# 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.

# 24 January 2011 Edition | Issue #185



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

Compiled & Annotated by Barry R. Ashpole

U.S. study among general practitioners: Scroll down to <u>Specialist Publications</u> and 'Discussing end-of-life issues in the last months of life' (p.9), published in the *Journal of Palliative Medicine*.

# Canada

Stark contrast with sensitive and compassionate care

#### No room at morgue for wife, man told

QUEBEC | *Montreal Gazette* – 22 January 2011 – A 'phone call direct from the Montreal General Hospital's morgue the same day his wife died in palliative care was the very last thing Jonathan Izenberg expected. But, Izenberg says, he got such a jarring call at home about 9:30 p.m. on 14 January ... which he paraphrased as 'We're busy. What can you do? When's the funeral home coming? Because we're overcrowded.' "I couldn't believe my ears," Izenberg said, given that he'd put a funeral home in charge of those arrangements more than 12 hours earlier. His loss was very fresh; Danica Krapec, 53, had succumbed to cancer at 7 a.m. Ian Popple, a spokesperson for the hospital, said any call from the morgue to next of kin "is not a common event," and "we'll certainly be looking into this." It's also a stark contrast with the sensitive and compassionate care Krapec received earlier. <a href="http://www.montrealgazette.com/news/todays-paper/room+morgue+wife+told/4148496/story.html">http://www.montrealgazette.com/news/todays-paper/room+morgue+wife+told/4148496/story.html</a>

Parliamentary Committee on Palliative & Compassionate Care

#### Canada needs end-of-life care plans: MPs

CANOE.CA | Online report – 21 January 2011 – MPs looking at compassionate end-of-life care say their final report will recommend national suicide prevention and palliative care plans. They're also considering ways to make it a legal right for Canadians to have access to long-term care, palliative care and home care when they're sick. NDP [New Democratic Party] MP Joe Comartin, Conservative MP Harold Albrecht and Liberal MP Michelle Simson lead a committee of MPs looking at suicide prevention, elder abuse, palliative care and disability issues. The suicide prevention and palliative care strategies would likely need national co-ordinating bodies, they said. <a href="http://cnews.canoe.ca/CNEWS/Politics/2011/01/21/16984366.html">http://cnews.canoe.ca/CNEWS/Politics/2011/01/21/16984366.html</a>

**N.B.** Parliamentary Committee on Palliative & Compassionate Care website: http://www.pcpcc-cpspsc.ca/index\_files/Page300.htm

# Objections to 15-bed hospice are not restricted to a single cultural community

BRITISH COLUMBIA | Vancouver Sun (OpEd) - 17 January 2011 - I was introduced to Helena [Tang] through Dr. Romayne Gallagher, the founding director of the palliative care division at the University of B.C. Gallagher, one of the most remarkable physicians in the country, has devoted her working life to the promotion of palliative care. Central to her work is the frank and honest discussion of death and dving, and the cultural taboos that surround them. Back in 2002, Gallagher and I had talked about doing stories involving palliative care patients, but the problem was finding someone who would agree to be the subject of them. One day, after weeks of trying, Gallagher phoned to say she might have a suitable candidate. It was Helena. I went out to meet her, and my first thought was, why would a woman as shy and quiet as Helena agree to be a subject in so public a forum? Well, Helena said, before she had come to Canada, she had been a palliative care nurse herself in Hong Kong. She witnessed first-hand the fear of death there, and the reluctance to talk about it. She wanted to do the stories with us, she said, to help break those taboos, to bring death and dying out into the open where they could be discussed without fear. Last week, those old cultural fears burst out into the open when a group of condominium owners on the UBC [University of British Columbia] campus complained that a 15-bed hospice was to be built near their building. The owners were Chinese. They had brought their taboos with them.http://www.vancouversun.com/health/C olumn+Objections+hospice+restricted+singl e+cultural+community/4123006/story.html

# Hospice critics don't speak for us, Chinese community says

GLOBE & MAIL | Online report – 18 January 2011 - Distancing themselves from condo owners who have opposed a hospice on cultural grounds, Chinese community representatives ... held a press conference to say the residents' views do not accurately represent Chinese culture or beliefs. The group – which included an academic, a feng shui practitioner and the executive director of the National Congress of Chinese Canadians - said while residents' concerns may reflect some aspects of Chinese folklore, it is false to claim that living next door to a hospice is incompatible with Chinese culture. http://www.theglobeandmail.com/news/national/br itish-columbia/hospice-critics-dont-speak-for-uschinese-community-says/article1875103/

# Gabriel Yiu: Why we called a news conference on the UBC hospice controversy

BRITISH COLUMBIA | Straight.com – 23 January 2011 – On a Cantonese open-line radio show discussing the UBC hospice controversy, a caller ridiculed community leaders who called a news conference responding to the issue. The caller thought that it was an overreaction triggered by the English media's coverage of the news. Since I'm the convener of the news conference, I would like to share my thoughts with you.

http://www.straight.com/article-369714/vancouver/gabriel-yiu-why-we-callednews-conference-ubc-hospice-controversy

From Media Watch dated 17 January 2011:

BRITISH COLUMBIA | CTV News – 13 January 2011 – 'Fear of ghosts spawns protest against ... hospice.' Asian condo owners at the University of B.C. are protesting plans to build a hospice nearby, saying they're afraid of plummeting property values – and ghosts. Janet Fan, who owns a unit in a high rise on campus, has started a petition against plans for a 15-bed hospice in the empty lot next door. "Eighty per cent of the residents in this building are Asian, and 100% of them are very upset," she told CTV News. Tan says the ... residents are wary of having the dying so close to home.http://www.ctvbc.ctv.ca/servlet/an/local/CTVNews/20110113/bc\_ubc\_hospice\_110113/20110113?hub=BritishColumbiaHome

# U.S.A.

#### **Editorial**

#### Little progress on end-of-life care

MINNESOTA | Star-Tribune (Minneapolis-St. Paul) – 21 January 2011 – Twenty years ago, a high-profile legal battle over a dying elderly Minnesota woman ignited a national life-support debate. This week, as a similar case garnered headlines in the state, it became sadly clear that we are no closer to agreeing on the best answer for the hard question Helga Wanglie's case posed: "What's the right thing to do when doctors decide that medical care is futile or unethical but the patient's loved one wants to preserve even the smallest spark of life?" If anything, despicable "death panel" demagoguery has made any end-of-life care issue virtually untouchable. Given that volatile political climate, the unusual legal action initiated recently by Park Nicollet's Methodist Hospital is both courageous and commendable. Doctors caring for 85-yearold Albert Barnes ... are seeking to replace his wife with a new guardian, arguing that she is no longer acting in his best interest and "fails to advocate as a competent health care agent." According to a court petition ... Barnes has been in a "non-communicative, vegetative state since 2005" and suffers from a long list of serious conditions: endstage respiratory distress, end-stage kidney failure, end-stage dementia, a progressive neurological disorder, recurrent pneumonia and infections. He is dependent on a

ventilator and a feeding tube. Court records indicate that Lana Barnes, 56, moves her husband from hospital to hospital, shopping for a doctor to agree that her husband can be cured with treatments that often have already been tried.

http://www.startribune.com/opinion/editorials/114394124.html?elr=KArksLckD8EQDUoaEyqyP4O:DW3ckUiD3aPc: Yyc:aUvDEhiaE3miUsZ

# Professional mediators help resolve elder-care issues

WASHINGTON POST | Online report - 22 January 2011 – The elderly man became increasingly alarmed as the battles among his grown children grew acrimonious. His two daughters, worried that he wasn't taking proper care of himself, wanted him to move to a retirement community. His three sons insisted he could manage in his own home. At a family meeting, their father made a jarring announcement: "I'm nearing the end of my life. and you are making me so unhappy that it might be easier if I killed myself and ended the fighting." His threat shocked the warring siblings into resolving their dispute, according to lawyer Karolyn Blume, who was present as a new kind of geriatric specialist: an elder-care mediator. http://www.mercurynews.com/bay-arealiving/ci 17140454?nclick check=1

MINNESOTA | Star-Tribune (Minneapolis-St. Paul) – 19 January 2011 – 'Wrenching court case: Doctors vs. patient's wife.' Al Barnes has been in eight hospitals in the past 10 months. His diagnoses include end-stage respiratory distress, renal failure, dementia and other maladies. Now the 85-year-old ... is at the center of a wrenching and unusual court struggle over who will control his medical care. A doctor ... will go to court ... seeking to replace Barnes' wife with a substitute decision-maker ... arguing that she is making futile and reckless decisions to prolong her husband's life.http://www.startribune.com/lifestyle/health/114181609.html?elr=KArksi8cyaiUo8cyaiUiD3aPc: Yyc:aU7DYaGEP7vDEh7P:DiUs

## 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.

# A final resting place at sea

MASSACHUSETTS | Boston Globe – 20 January 2011 – Waves gently slapped the sides of the boat as Nancy Mastrangelo's children and grandchildren, bundled against the mid-December chill, knelt on the bow one at a time to drop handfuls of her ashes into Massachusetts Bay. Mastrangelo, 78 ... died the week before, after a battle with cancer – just a few months after her husband's ashes were scattered at sea. "She wanted to be with him," said her daughter Wendi Mastrangelo. The Mastrangelos are among a growing number of people choosing to have their cremated remains, or even their bodies, released into the sea – rather than having them buried in a cemetery or spending eternity in an urn. The local office of the Environmental Protection Agency received 70 filings for New England burials at sea last year, up from just five in 2005. http://www.boston.com/business/articles/2011/01/20/as\_cremations\_rise\_ocean\_burials\_also\_gain/

#### **U.S. Centers for Disease Control & Prevention**

# Many U.S. hospices provide alternative therapies: Report

U.S. NEWS | Online report – 19 January 2011 – Nearly 42% of U.S. hospices offer some form of alternative medicine end-of-life care services. Support group therapy sessions are also available at 69% of such facilities, while music therapy is an option at about 62% of these end-of-life centers. Among hospices offering complementary and alternative therapies, pet therapy was available at nearly 59%, and meditative services (such as guided imagery or relaxation techniques) were provided by almost 53%. Prior research has suggested that although complementary and alternative therapies are not commonly covered by medical insurance, these services can help improve a critically ill patient's quality of life by alleviating symptoms of pain and anxiety, while helping to provide comfort and improve mood. <a href="http://health.usnews.com/health-news/family-health/pain/articles/2011/01/19/many-us-hospices-provide-alternative-therapies-report">http://health/pain/articles/2011/01/19/many-us-hospices-provide-alternative-therapies-report</a>

#### **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.

# U.S. laws a barrier for advance directives: Study

REUTERS | Online report - 18 January 2011 – U.S. laws surrounding advanced planning for end-of-life care set up too many practical roadblocks. In a study of advance directive laws across all U.S. states. researchers found that the documents used in end-of-life planning were written in legalese that the average American would be hard-pressed to understand. And most states, the study found, had practical restrictions that could make it difficult for many people to complete an advance directive. The study comes as Congress debates the future of health care reform, a debate that has included false rumors about "death panels" that would determine which Americans would receive care at the end of life. Among the most affected by existing laws would be people with limited literacy and those in nursing homes or other institutions who do not have family or friends, the researchers report in the Annals of Internal Medicine [see sidebar]. Advance directives are legal documents that allow people to state their wishes for end-of-life care, in the event they become too sick to make their own medical decisions. One example is a "living will," which spells out the types of life-prolonging measures a person does or does not want - whether, for instance, you want to be put on a ventilator if you cannot breathe on your own, or if you want doctors to attempt resuscitation if your heart stops. A 2007 Harris poll found that about two in five Americans have such living wills. Another type of advance directive is medical power of attorney, where people choose a "proxy" who will make healthcare decisions for them if they cannot do so

themselves. States each have their own laws on advance directives. But a common thread is that the laws set up obstacles that could deter people from end-of-life planning, according to the researchers on the new study. <a href="http://in.reuters.com/article/idlNTRE70">http://in.reuters.com/article/idlNTRE70</a> G65K20110117

#### Extract from Annals of Internal Medicine

Legal and content-related barriers included poor readability (that is, laws in all states were written above a 12th-grade reading level), health care agent or surrogate restrictions (for example, 40 states did not include same-sex or domestic partners as default surrogates), and execution requirements needed to make forms legally valid (for example, 35 states did not allow oral advance directives, and 48 states required witness signatures, a notary public, or both). Vulnerable populations most likely to be affected by these barriers included patients with limited literacy, limited English proficiency, or both who cannot read or execute advance directives: same-sex or domestic partners who may be without legally valid and trusted surrogates; and unbefriended, institutionalized, or homeless patients who may be without witnesses and suitable surrogates.

#### **Specialist Publications**

Of particular interest:

'Discussing end-of-life issues in the last months of life' (p.9), published in the *Journal of Palliative Medicine*.

ANNALS OF INTERNAL MEDICINE | Online article – 17 January 2011 – 'Lost in translation: The unintended consequences of advance directive law on clinical care.' Unintended negative consequences of advance directive legal restrictions may prevent all patients, and particularly vulnerable patients, from making and communicating their end-of-life wishes and having them honored. These restrictions have rendered advance directives less clinically useful. <a href="http://www.annals.org/content/154/2/121.abstract?sid=2e5f0c19-8a5e-4915-bba6-3529c55991ae">http://www.annals.org/content/154/2/121.abstract?sid=2e5f0c19-8a5e-4915-bba6-3529c55991ae</a>

#### Of related interest:

PENNSYLVANIA | University of Pittsburgh School of Medicine and the Graduate School of Public Health press release – 19 January 2011 – 'End-of-life decisions take longer if patient hasn't shared wishes with family.' Family caregivers who had not discussed life support measures with critically ill patients took nearly two weeks longer to decide to forego further medical intervention than those who had prior conversations about the issues, according to researchers. <a href="http://www.eurekalert.org/pub\_releases/2011-01/uops-pse011911.php">http://www.eurekalert.org/pub\_releases/2011-01/uops-pse011911.php</a>

# International

#### Palliative care in developing countries

#### New hope for terminal patients

BANGLADESH | bdnews24.com – 22 January 2011 – Terminally ill patients experiencing severe pain and discomfort can seek palliative care to lessen their sufferings and minimize the agony of their loved ones, experts say. They suggest integrating palliative care in the national health policy and involving community people to make the best use of the concept which is new in Bangladesh. Experts from different countries, in Dhaka to attend an international conference on palliative care, also offer ways to improve quality of life towards the end and reduce the cost of medical services. "Palliative care is very much effective in a resource-starved country like Bangladesh where many people do not see a doctor until the disease becomes incurable," David Praill, co-chair, World Palliative Care Alliance [said]. "The country needs to integrate it (palliative care) into national policy," he said, adding, "Of course, that would not cure the disease, but it can substantially lessen a patient's suffering." <a href="http://www.bdnews24.com/details.php?id=185153&cid=2">http://www.bdnews24.com/details.php?id=185153&cid=2</a>

#### U.K. home care described as a 'lottery'

U.K. | United Press International – 21 January 2011 – A consumer group says it has found huge discrepancies in the availability and cost of home healthcare in the U.K. based on where people live. Describing it as a "postcode lottery," the group Which? found elderly people living just a few miles apart can pay widely differing amounts for home care, which includes help with dressing, washing and bathing, with some couples paying more than \$1,400 a month. Some local authorities and councils are charging more than \$30 an hour for home care while others provide it for free, Which? said. The group also found only a handful of councils are making care available for all who need it, with 70% of authorities only providing for those with substantial or critical needs. <a href="http://www.upi.com/Top\_News/World-News/2011/01/21/UK-home-care-described-as-a-lottery/UPI-93991295631315/">http://www.upi.com/Top\_News/World-News/2011/01/21/UK-home-care-described-as-a-lottery/UPI-93991295631315/</a>

#### Do not resuscitate orders kept secret from patients, station claims

DENMARK | Copenhagen Post – 18 January 2011 – Doctors violate healthcare legislation when they fail to inform hospital patients that they will not be resuscitated in the event of emergency medical situations, experts say. In some cases decisions not to resuscitate are made against the patients' wishes and without families being informed. "Not informing the patients like this is clearly illegal," [says] Kent Kristensen, a legal expert from the University of Southern Denmark. "It is a violation of the patient's right to self-determination." <a href="http://www.cphpost.dk/news/national/88-national/50826-do-not-resuscitate-orders-kept-secret-from-patients-station-claims.html">http://www.cphpost.dk/news/national/88-national/50826-do-not-resuscitate-orders-kept-secret-from-patients-station-claims.html</a>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

U.K. | The Independent (London) – 24 January 2011 – 'Dr. Ann McPherson: The GP who believes she should be allowed help to end her life.' Some accuse her of advocating "medical killing." Others claim that she is destroying the trust between doctors and patients. But Ann McPherson is not deterred as she prepares to step up her campaign to change the law on assisted dying – at the same time as preparing for her own death. As the joint author of a million-selling guide to teenage health ... and the founder of the first – hugely successful – website where patients could share experiences of disease she is one of the best known GPs in the country. <a href="http://www.independent.co.uk/news/people/profiles/dr-ann-mcpherson-the-gp-who-believes-she-should-be-allowed-help-to-end-her-life-2192465.html">http://www.independent.co.uk/news/people/profiles/dr-ann-mcpherson-the-gp-who-believes-she-should-be-allowed-help-to-end-her-life-2192465.html</a>

Cont.

- SWITZERLAND | Swissinfo.cha 20 January 2011 'Suicide appeal dismissed by European court.' The European Court of Human Rights ... dismissed an appeal by the 58-year-old man, who after two suicide attempts in 2004 turned to Dignitas, a Swiss assisted suicide organisation. However, no doctor was prepared to write a prescription for the necessary 15 grams of sodium pentobarbital. He then turned to the cantonal authorities ... and the government to try to obtain the drug without a prescription. He was turned away, the rejection then confirmed by the federal court. <a href="http://www.swissinfo.ch/eng/news\_digest/Suicide\_appeal\_dismissed\_by\_European\_court.html?cid=29292862">http://www.swissinfo.ch/eng/news\_digest/Suicide\_appeal\_dismissed\_by\_European\_court.html?cid=29292862</a>
- U.K. | Press Association 20 January 2011 'Warning over 'assisted suicide' law.' The law on assisted suicide could lead to the worst possible "botched" death and must be changed, an inquiry has heard. Current guidelines, issued by the Director of Public Prosecutions last year, are "particularly bad," creating confusion and uncertainty, Baroness Warnock said. <a href="http://www.google.com/hostednews/ukpress/article/ALeqM5g02wIJBLXCiZCkcjBlOuL3Y-n5Ng?docld=N0246461295447248280A">http://www.google.com/hostednews/ukpress/article/ALeqM5g02wIJBLXCiZCkcjBlOuL3Y-n5Ng?docld=N0246461295447248280A</a>
- FRANCE | The Connexion 19 January 2011 'France considers euthanasia law.' French senators have made a first step towards legalising assisted suicide, but the proposed law looks unlikely to go much further. The senate's social affairs committee voted by 25 votes to 19 in favour of the euthanasia bill, which would allow a "fast and painless" death for patients in the "advanced" stage of a serious illness. <a href="http://www.connexionfrance.com/french-senate-euthanasia-assisted-suicide-law-vote-12431-view-article.html">http://www.connexionfrance.com/french-senate-euthanasia-assisted-suicide-law-vote-12431-view-article.html</a>
- ISRAEL | Ynet News 19 January 2011 'Knesset rejects euthanasia law proposal.' In a preliminary reading, the Knesset has rejected a law proposal that would have allowed terminally ill patients to take drugs that would cause them to die. <a href="http://www.ynetnews.com/articles/0,7340,L-4016034,00.html">http://www.ynetnews.com/articles/0,7340,L-4016034,00.html</a>
- BLOOMBERG BUSINESS WEEK | Online report 18 January 2011 'Suicide tourists make Swiss uneasy as terminally ill seek death.' Switzerland is the destination of choice for people from abroad who want to die. The office of the country's top legal official is pushing to change that. More than 25% of the 380 assisted suicides in Switzerland during 2009 involved foreigners, most of whom died after drinking water laced with a lethal dose of barbiturates. Former Justice Minister Eveline Widmer-Schlumpf ... has proposed making the practice more difficult by demanding oversight by doctors who aren't connected with one of the country's four right-to-die organizations. Assisted suicide has been legal in Switzerland since 1942. <a href="http://www.bloomberg.com/news/2011-01-18/suicide-tourists-make-swiss-minister-uneasy-as-terminally-ill-seek-escape.html">http://www.bloomberg.com/news/2011-01-18/suicide-tourists-make-swiss-minister-uneasy-as-terminally-ill-seek-escape.html</a>

# **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: <a href="http://www.mhpcn.ca/Physicians/resources.htm">http://www.mhpcn.ca/Physicians/resources.htm</a> (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.)

#### Palliative care in heart failure: Addressing the largest care gap

CURRENT OPINION IN CARDIOLOGY | Online article – 19 January 2011 – Heart failure is a chronic, fatally progressive and incurable condition characterized by periods of apparent stability interspersed with acute exacerbations. Treatment models have historically emphasized management of acute exacerbations of cardiovascular disease, during which end-of-life issues figure frequently and prominently, though in a setting that is inappropriate to address the comprehensive needs of patients and their families. Consequently, in comparison to patients with malignancy, heart failure patients at the end of life are less likely to access palliative resources, and more likely to access in-patient care and cardiovascular procedures. This report summarizes many of these suggestions and outlines future directions for the expansion and improvement of this critical need for heart failure patients. <a href="http://journals.lww.com/co-cardiology/Abstract/publishahead/Palliative care">http://journals.lww.com/co-cardiology/Abstract/publishahead/Palliative care in heart failure addressing the.99830.aspx</a>

From Media Watch dated 10 January 2011:

ONCOLOGIST | Online article – 6 January 2011 – 'Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center.' The authors previously found that the term "palliative care" was perceived by oncology professionals as a barrier to early patient referral. [The findings of this study indicate that] ... the name change to supportive care was associated with more inpatient referrals and earlier referrals in the outpatient setting. <a href="http://theoncologist.alphamedpress.org/future/16.1.dtl">http://theoncologist.alphamedpress.org/future/16.1.dtl</a>

From Media Watch dated 5 April 2010:

- CANADIAN JOURNAL OF CARDIOLOGY, 2010;26(3):135-141. 'End-of-life planning in heart failure: It should be the end of the beginning. Recommendations are made [in the Canadian Heart Health Strategy & Action Plan<sup>1</sup>] central to which is the need to reframe CVD [cardiovascular disease] as a condition ideally suited to a chronic disease management approach. Replacement of the term 'palliative care' with the term 'end-of-life planning and care' is proposed.

  http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=1&atlKy=9419&isuKy=907&isArt=t&fromfold=Current Issue
  - 1. Canadian Heart Health Strategy & Action Plan website: http://www.chhs-scsc.ca/

#### Pain management in developing countries

#### Opioid use at the end of life: Working out the physician's intentions

INDIAN JOURNAL OF MEDICAL ETHICS, 2011;8(1):39-41. Opioid use at the end of life has been a matter of debate among some doctors because of its perceived life-shortening effects. Opioid medications such as Morphine, Tramadol, Codeine, Oxycodone and Fentanyl are effective in relieving pain, but can also cause death through respiratory depression. Because of this possibility, it has been argued that doctors utilise such medications at the end of life if the premature death of the patient is intended. Because of this claim and the fact that euthanasia and physician-assisted suicide are illegal in most countries, many physicians are reluctant to use these medications for fear of having their intentions questioned. The result is that physicians fail in their duty of care because patients suffer unnecessarily though effective and proven treatments exist. This is a concern, given that studies have discounted the fear that the use of opioids at the end of life always or almost always precipitates death. Physicians using opioids in end-of-life care may find their decisions guestioned even when the justification for the use of these medications is documented, the drugs are used in accordance with established guidance, and a review of opioid administration and the events leading to it makes the physician's intention clear. The problem, therefore, is to make sure that the physician's intentions are beyond reproach. Yet understanding intention continues to be a thorny problem as evidenced by the continued debates on euthanasia in the courts. http://ijme.in/191ar39.html

#### Nationwide study among general practitioners

# Discussing end-of-life issues in the last months of life

JOURNAL OF PALLIATIVE MEDICINE | Online article – 21 January 2011 – The authors examined 252 patients who died non-suddenly, 38% of whom died of cancer, and 86% of whose treatment goal was palliative care. Their findings show that GPs [General Practitioners] often waited until very close to death before they discussed end-of-life issues with patients, and discussed spiritual and social issues less than physical symptoms, diagnoses, and psychological problems. In 74% of cases, the GPs were informed of their patients' preferred place of death; and 8 out of 10 patients with known preferences for place of death, died there. Being diagnosed with cancer was associated with a higher frequency of discussing all 10 end-of-life issues than diagnosis with other (non-cancer) conditions, but this is a state of mind the authors did not explore in this study. <a href="https://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0312">https://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0312</a>

# **Editorial**

# Who should palliative medicine be asked to see?

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(1):2-3. Now that the value of palliative care has been demonstrated, a pressing question is for whom are the specialist resources best deployed. There is a general sense that palliative medicine is underutilized in hospitals as well as in the community, even as successful teams complain they can barely cope with the volumes of patients and families they now see, and the amount of money available decreases. In an industrial model, such questions are answered rationally and dispassionately. One proxy has been the percent of deaths seen by the palliative care team. In this issue, one hospital found that 25% to 37% of such cases were seen – a likely marker of under-utilization. Yet, if the expertise of palliative medicine is the relief of suffering associated with serious illness, the number of deaths in a hospital is likely to underestimate need; the denominator will be too small. Most people suffering with advanced disease survive to discharge – they are just readmitted frequently in an ever increasing tempo until a final "terminal" admission. In addition, one can imagine that, with application of terminal care pathways like the Liverpool Pathway, 2 it might be that most deaths are well managed without specialist attention. It will be the people who are likely to die in the foreseeable future (months to years) that most need specialist expertise. The Center to Advance Palliative Care has stepped into the breach with a set of triggers that, applied at admission, would be expected to capture more of those who need palliative care during the hospitalization. http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9745

- JOURNAL OF PALLIATIVE MEDICINE, 2011;14(1):17-25 'Identifying patients in need of a
  palliative care assessment in the hospital setting.' Workforce shortages, late referrals, and
  palliative care program resource constraints present significant barriers to meeting the needs of
  hospitalized patients facing serious illnesses. The consensus panel developed primary and
  secondary criteria for two checklists one to use for screening at the time of admission and one for
  daily patient rounds. <a href="http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0347">http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0347</a>
  - N.B. Noted in Media Watch dated 13 December 2010.
- 2. Liverpool Care Pathway website: <a href="http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/">http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/</a>

#### 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. <a href="https://www.pcn-e.com/community/">https://www.pcn-e.com/community/</a>

# The palliative care interdisciplinary team: Where is the community pharmacist?

JOURNAL OF PALLIATIVE MEDICINE, 2011;14(1):7-11. In hospice and palliative care units in hospitals, clinical pharmacists are part of the interdisciplinary team and work closely with other health care professionals. However, this active involvement in the palliative care team is not reflected in the community setting, despite the community pharmacist being one of the most accessible professionals in the community, and visiting a community pharmacist is convenient for most people, even those who have limited access to private or public transport. This may be due to a general lack of understanding of skills and knowledge that particular health professionals bring to the interdisciplinary team, a lack of rigorous research supporting the necessity for the community pharmacist's involvement in the team, or it could be due to professional tensions. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0369

#### Return home at the end of life: Patients' vulnerability and risk factors

PALLIATIVE MEDICINE | Online article – 19 January 2011 – Most authors consider that the indispensable conditions for a return home are the patient's desire and presence of the family and caregivers with the appropriate skills. The aim of this study is to clarify how the return home is influenced by the vulnerability of the patient at the end of life, and by that of the family and caregivers. The authors carried out a multi-centric, observational, prospective, exhaustive and longitudinal epidemiological study including 146 patients hospitalized at the end of their life and desiring to return home. For these patients the caregivers respected their freedom to choose to die at home in over half the cases (56%). Their overall vulnerability (personal, family context and caregivers) had a significant influence on the return home. This overall vulnerability was in fact identified as applying in 40% of the clinical situations, and made the possibility of a return home 50% less likely. http://pmj.sagepub.com/content/early/2011/01/14/0269216310385876.abstract

#### Hope beyond (redundant) hope: How chaplains work with dying patients

PALLIATIVE MEDICINE, 2011;25(1):21-25. This study ... aimed to understand how palliative care chaplains work with patients at the point when it has been decided to cease active treatment, the point where they risk losing hope and falling into despair. The author identified four organic moments in the chaplain-patient relationship, each moment being a discernable development in the chaplain's being-with the patient: 'evocative presence,' 'accompanying presence,' 'comforting presence,' and 'hopeful presence.' The author represents the four moments as a theory of 'chaplain as hopeful presence' and offers a description of the way in which the quality of presence can facilitate patients to develop 'a hopeful manner' in which hope is reconfigured into an attribute of being. http://pmj.sagepub.com/content/25/1/21.abstract

# 'How do you tell someone with cancer that all hope has gone?'

U.K. | Daily Telegraph – 17
January 2011 – Doctors can
be far too brutal in their
approach to dying patients, as
Olga Maitland discovered
when her younger sister
became terminally ill.
http://www.telegraph.co.uk/he
alth/8257911/How-do-youtell-someone-with-cancerthat-all-hope-has-gone.html

# Assisted (or facilitated) death

Representative sample of recent articles, etc:

BOSTON COLLEGE INTERNATIONAL & COMPARATIVE LAW REVIEW, 2011;33(2):289-304. 'From "personal autonomy" to "death-on-demand": Will Purdy v. DPP [Director of Public Prosecutions] legalize assisted suicide in the U.K.?' In July 2009 the House of Lords addressed the question of whether the legal framework governing assisted suicide constitutes an unjustifiable infringement on privacy rights. The court decided that question in the affirmative, and ... [the author] ... uses evidence of legal developments in other jurisdictions that have grounded the right to assisted suicide in personal autonomy to argue that the Purdy court's reasoning and the DPP's response to the decision paves the way for a gradual breakdown in restrictions on the practice. http://lawdigitalcommons.bc.edu/cgi/viewcontent.cgi?article=1013&context=iclr

# **Worth Repeating**

#### Patient advocacy

## Pre-school as palliative care

JOURNAL OF CLINICAL ONCOLOGY, 2008;26(22):3797-3799. One privilege of caring for children with cancer is witnessing the courage with which families face life despite the disease. We don't often think of attending pre-school as either palliative or as an act of courage; in this case, it was both. A courageous mother advocated for her child (Keshaun) to attend school, the care team facilitated school enrolment, and courageous teachers did more than simply accept him into their classroom. Even now several years later, we remain awestruck by the courage of his lower socioeconomic, high school-educated mother. She had the courage to repeatedly challenge the "wisdom" of many health care and school professionals with greater formal education than herself. She is the one who most effectively advocated for her son. We are overwhelmed by the courage of Keshaun's mother, Keshaun, and the teachers who accepted this challenge. If we want to deliver good palliative care to children, we need to follow their lead, even if that takes us to very unfamiliar territory ... even if that takes us to pre-school. http://jco.ascopubs.org/cgi/content/full/26/22/3797

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