### 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.

## 14 November 2011 Edition | Issue #227



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

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Paediatric palliative care: Scroll down to <u>Specialist Publications</u> and 'Confronting death in legal disputes about treatment-limitation in children' (p.8), published in the *Journal of Bioethical Inquiry*.

### **Canada**

#### Palliative Care Outreach Program

#### For Harold, the end was like 'coming home'

ONTARIO | Ottawa Citizen – 13 November 2011 – [Harold Nightingale's] story touched Dr. Margaret Farncombe, who established the Palliative Care Outreach Program (PCOP) in 1997, 10 years after she became a physician. The service is the largest of three in Ottawa that provide care and comfort for the terminally ill at home. Despite their rural address, Farncombe says she couldn't ignore ... [Harold & Josina Nightingales'] isolation and desperation. Her team of doctors, which now numbers five, makes palliative home care available around the clock, seven days a week. http://www.ottawacitizen.com/health/Harold+like+coming+home/5703042/story.html

From Media Watch dated 22 March 2010:

ONTARIO | Ottawa Citizen – 21 March 2010 – 'Struggling to fulfil his final wish.' Harold
Nightingale is looking for a doctor who will help him fulfil his last wish in life. That is to die as
peacefully and with as much dignity as possible at his [rural] Dunrobin home on the Ottawa River.
http://www.ottawacitizen.com/health/Struggling+fulfil+final+wish/2708233/story.html

From Media Watch dated 11 January 2010:

JOURNAL OF RURAL HEALTH, 2010;26(1):78-84. 'Issues in rural palliative care: Views from
the countryside.' Findings indicated that the diversity in rural communities requires tailored
approaches to palliative care that consider the geographic, cultural and health aspects of residents
in order to optimize care. <a href="http://www3.interscience.wiley.com/journal/123232436/abstract">http://www3.interscience.wiley.com/journal/123232436/abstract</a>

**N.B.** The 11 January 2010 Media Watch lists several articles from past issues of the weekly report on the issue of the provision and delivery of palliative care in rural areas.

#### Canadian Virtual Hospice

## City doctor honoured for terminal illness website

MANITOBA | Winnipeg Free Press – 10 November 2011 – Dr. Michael Harlos was presented with the Clinical Leadership Award ... by the Canadian IHealth Informatics Association. A senior official with the Winnipeg [Regional] Health Authority, and medical director of its palliative care programs ... Harlos [a self-taught web developer] led a team that conceived and designed [Canadian] Virtual Hospice ... [believed to be] the world's first website that directly linked the public with health care specialists online. <a href="http://www.winnipegfreepress.com/local/breakingnews/City-doctor-nonoured-for-terminal-illness-website-133623343.html">http://www.winnipegfreepress.com/local/breakingnews/City-doctor-nonoured-for-terminal-illness-website-133623343.html</a>

**N.B.** Canadian Virtual Hospice website: http://www.virtualhospice.ca/en US/Main+Site+Navigation/Home.aspx

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ LIFE NEWS.COM | Online report – 8 November 2011 – 'Poll: Canadians want palliative care, hospice, not euthanasia.' A new Environics poll ... finds Canadians would rather kill the pain of patients rather than patients themselves, as they support palliative care and hospice over euthanasia. 95% of respondents want the government to make palliative and hospice care for the dying a high (66%) or medium (29%) priority – making it clear Canadians want improved access to end of life care, but worry about the impact of legalized euthanasia on the elderly. In the poll 74% also said they worry that if the law against euthanasia changed, a significant number of elderly, sick and disabled persons would actually be euthanized without their consent. An overwhelming majority, 82%, opposed legalizing euthanasia when the patient does not consent. Of those, 64% are strongly opposed. http://www.lifenews.com/2011/11/08/poll-canadians-want-palliative-care-hospice-not-euthanasia/

### U.S.A.

#### An advance medical directive ... cannot anticipate the circumstances you will face

### They said my mother's 'time had come,' but what if they were wrong?

WASHINGTON POST | Online OpEd - 11 November 2011 - Clearly, a pattern was developing. I suspect it was this pattern of more frequent problems, her age and her general frailty that led the hospital's medical staff to unite behind the view that her "time had come" ... This time, at every turn, they resisted aggressive procedures ... depriving her of the opportunity to test the inevitability of her death. And I was denied the comfort and certainty of knowing I gave her that chance. Their opposition was based on a subjective judgment related to the quality of her life. But they could not quantify the decline she would experience in that quality if she recovered, other than to say that it could be between 1 and 20%. They made statements with the certitude of the converted: "Your mother's life is coming to an end." "Your mother is 'actively dying'" (a phrase without clear definition). She would live eight days beyond those statements. All along, the constant message from the palliative-care staff was that I had to accept a conclusion made inevitable by their judgment and actions. After saying definitively that my mother had "hours to live, no more than a day," her doctors increased her morphine, decreased her oxygen and eliminated nutrition and hydration. Stunningly, I was told emphatically that I had "no more to say about this" because my mother was "suffering" and her death was "imminent." Yet she lived five days more, sustaining her vital signs and oxygen saturation almost until the end. They were right when, on her last day, they said that they weren't God and couldn't know when she would die. Unfortunately, until then their actions and pronouncements had implied that their opinions were rooted in some unquestionable Divine Truth. http://www.washingtonpost.com/opinions/they-saidmy-mothers-time-had-come-but-what-if-they-were-wrong/2011/10/27/gIQAprBADN story.html

# IPAL-EM launches to improve palliative care in emergency medicine

CENTER TO ADVANCE PALLIATIVE CARE | Press release - 10 October 2011 - A new national initiative, IPAL-EM (Improving Palliative Care in Emergency Medicine) will integrate and increase the use of palliative care when seriously ill patients are admitted to the emergency department. Despite growing recognition of the role of the palliative care in emergency medicine, integration of the two can often seem like a challenge of cultures and mindset. Developed by an interdisciplinary team of experts, IPAL-EM will support both emergency and palliative care professionals and will act as the central U.S. hub for shared expertise, evidence, tools and resources. The goal is to promote a paradigm shift in the way that seriously ill patients, and their families, are cared for in the emergency setting.

http://www.eurekalert.org/pub\_releases/201 1-11/tmsh-ilt110411.php

N.B. IPAL-EM website: www.capc.org/ipal

## Palliative care team helps woman recover from third-degree burns

NORTH CAROLINA | Shelby Star - 10 November 2011 - Lucille Camp, 70, stood up from her wheelchair and took crutches under her arms. Then with help from her daughter, Sandy Johnson, and nurse, Judy Tate, Camp slowly put one foot in front of the other and walked across the room. "That's the most she's done." said her daughter. Johnson said her mother's fierce determination has kept her alive and improving since she suffered third-degree burns over half her body in a fire 11 January 2009. Her mother was taken to Winston-Salem, where the doctor prepared the family for the worst. "The doctor told us she wouldn't make it the first 24 hours," Johnson said. "I said, 'You don't know my mom and her maker." Her mother survived and has continued to amaze her doctors, but her recovery has not been without its setbacks. Helping Camp overcome the challenges of her recuperation is the team from Palliative Care Cleveland County. http://www.shelbystar.com/news/camp-59949recover-lucille.html

#### Should I stay or should I go? What religion says about pulling the plug

FORBES | Online article – 10 November 2011 – In the past 30 years, medical ethicists have put more emphasis on patient autonomy and less on physician paternalism. As long as we can think for ourselves, we all have a state and federal constitutional right to refuse medical treatment; it stems from the right to privacy and liberty. But we have to say what we want. Otherwise, under state laws, medical facilities may refuse to end life-support. Some religious traditions ... advocate an uncompromising commitment to the preservation of human life under virtually all circumstances, regardless of prognosis, cost, the wishes of a family or the quality of life that may result. Other religions ... emphasize the right to die with dignity, which would allow patients and families to help decide when quality of life is so diminished that it justifies withholding or ending life-support. <a href="http://www.forbes.com/sites/deborahljacobs/2011/11/10/should-i-stay-or-should-i-go-what-religion-says-about-pulling-the-plug/">http://www.forbes.com/sites/deborahljacobs/2011/11/10/should-i-stay-or-should-i-go-what-religion-says-about-pulling-the-plug/</a>

#### Not-for profit hospice

#### Families plead for hospice reprieve

CONNECTICUT | Stamford Advocate – 7 November 2011 – Dozens of relatives, Rosenthal [Hospice] volunteers and concerned residents joined elected officials to ask the state Department of Social Services to reject a bid to close the 12-bed Rosenthal hospice. Last month, Visiting Nurse & Hospice Care of Southwestern Connecticut [VNHC] requested permission to close the non-profit home, which has been losing money, according to VNHC's application in support of the request. Legislators argued even a short reprieve could provide the margin needed to save the home, giving a chance for the community to raise funds and legislators to push a set of embattled regulatory revisions that would allow the Rosenthal to be eligible for Medicare reimbursements through final approvals. <a href="http://www.stamfordadvocate.com/local/article/Families-plead-for-hospice-reprieve-2257227.php">http://www.stamfordadvocate.com/local/article/Families-plead-for-hospice-reprieve-2257227.php</a>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

GEORGIA | WSBTV (Atlanta) – 7 November 2011 – 'Top Georgia court reviews assisted suicide law.' Georgia's top court is considering a high-profile debate over whether a state law designed to discourage assisted suicides also violates free speech rights. The arguments came before the Georgia Supreme Court after years of litigation between state authorities and four members of the Final Exit Network charged with breaking the law for helping a 58-year-old cancerstricken man die. <a href="http://www.wsbtv.com/ap/ap/crime/top-ga-court-reviews-assisted-suicide-law/nFXpH/">http://www.wsbtv.com/ap/ap/crime/top-ga-court-reviews-assisted-suicide-law/nFXpH/</a>

## **International**

#### 'Conversations' possible with vegetative state patients

U.K. | Daily Telegraph - 10 November 2011 Two-way "conversations" with people in a permanent vegetative state will be possible thanks to the discovery that an inexpensive device can read their brain activity, say neuroscientists. They have discovered that some people in the state are able to understand what is being said to them and follow commands to think certain thoughts. British researchers have been at the forefront of the project, which experts hope will "fundamentally change" the way such patients are cared for. The principle focus of the study ... was to see if electroencephalography was as good as MRI scanning at detecting such brain activity in these patients... Researchers found it was. Professor Susan Gathercole, of the Medical Research Council Cognition & Brain Sciences Unit, said the discovery brought them "one step closer" to "pin-pointing levels of awareness that were not previously

possible." But Paul Matthews, professor of neurosciences at Imperial College, London, cautioned that there was still a way to go before two-way communication was possible. <a href="http://www.telegraph.co.uk/health/healthnews/8879690/Conversations-possible-with-vegetative-state-patients.html">http://www.telegraph.co.uk/health/healthnews/8879690/Conversations-possible-with-vegetative-state-patients.html</a>

#### Extract from Daily Telegraph article

Julian Savulescu, director of the Oxford Centre for Neuroethics, said the study "raises more ethical questions than it answers." "Are these patients suffering?" he asked. "How bad is their life? Do they want to continue in that state? If they could express a desire, should it be respected? For some of these patients, consciousness could be the experience of a living hell." And he advised: "We need guidelines for when life-prolonging treatment should be withdrawn in these minimally conscious states."

'Bedside detection of awareness in the vegetative state: A cohort study,' *The Lancet*, published online 10 November 2011. <a href="http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext">http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61224-5/fulltext</a>

From Media Watch dated 11 July 2011:

ONTARIO | London Free Press – 8 July 2011 – 'Coma research no joke: London scientist to try to detect emotional response in coma patients.' People in a comatose state may someday have their own say on whether to live or die, thanks to research pioneered by a London neuroscientist. http://www.lfpress.com/news/london/2011/07/07/18390366.html

From Media Watch dated 1 November 2010:

ONTARIO | Globe & Mail – 29 October 2010 – 'Vegetative patients may be aware, newly-recruited researcher says.' Adrian Owen has pioneered a new way to communicate with seemingly unconscious patients by putting them in a brain imager and asking them to think particular kinds of thoughts. <a href="http://www.theglobeandmail.com/news/national/vegatative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/">http://www.theglobeandmail.com/news/national/vegatative-patients-may-be-aware-newly-recruited-researcher-says/article1779227/</a>

# Hospitals are treating the elderly 'like slabs of meat' says damning report into National Health Service care

U.K. | Daily Mail – 9 November 2011 – Hospitals are accused today of treating elderly patients like 'slabs of meat' in a damning report that lists a catalogue of abuse. Nurses have refused to give painkillers to dying patients, while relatives were so concerned at the lack of care for their loved ones that they stayed on the wards round the clock. The shocking examples have been highlighted by the Patients Association in a report which provides yet further evidence of poor care across the NHS [National Health Service]. <a href="http://www.dailymail.co.uk/health/article-2059211/NHS-care-Hospitals-treat-elderly-like-slabs-meat.html">http://www.dailymail.co.uk/health/article-2059211/NHS-care-Hospitals-treat-elderly-like-slabs-meat.html</a>

 We've been listening, have you been learning? The Patients Association, 2011. (Scroll down for link to report.) <a href="http://www.patients-association.com/default.aspx?tabid=80&">http://www.patients-association.com/default.aspx?tabid=80&</a> Id=23

From Media Watch dated 17 October 2011:

- U.K. | The Guardian 13 October 2011 'Half of National Health Service hospitals failing to care for elderly.'
   Twenty hospitals in England broke the law by failing to protect the dignity of older patients and ensure they got sufficient food and water, spot checks by National Health Service watchdogs have found..http://www.guardian.co.uk/society/2011/oct/13/nhs-hospitals-care-of-elderly?newsfeed=true
  - Dignity and nutrition inspection report: National overview, Care Quality Commission, 2011. <a href="http://www.cqc.org.uk/sites/def-ault/files/media/documents/201-11007">http://www.cqc.org.uk/sites/def-ault/files/media/documents/201-11007</a> dignity and nutrition in spection report final update.p

## Home help bills for elderly hit £20,000 in postcode lottery of home care

U.K. | Daily Mail - 10 November 2011 - Frail elderly people who need help at home are facing a postcode lottery of charges by councils ranging from £2,500 to £20,000 a year. The demands are being made to those who planned for their retirement and have savings, property or assets worth more than £23,250. This threshold is used by most councils as the dividing line between OAPS [old age pensioners] who are given free help and those who must pay. But a disparity in charges means that paying for basic help in some areas can cost the elderly almost as much as a place in a private residential care home. http://www.dailymail.co.uk/news/article-2059604/Home-help-bills-elderly-hit-20-000postcode-lottery-home-care.html?ito=feedsnewsxml

#### Of related interest:

■ U.K. | Third Sector – 10 November 2011 – 'Older people trust charities less to help with end-of-life care, survey finds.' Public trust in the ability of charities to help people cope with getting older falls with age. The annual 'Cost of Dying' survey ... says that 32% of 40 to 49-year-olds regard charities as a trustworthy source of help with end-of-life issues, such as providing care. But the proportion of people who see charities as trustworthy falls to 26% among 60 to 69-year-olds and to 16% for the over-70s. <a href="https://thirdsector.co.uk/news/Article/1103594/Older-people-trust-charities-less-help-end-of-life-care-survey-finds/">https://thirdsector.co.uk/news/Article/1103594/Older-people-trust-charities-less-help-end-of-life-care-survey-finds/</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="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

#### National strategy on palliative care expected soon

SINGAPORE | *Today* – 8 November 2011 – The Health Ministry will be working with the Assisi Hospice – one of Singapore's oldest hospices – to boost its capacity and develop it into a centre for palliative care training, as it prepares to release a National Strategy for Palliative Care, Health Minister Gan Kim Yong said. This as Singapore's changing lifestyle and healthcare needs bring about new challenges for end-of-life care. <a href="http://www.todayonline.com/Singapore/EDC111108-0000037/National-strategy-on-palliative-care-expected-soon">http://www.todayonline.com/Singapore/EDC111108-0000037/National-strategy-on-palliative-care-expected-soon</a>

From Media Watch dated 12 September 2011:

- SINGAPORE | Straits Times 6 September 2011 –

  'Subsidy dearth for end-of-life home care.' The dying would like to spend their last days at home, but the current health-care system makes it difficult for those without the financial means to do so. This was one of the findings that emerged in a recent study¹ conducted by the National University of Singapore's Centre for Biomedical Ethics.

  http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory 709910.html
  - What Doctors Say About Care Of The Dying, Lien Foundation, Singapore, September 2011. <a href="http://www.lienfoundation.org/pdf/news/What\_Doctors\_S">http://www.lienfoundation.org/pdf/news/What\_Doctors\_S</a> ay About Care of the Dying.pdf

#### **Specialist Publications**

Of particular interest:

'End-of-life care in the general wards of a Singaporean hospital: An Asian perspective' (p.9), published in the *Journal of Palliative Medicine*.

#### Of related interest:

SINGAPORE NEWS | Online report – 10 November 2011 – 'Some people are not afraid to talk about dying.' When he embarked on an end-of-life care planning pilot project two years ago, Dr lan Leong was surprised that patients did not view talking about death as taboo. The head of Tan Tock Seng Hospital's department of continuing and community care was also surprised that many of the patients and their families did not know or understand the full extent of their medical conditions. http://www.channelnewsasia.com/stories/singaporelocalnews/view/1164456/1/.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/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

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

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

#### U.S.A.

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

#### International

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

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

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

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

RADIO NETHERLANDS WORLDWIDE | Online report – 9 November 2011 – **'Euthanasia for Dutch dementia patient.'** A request for euthanasia from a woman in an advanced stage of dementia was granted for the first time this year. Under Dutch law people requesting euthanasia must be of sound mind. Patients who are no longer compos mentis can still be considered under certain circumstances. The 64-year-old woman was unable to express herself clearly but her request was granted since he had repeatedly indicated she wanted euthanasia before her dementia developed and had signed a statement to that effect. The decision was delayed for some time but she finally died in March this year. <a href="http://www.rnw.nl/english/bulletin/euthanasia-dutch-dementia-patient">http://www.rnw.nl/english/bulletin/euthanasia-dutch-dementia-patient</a>

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

#### Who pays for palliative care: An opportunity to get it right

BMJ JOURNAL OF SUPPORTIVE & PALLIATIVE CARE, 2011;1(3):279-280. In July 2010, the Secretary of State for Health convened an independent review of the funding of "dedicated palliative care" for adults and children in England. The aim was to develop, for the first time, a per patient mechanism to fund palliative care to meet the needs of the approximately 457,000 people who require palliative care every year, and in particular, the 92,000 who are currently not being reached. The review team aimed to create a fair and transparent funding system delivering better outcomes for patients and providing better value for the National Health Service. This required the development of a palliative care tariff based on assessed need, a funding system which incentivises good outcomes for patients irrespective of time and setting, and the commissioning of integrated care packages which stimulate community based services to enable more people to be cared for outside the acute sector. The team suggest important levers for change.

Before the tariff could be discussed, the knotty question of defining "dedicated palliative care services" had to be addressed. <a href="http://spcare.bmj.com/content/1/3/279.short">http://spcare.bmj.com/content/1/3/279.short</a>

From Media Watch dated 6 December 2010:

- U.K. | BBC News 2 December 2010 'Review says National Health Service must ensure good palliative care.' The National Health Service in England has failed to take responsibility for ensuring good end-of-life care, according to an independent review. The paper highlights some organisations that are doing "excellent" work. But it says funding and services have developed ad hoc. http://www.bbc.co.uk/news/health-11902757
  - Palliative Care Funding Review Interim Report, December 2010. http://www.palliativecarefunding.org.uk/InterimReport.pdf

## End-of-life preferences of elderly patients with chronic heart failure

EUROPEAN HEART JOURNAL | Online article – 8 November 2011 – Elderly heart failure (HF) patients are assumed to prefer improved quality of life over longevity, but sufficient data are lacking. Therefore, the authors assessed the willingness to trade survival time for quality-of-life (QoL) and the preferences for resuscitation. Elderly HF patients are willing to address their end-of-life preferences. The majority prefers longevity over QoL and half wished resuscitation if necessary. <a href="http://eurheartj.oxfordjournals.org/content/early/2011/11/08/eurheartj.ehr404.abstract">http://eurheartj.oxfordjournals.org/content/early/2011/11/08/eurheartj.ehr404.abstract</a>

#### Confronting death in legal disputes about treatment-limitation in children

JOURNAL OF BIOETHICAL INQUIRY I Online article – 4 November 2011 – Most legal analyses of selective non-treatment of seriously ill children centre on the question of whether it is in a child's best interests to be kept alive in the face of extreme suffering and/or an intolerable quality of life. Courts have resisted any direct confrontation with the question of whether the child's death is in his or her best interests. Nevertheless, representations of death may have an important role to play in this field of jurisprudence. The prevailing philosophy is to configure death as a release from a futile or painful existence and/or as a dignified end in an objectively hopeless situation. However, there can be disagreement about the meaning of death in these settings. Some parents object that death would be premature or that it represents a culpable neglect of their child. A closer examination of these discordant interpretations allows for a better comprehension of the cultural

understandings that underscore clinical and legal accounts of death following end-of-life decisions. <a href="http://www.springerlink.com/conte">http://www.springerlink.com/conte</a> nt/g06168046qql2751/

#### The rationality and morality of dying children

HASTINGS CENTER REPORT, 2011;41(6):30-42. Formal reason hides the real nature and extent of the rationality and the morality in our lives because it denigrates, if not ignores, our experience and our creativity. Attending to both reveals the richness, the complexity, and the power of our rational intelligence and our morality. One wonderful example is found in Myra Bluebond-Langner's work on how children with leukemia discover, despite a conspiracy of adult silence, that they are dying and then deal with that information in a way that enables them and their parents to retain their dignity, identity, and humanity.http://www.thehastingscenter.org/Public ations/HCR/Detail.aspx?id=5600

#### Of related interest:

■ PEDIATRIC CRITICAL CARE MEDICINE, 2011;12(6):e383-e385. 'Withholding or withdrawing life-sustaining treatments: An 8-yr retrospective review in a Spanish pediatric intensive care unit.' Withholding or withdrawing life-sustaining treatment was a frequent mode of death in [the authors'] pediatric intensive care unit, occurring at a rate that falls in the midrange of literature values.http://journals.lww.com/pccmjournal/Abstract/2011/11000/Withholding or withdrawing life sustaining.37.aspx

#### Legal aspects of end-of-life care in Australia

The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)

JOURNAL OF LAW & MEDICINE, 2011;18(4):773-797. This is the final article in a series of three that examines the legal role of medical professionals in decisions to withhold or withdraw lifesustaining treatment from adults who lack capacity. A review of the law in Victoria reveals that medical professionals play significant legal roles in these decisions. However, the law is problematic in a number of respects and this is likely to impede medical professionals' legal knowledge in this area. The article examines the level of training that medical professionals receive on issues such as refusal of treatment certificates and substitute decision-making, and the available empirical evidence as to the state of medical professionals' knowledge of the law at the end of life. It concludes that there are gaps in legal knowledge and that law reform is needed in Victoria. The article also draws together themes from the series as a whole, including conclusions about the need for more and better medical education and about law reform generally. http://sites.thomsonreuters.com.au/journals/2011/06/06/journal-of-law-and-medicine-update-june-2011/

Cont.

From Media Watch dated 30 May 2011:

- JOURNAL OF LAW & MEDICINE, 2011; 18(3):498-522. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)' (noted in Media Watch dated 30 May 2011).
- JOURNAL OF LAW & MEDICINE, 2011; 18(3):523-544. 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland)' (noted in Media Watch dated 30 may 2011).

**N.B.** Link to journal's content page (scroll down to the relevant abstract): <a href="http://sites.thomsonreuters.com.au/journals/2">http://sites.thomsonreuters.com.au/journals/2</a> <a href="http://sites.thomsonreuters.com.au/journals/2">011/04/15/journal-of-law-and-medicine-update-march-2011/</a>

## Bioethics and cancer: When the professional becomes personal

HASTINGS CENTER REPORT, 2011;41(6):14-18. In 2006, I was diagnosed with cancer. This began a crash course in real-world medical ethics. Having cancer was awful, but it was instructive, too. The experience gave me a new understanding of what my profession is about. Individuals in the bioethics field often address topics related to cancer, such as medical decision-making, the patient-physician relationship, clinical trials, and access to health care. Yet few engaged in this work have lived with cancer themselves. Experience as a cancer patient or family caregiver extends and deepens one's thinking about serious illness and bioethics. http://www.thehastingscenter.org/Publications/HC R/Detail.aspx?id=5598

#### End-of-life care in the general wards of a Singaporean hospital: An Asian perspective

JOURNAL OF PALLIATIVE MEDICINE | Online article – 7 November 2011 – Despite international differences in cultural perspectives on end-of-life issues, little is known of the care for the dying in the general wards of acute hospitals in Asia. In a retrospective medical chart review of all 683 adult patients who died without intensive care unit (ICU) admission in our Singaporean hospital in 2007 ...there were DNR orders for 66.2% of patients and neither commitment for DNR nor cardiopulmonary resuscitation (CPR) for 28.1%. Orders to limit life-sustaining therapies, including ICU admission, intubation, and vasopressors/inotropes were infrequent. Only 6.2% of the alert and conversant patients with DNR orders were involved in discussions on these orders. In contrast, such discussions with their family members occurred 82.9% of the time. Interventions in the last 24 hours of life included CPR (9.4%), intubation (6.4%), vasopressors/inotropes (14.8%), tube feeding (24.7%), and antibiotics (44.9%). Analgesia was provided in 29.1% of patients. http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0215

#### Dartmouth Atlas: Putting end-of-life care on the map but missing psychosocial detail

JOURNAL OF SUPPORTIVE ONCOLOGY | Online article – Accessed 11 November 2011 – In many ways, the Dartmouth Atlas has put end-of-life (EOL) care on the map of health-care policy debates. It has proven an invaluable resource to those interested in examining patterns of health-care utilization among elderly patients in the last two years of life. Most notably, the Dartmouth Atlas group has spearheaded research demonstrating dramatic regional variability in the healthcare provided to patients who have died. The authors applaud the creation of such a valuable data repository and consider the Dartmouth Atlas to be a remarkable tool for the promotion of an evidence-based evaluation of EOL care. They are also sympathetic with its mission – the reduction of unwarranted non-uniformities and inefficiencies in health-care delivery to terminally ill patients. Like the Dartmouth Atlas authors, they share a concern about the growing number of patients who receive aggressive and extremely costly care near death. Nevertheless, the Dartmouth Atlas alone does not provide a detailed, comprehensive view of the terrain that would be required for a thorough examination of EOL care and the influencing factors. <a href="http://www.supportiveoncology.net/views/supportive-insights/blog/article-in-press-dartmouth-atlas-putting-end-of-life-care-on-the-map-but-missing-psychosocial-detail/77012ee351.html">http://www.supportiveoncology.net/views/supportive-insights/blog/article-in-press-dartmouth-atlas-putting-end-of-life-care-on-the-map-but-missing-psychosocial-detail/77012ee351.html</a>

Cont.

From Media Watch dated 22 November 2011:

- WASHINGTON POST | Online report 17 November 2010 'Wide disparities are found in end-stage cancer treatment.' The proportion of cancer patients who die in the hospital and who get hospice care varies widely from region to region and hospital to hospital across the country, according to a new report.¹ Researchers found that one-third of patients spent their last days in hospitals and intensive-care units. But there was a big range. <a href="http://www.washingtonpost.com/wp-dyn/content/article/2010/11/16/AR2010111607032.html">http://www.washingtonpost.com/wp-dyn/content/article/2010/11/16/AR2010111607032.html</a>
  - Quality of End-of-Life Cancer Care for Medicare Beneficiaries: Regional and Hospital-Specific Analyses, The Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, November 2010. http://www.dartmouthatlas.org/downloads/reports/Cancer\_report\_11\_16\_10.pdf

## Law and cancer at the end of life: The problem of nomoigenic harms and the five desiderata of death law

PUBLIC HEALTH | Online article – 8 November 2011 – Good laws are a necessary, but not a sufficient, condition for the provision of good health care. At the end of life, there is a need for laws that foster and encourage the best possible outcomes for patients, their families and healthcare professionals. This article proposes five desiderata [desired things] for laws at the end of life. It uses the emerging Australian jurisprudence of end-of-life decision making to test and examine the desiderata. The article also proposes that poorly drafted and confusing laws may have a deleterious effect on patient care. These nomoigenic (law-caused) harms can be avoided by adherence to the five desiderata of death law. <a href="http://www.publichealthjrnl.com/article/S0033-3506(11)00311-8/abstract">http://www.publichealthjrnl.com/article/S0033-3506(11)00311-8/abstract</a>

# What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention

SUPPORTIVE CARE IN CANCER | Online article – 10 November 2011 – Tailored and specific interventions for informal caregivers in palliative care are rare. Carers [i.e., study participants] reported the need to be prepared for their caring role, to be visible to professionals, to receive clear and specific information about the patient's condition, and to be emotionally supported. They described challenges as uncertainty, distress at witnessing disease progression and the daily struggle with financial issues, personal time, own health and sleep problems. Considering the time pressures and restricted caregiver time, the intervention should be brief and should aim to enhance their visibility as service recipients, patient-specific information giving, preparation for their role, and emotional support. http://www.ncbi.nlm.nih.gov/pubmed/22072049

#### Of related interest:

PALLIATIVE MEDICINE | Online article – 10 November 2011 – 'Qualitative evaluation of a problem solving intervention for informal hospice caregivers.' The study findings provide much needed depth to the field's understanding of problem-solving interventions for informal hospice caregivers and can be used to enhance existing support services.
 <a href="http://pmj.sagepub.com/content/early/2011/11/09/0269216311427191.abstract">http://pmj.sagepub.com/content/early/2011/11/09/0269216311427191.abstract</a>

#### 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

#### Assisted (or facilitated) death

Representative sample of recent articles, etc:

■ EUROPEAN JOURNAL OF CANCER | Online article – 31 October 2011 – 'Evolution of requests to hasten death among patients managed by palliative care teams in France: A multicentre cross-sectional survey.' A national cross-sectional study on the requests to hasten death (RHD) was conducted among 789 French palliative care organisations. Data were collected for all patients with RHD encountered during year 2010. The large number of described cases provides, for the first time, comprehensive hard data on the evolution of RHDs in a country that has not legalised euthanasia. Whatever the way RHD are expressed, they are frequently maintained despite adequate palliative care with suitable control of pain and psychological support by specialists. http://www.ejcancer.info/article/S0959-8049(11)00733-7/abstract

### **Worth Repeating**

#### Can't we get this over with?

#### An approach to assessing the patient who requests hastened death

CANADIAN FAMILY PHYSICIAN, 2009; 9(55):260-261. Requests for hastened death or physician-assisted suicide are very troubling and emotionally challenging for physicians. It is often tempting to give the quick answer "I can't do that for you because it is illegal" and change the subject. The request for hastened death is a topic that typically upsets patients' families and friends; it makes them fearful and they avoid discussing it. However, entering into discussion with patients can lead to better understanding of their situations and often the prevention of suffering. An occasional request to die or an expression of the readiness to die can be quite common in those with advanced illness and will fluctuate over time. A persisting desire for assisted death is relatively uncommon, and although 10% to 20% of patients might consider it, a smaller number will actually pursue it with their doctors. Several studies have looked at the relationship between depression and desire for hastened death and have found that a much higher rate of depression exists among those requesting hastened death than among those with terminal illnesses who do not request hastened death. In general, the issues of psychosocial distress, such as being a burden, lack of social

support, spiritual distress, and poor quality of life, seem to be the main factors. Newer studies suggest that a request for hastened death can be predicted more by an individual's psychosocial traits and beliefs than by disease severity or symptomatic distress. <a href="http://www.cfp.ca/content/55/3/260.full?sid=16acee9c-cae7-4aa2-bd91-de5354ed71ae">http://www.cfp.ca/content/55/3/260.full?sid=16acee9c-cae7-4aa2-bd91-de5354ed71ae</a>

A systematic review of the literature on desire for hastened death categorized the factors associated with patients' requests by the following circumstances:

- Expressions of feelings and current reactions to their circumstances (fears regarding death and loss of control);
- Communication of distress and suffering, or a communication of exploring ways to relieve the distress;
- 3. Seeking information about suicide or euthanasia as a response to 1 or 2; and
- Specifically seeking health professional assistance with hastened death or acknowledging an intent to commit suicide.

#### **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.

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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.

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- **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.

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