## 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.

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England's Palliative Care Funding Review: Scroll down to <u>Specialist Publications</u> and 'Palliative care review will call for dedicated nurse for every patient' (p.6), published in *Nursing Times*.

## Canada

## Seven years and billions of dollars later, Health Accord goals only half met

CANADIAN PRESS | Online report – 30 May 2011 – It's been seven years and billions of dollars, but Canada's health-care system has only made incremental progress toward goals its own leaders set out for it with much fanfare in 2004. That's the thinking of the Health Council of Canada, charged with evaluating progress on the 10-year, \$41.3billion health accord enacted in 2004. At the time, the accord was called a "fix for a generation." It was meant to restore federal funding to a sufficient level and allow provincial and federal governments to cut back on wait times. It was also to provide round-the-clock access to health-care providers, create electronic records for everyone and improve drug coverage and home care. But a new report to be released this week will show that even as decisionmakers start putting together a new national

plan for health care, their goals for the previous decade have been only half met. <a href="http://www.google.com/hostednews/canadianpress/article/ALeqM5ipY\_wE2YCBv0zykwl8aoz7Gf6KUw?docld=6992918">http://www.google.com/hostednews/canadianpress/article/ALeqM5ipY\_wE2YCBv0zykwl8aoz7Gf6KUw?docld=6992918</a>

### **Extract from Canadian Press report:**

There is little nationwide co-ordination or planning, so it's hard to know who should be trained to do what. Progress on providing home care is hampered by similar problems – a hodgepodge of publicly funded projects that has led to rapid growth of private agencies to fill in the gaps. That's despite all governments' commitments in 2004 to support home care.

## **Specialist Publications**

Of particular interest:

**'Developing rural palliative care: Validating a conceptual model'** (p.10), for the findings of a Canadian study published in *Rural & Remote Health*.

## U.S.A.

### Gallup-Healthways Well-Being Index

## Family caregivers depressed, stressed

UNITED PRESS INTERNATIONAL | Online report – 28 May 2011 – Stress and depression affect caregivers for elderly parents, a spouse or a disabled family member more than others, a U.S. poll indicates. The Gallup-Healthways Well-Being Index involved 140,853 interviews of U.S. adults, who were employed full-time, of which 23,520 identified themselves as caregivers based on their response to the question: "Do you currently help care for an elderly or disabled family member, relative, or friend, or not?" Six percent of caregivers who were employed full-time were ages 18-29; 22% were ages 30-44; 65% were ages 45-64 and 6% were age 65 and older. Caregivers, who represent 16% of the full-time U.S. workforce, have an Emotional Health Index score of 78, which is significantly lower than the 81.9 found among non-caregivers, the poll indicates. <a href="http://www.upi.com/Health-News/2011/05/28/Family-caregivers-depressed-stressed/UPI-26111306556922/">http://www.upi.com/Health-News/2011/05/28/Family-caregivers-depressed-stressed/UPI-26111306556922/</a>

## OpEd

## Drawing lines for end-of-life care

FLORIDA | *Sun-Sentinel* (Fort Lauderdale) – 26 May 2011 – Recently, there has been much partisan debate on Capitol Hill in regards to Medicare reform and the spiraling cost of this program. From the health care reform bill to Paul Ryan's budget proposal, we've heard just about all the financial models and projections we can take. The debate rages over co-pays and premiums, subsidies and privatization. But at the end of the day, all of this dialogue and modeling is an endless shell game that is missing the heart of the problem. Nobody is asking the real question: How much is a human life worth? As the Baby Boomers begin their retirement, health care continues to advance at light speed. This means that Baby Boomers will continue to live longer. Which means more health care. Medicare spent \$55 billion on end-of-life care (last two months of life) last year. <a href="http://www.sun-sentinel.com/news/opinion/fl-forum-medicare-reform-0526-20110526,0,6855927.story">http://www.sun-sentinel.com/news/opinion/fl-forum-medicare-reform-0526-20110526,0,6855927.story</a>

#### Of related interest:

- SOUTH CAROLINA | 1250 WTMA Radio News (Charleston) 27 May 2011 'Doctors call to stop chemotherapy overuse, cut cancer costs.' Annual costs of cancer care are expected to rise to more than \$173 billion dollars by 2020, a nearly \$70 billion increase since 2006, according to the National Cancer Institute. But limiting chemotherapy for patients with metastatic or recurrent cancers would not only dramatically cut exorbitant medical costs but would also improve a patient's quality of life, two oncologists suggest in a paper published in the New England Journal of Medicine. <a href="http://www.wtma.com/rssltem.asp?feedid=116&itemid=29673015">http://www.wtma.com/rssltem.asp?feedid=116&itemid=29673015</a>
  - Bending the cost curve in cancer care.' New England Journal of Medicine, 2011;364(21):2060-2065. http://www.nejm.org/doi/full/10.1056/NEJMsb1013826

## House [of Representatives] endorses study on end-of-life care

TEXAS | Statesman (Austin) – 24 May 2011 – The Texas House voted to order an interim study on a state law that governs how and when doctors can allow patients to die by withholding life-sustaining treatment against the wishes of family members. The study would examine the law and recommend changes before the next session starts in 2013. In Texas, if doctors believe continued care would inhumanely extend suffering in a way that violates their oath to do no harm, they can overrule family wishes by asking the hospital's ethics committee for approval to halt life-sustaining treatment. <a href="http://www.statesman.com/blogs/content/shared-gen/blogs/austin/politics/entries/2011/05/24/house\_endorses\_study\_on\_endofl.html?cxntfid=blogspostcards">http://www.statesman.com/blogs/content/shared-gen/blogs/austin/politics/entries/2011/05/24/house\_endorses\_study\_on\_endofl.html?cxntfid=blogspostcards</a>

## Budget eliminates funding to assist poor in burying the dead

MICHIGAN | *Michigan Messenger* – 23 May 2011 – Poor residents of the state of Michigan who lose a family member will lose an assistance program to help pay funeral costs. The state spent \$4.1 million in the last 12 month helping low income residents bury a close relative. The program, which is designed to assist in covering funeral costs that average \$7,000, has seen cuts over the last several years. <a href="http://michiganmessenger.com/49267/budget-eliminates-funding-to-assist-poor-in-burying-the-dead">http://michiganmessenger.com/49267/budget-eliminates-funding-to-assist-poor-in-burying-the-dead</a>

## International

## Patients win right to choose

THAILAND | Bangkok Post (Editorial) – 28 May 2011 – Under the "right to die" clause of the National Health Act, patients can now make clear their decision in advance of treatment not to receive further medication to extend their lives or to be resuscitated. A living will setting out the boundaries of treatment would be signed before witnesses and close relatives. First, though, a doctor would have to advise a patient of his or her health condition so an informed decision could be made. http://www.bangkokpost.com/news/local/239329/patients-win-right-to-choose

## **Care Quality Commission**

## Why do the elderly so often bear the weight of neglect in our hospitals?

U.K. | *Telegraph* – 28 May 2011 – Perhaps the most haunting detail of last week's damning Care Quality Commission report<sup>1</sup> on the treatment of elderly people in hospitals was that some doctors had resorted to writing prescriptions for drinking water on patients' charts. If they did not provide this little memory-jogger, there was every chance that the nurses might allow their charges to thirst for a dangerously long time. What a grim portrait that evokes of wards in which essential care is failing. Doctors, perceiving an entrenched neglect that may end in untimely death, seek a pragmatic way round it. They know that only what is written down is acted on: a fusillade of indignation will soon evaporate in the general atmosphere of what the report condemned as "casual indifference." Readers will vary in their response to last week's findings. Some will have been lucky enough to experience the National Health Service at its best, during which they or their relatives met with only patience and kindness. Others will have witnessed rudeness and outright neglect, sometimes with life-threatening consequences. This is not an exercise in nurse-bashing: often the most trenchant criticism of poor nursing comes from those who are, or were, nurses. <a href="http://www.telegraph.co.uk/comment/columnists/jennymccartney/8543333/Why-do-the-elderly-so-often-bear-the-weight-of-neglect-in-our-hospitals.html">http://www.telegraph.co.uk/comment/columnists/jennymccartney/8543333/Why-do-the-elderly-so-often-bear-the-weight-of-neglect-in-our-hospitals.html</a>

 'Dignity and nutrition for older people,' Care Quality Commission, May 2011. <a href="http://www.cqc.org.uk/reviewsandstudies/inspectionprogramme-dignityandnutritionforolderpeople.cfm">http://www.cqc.org.uk/reviewsandstudies/inspectionprogramme-dignityandnutritionforolderpeople.cfm</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>

## Cash for palliative care

AUSTRALIA | *Australia Ageing Agenda* – 26 May 2011 – Millions of Australians will now have a greater opportunity to live out their final wish and die in the comfort of their own home, following the announcement of a new \$3 million federal government grant to Palliative Care Australia (PCA) for the purchase of specialised palliative care equipment. The funding ... will enable PCA to operate an equipment loans scheme that will provide palliative care patients with access to equipment when being cared for at home. The funding forms part of a larger federal government palliative care package ... which also includes \$5.6 million in grants of up to \$150,000 for 81 local organisations. <a href="http://www.australianageingagenda.com.au/2011/05/26/article/Cash-for-palliative-care/WNJDEIVTQX.html">http://www.australianageingagenda.com.au/2011/05/26/article/Cash-for-palliative-care/WNJDEIVTQX.html</a>

#### Of related interest:

- AUSTRALIA | Australia Ageing Agenda 24 May 2011 'We need to talk about death!' An alarming majority of Australians have never discussed their end of life care wishes with their loved ones, let alone put pen to paper to record an end of life care plan. Research has shown 82% of those surveyed had not prepared an end of life plan or recorded how they would prefer the end stage of their life to be handled. http://www.australianageingagenda.com.au/2011/05/24/article/Weneed-to-talk-about-death/QPVKWPYVVC
  - We need to talk about death Survey, Palliative Care Australia, May 2011. <a href="http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf">http://www.palliativecare.org.au/Portals/46/National%20Palliative%20Care%20Week%20Media%20release.pdf</a>

## More terminally-ill patients to get care

SINGAPORE | Channel News Asia – 26 May 2011 – In a move that will ramp up hospice care services in Singapore, the Dover Park Hospice said it is increasing its number of beds from 40 to 50, which will allow it to care for about 500 terminally-ill patients a year. The hospice has also begun offering home palliative care services on a small scale. It currently has two doctors and a nurse on the home care team, and hopes to expand it to a full-fledged team of eight to 10 employees next year. Pending the Health Ministry's approval, the hospice plans to acquire more land to set up a training centre and day care centre, said its chief executive Dr Yim Sau Kit. http://www.channelnewsasia.com/stories/singaporelocalnews/view/1131372/1/.html

**N.B.** Singapore was rated 18th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD">http://graphics.eiu.com/upload/QOD</a> main final edition Jul12 toprint.pdf

#### Deficits in palliative care skills need to be addressed

IRELAND | Irish Times – 24 May 2011 – The need for communication skills training for staff working with families in palliative care in Ireland has been identified by a new study which was presented at a major European conference. Dr. Margaret Clifford, specialist registrar in palliative care at Marymount Hospice and St Patrick's Hospital, Cork ... pointed out that the value of formal family meetings as a way of helping good communication between staff and patients' families was widely acknowledged. These meetings take place on a regular basis between the palliative care team and the

patient's family, with or without the patient present ... always with the patient's informed consent. <a href="http://www.irishtimes.com/newspap">http://www.irishtimes.com/newspap</a> er/health/2011/0524/1224297612101.html

# **Specialist Publications**

Of particular interest:

'Spanish government approves draft bill regulating terminal care' (p.6), published in the *British Medical Journal*.

## Homeless people need better palliative care, finds charity

U.K. | Community Care – 24 May 2011 – Homeless people are not receiving adequate end-of-life care because staff working with them cannot spot the signs of advanced liver disease, research has found. Palliative care training needs to be improved to enable staff to spot the signs of deterioration or impending death and provide appropriate support, stated the report by charities St. Mungo's and Marie Curie Cancer Care. Supporting Homeless People with Advanced Liver Disease Approaching the End of Life, said that most deaths from liver disease among homeless people were sudden and perceived to be unexpected. Those close to the deceased were often unprepared. <a href="http://www.communitycare.co.uk/Articles/2011/05/24/116870/homeless-people-need-better-palliative-care-finds-charity.htm">http://www.communitycare.co.uk/Articles/2011/05/24/116870/homeless-people-need-better-palliative-care-finds-charity.htm</a>

Noted in past issues of Media Watch:

- U.S.A. | San Francisco Chronicle (California) 6 April 2011 'Terminally ill and homeless: Saving a death.' <a href="http://www.sfgate.com/cgi-bin/blogs/gurley/detail?entry">http://www.sfgate.com/cgi-bin/blogs/gurley/detail?entry</a> id=86430
- PALLIATIVE MEDICINE | Online article 4 April 2011 'Illicit drug use as a challenge to the delivery of end-of-life care services to homeless persons: Perceptions of health and social services...' <a href="http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract">http://pmj.sagepub.com/content/early/2011/03/30/0269216311402713.abstract</a>
- CANADIAN HEALTHCARE NETWORK | Online article 9 November 2010 'End-of-life care for homeless.' <a href="http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956">http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956</a>
- ANNALS OF INTERNAL MEDICINE, 2010;153(2):76-84. 'Effect of an end-of-life planning intervention on the completion of advance directives in homeless persons.' http://www.annals.org/content/153/2/76.abstract
- U.S.A. | Kansas City Star (Missouri) 1 April 2009 'A last kindness to the homeless.' http://www.kansascity.com/news/local/story/1119812.html

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

INDIA | Inter Press Service – 27 May 2011 – 'Supreme Court verdict revives euthanasia debate.' In a secluded hospital bed in this bustling Indian metropolis, a woman who has lain brain dead for 37 years after a brutal sexual assault is at the centre of a national debate on mercy killing. India's Supreme Court has ruled that Aruna Shanbaug should live, while at the same time supporting passive euthanasia – or the withholding of medical treatments that are keeping her alive. http://ipsnews.net/news.asp?idnews=55809

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

#### **European Palliative Care Research Collaborative**

## Expert opinion on detecting and treating depression in palliative care: A Delphi study

BMC PALLIATIVE CARE | Online article – 27 May 2011 – This study applied the Delphi method to evaluate expert opinion on choice of screening tool, choice of antidepressant and choice of psychological therapy. The aim was to inform the development of best practice recommendations for the European Palliative Care Research Collaborative clinical practice guideline on managing depression in palliative care. There was contention regarding the benefits of screening, with 'routine informal asking' rated more highly than formal screening tools such as the Hospital Anxiety & Depression Scale. The range of expert ratings was broad, indicating discordance in the views of experts. <a href="http://www.biomedcentral.com/content/pdf/1472-684x-10-10.pdf">http://www.biomedcentral.com/content/pdf/1472-684x-10-10.pdf</a>

#### Four burials and a funeral

BRITISH MEDICAL JOURNAL | Online OpEd – 25 May 2011 – I cringe when I see relatives of the dying or dead ignored in hospitals, or when we expend huge efforts and technology on resuscitation only to treat the dead body as just something irrelevant and without meaning, and perhaps a sign of our failure to cheat death. Bereaved family members are as raw and sensitive as peeled eggs. Burials and funerals are healing rituals. http://www.bmj.com/content/342/bmj.d3241.extract

## Spanish government approves draft bill regulating terminal care

BRITISH MEDICAL JOURNAL | Online report – 20 May 2011 – The Spanish cabinet passed a new draft bill on 13 May reaffirming the right of doctors to use whatever drugs they deem necessary to provide relief to patients in the last hours or days of their life, even if this hastens their death. The Bill for Regulating the Rights of People Facing the End of Life aims to clarify the rights of terminally ill patients and the obligations of the medical personnel attending them. <a href="http://www.bmj.com/content/342/bmj.d3155.extract?sid=e22bdd69-fbc3-431b-9fd7-60f255e1ee0b">http://www.bmj.com/content/342/bmj.d3155.extract?sid=e22bdd69-fbc3-431b-9fd7-60f255e1ee0b</a>

#### Of related interest:

BMC FAMILY PRACTICE | Online article – 23 May 2011 – 'Effects of online palliative care training on knowledge, attitude and satisfaction of primary care physicians.' This study shows that there was a significant increase of knowledge of 14%-20% and a significant increase in the perception of confidence in symptom management and communication in the intervention group in comparison with the control group that received traditional methods of education in palliative care or no educational activity at all. <a href="http://www.biomedcentral.com/content/pdf/1471-2296-12-37.pdf">http://www.biomedcentral.com/content/pdf/1471-2296-12-37.pdf</a>

**N.B.** Spain was rated 26th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. <a href="http://graphics.eiu.com/upload/QOD">http://graphics.eiu.com/upload/QOD</a> main final edition Jul12 toprint.pdf

## Paramedic program reducing emergency room congestion

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 27 May 2011 – Proponents call it "bringing acute care to patients," and for many senior citizens who reside in 15 nursing homes throughout Halifax, Nova Scotia, it's eliminated lengthy waits for treatment at hospital emergency departments. In fact, so successful has a pilot project to provide on-site treatment of patients at nursing homes by "extended care paramedics" been that the province's health minister is considering expansion of the initiative to other parts of the province. The goal of the Extended Care Paramedic program, which was launched in February, was to "provide treatment sooner" to patients in nursing homes by essentially placing seven specially trained paramedics in nursing homes between the hours of 9 a.m. to 9 p.m., seven days a week, explains Dr. Andrew Travers, provincial medical

director for Emergency Health Services in Nova Scotia and assistant professor of emergency medicine at Dalhousie University.http://www.cmaj.ca/earlyreleases/ 27may11\_paramedic-program-reducingemergency-room-congestion.dtl

## Extract from Canadian Medical Association Journal

There have also been unexpected benefits, particularly with regard to the provision of palliative care. "A substantial number ... were end-of-life cases. [The paramedics] have been able to afford patients and their families the benefit of bringing the emergency room to them," [Dr. Andrew] Travers says. "Usually there is a do not resuscitate order. But they can still offer pain relief and fluids. It gives great comfort."

#### Assisted (or facilitated) death

# Social acknowledgement as a predictor of post-traumatic stress and complicated grief after witnessing assisted suicide

INTERNATIONAL JOURNAL OF SOCIAL PSYCHIATRY | Online article – 19 May 2011 – In Switzerland, right-to-die organizations such as Exit Deutsche Schweiz offer suicide assistance to their members. However, there is limited knowledge of the impact that witnessing assisted suicide has on the post-traumatic stress severity or the grief process of family members. Low perceived social acknowledgement may affect mental health. As expected, social acknowledgement as a survivor was related to PTSD (post-traumatic stress disorder) symptoms and CG (complicated grief) [in study participants]. In particular, perceived general disapproval was strongly correlated with all outcome measures, whereas recognition was not significantly related to PTSD or CG (intrusion and avoidance). Family members of patients who use assisted suicide may hesitate to disclose the manner of death, and the community and societal environment may express strong views concerning the end-of-life decision. This can lead to increased levels of PTSD and CG. http://isp.sagepub.com/content/early/2011/05/18/0020764011400791.abstract

#### Of related interest:

\* FRANCO ANGELI (Italy) | Online article – Accessed 25 May 2011 – 'When the patient requests the end of his/her life.' Mario Riccio [the author of this article] is the physician who assisted Piergiorgio Welby in the final phase of his life. Riccio makes an analysis of ... the Welby case and the [Eluana] Englaro case. He describes the current Italian situation about end of life under ethical, mental and legal frames. Finally, he provides a short comparison with other countries. <a href="http://www.francoangeli.it/Riviste/Scheda Rivista.aspx?idArticolo=42235&lingua=it">http://www.francoangeli.it/Riviste/Scheda Rivista.aspx?idArticolo=42235&lingua=it</a>

## Ethical issues on defibrillator deactivation in end-of-life patients

JOURNAL OF CARDIOVASCULAR MEDICINE | Online article – 22 May 2011 – This article is discusses the ethical issues of deactivation of the automatic implantable cardioverter defibrillator (AICD) in end-of-life patients. In the authors' opinion, the concept of autonomy or ownership of the device cannot be invocated to deactivate AICD. The ownership of the AICD does not give to the bearer the right to abuse it to harm him- or herself. The frequent electric shocks of AICD should not be regarded as futile; stopping the arrhythmia made by AICD, in case of electrical storm, is a 'benefit' to the patient's life. In fact, the clinical result of switching off the AICD is encountered at the next episode of ventricular fibrillation, when the patient dies. In our opinion, the patient's request to turn off the AICD to end the distress caused by the painful electrical shocks of the device is not acceptable, as the next malignant ventricular arrhythmia will be the cause of death because it cannot be interrupted by the device. To turn off the AICD may be rightly called 'passive euthanasia.' A seriously ill, end-of-life person who dramatically lives the extreme part of their life because of the frequent AICD shocks could be ... properly considered for sedation. http://journals.lww.com/jcardiovascularmedicine/Abstract/publishahead/Ethical issues on defibrillator deactivation in.99448.aspx

From Media watch dated 29 November 2010:

- AMERICAN MEDICAL NEWS | Online article 24 November 2010 'Turning off heart devices near life's end stirs ethical, legal debates.' Many physicians believe that deactivating heart devices is a form of physician-aided death, according to a survey published in the Mayo Clinic Proceedings.<sup>1</sup> <a href="http://www.ama-assn.org/amednews/2010/11/22/prsl1124.htm">http://www.ama-assn.org/amednews/2010/11/22/prsl1124.htm</a>
  - MAYO CLINIC PROCEEDINGS, 2010;85(11):981-990. 'Perspectives on withdrawing pacemaker and implantable cardioverter-defibrillator therapies at end of life: Results of a survey of medical and legal professionals and patients.' <a href="http://www.mayoclinicproceedings.com/content/85/11/981.abstract">http://www.mayoclinicproceedings.com/content/85/11/981.abstract</a>

## Hope and the act of informed dialogue: A delicate balance at end of life

JOURNAL OF LANGUAGE & SOCIAL PSYCHOLOGY, 2011;30(2):177-192. As a scholar who has focused on health communication, including end-of-life issues, for over 25 years, I found myself confronted by serious ethical dilemmas when I spent time with my sister-in-law and family as she was dying from ovarian cancer. The guidelines provided to me in the past research with which I was familiar, as well as my personal experiences regarding end-of-life discussion with family and friends, did not prepare me well to handle the dialectical tensions between maintaining hope and open discussion of end of life in this situation. In this article, I focus on an examination of the research on hope at end of life and try to reconcile it with the concomitant need for acknowledgment of impending terminality and the communication that should accompany this. <a href="https://jls.sagepub.com/content/30/2/177.abstract">https://jls.sagepub.com/content/30/2/177.abstract</a>

#### Of related interest:

THEORETICAL MEDICINE & BIOETHICS, 2011;32(3):143-160. 'Deep hope: A song without words.' Experience in palliative medicine has taught physicians that hope is durable and often thrives even in the face of imminent death. In this article, the author examines the perspectives of philosophers, theologians, psychologists, clinicians, neuroscientists, and poets, and provides a series of observations, connections, and gestures about hope, particularly about what he calls "deep hope." The article ends with some proposals about how such hope can be sustained and enhanced at the end of life. <a href="http://www.springerlink.com/content/p649h4188648l8hg/">http://www.springerlink.com/content/p649h4188648l8hg/</a>

# The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)

JOURNAL OF LAW & MEDICINE, 2011;18(3):498-522. This is the first article in a series of three ... and considers the position in New South Wales.

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).' This
article considers the position in Queensland, including the parens patriae jurisdiction of the
Supreme Court.

**N.B.** The reviews of the laws in the two Australia states reveal 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. These articles examine the level of training medical professionals receive on issues such as advance directives 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. They concludes that there are gaps in legal knowledge and that law reform are needed in both states. Journal content page (scroll down to 'Articles'): <a href="http://sites.thomsonreuters.com.au/journals/2011/04/15/journal-of-law-and-medicine-update-march-2011/">http://sites.thomsonreuters.com.au/journals/2011/04/15/journal-of-law-and-medicine-update-march-2011/</a>

## A qualitative investigation of selecting surrogate decision-makers

JOURNAL OF MEDICAL ETHICS | Online article – 27 May 2011 – Most respondents [i.e., study participants] talked about choosing someone who was caring and competent in certain ways, giving interesting evidence for their judgements. Surprisingly few highlighted how well they thought their chosen surrogate knew their preferences and would be able to make a substituted judgement. Moreover, few specified that their chosen surrogate had similar attitudes and values to their own and so would make a similar decision to theirs in the circumstances presented. Some respondents also referred to the social role of their chosen surrogate or the social dynamics of their situation which influenced their choices, as well as to ideas of reciprocity and characteristics of honesty and loyalty. <a href="https://jme.bmj.com/content/early/2011/05/27/jme.2010.037978.abstract">https://jme.bmj.com/content/early/2011/05/27/jme.2010.037978.abstract</a>

#### Qualitative study of video-recorded patient consultations

## Courteous but not curious: How doctors' politeness masks their existential neglect

JOURNAL OF MEDICAL ETHICS | Online article – 24 May 2011 – The doctors [i.e., study participants] were concerned about their patients' health and how their medical knowledge could be of service. This medical focus often over-rode other important aspects of the consultations, especially existential elements. The doctors actively directed the focus away from their patients' existential concerns onto medical facts and rarely addressed the personal aspects of a patient's condition, treating them in a biomechanical manner. At the same time, however, the doctors attended to their patients with courteousness, displaying a polite and friendly attitude and emphasising the relationship between them. The study suggests that the main failing of patient-doctor encounters is not a lack of courteous manners, but the moral offence patients experience when existential concerns are ignored. Improving doctors' social and communication skills cannot resolve this moral problem, which appears to be intrinsically bound to modern medical practice. http://jme.bmj.com/content/early/2011/05/24/jme.2010.041988.abstract

## Of related interest:

■ AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 25 May 2011 – 'Culture and end-of-life care: An epidemiological evaluation of physicians.' The purpose of the study was to determine the degree to which cultural beliefs influence a physician's decision to introduce the concept of hospice to terminally ill patients. This study explored the perceptions of 14 physicians practicing medicine in Mercer County, New Jersey. Analysis of the textural data revealed the following five themes: a) physician personal perspectives; b) physician perspectives on culture; c) perspectives on hospice care; d) communication with patients; and, e) training and experience. http://ajh.sagepub.com/content/early/2011/05/24/1049909111410294.abstract

# Spirituality at the end of life: Conceptualization of measurable aspects – a systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online article – 25 May 2011 – Although spiritual caregiving is a key domain of palliative care, it lacks a clear definition, which impedes both caregiving and research in this domain. The aim of this study was to conceptualize spirituality by identifying dimensions, based on instruments measuring spirituality in end-of-life populations. A systematic literature review was conducted. In 36 articles that met the inclusion criteria we identified 24 instruments. Nine instruments with adequate content validity were used to identify dimensions of spirituality. To adequately represent the items of the instruments and to describe the relationships between the dimensions, a model defining spirituality was constructed. The model distinguishes the dimensions of Spiritual Well-being (e.g., peace), Spiritual Cognitive Behavioral Context (spiritual beliefs, spiritual activities, and spiritual relationships), and Spiritual Coping, and also indicates relationships between the dimensions. This model may help researchers to plan studies and to choose appropriate outcomes, and assist caregivers in planning spiritual care. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0356

## Palliative day care: A qualitative study of service users' experiences in the U.K.

NURSING & HEALTH SCIENCES | Online article – 20 May 2011 – In many countries, specialist palliative day care for patients with life-limiting conditions is provided by specific teams of professionals from a range of relevant disciplines. During 2006 to 2007, the day care services at a hospice in the U.K. were redesigned so that specialist palliative care sessions replaced the existing long-established, traditional day care model. The purpose of this study was to enhance the understanding of those aspects of the service that the users valued most. Data are presented under three themes: the quality of the staff; the sense of community; and, relationships. Of these, the relationships between and within the staff and patient groups held the greatest significance for the patients. http://onlinelibrary.wiley.com/doi/10.1111/j.1442-2018.2011.00598.x/full

## Palliative care review will call for dedicated nurse for every patient

NURSING TIMES (U.K.) | Online report – 24 May 2011 – Every palliative care patient should be assigned a nurse, or alternative care worker, to "help them navigate their way to a dignified death," a major review looks set to recommend. Tom Hughes-Hallett, chair of the Palliative Care Funding Review ... set out the two key recommendations he expects to come out of the soon-to-be published review ... commissioned by the Department of Health. He said: "It is likely that [one of the two] core recommendations that will be in the review ... will be that every patient, every family, should have a proper assessment of their needs: What do they actually need to support them in the community?" He added: "The second recommendation that's almost certainly going to be there is that every patient and family should have a case worker assigned to them." The "case worker" would be a "chauffeur to help them navigate their way to a dignified death," he said. In the majority of cases, the role is expected to fall to district nurses, specialist nurses or nursing staff working in hospices. Palliative care review will call for dedicated nurse for every patient. <a href="http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/palliative-care-review-will-call-for-dedicated-nurse-for-every-patient/5030098.article">http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/palliative-care-review-will-call-for-dedicated-nurse-for-every-patient/5030098.article

N.B. Palliative Care Funding Review website: http://palliativecarefunding.org.uk/

## Developing rural palliative care: Validating a conceptual model

RURAL & REMOTE HEALTH | Online article - 19 May 2011 - The purpose of this research was to validate a conceptual model for developing palliative care in rural communities. The model has roots in concepts of community capacity development, evolves from collaborative, generalist rural practice, and utilizes existing health services infrastructure. It addresses how rural providers manage challenges, specifically those related to: lack of resources, minimal community understanding of palliative care, health professionals' resistance, the bureaucracy of the health system, and the obstacles of providing services in rural environments. http://www.rrh.org.au/articles/printviewnew.a sp?ArticleID=1717

From Media Watch dated 21 March 2011:

■ JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 14 March 2011 – 'A shared care model pilot for palliative home care in a rural area: Impact on symptoms, distress, and place of death.' Shared care models build on family physician capacity and as such are promising in the development of palliative home care programs to improve access to quality palliative home care and foster health system integration.

http://www.ipsmiournal.com/article/S088

5-3924(11)00031-5/abstract

#### **Media Watch Online**

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

#### Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <a href="http://www.hnhbhpc.net/Resources/UsefulLinks/M">http://www.hnhbhpc.net/Resources/UsefulLinks/M</a> ediaWatch/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:

http://www.prisonterminal.com/news%20media%2 0watch.html

#### International

news.php

Global | Palliative Care Network Community: <a href="http://www.pcn-e.com/community/pq/file/world/world/">http://www.pcn-e.com/community/pq/file/world/world/</a>

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

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

Cont.

From Media Watch dated 16 August 2010:

■ PALLIATIVE MEDICINE | Online article – 9 August 2010 – 'Examining the politics of palliative care in rural British Columbia, Canada.' Three types of politics impacting on palliative care provision are identified: inter-community, inter-site, and inter-professional. Three themes crosscut these politics: ownership, entitlement, and administration. The politics revealed ... a heretofore underexplored in the palliative literature, have implications for the delivery of palliative care. http://pmi.sagepub.com/content/early/2010/08/06/0269216310378784.abstract

## The interface between medical oncology and supportive and palliative cancer care

SEMINARS IN ONCOLOGY, 2011;38(3):337-342. Palliative medicine physicians have particular expertise in communication and symptom control, especially, for example, with pain management. Medical oncologists also have need of excellent communication skills and knowledge of supportive care issues, such as the management of emesis, bone marrow suppression, mucositis, neuropathy, and symptoms created by treatment. This article examines the interface between medical oncology and supportive and palliative care to emphasize how each can benefit from the others. <a href="http://www.seminoncol.org/article/S0093-7754(11)00091-1/abstract">http://www.seminoncol.org/article/S0093-7754(11)00091-1/abstract</a>

SEMINARS IN ONCOLOGY, 2011;38(3):362-366. 'Geriatric oncology and palliative medicine.'
Understanding the importance of supportive management during antineoplastic treatment and
developing an intentional approach to palliative care issues (which are an important part of treating
elderly patients with cancer) will help patients complete a full treatment course and maintain quality
of life. http://www.seminoncol.org/article/S0093-7754(11)00074-1/abstract

#### **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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#### **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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