Times* (OpEd) – 29 July 2009 – The General Medical Council advises that patients' wishes or those of their immediate families should be carefully considered when the time comes to make decisions about end-of-life care. A hospital doctor may have to choose whether to perform cardiopulmonary resuscitation on an elderly patient, or a GP may have to decide whether to admit a dying patient to hospital or to keep him comfortable at home. This is a different issue from that of assisting suicide and in many ways it is more challenging. To help a patient end his life, either by providing a prescription or personally administering a fatal overdose, is an active process, but one in which the patient has played a pivotal role. Deciding to withhold treatment from patients who may not have the capacity to refuse it for themselves is a medico-legal tightrope. [http://www.timesonline.co.uk/tol/life\\_and\\_style/health/article6731118.ece](http://www.timesonline.co.uk/tol/life_and_style/health/article6731118.ece)

From Media Watch dated 27 July 2009:

- U.K. | BBC News – 22 July 2009 – **'Can doctors just say no?'** In days gone by, there was a perception that doctors knew best and had the final say – but things have changed and patients are increasingly instrumental in decisions about their care. The Medical Defence Union says doctors sometimes still have to say no. <http://news.bbc.co.uk/2/hi/health/8149524.stm>

## **Palliative care deficits will be hard to address**

IRELAND | *Irish Times* – 28 July 2009 – Implementing measures ... to address shortcomings in the State's palliative care services will present "a significant challenge." The admission is contained in *Palliative Care Service – Five Year Development Framework (2009-2013)*, published by the HSE (Health Service Executive).<sup>1</sup> The framework of actions identifies 41 national priorities required to address deficits in palliative care service provision in the four HSE regions around the State. More than 6,000 people use hospice services every year and it is estimated that, because of Ireland's ageing population, up to 13,000 patients will use hospice services each year by 2016. <http://www.irishtimes.com/newspaper/health/2009/0728/1224251483878.html>

1. *Palliative Care Service – Five Year Development Framework (2009-2013)*, Health Service Executive, 2009. <http://www.hse.ie/eng/Publications/corporate/palframework.html>

## **Report urges regulation of homecare services**

IRELAND | *Irish Times* – 28 July 2009 – Independent inspections and care standards for professional home carers should be introduced ... according to a Law Reform Commission consultation paper.<sup>1</sup> At present, there is no regulation of such services despite the fact that thousands of older people receive professional assistance to allow them to live independently at home. In contrast, the domiciliary care sector is heavily regulated in the U.K. and other jurisdictions. <http://www.irishtimes.com/newspaper/ireland/2009/0728/1224251488576.html>

1. *Consultation Paper on Professional Home Carers*, Law Reform Commission, 2009.

## **Pupils give care boxes to patients in hospice**

U.K. | *Worcester News* – 28 July 2009 – The youngsters at Stanley Road Primary School have created special spiritual care boxes for patients at St Richard's Hospice. Each decorated box ... includes a relaxing video of nature images and gentle music, a compact disc of relaxing music, cards, books, a Gideon's Bible, holding cross, prayer beads and scented candles. One of the boxes will be specially designed for use by Muslim patients and decorated in an Islamic style. [http://www.worcesternews.co.uk/news/local/4514700.Pupils\\_give\\_care\\_boxes\\_to\\_patients\\_in\\_hospice/](http://www.worcesternews.co.uk/news/local/4514700.Pupils_give_care_boxes_to_patients_in_hospice/)

## Hospices get (National) Assembly (of Wales) cash boost

U.K. (WALES) | *South Wales Argus* – 28 July 2009 – Palliative care services across Wales will get £4 million; £2.1 million will go to 18 hospices, with the remaining £1.9 million being spent on NHS (National Health Service) palliative care services. Cash was awarded ... to ensure fairer funding for hospices based on poverty, areas of ageing populations and how rural an area is.  
[http://www.southwalesargus.co.uk/news/4515568.Hospices\\_g\\_et\\_Assembly\\_cash\\_boost/](http://www.southwalesargus.co.uk/news/4515568.Hospices_g_et_Assembly_cash_boost/)

## Doctorate in control of pain

U.K. | *Lancashire Evening Post* – 27 July 2009 – A Lancashire university is to launch the world's first doctorate in palliative care. It will be aimed at people working in a variety of settings from doctors and managers to educators and policy makers. The institution already boasts an internationally acclaimed Observatory on End of Life Care, which is renowned for teaching and research. <http://www.lep.co.uk/news/Doctorate-in-control-of-pain.5496124.jp>

**N.B.** Observatory on End of Life Care website:  
<http://www.eolc-observatory.net/index.htm>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (NORTHERN IRELAND) | BBC News – 31 July 2009 – '**Director of Public Prosecutions to produce suicide guidance.**' The Director of Public Prosecutions for Northern Ireland is to produce a new policy on how prosecutors should treat assisted suicide cases, following the judgement in the Debbie Purdy case. [http://news.bbc.co.uk/2/hi/uk\\_news/northern\\_ireland/8178170.stm](http://news.bbc.co.uk/2/hi/uk_news/northern_ireland/8178170.stm)
- U.K. | *Guardian* – 31 July 2009 – '**Right-to-die law to be clarified.**' The Director of Public Prosecutions (for England & Wales) is to issue urgent guidance to clarify the law on assisted suicide after Debbie Purdy, who has multiple sclerosis, won a historic judgment from the House of Lords. <http://www.guardian.co.uk/uk/2009/jul/31/assisted-suicide-law-debbie-purdy>

**N.B.** Following the House of Lords' judgement, the Director of Public Prosecutions (DPP) issued a statement. He said, in part: "I have ... decided that once our interim policy is published, we will undertake a public consultation exercise in order to take account of the full range of views on this subject." DPP's statement: [http://www.direct.gov.uk/en/NI1/Newsroom/DG\\_179530](http://www.direct.gov.uk/en/NI1/Newsroom/DG_179530)

The panel on the BBC current affairs program 'Any Questions' (aired 31 July 2009) discussed the House of Lord's ruling: [http://www.bbc.co.uk/iplayer/episode/b00lt16t/Any\\_Questions\\_31\\_07\\_2009/](http://www.bbc.co.uk/iplayer/episode/b00lt16t/Any_Questions_31_07_2009/) In response, listeners called in the next day on the program 'Any Answers' with their comments, etc. ([http://www.bbc.co.uk/iplayer/episode/b00ltm3s/Any\\_Answers\\_01\\_08\\_2009/](http://www.bbc.co.uk/iplayer/episode/b00ltm3s/Any_Answers_01_08_2009/))

- U.K. | *Daily Telegraph* – 31 July 2009 – '**Debbie Purdy wins House of Lords victory to have assisted suicide law clarified.**' Purdy has won a landmark court case to have the law on assisted suicide clarified. Ms. Purdy brought the case against the Director of Public Prosecutions because she wanted to know if her husband would be prosecuted were he to help her commit suicide overseas. <http://www.telegraph.co.uk/news/newstoppers/politics/lawandorder/5942603/Debbie-Purdy-wins-House-of-Lords-victory-to-have-assisted-suicide-law-clarified.html>

## TV death scenes

AUSTRALIA | *The Age* (Commentary) – 28 July 2009 – Births, deaths and marriages. They're the staples of television drama. But of the three, nothing packs quite the punch of a good death. We're not talking about the weekly murder toll of *CSI* or *Law & Order*, but those judiciously timed, carefully built and – hopefully – surprising departures that have us forgetting that it's all make-believe.  
<http://www.theage.com.au/news/entertainment/tv--radio/tv-reviews/tv-death-scenes/2009/07/23/1247942011451.html>

Cont.

- U.K. | *Daily Telegraph* – 31 July 2009 – '**Debbie Purdy should have been careful what she asked for.**' Debbie Purdy ... may well have put her partner in greater danger of prosecution than if she had not brought her action. And so, tragically, she may have achieved the exact opposite of what she set out to do, closing the door to a later suicide and a longer life. The pro-euthanasia lobby, looking for "martyrs" and cynically using Ms. Purdy as a Trojan Horse for their own ends and for assisted-suicide publicity, won't lose much sleep over that.  
<http://blogs.telegraph.co.uk/news/georgepitcher/100005297/debbie-purdy-should-have-been-careful-what-she-asked-for/>
- BELGIUM | Reuters Health – 30 July 2009 – '**Legalized euthanasia not linked to reduced use of palliative care.**' The results of a study in Belgium suggest that legalized euthanasia and other measures that can shorten life are not significantly associated with lower use of palliative care.<sup>1</sup>  
[http://www.rtmagazine.com/reuters\\_article.asp?id=20090730ethc001.html](http://www.rtmagazine.com/reuters_article.asp?id=20090730ethc001.html)
  1. Scroll down to [Specialist Publications](#) and *British Medical Journal*, '**Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium**' ...and, accompanying editorial, '**End of life decisions and quality of care before death.**'
- SOUTH KOREA | *Korea Herald* – 30 July 2009 – '**New name given to 'right to die' cases.**' The highly controversial term "right to die with dignity" will be replaced by "discontinuance of life prolongation," a softer term less prone to social misconception. The new term will prevent unnecessary social misunderstanding and keep the related debates from expanding into euthanasia or medical suicide issues, said the National Evidence-based Healthcare Collaborating Agency. [http://www.koreaherald.co.kr/NEWKHSITE/data/html\\_dir/2009/07/31/200907310037.asp](http://www.koreaherald.co.kr/NEWKHSITE/data/html_dir/2009/07/31/200907310037.asp)
- U.K. (SCOTLAND) | *Guardian* – 30 July 2009 – '**Scotland to consider legalising assisted suicide.**' A bill to legalise assisted suicide in Scotland is expected to be brought before the Scottish parliament this autumn after the independent MSP Margo MacDonald won cross-party backing.  
<http://www.guardian.co.uk/society/2009/jul/30/scotland-considers-assisted-suicide-law>
- AUSTRALIA | ABC News – 29 July 2009 – '**(U.S.) Doctors warn Tasmanian death bill too strict.**' Doctors in the U.S. are warning that a Tasmanian private member's bill is too restrictive. The bill ... to legalise euthanasia for the terminally ill will be debated in the state parliament later this year. The sponsor of the bill met politicians and doctors in (the U.S. State of) Oregon to discuss the state's euthanasia legislation. <http://www.abc.net.au/news/stories/2009/07/30/2640813.htm>

### [Media Watch: Editorial Practice](#)

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of an abstract or introductory paragraph. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced and representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

### [Links to Sources](#)

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### [Something Missed or Overlooked?](#)

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

### **Knowledge of late-life depression: An empirical investigation of aged care staff**

*AGING & MENTAL HEALTH*, 2009;13(4):577-586. This study examined knowledge of late-life depression among staff working in residential and community aged care settings, as well as their previous training in caring for older people with depression. Less than half of the participating aged care staff had received any training in depression, with particularly low rates in residential care. Although aware of the importance of engaging with depressed care recipients and demonstrating moderate knowledge of the symptoms of depression, a substantial proportion of staff members saw depression as a natural consequence of bereavement, aging or relocation to aged care. <http://www.informaworld.com/smpp/content~db=all~content=a913272716>

Of related interest:

- *PSYCHIATRY*, 2009;8(6):212-215. **'Palliative care psychiatry.'** The authors describe the problem of depression in the context of advanced disease (and go on to) discuss definitions and diagnosis, the potential adverse consequences of depression, and the assessment and management of depression. [http://www.psychiatryjournal.co.uk/article/S1476-1793\(09\)00048-2/abstract](http://www.psychiatryjournal.co.uk/article/S1476-1793(09)00048-2/abstract)
- *PSYCHIATRIC SERVICES*, 2009;60(8):1132-1134. **'Management of psychosocial distress by oncologists.'** Researchers surveyed oncologists about their management of psychosocial distress. Most (participants) delivered some level of psychosocial care, although only half had affiliated mental health services. <http://psychservices.psychiatryonline.org/cgi/content/abstract/60/8/1132>

### **Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium**

*BRITISH MEDICAL JOURNAL* | Online article – 30 July 2009 – The authors explored the relation between the care provided in the final three months of life and the prevalence and types of end of life decisions. The two-year, nationwide retrospective study, examined 1,690 non-sudden deaths. The authors conclude that end of life decisions that shorten life, including euthanasia or physician assisted suicide, are not related to a lower use of palliative care in Belgium and often occur within the context of multidisciplinary care. [http://www.bmj.com/cgi/content/abstract/339/jul30\\_2/b2772](http://www.bmj.com/cgi/content/abstract/339/jul30_2/b2772)

- *BRITISH MEDICAL JOURNAL* | Online editorial – 30 July 2009 – **'End of life decisions and quality of care before death.'** The findings are a valuable contribution to understanding the context of dying in Belgium. However, the authors' interpretation of the data and the conclusions they reach raise questions. [http://www.bmj.com/cgi/content/extract/339/jul30\\_2/b2730](http://www.bmj.com/cgi/content/extract/339/jul30_2/b2730)

Of related interest:

- *INTERNATIONAL JOURNAL OF NURSING STUDIES*, 2009;46(9):1209-1218. **'Attitudes of nurses towards euthanasia and towards their role in euthanasia: A nationwide study in Flanders, Belgium.'** There is broad support among nurses for euthanasia for terminally ill patients and for their involvement in consultancy in case of euthanasia requests. Guidelines could help to make their role more transparent, taking into account the differences between health care settings. [http://www.journalofnursingstudies.com/article/S0020-7489\(09\)00067-4/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(09)00067-4/abstract)
- *NURSING TIMES (U.K.)* | Online article – 30 July 2009 – **'Exploring the nursing implications of physician-assisted suicide in the U.K.'** A review of the practical, legal, ethical and educational implications for nurses of any legislative changes that would allow physician-assisted suicide. <http://www.nursingtimes.net/nursing-practice-clinical-research/exploring-the-nursing-implications-of-physician-assisted-suicide-in-the-uk-1/5004645.article>

## Caring for the child with chronic illness

*CONTEMPORARY PEDIATRICS* | Online article – 30 July 2009 – The words "hospice" and "palliative care" have long made parents cringe – and it appears that they might scare off some pediatricians, too. "Most ... define palliative care (as) similar to hospice and think of it as end-of-life therapy, when curative therapy is no longer an option," explains Lindsay Thompson, assistant professor of pediatrics at the University of Florida, who headed research published (recently) in *Pediatrics*.<sup>1</sup> "Our research found that ... there needs to be a practical definition of this kind of care – one that emphasizes different kinds of services throughout the course of a child's lifetime." <http://contemporarypediatrics.modernmedicine.com/contpeds/Adolescent+Medicine+Top+Story/Caring-for-the-child-with-chronic-illness/ArticleStandard/Article/detail/615278?contextCategoryId=40172>

1. *Pediatrics*, 2009;123(5):e777-e782. 'Pediatricians' perceptions of and preferred timing for pediatric palliative care.' <http://pediatrics.aappublications.org/cgi/content/abstract/123/5/e777>

## Palliative and end-of-life care in cystic fibrosis: what we know and what we need to know

*CURRENT OPINION IN PULMONARY MEDICINE* | Online article – 30 July 2009 – The authors examine what is now known about palliative and end-of-life care for cystic fibrosis (CF) patients, including the changing demographics and context of such care, and then outline a brief research agenda to guide further work in this area. They conclude that the time has come for national, multicenter studies of palliative and end-of-life care practices in CF, followed by systematic evaluation of the efficacy of existing interventions. [http://journals.lww.com/co-pulmonarymedicine/Abstract/publishahead/Palliative\\_and\\_end\\_of\\_life\\_care\\_in\\_cystic.99942.aspx](http://journals.lww.com/co-pulmonarymedicine/Abstract/publishahead/Palliative_and_end_of_life_care_in_cystic.99942.aspx)

## End of life care in dementia: Building bridges for effective multidisciplinary care

*DEMMENTIA*, 2009;8(3):331-334 (Editorial). The figures speak for themselves: by 2021 one million people in the U.K. will experience dementia ... and there will be similar increases in dementia prevalence throughout the world. One in three of us over the age of 60 years will die whilst having a dementia ... and the quality of end of life care received by people with dementia may be less than optimal ... The U.K. Government has attempted to address these issues through the End of Life Care Strategy and the National Dementia Strategy. It is interesting, however, that there is little overlap or interaction between the two strategies. and concerns have been expressed that people with dementia may ... not have their palliative care needs adequately addressed. <http://dem.sagepub.com/cgi/reprint/8/3/331>

**N.B.** This issue of *Dementia* focuses on end of life care for people with dementia, and their families and caregivers. Journal contents page with links to each article: <http://dem.sagepub.com/current.dtl>

Of related interest:

- *ISSUES IN MENTAL HEALTH NURSING*, 2009;30(8):514-521. 'The hope experience of family caregivers of persons with dementia.' The main concern of the study participants was "fading hope." <http://www.informaworld.com/smpp/content~db=all-content=a913034832>
- *PSYCHOLOGY TODAY* | Online consumer column – 30 July 2009 – 'The caregiver: Family caregiving solutions as parents age.' Five tips for working with your parent's doctors. <http://www.psychologytoday.com/blog/the-caregiver/200907/5-tips-working-your-parents-doctors>

### [Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. PCN-e link: <http://www.pcn-e.com/>

## Legal aspects of palliative care

HOSPICE PALLIATIVE CARE ASSOCIATION OF SOUTH AFRICA | Online announcement – 24 July 2009 – The Association has produced a manual ... to make key legal and medical issues accessible to anyone seeking to improve their understanding of the impact of life-limiting illness.<sup>1</sup> The manual offers guidance on policy and ways to improve the identification and referral of legal problems, with the ultimate aim of integrating this knowledge into the practice of high-quality palliative care and legal services. <http://www.hospicepalliativecaresa.co.za/legal.html>

1. *Legal Aspects of Palliative Care*, Hospice Palliative Care Association of South Africa, 2009. <http://www.hospicepalliativecaresa.co.za/pdf/legal/Prelims.pdf>

## The clinical reality of artificial nutrition and hydration for patients at the end of life

*NATIONAL CATHOLIC BIOETHICS QUARTERLY* (U.S. National Catholic Bioethics Center), 2009;9(2):293-304. The author discusses the clinical facts pertinent to artificial nutrition and hydration (ANH) for patients with the most common terminal illnesses, as well as the benefits and burdens of ANH in terms of its ability to nourish, relieve physical suffering, and provide comfort to patients in the final stages of a terminal illness. Data presented here indicate that ANH can cause significant harm and, in some cases, may shorten life if administered in inappropriate circumstances. <http://ncbcenter.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,7,9;journal,1,34;linkingpublicationresults,1:119988,1>

Of related interest:

- *Journal of Medical Ethics*, 2009;35:508-511. **'Functional neuro-imaging and withdrawal of life-sustaining treatment from vegetative patients.'** Recent studies using functional magnetic resonance imaging of patients in a vegetative state have raised the possibility that such patients retain some degree of consciousness. <http://jme.bmj.com/cgi/content/short/35/8/508?rss=1>
- *Nutrition in Clinical Practice*, 2009;24(2):206-213. **'The artificial nutrition debate: Still an issue... after all these years.'** In more than 35 years, surprisingly little has changed with regard to withdrawal or withholding of artificial nutrition. As the (Terri) Schiavo case revealed, despite a sense in bioethics of a firm consensus about handling the withdrawal of food and water, many are still searching for answers to this dilemma. <http://ncp.sagepub.com/cgi/content/abstract/24/2/206>
- *Pediatrics*, 2009;124(2):813-822. **'Forgoing medically provided nutrition and hydration in children.'** The withdrawal of medically administered fluids and nutrition for pediatric patients is ethically acceptable in limited circumstances, concludes the American Academy of Pediatrics. <http://pediatrics.aappublications.org/cgi/content/full/124/2/813>

## Supportive care trials face challenge of scientific and ethical inadequacies

*NCI CANCER BULLETIN* (U.S. National Cancer Institute) | Online report – 28 July 2009 – In a systematic review published in the *Journal of Clinical Oncology*, researchers argued that the vast majority of clinical trials comparing an experimental treatment against best supportive care (also called palliative care) have been neither scientifically valid nor ethical, due to a lack of standardization in the supportive care provided to patients.<sup>1</sup> Studies have previously indicated that supportive care in the clinic routinely fails to provide adequate pain and other symptom management or psychological and family support, stated the authors. "In addition," they explained, "evidence indicates that oncologists frequently feel inadequately prepared for this aspect of their work." In this review of oncology clinical trials published between 1966 and 2008, these issues that bedevil supportive care delivered in the clinic have now been shown to carry over into research. <http://www.cancer.gov/ncicancerbulletin/072809/page6>

1. *Journal of Clinical Oncology* | Online article – 29 June 2009 – **'Improving the methodological and ethical validity of best supportive care studies in oncology: Lessons from a systematic review.'** <http://jco.ascopubs.org/cgi/content/abstract/JCO.2009.21.9592v1>

## Barriers to advance care planning in chronic obstructive pulmonary disease

*PALLIATIVE MEDICINE* | Online article – 31 July 2009 – The findings from this study indicate that for patients with obstructive pulmonary disease significant service improvement is needed before the objective of the (U.K.) End of Life Care Strategy regarding patient participation in end of life decision-making is to be achieved. Whilst findings support the Strategy's recommendations regarding an urgent (need) for both professional education and increased public education about end of life issues, they also indicate that these alone will not be enough to effect the level of change required. <http://pmj.sagepub.com/cgi/content/abstract/0269216309106790v1>

- *Progress in Palliative Care*, 2009;17(4):170-178. '**Advance care planning (ACP) in patients with end-stage renal disease.**' This review explores ACP within the context of end-stage renal disease. <http://www.ingentaconnect.com/content/maney/ppc/2009/00000017/00000004/art00003>
- *Qualitative Health Research* | Online article – 29 July 2009 – '**Using narratives to understand older people's decision-making processes.**' This article describes how narratives ... help identify decision- and choice-making influences. <http://qhr.sagepub.com/cgi/content/abstract/1049732309344175v1>

## Worth Repeating

### Older people's views about home as a place of care at the end of life

*PALLIATIVE MEDICINE*, 2004;18(5):460-467. The authors of this study explored the attitudes of older people towards home as a place of care when dying. To participants (in the study), home was more than a physical location, representing familiarity, comfort and the presence of loved ones. While participants anticipated that home would be their ideal place of care during dying, practical and moral problems associated with it were recognised by many. Some had no informal carer. Others did not want to be a "burden" to family and friends, or were worried about these witnessing their suffering. Those who had children did not wish them to deliver care that was unduly intimate. Concerns were expressed about the quality of care that could be delivered at home, particularly in relation to accommodating health technologies and providing adequate symptom relief. Worries were also expressed about those living in poor material circumstances. Mixed views were expressed about the presence of professional carers within the home. Although they were seen to provide much needed support for the informal carer, the presence of "strangers" was regarded by some as intrusive and compromising the ideal of "home." The authors conclude that older people perceive factors they associate with "home" as crucial to a good death, most notably presence of friends and family, but many anticipate that they would prefer to be cared for elsewhere when dying. These findings run counter to assumptions that the medicalised, institutional death cannot be a "good death." It is important that dying in hospital is not demonized, but rather efforts made to examine how institutional deaths can take on a more meaningful quality. <http://pmj.sagepub.com/cgi/content/abstract/18/5/460>

### Quotable Quotes

*We say that the hour of death cannot be forecast, but when we say this we imagine that hour as placed in an obscure and distant future. It never occurs to us that it has any connection with the day already begun or that death could arrive this same afternoon, this afternoon which is so certain and which has every hour filled in advance. Marcel Proust (1871-1922)*

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