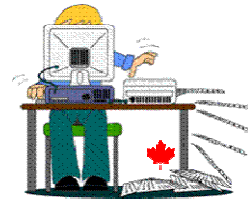


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

Advocacy: Liberal Senator Sharon Carstairs speaks about palliative care in this 17 March 2010 video posted @ the Liberal Senate Forum: http://www.liberalsenateforum.ca/Liberal-Team/Video/8770_Senator-Carstairs-speaks-about-palliative-care

Canada

Access to palliative care

Struggling to fulfil his final wish

ONTARIO | *Ottawa Citizen* – 21 March 2010 – 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 Dunrobin home on the Ottawa River. He dreads the thought of dying in hospital, a hospice or nursing home. Harold says if an emergency arose in which he needed immediate hospital care, he would not get into an ambulance for fear that he would never see his home again. Each time Harold suffered a relapse since 2002, Josina [his wife] tried in vain to find a palliative-care doctor to examine and treat her husband in their home. Experts say palliative care at home is more humane and much less costly for the health system than waiting for the terminally ill to die in an institution. Josina has called hospitals, palliative-care hospices, doctors' clinics, medical centres and health agencies such as the Champlain Community Care Access Centre. The latter does provide nursing care for Harold twice weekly. There are two small groups of doctors known as the Community Palliative Care Network & Palliative Care Outreach, but they only have the time and resources to serve patients in the urban Ottawa area. The doctors cannot afford nearly two hours, most of it driving, for a house call to rural Dunrobin. They can see three to four patients in the urban area in that time. A rural situation would become even more difficult as a patient's condition gets worse and the doctor is needed more often – sometimes in the middle of the night. <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. <http://www3.interscience.wiley.com/journal/123232436/abstract>

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

Curative vs. healing: Interview...

With Dr. Tom Hutchinson, Director, McGill Programs in Whole Person Care

QUEBEC | [University of] *McGill Reporter* – 18 March 2010 – In 1999, Dr. Balfour Mount, the father of Palliative Care in North America, and Dr. Abraham Fuks, then Dean of Medicine, instituted the McGill Programs in Whole Person Care with a simple goal: to establish research and educational programs that integrate the existential and physical aspects of illness as a way to better understand how to respond to suffering while enhancing the quality of patients' lives. A few years later, Dr. Tom Hutchinson, a McGill-trained, Dublin-born Nephrologist/Internist, decided to widen his focus on the quality of patients' lived experience and joined Mount in developing McGill Programs in Whole Person Care. <http://publications.mcgill.ca/reporter/2010/03/with-dr-tom-hutchinson-director-mcgill-programs-in-whole-person-care/>

From Media Watch dated 20 April 2009:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2009;180(8):845-846. **'Whole person care: encompassing the two faces of medicine.'** Physicians and other health care workers need to relearn an important skill: how to retain a broad enough awareness to encompass simultaneously the needs of both curing and healing... <http://www.cmaj.ca/cgi/content/full/180/8/845>

Within the scope of palliative care

Fewer ER visits for cancer patients possible

ONTARIO | CBC News – 17 March 2010 – People dying of cancer are frequent visitors to emergency departments, but many of the trips may be avoidable, a Canadian study suggests.¹ For people dying of cancer and their families, visits to emergency can be disruptive, distressing and exhausting, with long, uncomfortable waits for care, researchers say. Between 2002 and 2005, 91,561 people died of cancer in the province [of Ontario], radiation oncologist Dr. Lisa Barbera of the University of Toronto and her co-authors found. "Ideally, the symptoms of a patient near death would be adequately controlled and the patient would be cared for in the setting of his or her choice, rather than on an emergency basis," Barbera and her co-authors wrote. Of the people included in the study, 75,759 patients visited emergency during their final six months of life, with nearly 37% making one visit. The most common reasons to visit emergency both in the last six weeks and last two weeks of life were: abdominal pain; shortness of breath or dyspnea; pneumonia; malaise and fatigue; and, fluid in the chest. Diagnoses involving pain accounted for 9.4% or 18,267 visits during the final six months and 5.1% or 1,857 visits made during the final two weeks of life, the researchers said. <http://www.cbc.ca/health/story/2010/03/17/cancer-end-of-life-palliative-ontario.html>

1. Scroll down to [Specialist Publications](#) and **'Dying cancer patient visits to emergency departments can be avoided'** for the findings of the descriptive, retrospective cohort study published in the *Canadian Medical Association Journal* (p.10).



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.

Woman forced to choose between cancer drug and bankruptcy

ONTARIO | TorStar News Agency – 17 March 2010 – Her kidneys ravaged by chronic disease and advanced cancer, Judy Pope had been doing remarkably well with a new drug. For five years, the medicine had kept the Cambridge woman's cancer under control. But when her husband's work insurance was changed to another provider, a cap on coverage put the expensive drug financially out of reach. Pope and her husband Gary could not afford the monthly \$3,200 cost of the medication on his modest income and her disability pension. As well, the province's [Exceptional Access Program] ... to help people with prescription drug costs denied applications for help. Pope had no choice but to stop taking the drug that had kept her alive by slowing the growth of the kidney cancer. She suffered a drastic decline, then died. She was 59. <http://www.thespec.com/News/BreakingNews/article/738878>

Of related interest (from Media Watch dated 15 March 2010):

- U.K. | *The Independent* – 15 March 2010 – **'Scandal of cancer drugs kept from dying victims.'** Thousands of cancer patients are being denied access to costly drugs by the National Institute for Clinical Excellence ... a year after ministers ordered the institute to relax its spending criteria for patients close to the end of their lives, campaigners claim. <http://www.independent.co.uk/life-style/health-and-families/health-news/scandal-of-cancer-drugs-kept-from-dying-victims-1921426.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Ottawa Citizen* – 19 March 2010 – **'Pulling the plug' isn't euthanasia.** Except in very rare circumstances – for instance, if the treatment were withdrawn without the necessary consent or against the patient's wishes – withdrawal of life-support treatment is not euthanasia. <http://www.ottawacitizen.com/health/Pulling+plug+euthanasia/2703737/story.html>
- ONTARIO | *Toronto Star* – 17 March 2010 – **'Assisted-suicide bill a 'slippery slope,' critic warns.'** Bloc Québécois MP's bid to give Canadians 'right to die with dignity' meets with resistance. <http://www.thestar.com/news/canada/article/780995--assisted-suicide-bill-a-slippery-slope-critic-warns>

N.B. Hansard transcript of House of Commons proceedings *vis-à-vis* the 16th March 2010 reading of Bill C-384: <http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=3&DocId=4351440#OOB-3041166>;

U.S.A.

[State] Law dictates who decides on care for the incapable

NEW YORK TIMES | Online report – 17 March 2010 – It is one of those medical quandaries often faced by families dealing with older and dying parents: Who makes decisions for patients who cannot make their own and have not left written instructions? It took more than 17 years for New York to answer the question, but on Tuesday, Governor David A. Paterson signed a law providing a road map for such matters. The bill [the Family Health Care Decisions Act] sets up an order for who is responsible for such decisions, ranking spouses and domestic partners first in a hierarchy of surrogates (unless there is a court-appointed guardian), followed by children, parents, siblings and close friends. <http://www.nytimes.com/2010/03/18/health/policy/18decisions.html>

Study shows strong interest in palliative care programs, services and integration vary across nation

TEXAS | M.D. Anderson Cancer Center (University of Texas) press release – 17 March 2010 – A recent study from ... [the Center] ... reports that cancer centers in the U.S. provide patients and their families with palliative care, though the depth, range and integration of programs and services widely vary.¹ Despite the many advances in cancer research, palliative care ... continues to play a vital role in the continuum of cancer care. "We know that palliative care is most effective when incorporated early in oncology care," said David Hui ... lead author of the study. http://www.eurekalert.org/pub_releases/2010-03/uotm-sss031710.php

1. Scroll down to [Specialist Publications](#) and '**Availability and integration of palliative care at U.S. cancer centers**' for the findings of the study published in the *Journal of the American Medical Association* (p.9).

Push to change [State] health care conscience bill fails

IDAHO | Associated Press – 16 March 2010 – House Democrats failed to narrow a bill that seeks to give health workers' permission to abstain from giving care they find morally objectionable. Democrats proposed an amendment ... to strike a provision that frees nurses, pharmacists and others from having to provide end-of-life treatment for dying patients, if it violates their conscience. <http://www.kpvi.com/Global/story.asp?S=12151503>

Heart-shock device may disrupt quiet hospice death

ASSOCIATED PRESS | Online report – 15 March 2010 – If you have a heart-zapping defibrillator implanted in your chest but now are dying of something else, when do you have it turned off? It's not unusual for health professionals to avoid the topic, says Dr. Nathan Goldstein of New York's Mount Sinai Medical Center. His research [published in *the Annals of Internal Medicine*] ... suggests most hospices – expert in end-of-life care – aren't making defibrillator decisions part of their routine. Nearly 60% of hospices he examined had at least one patient shocked within the past year, sometimes multiple times at once. Yet just one in 20 hospices had a method even to identify who harbored the implant when they entered the program. <http://www.google.com/hostednews/ap/article/ALeqM5jT5AlbJJR0Frahvc-2rov66FnAUwD9EF91MO1>

Corrections & Clarifications

In the Associated Press report (left) about hospices being slow to turn off patients' defibrillators, the newswire service reported erroneously the proportion that had a way to identify implant recipients. The study found 20% had a method to do so, *not* one in 20. <http://www.washingtonpost.com/wp-dyn/content/article/2010/03/18/AR2010031802602.html>

From Media Watch dated 8 March 2010:

- *ANNALS OF INTERNAL MEDICINE*, 2010;152(5):296-299. '**Management of implantable cardioverter-defibrillators in hospice.**' Ensuring that hospices have policies in place to address deactivation may improve the care for patients with these devices. The authors provide a sample deactivation policy. <http://www.annals.org/content/152/5/296.abstract>

From Media Watch dated 15 March 2010:

- *AMERICAN ASSOCIATION OF RETIRED PERSONS (AARP)* | News release – 11 March 2010 – '**Idaho House committee says "conscience" trumps patient's rights.**' The Health Freedom of Conscience Bill[s] ... vague language will mean any end of life service could be denied. http://www.aarp.org/community/AARPID/journals/IDAHO_HOUSE_COMMITTEE_SAY/2590472

Health care reform

The medicalization of life

CALIFORNIA | *Los Angeles Times* (OpEd) – 15 March 2010 – Here's a question that's not being asked in the healthcare debate: How much medical care do we want in our lives? It's something we should be discussing. Start with the two life events we all experience, birth and death. My profession has gotten pretty good at terrifying (and operating on) pregnant women during what should be one of the greatest experiences in life. And we are equally proficient at dragging the elderly through all sorts of misery on the road to death. http://www.latimes.com/news/opinion/la-oe-welch15-2010mar15_0,6629446.story

- NBC | Online report – 16 March 2010 – **'NBC poll: Public split on health bill.'** As Congress prepares for a crucial and possibly decisive vote on the fate of President Barack Obama's health care plan, the American public is evenly divided about whether the legislation should be passed or rejected. <http://firstread.msnbc.msn.com/archive/2010/03/16/2230245.aspx>

N.B. A revised bill has been narrowly passed by House of Representatives and now goes to the Senate.

When the only hope is a peaceful ending

NEW YORK TIMES | Online OpEd – 15 March 2010 – This is a very personal story of living gracefully with a fatal diagnosis. When I wrote *Jane Brody's Guide to the Great Beyond* (New York: Random House, 2009), I had no idea that I'd be putting its precepts into practice in my immediate family within a year of publication. But as I said in the book, "You never know." You never know when your time will be up, and so it is best to prepare for the end sooner rather than later. <http://www.nytimes.com/2010/03/16/health/16brod.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- UNITED PRESS INTERNATIONAL | Newswire report – 21 March 2010 – **'The right to die vs. the value of life.'** Nothing arouses passions both inside and outside the courtroom more than the theoretical right to die – in effect, to be free from a life of constant pain and a terminal illness, or from being hooked up to multiple medical devices designed to keep the body, if not the brain, alive. <http://www.istockanalyst.com/article/viewiStockNews/articleid/3964510>

International

Most carers say their loved one's needs are "overwhelming"

IRELAND | *Galway Advertiser* – 18 March 2010 – More than three out of four family carers say their ageing loved one's needs are "overwhelming," according to a new study. The recent stress test, carried out by Home Instead Senior Care, indicated that of the 8,000 family carers who participated, 91% said at times they feel anxious or irritable; 73% have disturbed sleep patterns, while 56% seem to become ill more frequently. <http://www.advertiser.ie/galway/article/23654>

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | *Inverell Times* – 19 March 2010 – **'Hospice mentoring program.'** HOME Hospice's Community Mentoring Program ... is offering peer support to people caring for someone with a terminal illness at home. Trained volunteer mentors are contactable seven days a week to give practical guidance and support to carers. <http://www.inverelltimes.com.au/news/local/news/general/home-hospice-mentoring-program/1780946.aspx>

Individuals must be supported to die in their place of choice

U.K. (NORTHERN IRELAND) | Northern Ireland Executive press release – 18 March 2010 – Health Minister Michael McGimpsey has said that everyone should have the chance to be supported to die in their place of choice. The Minister was speaking as he launched 'Living Matters: Dying Matters,' a new Strategy for Palliative & End of Life Care for Northern Ireland. The strategy is designed to ensure that people with palliative and end of life care needs, and their families and carers, are provided with high quality care across all settings and conditions. The launch of the Pallcareni website was announced.¹ <http://www.northernireland.gov.uk/news/news-dhssps/news-dhssps-18032010-individuals-must-be.htm>

1. Pallcareni website: <http://www.pallcareni.net/>

42% of terminal cancer patients unaware of status

THE KOREA HERALD | Online report – 16 March 2010 – Nearly half of terminal cancer patients were not aware of their health conditions fully, a survey has found. The National Cancer Center conducted a questionnaire on the experiences of 481 cancer patients and 381 family caregivers associated with the patients at 11 hospitals nationwide. Of the terminally-ill patients surveyed, 42% did not know that their status was terminal. The figure in their family members was 16.6%. http://www.koreaherald.co.kr/NEWKHSITE/data/html_dir/2010/03/16/201003160056.asp

Study looks at dying, death, bereavement among Māori

NEW ZEALAND | University of Waikato online posting – 15 March 2010 – Researchers are embarking on a three-year study of dying, death and bereavement among contemporary Māori. The Kia Ngawari study aims to increase knowledge and understanding of Māori palliative needs, both within the healthcare system and among whānau [extended family]. The study will also help identify the gaps in help available from formal and informal services, such as the health care system, rest homes, funeral services and Māori support systems. <http://www.waikato.ac.nz/news-events/media/2010/03Study%20looks%20at%20dying,%20death,%20bereavement%20among%20M%C4%81ori%20.shtml>

From Media Watch dated 22 February 2010:

- *SOCIAL SCIENCE & MEDICINE* | Online article – 16 February 2010 – '**Māori healers' views on well-being: The importance of mind, body, spirit, family and land.**' The present study aimed to explore Māori spiritual healers' views on healing and healing practices. Māori cultural perspectives influence views of the mind, body and spirit. Healers identified two additional aspects as significant and fundamental to a person's health, namely *whānau whakapapa* [family and genealogy] and *whenua* [land]. [http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4YDC3R9-2&_user=10&_coverDate=02%2F16%2F2010&_rdoc=4&_fmt=high&_orig=browse&_srch=doc-info\(%23toc%235925%239999%2399999999%2399999%23FLA%23display%23Articles\)&_cdi=5925&_sort=d&_docanchor=&_ct=93&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=772c7c83e7a7553b9cb5cb29e7f3d246](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-4YDC3R9-2&_user=10&_coverDate=02%2F16%2F2010&_rdoc=4&_fmt=high&_orig=browse&_srch=doc-info(%23toc%235925%239999%2399999999%2399999%23FLA%23display%23Articles)&_cdi=5925&_sort=d&_docanchor=&_ct=93&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=772c7c83e7a7553b9cb5cb29e7f3d246)

From Media Watch dated 4 January 2010:

- NEW ZEALAND | Ministry of Health online report – December 2009 – '**Gap analysis of specialist palliative care in New Zealand.**' This gap analysis confirmed the anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care at both local and regional levels. [http://www.moh.govt.nz/moh.nsf/pagesmh/9843/\\$File/palliative-care-gap-analysis-09.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/9843/$File/palliative-care-gap-analysis-09.pdf)

Don't let death be a conversation killer

U.K. | Dying Matters Coalition online posting – 15 March 2010 – A surprising and worrying lack of preparedness for dying and death among individuals in England has been revealed in the results of a new survey. 81% of people have not written down any preferences around their own death, and only a quarter of men and just over one in three women across England have told anyone about the funeral arrangements they would like to have after they die. Nearly two-thirds of people have not written a will – including a quarter of over-65s. <http://www.dyingmatters.org.uk/news/13>

Additional funding for end of life care cannot be accounted for

U.K. | National Council for Palliative Care press release – 15 March 2010 – A survey carried out by the Council to monitor the first year of the government's additional investment in end of life care has found that 35% of the Primary Care Trusts who responded were unable to identify how much they have spent on end of life care in the current year (2009-2010). http://www.ncpc.org.uk/download/newsroom/pressReleases/Funding_Survey_PR.pdf

Of related interest:

- U.K. | BBC News – 17 March 2010 – '**Government loses four Lords votes on home care plans.**' The government has been defeated ... over plans to offer free personal care at home to 400,000 elderly and disabled people. It is estimated the scheme, for vulnerable people in England, would cost £670m a year, a third of which would be funded by councils. Peers voted to delay the measure until an independent review is carried out. http://news.bbc.co.uk/2/hi/uk_news/politics/8573621.stm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SINGAPORE | *Straits Times* – 21 March 2010 – '**[Gerald] Ee opposes assisted suicide.**' Mr. Ee, who is chairman of the National Kidney Foundation, responds to an article in the latest issue of the *Singapore Academy of Law Journal*, which called for laws to allow physician-assisted suicides. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_504691.html
- SPAIN | *The Olive Press* – 18 March 2010 – Andalucía has passed a landmark ruling allowing euthanasia. The historical legislation – the first to be approved in Spain – obtained cross party support in Sevilla. <http://www.theolivepress.es/2010/03/18/landmark-euthanasia-bill-in-andalucia/>
N.B. Andalucía is an autonomous community of Spain.
- SWEDEN | *The Local* – 18 March 2010 – '**Paralysed woman demands right to die.**' A 31-year-old woman who is completely paralysed and has been on a respirator since she was six, has demanded the right to die in a letter to the Swedish National Board of Health & Welfare. <http://www.thelocal.se/25596/20100318/>
- AUSTRALIA | Adelaide Now – 17 March 2010 – '**Voluntary euthanasia 'never will be policy' says SA Liberal leader Isobel Redmond.**' Liberal Leader Isobel Redmond would have liked to have had the option to give her dying mum "a needle," but says voluntary euthanasia will "never become party policy." <http://www.adelaidenow.com.au/news/in-depth/sa-liberal-leader-isobel-redmond-says-she-supports-voluntary-euthanasia/story-fn2sdwup-1225841868167>

[Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/>

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

Changing the cultural view and coverage of end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 15 March 2010 – Since the mid-60s, the trend has been for treatment to stand at the forefront of medicine and when death occurs, it is seen as a failure of intervention. Institutional deaths are far greater today for the elderly and terminally ill patients than prior to the Medicare era. The safety, comfort, desires, and mental/spiritual well-being of the patient (and their family) are often lost in the attempt to treat rather than comfort. The cost of end-of-life care continues to spiral out of control (along with the rest of health care costs), yet there has been very little impact on longevity in spite of all the technological advances. A change in attitude is needed to properly provide and pay for end-of-life care. <http://ajh.sagepub.com/cgi/content/abstract/1049909110361732v1>

Of related interest:

- *REHABILITATION NURSE*, 2010;35(2):60-64. **'Palliative or hospice care? Understanding the similarities and differences.'** Palliative care may be confused with hospice care, as both focus on symptom management and improved quality of life for those with chronic life-limiting disease. A better understanding of each healthcare option is needed for appropriate and timely patient referral. <https://www.rehabnurse.org/pdf/rnj318.pdf>

Personality characteristics of hospice palliative care volunteers: The "big five" and empathy

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 15 March 2010 – The goal of this study was to examine the personality characteristics of hospice palliative care volunteers by measuring the so-called big five personality traits and four separate aspects of empathy. The vast majority (84%) of the volunteers (i.e., study participants) were females [and] scored significantly higher on the traits of agreeableness, extraversion, and openness and significantly lower on the trait of neuroticism. On the empathy measure, female hospice palliative care volunteers scored significantly higher on the empathic concern and perspective taking subscales compared to the female norms, and significantly lower on the personal distress and fantasy subscales. <http://ajh.sagepub.com/cgi/content/abstract/1049909110364017v1>

Of related interest:

- *PSYCHO-ONCOLOGY* | Online article – 17 March 2010 – **'What is the role of friends when contributing care at the end of life?'** A cohort of younger caregivers may reflect changing social mores as the extended family shrinks and people turn to friendship networks for care and support at the end of life. <http://www3.interscience.wiley.com/journal/123323361/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: <http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

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

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/>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-provides-global-roundup-of-end-of-life-issues-n-96.htm>

Advanced care planning in children with life-limiting conditions – the Wishes Document

ARCHIVES OF DISEASE IN CHILDHOOD, 2010;95(2):79-82. In April 2009, the Association for Children's Palliative Care (ACT) endorsed the Wishes Document as a template for end-of-life discussions in children with life-limiting conditions (Child & Family Wishes Document).¹ A life-limiting condition has been defined as "One for which there is currently no cure available and the likelihood is that the condition will lead to the child dying prematurely." This describes many of the children that are familiar to paediatricians – those with severe cerebral palsy, neurodegenerative conditions, severe congenital heart disease, and metabolic and chromosomal disorders, to name but a few. Advances in medical care, along with increasing societal expectations, have resulted in children with these conditions living much longer. This review discusses the importance of sensitive end-of-life planning for such patients and describes the history and format of the Child & Family Wishes Document. <http://www.fetalneonatal.com/content/95/2/79.full>

1. 'Child & Family Wishes Document,' Association for Children's Palliative Care, October 2008. Scroll down to foot of web page and 'You can download a copy of the Family Wishes document here.' <http://www.act.org.uk/page.asp?section=107&search=Child+%26+Family+Wishes+Document>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2010;39(3):605-609. '**Dying tax free: The modern advance directive and patients' financial values.**' This case study and commentary puts forth a situation in which a palliative care consultation team encountered a patient with an advance directive that instructed her proxy decision maker to consider estate tax implications when making end-of-life decisions. [http://www.jpmsjournal.com/article/S0885-3924\(10\)00100-4/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00100-4/abstract)

Cancer and the news media

How does the news [media] report on treatment and outcomes?

ARCHIVES OF INTERNAL MEDICINE | Online article – 16 March 2010 – To determine how cancer news coverage reports about cancer care and outcomes, then authors conducted a content analysis of U.S. cancer news reporting in 8 large-readership newspapers and 5 national magazines. News reports about cancer frequently discuss aggressive treatment and survival but rarely discuss treatment failure, adverse events, end-of-life care, or death. These portrayals of cancer care ... may give patients an inappropriately optimistic view of cancer treatment, outcomes, and prognosis. <http://archinte.ama-assn.org/cgi/content/abstract/2010.11v1?home=>

Of related interest:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2010;303(11):1094-1095. '**Caring for patients with cancer.**' Despite the declaration of the "war on cancer" nearly 40 years ago, efforts of dedicated physicians and other clinicians who provide care for patients with cancer, billions of dollars in funding for cancer research, and increased public attention and interest in early cancer detection, cancer remains a leading cause of death worldwide, accounting for nearly 7 million deaths annually. <http://jama.ama-assn.org/cgi/content/extract/303/11/1094>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2010;303(11):1054-1061. '**Availability and integration of palliative care at U.S. cancer centers.**' Most cancer centers reported a palliative care program, although the scope of services and the degree of integration varied widely. <http://jama.ama-assn.org/cgi/content/abstract/303/11/1054>

Universal access to HIV treatment will not be achieved by 2015 without radical action

BRITISH MEDICAL JOURNAL | Online report – 17 March 2010 – Despite international commitment to achieving universal access to treatment for HIV, 10 million infected people still lack access to antiretrovirals, and the goal will not be achieved unless decisive measures are taken to revitalise the process, the U.K.'s international development minister, Gareth Thomas, said last week. http://www.bmj.com/cgi/content/extract/340/mar17_2/c1483

Italy sets up national palliative care service

BRITISH MEDICAL JOURNAL | Online report – 15 March 2010 – Managing pain will be easier for Italian doctors after a long awaited law on palliative care was unanimously approved by the Italian parliament. The new law, hailed by doctors and patients' associations as an important milestone, creates two national networks – one for treatment of pain and one for palliative care – with the aim of ensuring that patients all over the country, including children, get the same levels of care. Surveys show that Italy lags behind many other countries in palliative care. Consumption of opiates per person is still among the lowest in Europe, although it is rising. Terminally ill patients often receive adequate pain care only very late. The new law makes it easier for doctors, especially those in the state system, to prescribe strong painkillers, such as opiates.
http://www.bmj.com/cgi/content/extract/340/mar15_1/c1481

Dying cancer patient visits to emergency departments can be avoided

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 15 March 2010 – Many visits by dying cancer patients to the emergency department can be avoided with effective palliative care. In Ontario, about 40% of cancer patients visit the emergency department in the last two weeks of life. A study was conducted to examine how often and why people dying of cancer visit the emergency department near the end of life. These visits are an ordeal since wait times are long and uncomfortable. They are also disruptive, distressing and exhausting for patients and their families. Emergency room visits at the end of life are considered an indicator of poor quality care for cancer patients. "Patients who are near death should have their symptoms controlled and cared for in a setting of their choice, instead of on an emergency basis," write Dr. Lisa Barbera, Odette Cancer Centre (Toronto, Ontario) and co-authors. "While some people have unexpected urgent medical problems that need an emergency department visit, the rest of the visits are likely avoidable." In Ontario, 91,561 patients died of cancer between 2002 and 2005 and were included in this study. In the last six months of life, 76,759 patients had 194,017 visits to the emergency department and 31,076 patients had 36,600 visits to the emergency department in the last two weeks of life. Abdominal pain, breathing difficulties, pneumonia, malaise and fatigue and fluid in the chest were the most common reasons for visits to the emergency department both in the last six months and two weeks of life. Lung cancer was the most common primary cancer. "With comprehensive and coordinated palliative care, individuals could be managed in the clinic, at home and in palliative care units or residential hospices without the need for an emergency visit," write the authors. "The majority of the reasons for visits are within the scope of palliative care expertise."

Links:

- Canadian Medical Association press release: http://www.eurekalert.org/pub_releases/2010-03/cmaj-dcp030910.php
- *Canadian Medical Association Journal* article ('Why do patients with cancer visit the emergency department near the end of life?'): <http://www.cmaj.ca/cgi/content/abstract/cmaj.091187v1>

Ethical issues in end of life treatments for patients with dementia

EUROPEAN JOURNAL OF NEUROLOGY | Online article – 17 March 2010 – Dementia is a terminal disease, associated with great suffering and difficult decisions in the severe stage. The decision-making process is characterized by uncertainty because of lack of scientific evidence in treatments and by the need to reconcile conflicting points of view. In intercurrent diseases, aggressive interventions are used without consideration of its futility; in comparison with cancer, several consequences of physicians' attitude not to consider dementia as a terminal disease have been reported, especially concerning pain relief. Lack of evidence of artificial nutrition and hydration effectiveness makes advance care planning relevant.
<http://www3.interscience.wiley.com/journal/123323299/abstract>

Bioethics and "human dignity"

JOURNAL OF MEDICINE & PHILOSOPHY, 2010;35(2):180-196. The term "human dignity" is the source of considerable confusion in contemporary bioethics. It has been used by Kantians to refer to autonomy, by others to refer to the sanctity of life, and by still others (e.g., the President's Council on Bioethics) to refer – albeit obliquely – to an important but infrequently discussed set of human goods. In the first part of this article, I seek to disambiguate the notion of human dignity. The second part is a defense of the philosophical utility of such a notion; I argue that there is nothing implausible about appealing to a deontological "principle of dignity" to solve bioethical problems, especially those concerning the development of new biotechnologies. There may, however, be problems associated with any attempt to use dignity as a basis for public policy. <http://jmp.oxfordjournals.org/cgi/content/abstract/35/2/180>

Of related interest:

- *JOURNAL OF MEDICAL ETHICS*, 2010;36(3):132-137. **'Evolution of hospital clinical ethics committees in Canada.'** The percentage of hospitals with clinical ethics committees (CEC) in the authors' sample was found to be 85% compared with 58% and 18% in 1989 and 1984, respectively. <http://jme.bmj.com/content/36/3/132.abstract>

Health systems find opportunities and challenges in palliative care development

JOURNAL OF PALLIATIVE MEDICINE | Online article – 22 March 2010 – Of the nearly 1400 hospitals reporting a palliative care service on American Hospital Association's 2008 annual survey, the overwhelming majority are part of a health care system. What is the influence of these systems on palliative care program development and quality? How do a system's mission, resources, and requirements drive or inhibit palliative care program feasibility and impact? The purpose of this essay is to explore the perspectives of palliative care program and health care system leaders on the contributions and perceived importance of palliative care services within health care systems. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9848>

Cancer in the London [England] prison population, 1986–2005

JOURNAL OF PUBLIC HEALTH | Online article – 3 March 2010 – London prisons contribute a small number of patients each year who require ... cancer care, including those with advanced cancer who are released before death. Future studies should investigate cancer incidence for the national prison population, methods for improving screening coverage and follow-up, timeliness of access to cancer treatments and end-of-life care, and prisoners' and health professionals' experiences of care. <http://jpubhealth.oxfordjournals.org/cgi/content/abstract/fdq009v1>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. For those interested in prison hospice, a compilation of these articles and reports in a single document is available on request.

Different worlds: A cultural perspective on nurse-physician communication

NURSING CLINICS OF NORTH AMERICA, 2010;45(1):71-79. Although numerous studies have documented the value of effective nurse-physician communication on patient outcomes and on nurse and physician satisfaction, communication between many physicians and nurses continues to be poor. A variety of reasons for this disconnect have been identified, including differences in education, role expectations, gender, and approach to practice. Based on the principle that it is more important to understand than to be understood, application of a cultural competence model offers nurses the opportunity to better understand their physician colleagues. Because of the imperative to provide sensitive care to a diverse population, nurses are expected to assess cultural variations when planning care. That same skill can be applied to improving professional relationships with physicians. [http://www.nursing.theclinics.com/article/S0029-6465\(09\)00088-7/abstract](http://www.nursing.theclinics.com/article/S0029-6465(09)00088-7/abstract)

Paramedic knowledge, attitudes, and training in end-of-life care

PREHOSPITAL & DISASTER MEDICINE, 2009;24(6):529-34. Paramedics often are asked to care for patients at the end of life. To do this, they must communicate effectively with family and caregivers, understand their legal obligations and know when to withhold unwanted interventions. The objectives of this study were to ascertain paramedics' attitudes toward end-of-life (EOL) situations and the frequency with which they encounter them; and to compare paramedics' preparation during training for a variety of EOL care skills. The authors conclude that there is a need to include more training in EOL care into pre-hospital training curricula, including how to verify and apply advance directives, when to withhold treatments, and how to discuss death with victims' family or friends. <http://pdm.medicine.wisc.edu/>

Research with vulnerable families caring for children with life-limiting conditions

QUALITATIVE HEALTH RESEARCH, 2010;20(4):496-505. Methodological challenges associated with sensitive research, such as research with vulnerable families, have been well described, but there are few examples of how such challenges have been addressed in specific projects. To help address this gap, the authors describe how they designed and conducted a qualitative study. Although some issues associated with researching sensitive topics were anticipated, others were encountered that were not expected. They discuss insights gained from this study. <http://qhr.sagepub.com/cgi/content/abstract/20/4/496>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MEDICAL NEWS TODAY* | Online article – 19 March 2010 – **'What is the definition of assisted suicide or euthanasia?'** Euthanasia, also known as assisted suicide, physician-assisted suicide (dying), doctor-assisted dying (suicide), and more loosely termed mercy killing, basically means to take a deliberate action with the express intention of ending a life to relieve intractable (persistent, unstoppable) suffering. Some interpret euthanasia as the practice of ending a life in a painless manner. Many disagree with this interpretation, because it needs to include a reference to intractable suffering. <http://www.medicalnewstoday.com/articles/182951.php>

Worth Repeating

Taking "existential" suffering seriously

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2007; 34(1):108-110. Nurses, chaplains, social workers, and counsellors who work in palliative care are trained to relieve suffering by providing hands-on care, spending time – lots of time – with patients and families, and helping them to deal with the personal and household impact of terminal illness. These professionals, who value "being with" patients and families, may have difficulty advocating for patients and families. They may be frustrated and anguished when they observe physicians focusing on symptoms in isolation, rather than attending to the suffering person and the family in need of support, comfort, and clear information. They have less power than physicians ... so may hold back from involvement in clinical decision making, or may be excluded from it. <http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392407002631.pdf>

Quotable Quotes

"Spiritual," similar to "existential," is one of those words that are poorly or inconsistently defined in clinical medicine, but both signify something about that broken patient who remains a whole person."
Nancy Berlinger, PhD

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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