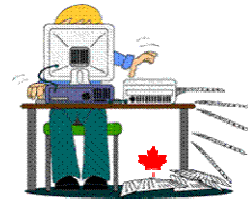


## Media Watch...

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.

## 21 February Edition 2011 | Issue #189



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Compiled & Annotated by Barry R. Ashpole

**Patient factors in determining the intensity of end-of-life care: Scroll down to [Specialist Publications](#) and 'What is the "right" intensity of care at the end of life and how do we get there?' (p.8), published in *Annals of Internal Medicine*.**

## Canada

### Helping ease terminal patients' No. 1 fear

ONTARIO | *Toronto Sun* – 19 February 2011 – As a physician, I've always known that pain is the overwhelming fear, particularly for cancer patients. I've also known that heroin has been available in Britain for 90 years to ease the final agony of death. This knowledge triggered a visit to England more than 30 years ago to witness its use and to question why it wasn't used for this purpose in Canada. I didn't realize my probe would engender so much controversy. British pain specialists shot down the myths of heroin held by critics in North America. The most asinine is that terminal cancer patients become addicted to heroin. They don't, because it's used for pain relief, not pleasure. <http://www.torontosun.com/life/healthandfitness/2011/02/17/17312936.html>

### Seniors find little care in provincial aging strategy

ONTARIO | *Toronto Star* – 18 February 2011 – A *Toronto Star* investigation has found the \$1.1 billion strategy is failing many seniors by not providing the care they need to continue living at home. Most of the money has been diverted to a provincial plan that provides home care for seniors discharged from hospital beds and to provide care for very sick seniors so that they do not go to hospital emergency rooms. Today, almost 5,000 seniors are stuck in Ontario hospitals though they no longer need hospital care. The problem: Thousands of other aging seniors who do not receive home care are ending up in hospital or on waiting lists for scarce nursing

home beds, two expensive prospects that cash-strapped Ontario cannot afford. <http://www.thestar.com/news/article/941343--seniors-find-little-care-in-provincial-aging-strategy>

#### Related *Toronto Star* articles:

'Home care promised by hospital never arrives.' <http://www.thestar.com/article/941699>

'Computer program says "no."' <http://www.thestar.com/news/article/941679>

Cont.

Of related interest:

- *NATIONAL POST* | Online report – 15 February 2011 – '**Caring for elderly parent falls primarily to one sibling: Study.**' Caring for an elderly parent can tear apart sibling relationships, especially when the division of responsibilities is less than equitable ... one of the conclusions of research that says when adult siblings have elderly parents in need of care, one usually takes on the bulk of responsibility. <http://www.nationalpost.com/news/Caring+elderly+parent+falls+primarily+sibling+study/4289202/story.html>

**N.B.** Several articles, reports, etc., on the topic of caring for an elderly parent or family member are noted in Media Watch dated 14 February 2011 (p.2).

### **Judge orders baby off life-support**

ONTARIO | *Toronto Sun* – 18 February 2011 – Joseph Maraachli, who's in a vegetative state from a neurodegenerative disease, will die after his breathing tube is removed from his tiny body at a London hospital, ending an ethical and legal dilemma that tried to balance unwanted suffering with the needs of a child and his family. An emotional Superior Court Justice Helen Rady, who called it "heartbreaking" and "such a sad and difficult case," decided last Thursday not to allow the family's appeal of a decision last month by Ontario's Consent & Capacity Board to have the child's breathing tube removed and put in place a do-not-resuscitate order and palliative care. <http://www.torontosun.com/news/canada/2011/02/18/17322476.html>

### **We've been misled about how to grieve**

*MACLEAN'S MAGAZINE* | Online article – 14 February 2011 – Many years ago, Nancy Moules, a pediatric oncology nurse who specializes in grief, got a call from a family member of one of her clients, a woman in her late 20s whose six-year-old daughter had died of leukemia a month or so earlier. The relative told Moules the woman was carrying an urn full of her daughter's ashes everywhere she went; that if you met her for lunch she'd get a table for three; that, in a nutshell, the family was concerned about how she was coping. Sure enough, when Moules later met the client for lunch, they ate with the ashes at the table. "So, are you wondering why I invited you out?" Moules asked. "Oh no, I know," the woman said. "Somebody phoned you, they're worried about me. They think I'm crazy." Moules probed further: "Do you think it's crazy?" she asked. "No," said the woman. "F—k them. This is the last human, physical connection that I have to her and I'll put her down when I'm ready to put her down." For Moules, who now lectures on grief as a nursing professor at the University of Calgary, the young mother's story helps illustrate the sometimes paradoxical relationship many of

us have with the emotions accompanying a loved one's death. "There's all these cultural expectations of grief that are contradictory," she says. "One is, 'Get over it, you should be over it by now!' And the other is, 'What's wrong with you that you aren't continuing to feel it? Didn't you love the person?' And we turn all those judgments inward." Many of these expectations have, over the past four decades, been set by Elisabeth Kübler-Ross, a Swiss-born psychiatrist who used her interviews with a handful of dying patients ... in the mid-'60s as the basis for a theory of grief that quickly gripped the world's imagination and never let go. <http://www2.macleans.ca/2011/02/14/weve-been-misled-about-how-to-grieve/>

#### **Extract from *Maclean's Magazine***

Studies show people who undergo bereavement counselling emerge from grief no more quickly than people who don't – except in the lengthiest cases, where the death of an intimate has likely exposed underlying depression (a condition now often called "complicated grief").

**N.B.** Scroll down to [Specialist Publications](#) and '**Grief therapy for those left behind**' (p.9), published in the *Canadian Medical Association Journal*.

## Inequities in funding end-of-life care

### **Markham hospice needs funding: Director**

ONTARIO | Yorkregion.com – 14 February 2011 – Evergreen Hospice has enlisted York University graduate students to gather data to convince the provincial government of its worth. Post-graduate students in the university's school of health policy and management will collect statistics that demonstrate how using the hospice's services can save the health care system money. "What (the provincial government) says is 'show us the money. Show us how much you can save us,'" said Jan Pearce, executive director. The hospice is in dire need of funding, according to Ms. Pearce. In previous years ... received increases in funding from the Central LHIN (Local Health Integration Network), however, over the past two years, the hospices received no increase, she said. "All of the hospices are in the same boat. None got re-allocation funding." The funding is granted by the Ministry of Health, but the decision about allocation is made by the health network. <http://www.yorkregion.com/news/article/954360--markham-hospice-needs-funding-director>

## **U.S.A.**

### **The philosophy and truths of hospice care**

COLORADO | *Post Independent* (Glenwood Springs) – 20 February 2011 – There's no way to sugar coat that hospice is a philosophy of care and a humanitarian service provided when someone has a terminal disease or diagnosis. But the more important thing to remember is that we do not create the need, we provide the care and compassion and love so necessary to navigating the time in someone's life once the need is there. Hospice is about showing up in the middle of the night to hold the hand of a woman as she watches her husband slip from her life after 60 years of marriage. It's about helping a homeless patient find a warm, safe, dry room during the coldest winter months while we continue to provide nursing services, meals, dog food and volunteers. It's about coming alongside the

#### **Extract from Yorkregion.com**

While York Region hospices receive about 25% of their funding from the Central Local Health Integration Network, hospices in other parts of Ontario get up to 90% of their funding through their health networks.

Of related interest:

- ONTARIO | *Sudbury Star* – 17 February 2011 – **'Hospice care needs more money: Nurses.'** A Sudbury clinical nurse specialist in palliative care says staff at residential hospices that care for the dying should spend their time caring for clients and their families, not fundraising to make ends meet. Ontario hospices now receive funding to pay the salaries of nurses and personal support staff, but that money often doesn't cover costs. <http://www.thesudburystar.com/ArticleDisplay.aspx?e=2982980>

wife of a patient who has just died and offering her the encouragement, and in a way, giving her permission, to hold her husband one last time, to gently and lovingly hold a body that for six years she had been denied access to because his cancer made being touched so painful. <http://www.postindependent.com/article/20110220/VALLEYNEWS/110219852/1083&ParentProfile=1074>

Hospice comes to be about hope, in that we all hope to die free from pain and suffering, peacefully, surrounded by love and with the knowledge that the loved ones we are leaving will not be alone.

## White House revises Bush-era 'conscience clause'

NATIONAL PUBLIC RADIO | All Things Considered – 18 February 2011 – The Obama administration has revised controversial regulations intended to protect medical workers' moral and religious beliefs. First instituted by the Bush administration, the "conscience" rules permit health care workers to opt out of performing duties if they have moral objections. Opponents, however, said the rules were so broad they could be interpreted to let workers opt out of providing not just abortion, but also birth control, treatments for AIDS and HIV, and end-of-life care. The revisions announced today narrow the conditions under which doctors, nurses and pharmacists can refuse to provide services. <http://www.wbur.org/npr/133875483/White-House-Revises-Conscience-Clause>

Of related interest:

- IDAHO | *The Street* (Boise) – 17 February 2011 – **'Idaho's 'conscience' law leaves living wills in limbo...'** Thousands of phone calls, letters and emails urging legislators to fix Idaho's so-called "conscience" law, which allows health care professionals to refuse to honor advance directives, have so far fallen on deaf ears at the State Capitol. The 'conscience' law flies in the face of existing Idaho law, the Medical Consent & Natural Death Act, which is meant to guarantee advance directive documents are honored. <http://www.thestreet.com/story/11014577/1/idahos-conscience-law-leaves-living-wills-in-limbo-aarp-says-time-to-fix-it.html>

## Health care reform will change hospice

VIRGINIA | *Daily Times* (Anoncock) – 16 February 2011 – The Eastern Shore of Virginia's hospice care providers along with the rest of the nation will have to grapple with major changes during the next few years, according to the chief executive officer of the national organization representing hospice and palliative care programs. Hospice organizations in the U.S. face permanent reductions in Medicare and Medicaid reimbursements of \$6.8 billion over the next decade, Dr. J. Donald Schumacher, of the National Hospice & Palliative Care Organization, told a group of doctors, nurses, social workers and others assembled for Hospice & Palliative Care of the Eastern Shore's professional advisory board and program meeting. Schumacher spoke about the effects of health care reform legislation passed last year by Congress and other challenges facing hospice groups. <http://www.delmarvanow.com/article/20110216/ESN04/102160402>

### Family caregivers mitigate Medicare costs

UNITED PRESS INTERNATIONAL | Online report – 15 February 2011 – Medicare costs in the last six months of life are driven by the patient's abilities, the severity of the illness and family support, U.S. researchers say.<sup>1</sup> Lead author Dr. Amy Kelley and colleagues at Mount Sinai School of Medicine in New York and the University of California in Los Angeles say Medicare costs at the end of life are influenced more by patient characteristics than by regional factors such as the number of hospital beds available. [http://www.upi.com/Health\\_News/2011/02/15/Family-caregivers-mitigate-Medicare-costs/UPI-41711297816186/](http://www.upi.com/Health_News/2011/02/15/Family-caregivers-mitigate-Medicare-costs/UPI-41711297816186/)

1. Scroll down to [Specialist Publications](#) and **'Resource use in the last 6 months of life: What does it mean to patients'** (p.8), published in *Archives of Internal Medicine*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *VERMONT BAR JOURNAL*, 2011;36(4):1-4. **'Physician-assisted suicide: A recipe for elder abuse and the illusion of personal choice.'** Legalization of assisted suicide is a recipe for elder abuse. It devalues people with disabilities. Its promise of individual choice is an illusion. Vermont has repeatedly rejected assisted suicide. Don't make Oregon and Washington's mistake. <https://www.vtbar.org/Images/Journal/journalarticles/winter2011/PhysicianAssistedSuicide.pdf>

## International

### National Council of the Forum on End of Life

#### **A strategy for end of life**

*IRISH TIMES* | Online report – 18 February 2011 – End-of-life issues get little political attention. Nearly 30,000 people die annually in Ireland and perhaps ten times more are bereaved, yet politicians have been slow to articulate their policy positions on something that at some stage concerns everyone. Despite many gaps, Ireland has achieved high international rankings for hospice and palliative care but there is much more involved in end of life and the issues go beyond the medical.<sup>1</sup> That is why the National Council of the Forum on End of Life has urged the next government to prepare a national strategy on the subject. It wants wider recognition of the social, economic, emotional, philosophical, spiritual and environmental dimensions of dying and death. <http://www.irishtimes.com/newspaper/opinion/2011/02/18/1224290139083.html>

1. Ireland rated 4th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

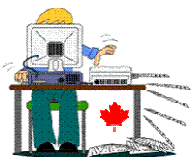
Of related interest:

- *IRISH HEALTH* | Online report – 15 February 2011 – **'Funeral industry is 'sub-standard.'** Ireland's funeral industry, which is responsible for the burial or cremation of up to 30,000 people a year, is sub-standard, the National Council of the Forum on End of Life in Ireland has said. According to the council, 'there are major problems in Ireland with regard to sub-standard funeral care.' <http://www.irishhealth.com/article.html?id=18665>

#### **End of life training boosts GP's confidence**

U.K. | Dying Matters posting – 17 February 2011 – Doctors feel more confident discussing death with patients when they receive the right support, according to new research.<sup>1</sup> With limited intervention it is possible to transform the confidence of GPs in talking about dying and consequently measurably improve end of life care. In the study, 59 GPs were provided with focused training in how to hold and sustain conversations about dying, supported by tailored materials including leaflets, posters and postcards. As well as boosting GP confidence, the study also had a tangible effect on patient outcomes and increased the numbers of patients who communicated openly about their needs and preferences at the end of life. At the start of the study, 60% of the participating GPs said they were worried that patients would reject the conversation or would find it distressing. But 90% of the patients continued the conversation once it has been initiated by their GP. <http://www.dyingmatters.org.uk/news/97>

1. Evaluation of the Dying Matters GP Pilot Project, February 2011  
[http://www.dyingmatters.org.uk/documents/Dying\\_Matters\\_GP\\_Pilot\\_Evaluation\\_-\\_final.pdf](http://www.dyingmatters.org.uk/documents/Dying_Matters_GP_Pilot_Evaluation_-_final.pdf)



#### 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.

## Survey puts spotlight on palliative patient care

AUSTRALIA (NORTHERN TERRITORY) | ABC News – 15 February 2011 – The co-author of a new survey on palliative patient care says the Alice Springs Hospital was selected as the research site because of the demographics of its patients.<sup>1</sup> Professor David Currow from Flinders University says the survey aims to find out how intensive care can be used effectively to improve patients' comfort as they come to the end of their lives. He says Australians are more likely to die in hospital than anywhere else, so it is important to find out what actually happens when people come to a hospital and die. <http://www.abc.net.au/news/stories/2011/02/16/3140442.htm>

1. *AUSTRALIAN JOURNAL OF RURAL HEALTH*, 2011;19(1):4-8. 'As death approaches: A retrospective survey of the care of adults dying in Alice Springs Hospital.' This survey highlights the continuing need to diagnose dying, understand optimal use of intensive care and improve comfort care at the end of life. <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1584.2010.01169.x/abstract>

N.B. Noted in Media Watch dated 31 January 2011.

## Parliamentary & Health Service Ombudsman

### National Health Service shamed over callous treatment of elderly

U.K. | *Daily Telegraph* – 14 February 2011 – A study of pensioners who suffered appalling treatment at the hands of doctors and nurses says that half were not given enough to eat or drink.<sup>1</sup> One family member said the maltreatment amounted to "euthanasia." Some were left unwashed or in soiled clothes, while others were forgotten after being sent home or given the wrong medication. In several cases considered by the Health Service Ombudsman, patients died without loved ones by their sides because of the "casual indifference" of staff and their "bewildering disregard" for people's needs. The damning report warns that extra money will not help the NHS [National Health Service] meet required standards of care and that more problems are likely as the population ages. Ann Abraham, who as health ombudsman carries out independent investigation of complaints against the health service, said: "The findings of my

investigations reveal an attitude – both personal and institutional – which fails to recognise the humanity and individuality of the people concerned and to respond to them with sensitivity, compassion and professionalism." <http://www.telegraph.co.uk/health/healthnews/8324569/NHS-shamed-over-callous-treatment-of-elderly.html>

1. *Care and Compassion?* Parliamentary & Health Service Ombudsman, February 2011. <http://www.ombudsman.org.uk/about-us/media-centre/press-releases/2011/?a=6666>

#### Extract from *Daily Telegraph*

The Ombudsman warned that the cases detailed in the report were not exceptional, with almost one in five of the 9,000 complaints it received last year concerning the care of older people.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* – 18 February 2011 – 'German Medical Association eases rules on assisted suicide.' The German Medical Association has presented new guidelines for physician-assisted suicide, allowing greater leeway for doctors to rely on their own conscience when deciding whether to help ill patients die. The new text ... reads: "The doctor's assistance with suicide is not a medical duty." <http://www.dw-world.de/dw/article/0,,14851309,00.html>

Cont.

- *IRISH TIMES* | Online report – 17 February 2011 – '**Euthanasia advocate urges courage over legislation.**' Assisted suicide advocate Dr. Philip Nitschke last night urged Irish politicians to show courage and not to fear the wrath of the church when it came to legislating for euthanasia. The Australian doctor took part in a debate at University College Dublin ... almost a year after his first, controversial public meeting in the Republic. His group, Exit International, provides information on assisted suicide and campaigns for the right of people to make informed decisions about when and how they will die. <http://www.irishtimes.com/newspaper/ireland/2011/0217/1224290026783.html>
- U.K. | *Daily Telegraph* – 12 February 2011 – '**Ian McEwan: The full interview.**' A transcript of [the popular English novelist and screenwriter] Ian McEwan's interview with *The Daily Telegraph*, in which he calls for new laws to allow terminally ill patients to receive medical help to die. <http://www.telegraph.co.uk/news/uknews/8319583/Ian-McEwan-the-full-interview.html>

### 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 the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, 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.

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### 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.

### Media Watch Online

The weekly report can be accessed at several websites, among them:

#### **Canada**

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:  
<http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services:  
<http://www.hpcconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network:  
<http://www.mhpcn.ca/Physicians/resources.htm>  
(Scroll down to 'Newsletters/Media Updates')

#### **U.S.A.**

*Prison Terminal:*  
<http://www.prisonterminal.com/news%20media%20watch.html>

#### **International**

Global | Palliative Care Network Community:  
<http://www.pcn-e.com/community/search/?tag=Media+Watch>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

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

### What is the "right" intensity of care at the end of life and how do we get there?

*ANNALS OF INTERNAL MEDICINE*, 2011;154(4):283-284. What is the "right" intensity of care at the end of life? The answer to this question is simple: It depends. However, the interesting and important follow-up questions are what does it depend on and what should it depend on? Kelley and colleagues report results of a study that add to our understanding of the determinants of intensity of care at the end of life.<sup>1</sup> This study, and others before it, demonstrates that the intensity of end-of-life care depends on geographic region and is associated with regional characteristics, including number of hospital beds per capita and access to hospice. There is also evidence suggesting that geographic variability cannot be explained by regional differences in patient preferences. The current study extends what we know by identifying patient characteristics associated with higher intensity of care at the end of life, including minority race or ethnicity, decline in functional status, certain chronic diseases ... and the absence of a family caregiver. These patient-level factors accounted for 10% of the variability in intensity of care at the end of life – a proportion that remained constant after controlling for geographic region, which accounted for an additional 5% of the variability. <http://www.annals.org/content/154/4/283.short>

1. *ANNALS OF INTERNAL MEDICINE*, 2011;154(4):235-242. **'Determinants of medical expenditures in the last 6 months of life.'** End-of-life medical expenditures exceed costs of care during other years, vary across regions, and are likely to be unsustainable. Identifying determinants of expenditure variation may reveal opportunities for reducing costs. [In this study] patient characteristics, such as functional decline, race or ethnicity, chronic disease, and nearby family, are important determinants of expenditures at the end of life, independent of regional characteristics. <http://www.annals.org/content/154/4/235.abstract>

Of related interest:

- *ARCHIVES OF INTERNAL MEDICINE*, 2011;171(3):194-195. **'Resource use in the last 6 months of life: What does it mean for patients?'** Countries around the world expend substantial resources to relieve the suffering caused by the burden of disease. Three articles ... in the *Archives of Internal Medicine* examine health care at the end of life.<sup>1,2,3</sup> Two ... report on health care use and costs of care for older patients with heart failure in the last 6 months of life. One study was performed in the U.S. and the other in Canada, two countries that have markedly different health care systems. The third article examines the use of hospice in men with prostate cancer in the U.S. <http://archinte.ama-assn.org/cgi/content/extract/171/3/194>

1. *ARCHIVES OF INTERNAL MEDICINE*, 2011;171(3):211-217. **'Resource use in the last 6 months of life among patients with heart failure in Canada.'** Resource use in the last 6 months of life among patients with heart failure in Alberta is changing with a reduction in hospitalizations, in-hospital deaths, and an increase in the use of outpatient services. However, end of life costs are substantial and continue to increase. <http://archinte.ama-assn.org/cgi/content/abstract/171/3/211>
2. *ARCHIVES OF INTERNAL MEDICINE*, 2011;171(3):204-210. **'Hospice use and high-intensity care in men dying of prostate cancer.'** The proportion of individuals using hospice is increasing, but the timing of hospice referral remains poor. Those who enroll in hospice are less likely to receive high-intensity end-of-life care. <http://archinte.ama-assn.org/cgi/content/abstract/171/3/204>

#### **Variation between end-of-life health care costs in Los Angeles and San Diego: Why are they so different?**

*JOURNAL OF PALLIATIVE MEDICINE* | Online article – 12 February 2011 – Medical care, particularly at the end of life, is significantly more expensive in Los Angeles than in San Diego, yet quality measures tend to favor in San Diego. Non-emergent hospital admissions and inpatient care at the end of life are important contributors to the cost differences. There is little reason to believe that the greater spending for health care in LA results in better patient outcomes. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0285>

Cont.



3. *ARCHIVES OF INTERNAL MEDICINE*, 2011;171(3):196-203. '**Resource use in the last 6 months of life among Medicare beneficiaries with heart failure, 2000-2007.**' Among Medicare beneficiaries with heart failure, health care resource use at the end of life increased over time with higher rates of intensive care and higher costs. However, the use of hospice services also increased markedly, representing a shift in patterns of care at the end of life. <http://archinte.ama-assn.org/cgi/content/abstract/171/3/196>

### Providing hospice in the womb

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online article – 17 February 2011 – Amy Kuebelbeck was 25 weeks into her pregnancy when she received the terrible news. Her fetus had been diagnosed with an incurable heart defect. If she carried through with her pregnancy, her baby's life would be a brief one. Kuebelbeck did continue her pregnancy and gave birth to a boy. Her new son, Gabriel, was even sicker than anticipated. He died a few hours after his birth. "He lived for nine months before he was born," says Kuebelbeck, "and for two and a half peaceful hours afterward." That was in 1999, a time when perinatal palliative care – support for families expecting babies with life-limiting illnesses – was still very much in the concept stage. There was no formal support program at the hospital where Kuebelbeck ... received care during her pregnancy with Gabriel. There was, however, one person on staff who helped her family through the entire process. "One person validated for us that we still had a profound opportunity to parent and love this baby," says Kuebelbeck. [http://www.cmaj.ca/earlyreleases/17feb11\\_providing-hospice-in-the-womb.dtl](http://www.cmaj.ca/earlyreleases/17feb11_providing-hospice-in-the-womb.dtl)

**N.B.** Perinatal hospice and palliative care support: [http://perinatalhospice.org/Perinatal\\_hospices.html](http://perinatalhospice.org/Perinatal_hospices.html)

### Grief therapy for those left behind

*CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online article (see sidebar) – 16 February 2011 – Palliative care programs are primarily designed to provide care and comfort to dying patients, but most also attempt to help patients' bereaved families cope with their loss. At least in theory. "Care of the family is part of the rhetoric of palliative care – supporting children and spouses, as well as the dying patient. While that is an admirable goal, putting that into a model that works well is challenging to do," says Dr. David Kissane, chair of the department of psychiatry and behavioural sciences at Memorial Sloan-Kettering Cancer Center in New York City. "In practice, most of the focus is on the patient. The broad principle of supporting the family is there but doesn't always get translated into practice." It is only natural, says Kissane, that palliative care programs focus more on active patients than on the families of deceased patients. Hospices can only use only so much of their limited resources on services for bereaved families, so those services are usually offered for limited periods. [http://www.cmaj.ca/earlyreleases/16feb11\\_grief-therapy-for-those-left-behind.dtl](http://www.cmaj.ca/earlyreleases/16feb11_grief-therapy-for-those-left-behind.dtl)

#### **This is the ninth article in a series on end-of-life care**

- Part I:** 'Preparing for the inevitable.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3704](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3704)
- Part II:** 'Advance directives: Obstacles in preparing for the worst.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3743](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3743)
- Part III:** 'End-of-life planning framework calls for fewer checklists, more conversation.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3746](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3746)
- Part IV:** 'Tools help patients tackle tough choices for end-of-life care.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3750](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3750)
- Part V:** 'National home care standards urged.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3731](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3731)
- Part VI:** 'Access to palliative care varies widely across Canada.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3763](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3763)
- Part VII:** 'Framework urges physicians to proceed with caution on palliative sedation.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3766](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3766)
- Part VIII:** 'Pocket-sized help for people with dementia.'  
[www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3705](http://www.cmaj.ca/cgi/doi/10.1503/cmaj.109-3705)

## **Religious and non-religious spirituality in relation to death acceptance or rejection**

*DEATH STUDIES*, 2011;35(2):124-146. Meanings of religious and non-religious spirituality are explored, with implications for death acceptance, death rejection, and life extension. In the first of two exploratory studies, 16 elders low on intrinsic religiosity were compared with 116 elders high in religiosity; they differed both in qualitative responses and on death attitudes. In the second, 48 elders were assessed on religious and non-religious spirituality and compared on attitudes toward death rejection, life extension, and death acceptance. A sizable minority ... hold non-religious spirituality beliefs, and these beliefs are related to greater acceptance of life extension and death rejection. <http://www.informaworld.com/smpp/content~db=all~content=a933337761~frm=abslink>

## **Living wills: Is it time to pull the plug?**

*ELDER LAW JOURNAL* | Online article – Accessed 15 February 2011 – Although an intensely personal decision, there are numerous professionals and institutions that have a specific interest in the patient's decision-making process; typically these professionals are not as concerned with what decision the patient makes as they are concerned with how the decision is made and documented. Family members are interested in the patient's desires for end-of-life care and treatment to ensure that any decisions a loved one has to make on behalf of their dying relative are consistent with the relative's desires. Doctors are interested in the patient's desires to ensure they are followed at suitable times and in accordance with a physician's medical judgment. Lawyers are interested in the patient's desires inasmuch as they are professionally positioned to help their clients pre-plan for these eventualities and navigate the necessary forms and statutes applicable to these decisions. Lawyers are also interested in the patient's desires when they represent physicians whose provision of care at the end of life may be subject to scrutiny by disgruntled family members, review boards, and insurance companies. <https://litigation-essentials.lexisnexis.com/webcd/app?action=DocumentDisplay&crawlid=1&doctype=cite&docid=18+Elder+L.J.+289&srctype=smi&srcid=3B15&key=4e94a00ed3865609eaa1e93e5d20fb9e>

## **Geriatric rehabilitation and palliative care: Opportunity for collaboration or oxymoron?**

*GERIATRIC REHABILITATION*, 2011;27(1):229-235. Over the past decade, there has been much collaboration among clinicians in the area of palliative care and several medical specialties including physical medicine and rehabilitation (PM&R). PM&R's primary focus is on restoring function, coping with disability, and decreasing the illness burden of chronic disease. Thus, there is a natural compatibility between these two fields, which provide increasing opportunities for clinical interface in the comprehensive treatment of seriously ill patients. Although improvements in medical technology have allowed many patients to live longer, a paradox of this success is that many will struggle in managing a wide range of diseases, symptoms, and disabilities. [http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2011/01000/Geriatric\\_Rehabilitation\\_and\\_Palliative\\_Care\\_.5.aspx](http://journals.lww.com/topicsingeriatricrehabilitation/Abstract/2011/01000/Geriatric_Rehabilitation_and_Palliative_Care_.5.aspx)

**N.B.** This issue of *Geriatric Rehabilitation* includes several articles on end of life care. Contents page: <http://journals.lww.com/topicsingeriatricrehabilitation/pages/currenttoc.aspx>

### **[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. <http://www.pcn-e.com/community/>

## 'Am I going to die?'

*MEDICAL POST* | Online article – 14 February 2011 – A life-changing diagnosis brings with it some of the toughest questions in medicine to both ask and answer. Dr. Valerie Jefford, a breast surgical oncologist ... spent her residency learning from her medical mentor how to respond to them. "Patients always felt good after talking to him, even if he had to give them bad news," says Dr. Jefford. "If they understand, it takes a huge part of the anxiety away." That's why Dr. Jefford attends local cancer support groups as often as she can to field difficult questions. She's heard it all, from "How long do I have?" and "Is there a cure?" to "What do I tell my family?" and "Why wasn't this caught earlier?" Dr. Jefford approaches these questions by giving realistic answers while remaining positive. <http://www.canadianhealthcarenetwork.ca/physicians/clinical/health-index-therapeutics/oncology/am-i-going-to-die-14289>

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY*, 2011;29(6):e145-e146. **'Disclosing the cancer diagnosis: The myth and the truth.'** We read with interest the article ... published ... in *Journal of Clinical Oncology*.<sup>1</sup> The authors attempt to investigate how cancer diagnosis is disclosed to patients, under what circumstances, in what settings, and who delivers the diagnosis. They also attempt to explore patients' satisfaction with their physicians' communication abilities when they discuss the cancer diagnosis. This study has many limitations that need to be highlighted, because ... one can come to the conclusion that physicians are insensitive to patients' needs and either too busy or unwilling to discuss a life-threatening event. <http://jco.ascopubs.org/content/29/6/e145.short?rss=1>

1. **'Disclosing a diagnosis of cancer: Where and how does it occur?'** *Journal of Clinical Oncology*, 2010;28(22):3630–3635. <http://jco.ascopubs.org/content/28/22/3630.full.pdf+html>

**N.B.** Online version noted in Media Watch dated 12 July 2010.

From Media Watch dated 31 January 2011:

- CNN (CABLE NEWS NETWORK) | Online report – 24 January 2011 – **'Terminally ill patients need frank conversation about prognosis, cancer group says.'** In an effort to improve the communications between doctors and patients, the American Society of Clinical Oncologists [have] released a new policy statement and a patient guide for conversations about the time when treatment options run out.<sup>1</sup> <http://pagingdr Gupta.blogs.cnn.com/2011/01/24/terminally-ill-patients-need-frank-conversation-about-prognosis-cancer-group-says/>

1. *JOURNAL OF CLINICAL ONCOLOGY* | Online article – 24 January 2011 – 'American Society of Clinical Oncology statement: Toward individualized care for patients with advanced cancer.'  
<http://jco.ascopubs.org/content/early/2011/01/24/JCO.2010.33.1744.abstract>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN PSYCHIATRY* | Online article – 11 February 2011 – **'Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.'** Despite continuing political, legal and moral debate on the subject, assisted suicide is permitted in only a few countries worldwide. However, few studies have examined the impact that witnessing assisted suicide has on the mental health of family members or close friends. A higher prevalence of post-traumatic distress disorder ... and depression was found in the ... [participants in this cross-sectional survey] ... than reported for the Swiss population in general. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VM1-5253KXM-4&\\_user=10&\\_coverDate=02%2F11%2F2011&\\_rdoc=1&\\_fmt=high&\\_orig=search&\\_origin=search&\\_sort=d&\\_docanchor=&\\_view=c&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=7233fae3a57c4a28dc511fb24bdd6e17&searchtype=a](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VM1-5253KXM-4&_user=10&_coverDate=02%2F11%2F2011&_rdoc=1&_fmt=high&_orig=search&_origin=search&_sort=d&_docanchor=&_view=c&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=7233fae3a57c4a28dc511fb24bdd6e17&searchtype=a)

## Worth Repeating

### Informing critical care patients of a loved one's death

*CRITICAL CARE NURSE*, 2008;28(3):52-63. Much has been written about how to break bad news to patients regarding their own illness and diagnoses and about making death notifications in the community. Little, however, has been written about informing critical care patients of bad news regarding the death of a loved one. Aspects of previously published literature and protocols can be adapted for situations in which a critical care patient must be informed of such a death. In this article, the critical care patients are adult patients in any intensive care unit ... who in the course of a hospitalization have had a loved one die either in a related incident or because of other injury or health issues. The approach recommended focuses on the importance of the timing of the news, provides patients with a safe and healthy beginning for their grieving, considers the needs of the other grieving family members and the hospital staff caring for the grieving patients, and identifies the hospital chaplain, with his or

her experience and training, as the one to be the giver of the news.

<http://ccn.aacnjournals.org/content/28/3/52.full.pdf+html>

#### **Fourteen elements for patients' families to rank on the basis of the level of importance when receiving bad news**

Ability/knowledge to answer questions  
Attire: How the news giver is dressed  
Attitude of the news giver  
Autopsy information  
Clarity of the message  
Clergy available  
Directions after death  
Family given time to ask questions  
Follow-up call  
Location of conversation  
Privacy of conversation  
Seniority: Rank of news giver  
Sympathy of the news giver  
Timing of conversation

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Barry R. Ashpole  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [baryashpole@bellnet.ca](mailto:baryashpole@bellnet.ca)