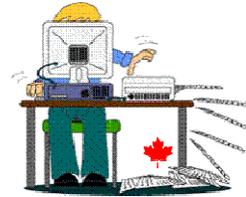


## Media Watch...

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 and research.

2 April 2012 Edition | Issue #247



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Fundamental part of all doctor's training: Scroll down to [Specialist Publications](#) and 'End-of-life care: The neglected core business of medicine' (p.11), an editorial published in *The Lancet*.

## Canada

### Economic climate and end-of-life care

#### **Budget pressures will force Bruyère to close beds, cut staff**

ONTARIO | *Ottawa Citizen* – 29 March 2012 – Eastern Ontario's old, sick and dying will feel the squeeze as budget pressures force Bruyère Continuing Care to close beds, cut staff and trim services. Heading into the new fiscal year ... Bruyère is facing a shortfall of as much as \$3.2 million on a \$130-million budget. And that's before the 2012-1213 budget has been finalized under a new provincial funding formula, which could carve an even bigger chunk out of the hospital's revenues, leading to deeper cuts. The ... hospital group includes the Elisabeth Bruyère Health Centre, which has 90 rehabilitation beds and 36 palliative-care beds; Saint-Vincent chronic-care hospital, which has 336 beds; and the Villa Marguerite and Résidence Saint-Louis, which have 278 long-term-care beds. While the nursing homes will be spared any cuts and no clinical programs will be eliminated, key services such as rehab and palliative care will be scrutinized for savings.  
<http://www.ottawacitizen.com/business/Budget+pressures+will+force+Bruyere+close+beds+staff/6381746/story.html>

### Lack of public engagement

#### **Local Health Integration Network sets timeline for palliative care decision**

ONTARIO | *Sun Times* (Owen Sound) – 28 March 2012 – A task force has 60 days ... to accomplish what couldn't be done in seven years – devise a recommendation on palliative care in Grey-Bruce for the South West Local Health Integration Network board to vote on. The board must decide between a residential hospice, an outreach model of interdisciplinary teams that would help people die at home, or some combination of the two. It's a decision that has been years in the making. The [provincial] Ministry of Health & Long Term Care has set aside \$600,000 annually for a Grey-Bruce hospice for nearly seven years. That money has never been used for a hospice as planning stalled and other methods of palliative care were discussed by a steering committee.  
<http://www.owensoundsuntimes.com/ArticleDisplay.aspx?e=3519141>

## U.S.A.

### Trends in hospice

#### **Challenges ahead for long term care industry despite \$259 billion of revenue in 2011**

*SENIOR HOUSING NEWS* | Online report – 1 April 2012 – The long-term care industry, including nursing homes, assisted living, home care, and hospice care, raked in \$259 billion in revenue in 2011, according to health care market research publisher Kalorama Information. Between 2006 and 2011, the industry grew 5.5% for a "healthy" growth rate that reflects positive demographics and industry performance. The hospice and home care segments saw the strongest growth...

<http://seniorhousingnews.com/2012/04/01/challenges-ahead-for-ltc-industry-despite-259-billion-of-revenue-in-2011/>

Of related interest:

- LOUISIANA | *Daily Comet* (Lafourche) – 27 March 2012 – **'Demand for nurses remains unabated.'** Home-health agencies report the largest vacancy rates, and hospice care, which has the highest turnover rate among registered nurses, is expected to see the most growth in coming years. <http://www.dailycomet.com/article/20120327/ARTICLES/120329594?Title=Demand-for-nurses-remains-unabated>

#### **Taking responsibility for death**

*NEW YORK TIMES* | Online OpEd – 30 March 2012 – As the aging baby boom generation places unprecedented demands on the health care system, there is little ordinary citizens can do – witness the tortuous arguments in the Supreme Court this week over the constitutionality of the Affordable Care Act – to influence either the cost or the quality of the treatment they receive. However, end-of-life planning is one of the few actions within the power of individuals who wish to help themselves and their society. Too few Americans are shouldering this responsibility. Of course many people want more aggressive treatment... And advance directives aren't "death panels"; they can also be used to ensure the deployment of every tool of modern medicine. They can be

changed or withdrawn at any time by a mentally competent person. But public opinion polls consistently show that most Americans, like my mother, worry about too much rather than too little medical intervention.

[http://www.nytimes.com/2012/03/31/opinion/taking-responsibility-for-death.html?\\_r=1](http://www.nytimes.com/2012/03/31/opinion/taking-responsibility-for-death.html?_r=1)

#### Specialist Publications

Of particular interest:

**'Acceptance of dying: A discourse analysis of palliative care literature'** (p.11), published in *Social Science & Medicine*.

Of related interest:

- *NEW YORK TIMES* | Online Commentary – 30 March 2012 – **'Among doctors, fierce reluctance to let go.'** Dr. [Daniel] Matlock, a geriatrician who specializes in palliative care, had been called in to consult when a woman in her 70s arrived at the University of Colorado Hospital, unresponsive after a major stroke. She'd done what we're forever chiding people for not doing: She'd drafted a very specific advance directive and had even taken the trouble to have it notarized. It unambiguously said: no life support, no artificial nutrition or hydration, no nursing home. The ambulance crew had put her on a ventilator – standard procedure. After the palliative team removed it, she was able to breathe on her own, which isn't uncommon. She even opened her eyes, though she couldn't track or follow objects and remained unresponsive. That's when the prominent surgeon directing her care ordered intravenous fluids. After talking with the patient's sister ... he called the surgeon to suggest stopping the IV. "You would have been hung in World War II for doing what you are doing now," the surgeon said. <http://newoldage.blogs.nytimes.com/2012/03/29/among-doctors-fierce-reluctance-to-let-go/>

## Health matters: Palliative care a team approach

FLORIDA | WZVN-HD (Fort Myers) – 28 March 2012 – When someone is facing a serious illness, they may have one team on their side, which has no stake in their disease but is more concerned about their well-being. "Palliative care is an interdisciplinary medicine usually composing a physician, nurse, chaplain and social worker that works to support and provide care for quality of life for patients with serious medical illnesses," says Dr. Sherika Newman, a palliative care physician with Lee Memorial Health System. Palliative care is the best thing you may have never heard of. It's recently gaining traction as health care recognizes a patient's physical and mental well-being and finds a way to treat them both. <http://www.abc-7.com/story/17273449/health-matters-palliative-care-a-team-approach>

### Family dynamics

## Cancer docs often don't notice family discord

REUTERS | Online report – 28 March 2012 – Doctors caring for lung cancer patients are often unaware when patients and their caregivers disagree about the best course of treatment, according to a new study.<sup>1</sup> "Unless you're doing an assessment of conflict, which oncologists do not do, I'm not surprised that they wouldn't perceive it," said Betty Kramer, who studies aging and family caregiving at the University of Wisconsin-Madison School of Social Work, but wasn't involved in this research. Laura Siminoff, from the Virginia Commonwealth University School of Medicine in Richmond, said she's seen there's often a disconnect between caregivers and patients about their goals and desires for cancer treatment. "We then asked ourselves, are oncologists seeing what is happening between patient and family or is this hidden from them?" she said. <http://www.reuters.com/article/2012/03/28/us-cancer-docs-idUSBRE82R1BR20120328>

1. 'Oncologists' assessments of lung cancer patient and family disagreements regarding treatment decision making,' *Lung Cancer*, published online 8 March 2012. [http://www.lungcancerjournal.info/article/S0169-5002\(12\)00068-2/abstract](http://www.lungcancerjournal.info/article/S0169-5002(12)00068-2/abstract)

## State hospice care bill passes committee vote

CONNECTICUT | Associated Press (Hartford) – 27 March 2012 – A bill that would revamp decades-old regulations in Connecticut to allow more hospice organizations to offer inpatient services has passed its first legislative hurdle. Members of the General Assembly's Public Health Committee voted 26-0 in favor of the legislation Monday. The bill now awaits further legislative action in the House. Under the proposed legislation more hospice providers would be able to offer inpatient services. Advocates for Connecticut Hospice, a Branford inpatient facility, say they are concerned that proposed hospice residences would refer patients to emergency rooms to handle acute pain. Other hospice groups argue that Connecticut families need more local choices for end-of-life care. <http://www.theday.com/article/20120327/NWS12/303279914/-1/NWS>

Of related interest:

- IDAHO | Associated Press (Boise) – 26 March 2012 – **'House panel passes end-of-life care bill.'** The House State Affairs committee voted unanimously to advance legislation that would bar medical personnel from denying life-prolonging treatment to patients who have requested them. This measure closes a loophole allowing doctors to deny end-of-life care if they've tried and failed to find another physician willing to treat the patient. [http://www.necn.com/03/26/12/House-panel-passes-end-of-life-care-bill/landing\\_politics.html?&apID=90e3fd71103f4f02951750deb3cb7411](http://www.necn.com/03/26/12/House-panel-passes-end-of-life-care-bill/landing_politics.html?&apID=90e3fd71103f4f02951750deb3cb7411)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *Boston Magazine* – 30 March 2012 – **'Massachusetts voters want their parents to die with dignity.'** The practice of medicine here in Massachusetts could soon be getting a makeover. Voters here seem poised to pass both medical marijuana and physician assisted suicide come November, according to a recent survey by Public Policy Polling. A slim majority of voters would vote to approve physician-assisted suicide, the poll found: 43% are in favor, and 37% are against. If passed, we'd be the fourth state with a legal backing for physician-assisted suicide. [http://blogs.bostonmagazine.com/boston\\_daily/2012/03/30/massachusetts-voters-want-their-parents-to-die-with-dignity/](http://blogs.bostonmagazine.com/boston_daily/2012/03/30/massachusetts-voters-want-their-parents-to-die-with-dignity/)
- GEORGIA | *Atlanta Journal-Constitution* – 27 March 2012 – **'Assisted suicide ban passes Senate.'** Assisting someone in committing suicide would become a felony in Georgia under a bill passed by the state Senate. House Bill 1114 was introduced in the wake of a Georgia Supreme Court decision that struck down Georgia's previous assisted-suicide law as unconstitutional. It passed the House earlier this month. The Senate vote was 48-1. Because of tweaks made in the Senate by committee, the bill now goes back to the House. <http://www.ajc.com/news/georgia-government/assisted-suicide-ban-passes-1399969.html>

## International

### 'Israelis stress less than Americans in home care'

ISRAEL | *Jerusalem Post* – 31 March 2012 – Surprisingly, Israeli working couples in the "sandwich generation" who take care both of elderly parents and their own young children suffer less burnout than their American counterparts. This is a finding of a new Ben-Gurion University of the Negev study<sup>1</sup> that looked at job and couple burnout rates in a cross-cultural comparison of Americans and Israelis. Representative samples of Israeli and American sandwiched couples responded to a questionnaire that included measures of job burnout, couple burnout and accounts of the stressors and rewards associated with work, marriage, parenting and caring for aging parents. Findings revealed significant differences in burnout type (job burnout was higher than couple burnout); gender (wives were more burned out than husbands); and country (Americans

were more burned out than Israelis). They also documented the role of job-related stressors and rewards as well as caring for parents as predictors of job burnout and the role of marital stressors and rewards as predictors of couple burnout. <http://www.jpost.com/Health/Article.aspx?id=264253>

### Specialist Publications

Of particular interest:

**'Predictors of caregiver distress among palliative home care clients in Ontario: Evidence based on the interRAI Palliative Care'** (p.12), published in *Palliative & Supportive Care*.

1. 'Job burnout and couple burnout in dual-earner couples in the sandwiched generation,' *Social Psychology Quarterly*, 2011;74(4):361-386. <http://spq.sagepub.com/content/74/4/361.abstract>

### 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/pg/file/owner/MediaWatch>

## Tomb Sweeping Day

### Live expensively, die expensively?

CHINA DAILY | Online report – 30 March 2012 – The Chinese government's new regulations to clamp down on rocketing funeral and burial prices has prompted heated discussion online in the run-up to China's traditional day of honoring ancestors, as the public fret that the policies may have limited power to curb profiteering by morticians. The National Development & Reform Commission, the country's top price regulator, and the Ministry of Civil Affairs released pricing guidelines on funeral services last weekend. It was a timely move with Tomb Sweeping Day, when online outcries over spiraling funeral expenses usually peak, falling on 4 April this year. [http://www.chinadaily.com.cn/china/2012-03/30/content\\_14954536.htm](http://www.chinadaily.com.cn/china/2012-03/30/content_14954536.htm)

### Time to act as dementia crisis looms, says report

AUSTRALIA | *Sydney Morning-Herald* – 29 March 2012 – With dementia rates set to soar, it is imperative more Australians plan for when they can no longer manage their health care, end-of-life care, or financial affairs, a new report says. Only about 55% of Australians have a will, and an even smaller proportion have recorded their wishes in legally binding directives about nursing, guardianship, or power of attorney arrangements. The report, by Alzheimer's Australia, calls on the federal government to implement a national awareness campaign about planning. The report reveals a looming dementia epidemic for New South Wales, with the number of people with the condition set to increase from 95,000 to 303,500 by 2050.

A separate analysis shows the electorates expected to be most affected include Tweed, Port Macquarie, Myall Lakes, Bega, Wyong and Port Stephens, with projected increases of up to 400%.

<http://www.smh.com.au/national/time-to-act-as-dementia-crisis-looms-says-report-20120328-1vyon.html>

#### Specialist Publications

Of particular interest:

**'Integrating palliative medicine with dementia care'** (p.10), published in *Aging Well*.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- RUSSIA | Russian Legal Information Agency – 1 April 2012 – **'Legislatures worldwide grapple with the right to die.'** Albert Camus once wrote, "There is but one truly serious philosophical problem and that is suicide." While the context may have changed since the 1940s, these words remain as true as ever today as legislatures worldwide grapple with questions of the legality and ethicality of assisted suicide and euthanasia. On 1 April 2002, The Netherlands' euthanasia legislation entered into force. We would like to commemorate the anniversary with a discussion of the legal status of euthanasia and assisted suicide in various countries that have legalized such end-of-life choices, as well as those whose courts and legislatures have continued to struggle with the decision to do so. [http://rapsinews.com/legislation\\_news/20120401/262585738.html](http://rapsinews.com/legislation_news/20120401/262585738.html)
- SWITZERLAND | Swissinfo.ch (Bern) – 27 March 2012 – **'First data on assisted suicide published.'** Cases of assisted suicide in Switzerland have gradually increased over a decade to reach nearly 300 in 2009, according to the Federal Statistics Office. Most people were over the age of 55 and suffered from cancer. No figures are available for the period before 1998. The statistics office said international comparisons are difficult as legislation varies considerably from one country to the next. The Swiss government last year decided to drop plans for specific legislation on assisted suicide. The method is legal if performed by a non-physician with no vested interest. There are two main organisations, Exit and Dignitas, which offer their services to terminally ill patients. [http://www.swissinfo.ch/eng/swiss\\_news/First\\_data\\_on\\_assisted\\_suicide\\_published.html?cid=32370072](http://www.swissinfo.ch/eng/swiss_news/First_data_on_assisted_suicide_published.html?cid=32370072)

Cont.

- U.K. (ENGLAND & WALES) | BBC – 27 March 2012 – '**Assisted suicide [parliamentary] debate...**' MPs began debate on a motion on assisted suicide that welcomed the 2010 policy of the Director of Public Prosecutions (DPP).<sup>1</sup> The DPP must give consent before an individual can be prosecuted. Conservative MP Richard Ottaway, whose motion was supported by 15 MPs from different political parties, acknowledged it is a sensitive area of law which "evokes deep emotions." Mr. Ottaway emphasised "assisted suicide will remain a criminal offence" and that MPs were not being asked to express a view on volun-

tary euthanasia – which would entail changing the law on murder – but expressed sympathy for people who may wish to end a loved one's suffering.

### [Specialist Publications](#)

Of particular interest:

**'MPs back guidance on assisted suicide in first Commons debate for 40 years'** (p.13), published in the *British Medical Journal*.

Part I of debate: [http://news.bbc.co.uk/democracylive/hi/house\\_of\\_commons/newsid\\_9709000/9709462.stm](http://news.bbc.co.uk/democracylive/hi/house_of_commons/newsid_9709000/9709462.stm)

Part II of debate: [http://news.bbc.co.uk/democracylive/hi/house\\_of\\_commons/newsid\\_9709000/9709037.stm](http://news.bbc.co.uk/democracylive/hi/house_of_commons/newsid_9709000/9709037.stm)

1. 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide,' Crown Prosecutors Service, February 2010 (noted in Media Watch, 1 March 2010).  
[http://www.cps.gov.uk/publications/prosecution/assisted\\_suicide\\_policy.html](http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html)

### [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/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County):  
<http://www.hpcconnection.ca/newsletter/inthenews.html>

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

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

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

#### **Europe**

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm> (Scroll down to 'International End of Life Roundup')

#### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipccr.net/archive-global-palliative-care-news.php>

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

### Family optimism in ICU can impede end-of-life care decisions

AMERICAN MEDICAL NEWS | Online report – 26 March 2012 – Relatives of patients in the intensive care unit respond to grim assessments of recovery with unwarranted optimism, says a study.<sup>1</sup> For good prognoses, family interpretations were on target, but when the odds of survival got worse so did the accuracy of surrogates' interpretations, said the study. Surrogates ... hold on to hope and doubted the accuracy of the prognosis. "Family members want to see the glass as half full, even if it's really nearly empty," said Douglas B. White, MD, the study's lead author. He said such optimism can delay difficult discussions about moving away from aggressive interventions toward comfort care. <http://www.ama-assn.org/amednews/2012/03/26/prbf0326.htm>

1. 'Surrogate decision makers' interpretation of prognostic information,' *Annals of Internal Medicine*, 2012;12(156):360-366 (noted in Media watch, 12 March 2012). <http://www.annals.org/content/156/5/360.abstract>

Of related interest:

- AMERICAN JOURNAL OF CARDIOLOGY | Online article – 30 March 2012 – **'Knowledge of and preference for advance care planning by adults with congenital heart disease.'** Only 5% of patients [i.e., study participants] reported that they had completed advance directives; 56% had never heard of them. However, most patients (87%) reported that they would prefer to have an advance directive available if they were dealing with their own dying and were unable to speak for themselves. [http://www.ajconline.org/article/S0002-9149\(12\)00704-7/abstract](http://www.ajconline.org/article/S0002-9149(12)00704-7/abstract)
- JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article – 28 March 2012 – **'Effect of a disease-specific advance care planning intervention on end-of-life care.'** Patients and their surrogates [i.e., study participants] were generally willing to discuss preferences with a trained facilitator. Most patients received the care they desired at end of life or altered their preferences to be in accord with the care they could receive. A larger sample with surrogate decision-makers is needed to detect significant differences. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2012.03917.x/abstract>
- JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2012;14(2):99-106. **'Why surrogates don't make decisions the way we think they ought to: Insights from moral psychology.'** The purpose of this article was to examine five assumptions about surrogate decision making that are implicit in the three-standard hierarchy. The authors apply a moral psychology perspective to offer explanations about why surrogates may make decisions that conflict with this framework. Implications for practice and research are suggested to assist clinicians and researchers to develop appropriate. [http://journals.lww.com/jhpn/Abstract/2012/03000/Why\\_Surrogates\\_Don\\_t\\_Make\\_Decisions\\_the\\_Way\\_We.3.aspx](http://journals.lww.com/jhpn/Abstract/2012/03000/Why_Surrogates_Don_t_Make_Decisions_the_Way_We.3.aspx)

#### **I could never quite get it together: Lessons for end-of-life care in Harold Pinter's *The Caretaker***

JOURNAL OF MEDICAL HUMANITIES | Online article – 18 March 2012 – *The Caretaker* explores interpersonal tensions relating to terminal illness. This paper interrogates notions of care, suffering, ownership, dignity and the consequences of active intervention and inaction in two key sections of the play: Aston's monologue concerning his own brutal treatment (active intervention) and Davies's final rejection by the brothers who fail to provide accommodation and care (inaction). This ... analysis combines theatrical and clinical perspectives to create insights which can enhance empathy improve decision-making in end of life care and can inform the education of healthcare professionals. <http://www.springerlink.com/content/c6637225291246p8/>

## Canada's Compassionate Care Benefit

### **The workplace perspective on supporting family caregivers at end of life: Evaluating a new Canadian social program**

*COMMUNITY, WORK & FAMILY* | Online article – 26 March 2012 – There is a growing realization that employers need to accommodate the issue of work-life balance for employees who are also providing care for family members or friends in palliative or end-of-life situations, as this phenomenon is only expected to increase within developed nations in the future given demographic trends and health care restructuring. This research aims to uncover the expectations that Canadian employers/human resources (HR) professionals have of the Compassionate Care Benefit (CCB), in addition to their experienced realities of having staff utilize this social program. The CCB provides employed family/informal caregivers with a job-secured work leave and six weeks of employment insurance benefits while they take time off to provide care to a dying family member or close other, often at home (in the community). Five focused discussions were implemented with employers/HR across Canada. Using thematic analysis, the data reveal how well (or not) the CCB meets caregivers' needs, as well as the informational and procedural needs of workplaces. In light of these findings, suggestions for program improvement, with respect to the CCB, are made in order to advocate for continued support of family/informal caregivers whose voices are rarely heard. <http://www.tandfonline.com/doi/abs/10.1080/13668803.2012.664891>

From Media Watch dated 19 September 2011:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online article – 15 September 2011 – **'Family caregivers' ideal expectations of Canada's Compassionate Care Benefit.'** <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01028.x/abstract>

From Media Watch dated 23 May 2011:

- *BMC PUBLIC HEALTH* | Online article – 18 May 2011 – **'Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?'** <http://www.biomedcentral.com/content/pdf/1471-2458-11-335.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. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

 World hospice &  
palliative care day **October 13 2012**

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

## A review of pediatric palliative care service utilization in children with a progressive neuromuscular disease who died on a palliative care program

*JOURNAL OF CHILD NEUROLOGY* |

Online article – 23 March 2012 – Recent studies and consensus statements have expressed the need to involve palliative care services in the care of children with progressive neuromuscular diseases (PMD), yet there have been no reviews of the utilization of palliative care services by children who died on a palliative care program. The authors conducted a retrospective chart review of all children who had a PMD who died on a single-center palliative care program. Services utilized by these patients included respite care, transition services, pain and symptom management, and end-of-life care. Good symptom management can be achieved. <http://jcn.sagepub.com/content/early/2012/03/20/0883073812439345.abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(3):115-120. **'Education in children's palliative care across Europe and internationally.'** This paper discusses children's palliative care (CPC) education and training from a European and global perspective, highlighting some of the principles and challenges. It also looks at the recent efforts of the European Association for Palliative Care and the International Children's Palliative Care Network... [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=90587;article=IJPN\\_18\\_3\\_115](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=90587;article=IJPN_18_3_115)

## Must we ration health care for the elderly?

*JOURNAL OF LAW, MEDICINE & ETHICS*, 2012;40(1):10-16. This article lays out the need for rationing, based on projections of Medicare expenditure in the near future, and the judgment of policy experts that there will be no technological breakthrough that might lower costs. Various forms of rationing possibilities are discussed as well as cultural and political obstacles to needed reform. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2012.00640.x/abstract>

Of related interest:

- *JOURNAL OF LAW, MEDICINE & ETHICS*, 2012;40(1):17-25. **'Can health care rationing ever be rational?'** Americans' appetite for life-prolonging therapies has led to unsustainable growth in health care costs. It is tempting to target older people for health care rationing based on their disproportionate use of health care resources and lifespan already lived, but aged-based rationing is unacceptable to many. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2012.00641.x/abstract>

## Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?

*JOURNAL OF MEDICAL ETHICS* | Online article – 30 March 2012 – Religion is an important element of end-of-life care on the paediatric intensive care unit with religious belief providing support for many families, as well as for some staff. However, not infrequently the authors have found religious claims used by families to challenge cessation of aggressive therapies considered futile and burdensome by a wide range of medical and lay people. While it is vital to support families in such challenging times, the authors are increasingly concerned that deeply held belief in religion, especially with more fundamentalist religions, leads to children being subjected to burdensome care in expectation of 'miraculous' intervention. The authors reviewed cases involving end-of-life decisions over a 3-year period on the intensive care unit during which they had recourse to the Great Ormond Street Hospital for Children National Health Service Trust's clinical ethics service, as neither extended discussions with medical teams nor local support mechanisms lead to resolution. <http://jme.bmj.com/content/early/2012/03/08/medethics-2011-100104.abstract>

### **The importance of saying goodbye to a loved one in a pain-free environment**

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2012;26(1):55-56. When a loved one is diagnosed with a terminal illness, it's devastating to everyone close to them. At these moments creating a pain free environment is essential, not just to the person receiving the medication, but also to those who love and care for them. In these situations pain is not just physical, it's emotional, and when people have to watch a loved one suffer, it amplifies the emotional pain they are already experiencing at the realization of losing them. As for the patient who is dying, they are experiencing pain and emotions on so many levels. They are watching their loved ones experience their emotional turmoil, but they are also coming to grips with having to say goodbye to everyone who ever meant anything to them. The physical pain is the most immediate and the easiest to understand and it also happens to be the simplest type of pain to deal with.

<http://informahealthcare.com/doi/abs/10.3109/15360288.2011.650356>

### **The meaning of parenteral hydration to family caregivers and patients with advanced cancer receiving hospice care**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 29 March 2012 – Patients and their family caregivers saw hydration as meaning hope and comfort. Hope was the view that hydration might prolong a life of dignity and enhance quality of life by reducing symptoms such as fatigue and increasing patients' alertness. Patients and caregivers also described hydration as improving patients' comfort by reducing pain; enhancing the effectiveness of pain medication; and nourishing the body, mind, and spirit. These findings differ from traditional hospice beliefs that dehydration enhances patient comfort, given that patients and their families in the study viewed fluids as enhancing comfort, dignity, and quality of life. Discussion with patients and families about their preferences for hydration may help tailor care plans to meet specific patient needs.

[http://www.jpsmjournal.com/article/S0885-3924\(11\)00773-1/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00773-1/abstract)

### **Short-stay, specialist beds in a U.K. teaching hospital as a model to integrate palliative care into the acute hospital culture**

*JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH*, 2012;42(1):8-14. Three short-stay beds were re-allocated to specialist palliative care as part of a pilot programme. This paper describes the first 100 admissions of patients with inadequately controlled symptoms or distress. Median pain and distress scores were both seven out of a maximum of 10, reducing to 3.5 and 0 after 48 hours. Median length of stay was five days; 77% of patients were discharged: 32% to home, 26% to a hospice or community hospital, 19% to their original ward for treatment and 23% died in the unit. A unit education ... attracted 600 staff members. Pain and distress were rapidly improved by brief, intense palliative care in a small onsite facility. The pilot programme also influenced the understanding of palliative care in the hospital, demonstrating what it offered patients, family and staff. It demonstrated effective, concurrent working alongside an active disease-management approach, and encouraged collaborative discussions about the goals of care. [http://www.rcpe.ac.uk/journal/issue/journal\\_42\\_1/levack.pdf](http://www.rcpe.ac.uk/journal/issue/journal_42_1/levack.pdf)

Of related interest:

- *AGING WELL*, 2012;5(2):18. **'Integrating palliative medicine with dementia care.'** Healthcare professionals ... should offer a gradually changing blend of restorative, maintenance, and palliative care services as a patient's function and the goals of care shift. Familiarity with disease terminal trajectories is essential to know when to commence palliative care. It is preferable to request specialist advice early, especially when considering potentially invasive and possibly harmful diagnostics and therapeutic interventions. <http://www.agingwellmag.com/archive/031912p18.shtml>

## End-of-life care: The neglected core business of medicine

*THE LANCET*, 2012;379(9822):1171. Last week, a report into care of patients at the end of their lives drew attention to the lack of appropriate training in this area given to many doctors. Despite several reports and guidelines over the past few years on the importance of managing end-of-life care, knowledge and confidence among hospital doctors is still far from ideal when looking after those in the last few days, weeks, months, or even years of their lives. 'With Improving end-of-life care: Professional development for physicians,'<sup>1</sup> the Royal College of Physicians in the U.K. hopes to support hospital doctors in caring for people nearing death. Improving the quality of end-of-life care begins with recognition that the patient has reached the last phase of life, and acceptance by all (patient, carers, and medical staff) that supportive or palliative care is now the only option. In many cultures, this stage is never reached, often because of fear or non-acceptance of talking about death. Initiating conversations about death seems to be particularly difficult for doctors caring for those with non-malignant diseases. In general, open discussion with patients frequently does not happen until the last days of life, leading to most people dying in the acute hospital environment. Doctors must remember that while a few patients might choose to die on an acute medi-

cal ward, and sometimes it is unavoidable or unpredictable, most would choose to die in their familiar, and comforting, home. Identifying those patients in the end-of-life phase is only part of the problem.

[http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)60490-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60490-5/fulltext)

### Acceptance of dying: A discourse analysis of palliative care literature

*SOCIAL SCIENCE & MEDICINE* | Online article – 28 March 2012 – The subject of death denial in the West has been examined extensively in the sociological literature. However, there has not been a similar examination of its "opposite," the acceptance of death. This paper focuses on the theme of acceptance as integral to palliative care, which had sub-themes of acceptance as a goal of care, personal acceptance of healthcare workers, and acceptance as a facilitator of care. For patients and families, death acceptance is a goal that they can be helped to attain; for palliative care staff, acceptance of dying is a personal quality that is a precondition for effective practice. Acceptance not only facilitates the dying process for the patient and family, but also renders care easier. The analysis investigates the intertextuality of these themes with each other and with previous texts.

<http://www.sciencedirect.com/science/article/pii/S0277953612002341?v=s5>

1. 'Improving end-of-life care: Professional development for physicians – a report of a working group,' Royal College of Physicians, March 2012 (noted in Media Watch, 26 March 2012). <http://www.rcplondon.ac.uk/sites/default/files/improving-end-of-life-care.pdf>

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2012;307(12):124-1242. '**Cancer experts recommend introducing palliative care at time of diagnosis.**' A movement to recognize more realistic scenarios that follow a cancer diagnosis is encouraging the use of palliative care much earlier in the treatment course. This shift is noticeable in the provisional clinical opinion released by the American Society of Clinical Oncology<sup>1</sup> recommending that all patients with metastatic non-small cell lung cancer be offered palliative care along with standard cancer therapy beginning at the time of diagnosis. <http://jama.ama-assn.org/content/307/12/1241.extract>
  1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online (noted in Media Watch, 13 February 2012). <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>
- *SURGERY*, 2012;30(4):203-206. '**Medical and psychological aspects of palliative medicine.**' Palliative medicine no longer focuses on care of the dying only but is an integral part of the management of patients with a life-limiting illness. This article aims to give an overview of the principles of palliative medicine and guidance on management of particular, frequently seen symptoms, emergencies and end of life care. [http://www.surgeryjournal.co.uk/article/S0263-9319\(12\)00017-8/abstract](http://www.surgeryjournal.co.uk/article/S0263-9319(12)00017-8/abstract)

## Angels of mercy? The legal and professional implications of withdrawal of life-sustaining treatment by nurses in England & Wales

*MEDICAL LAW REVIEW* | Online article – 27 March 2012 – In circumstances where life-sustaining treatment appears merely to be drawing out the inevitable, it is usual practice for the healthcare team to withdraw aggressive life-sustaining measures, once agreement is reached with the patient and their family. In the absence of a specific body of law related to nurses taking the actions that withdraw life-sustaining treatment, the author discusses the probable legal response by considering parallel cases. Examining some of the circumstances in which doctors are allowed to take life, he argues that the legal dispensation by which doctors are permitted to perform these tasks rests largely on their identity as doctors rather than any distinctive feature of their activities themselves. This uniqueness means that medical law for nurses is quite distinct from that for doctors. While it may nevertheless give nurses practical exemption from the

legal consequences of their actions in withdrawal, it depends upon a judicial view that nurses are instruments of doctors. This judicial position is at odds with nurses' professional responsibilities, which envisage them as independent professionals liable for their own actions, inviting potentially adverse consequences from their professional registrar. <http://medlaw.oxfordjournals.org/content/early/2012/03/27/medlaw.fws007.abstract>

### Extract from *Medical Law Review* article

Common law gives doctors several defences to allegations of criminality or malpractice in taking the key actions that withdraw treatment and result in the patient's death; however, the legal defensibility of nurses undertaking this role has not been explored.

## Predictors of caregiver distress among palliative home care clients in Ontario: Evidence based on the interRAI Palliative Care

*PALLIATIVE & SUPPORTIVE CARE* | Online article – 22 March 2012 – Caregiver distress affects approximately one in five palliative care clients in the community [study participants]. This may lead to a number of adverse outcomes for the caregiver and client. The experience of distress is affected by client, caregiver, and agency characteristics that are readily identified by the interRAI PC assessment instrument. The present results point to the need for a care planning protocol that may be used on a targeted basis for clients experiencing or at elevated risk of caregiver distress. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8518883&fulltextType=RA&fileId=S1478951511000824>

Of related interest:

- *PROGRESS IN PALLIATIVE CARE* | Online article – 26 March 2012 – '**The effect of caring on post-bereavement outcome: Research gaps and practice priorities.**' This paper highlights the need to address two important gaps in understanding the effects of caregiving and bereavement: 1) caregivers' understandings and experiences of the anticipating and preparing for the death of the person for whom they are caring; and, 2) the relationship between caregivers' pre-death grief and distress and post-death adjustment. Caregivers relieve significant costs from the health system, and improved support, pre- and post-bereavement, will continue to benefit them as well as society. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000003>
- *PSYCHOTHERAPIE · PSYCHOSOMATIK · MEDIZINISCHE PSYCHOLOGIE* | Online article (in German) – 22 March 2012 – '**Family caregivers of palliative cancer patients: Health-related quality of life and care-related burden.**' This current evaluates support needs in family caregivers of palliative cancer patients. Family caregivers suffered of reduced social and emotional function. Female and older caregivers reported a stronger home care burden than male and younger caregivers. For female and older family caregivers of palliative cancer patients, home care is very burdensome. Female caregivers need, above all, psychosocial support, whereas older caregivers need the most support in a physical and social level. <https://www.thieme-connect.com/ejournals/abstract/ppmp/doi/10.1055/s-0032-1304601>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online report – 29 March 2012 – '**MPs back guidance on assisted suicide in first Commons debate for 40 years.**' The House of Commons has thrown its overwhelming support behind guidelines on assisted suicide from the Director of Public Prosecutions, in the first full debate on assisted dying to take place on the floor of the U.K.'s elected chamber since 1970. MPs taking part in the debate, which was allowed by the Commons backbench business committee, also backed the further development of specialist palliative care and hospice provision. <http://www.bmj.com/content/344/bmj.e2424>
- *JOURNAL OF BIOETHICAL INQUIRY* | Online article – 21 March 2012 – '**The moral difference or equivalence between continuous sedation until death and physician-assisted death: Word games or war games? A qualitative content analysis of opinion pieces in the indexed medical and nursing literature.**' Continuous sedation until death (CSD) ... often provokes medical-ethical discussions in the opinion sections of medical and nursing journals. Some argue that CSD is morally equivalent to physician-assisted death (PAD), that it is a form of "slow euthanasia." Arguments pro and contra a moral difference refer basically to the same ambiguous themes, namely intention, proportionality, withholding artificial nutrition and hydration, and removing consciousness. This demonstrates that the debate is first and foremost a semantic rather than a factual dispute... Given the prevalent ambiguity, the debate on CSD appears to be a classical symbolic struggle for moral authority. <http://www.springerlink.com/content/u8857m5t84ug846w/>
- *JOURNAL OF LAW, MEDICINE & ETHICS*, 2012;40(1):57-65. '**Physicians should "assist in suicide" when it is appropriate.**' Palliative care and hospice should be the standards of care for all terminally ill patients. The first place for clinicians to go when responding to a request for assisted death is to ensure the adequacy of palliative interventions. Although such interventions are generally effective, a small percentage of patients will suffer intolerably despite receiving state-of-the-art palliative care, and a few of these patients will request a physician-assisted death. Patient, family, and clinicians should search for the least harmful way to respond to intolerable end-of-life suffering in ways that are effective and also respect the values of the major participants. A system that allows an open response to such cases ultimately protects patients by ensuring a full clinical evaluation and search for alternative responses, while reinforcing the need to be responsive and to not abandon. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2012.00646.x/abstract>
- *JOURNAL OF LAW, MEDICINE & ETHICS*, 2012;40(1):66-84. '**Are the distinctions drawn in the debate about end-of-life decision making "principled"? If not, how much does it matter?**' The current ethical-legal consensus – prohibiting assisted suicide and euthanasia, but 1) allowing patients to forgo all life-saving treatment; and, 2) permitting pain relief that increases the risk of death – is a means of having it both ways. This is how we often make "tragic choices." <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2012.00647.x/abstract>
- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2012;26(1):30-39. '**Review of palliative sedation and its distinction from euthanasia and lethal injection.**' A number of intolerable and intractable symptom burdens can occur during the end of life period that may require the use of palliative sedation. When patients receive palliative sedation, the continued use of hydration and nutrition becomes an issue of consideration and there are contentious bioethical issues involved in using or withholding these life-sustaining provisions. A general understanding of biomedical ethics helps prevent abuse in the practice of palliative sedation. Although there are some similarities in the pharmacotherapy of palliative sedation, euthanasia, physician-assisted suicide, and lethal injection, there is a difference in how the drugs are administered with each practice. <http://informahealthcare.com/doi/abs/10.3109/15360288.2011.650353>

## Worth Repeating

### **Ethical issues for hospice volunteers**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2009;25(6):458-462. Health care professionals usually receive professional education in ethics, but the half million hospice volunteers in the U.S. may receive only brief training that is limited to confidentiality and the volunteer role. The purpose of this study was to explore ethical issues hospice volunteers confront in their work. Interviews with 39 hospice volunteers were conducted, audio recorded, transcribed, and analyzed using qualitative methods. Prominent themes were dilemmas about gifts, patient care and family concerns, issues related to volunteer roles and boundaries, and issues surrounding suicide and hastening death. Suggestions for training include discussions of ethics after initial training once volunteers had confronted ethical issues, with special emphasis on strategies for negotiating their uneasy role positioned between health care professional and friend.

<http://ajh.sagepub.com/content/25/6/458.short>

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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.

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