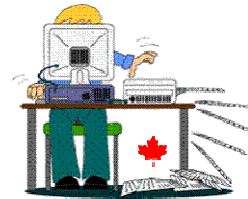


Media Watch...

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, 2011 ©

Compiled & Annotated by Barry R. Ashpole

Advance care directives: Scroll down to [International](#) and 'It's just a piece of paper' (p.5), published in *Australian Ageing Agenda*.

Canada

Compassionate Care Benefit

Family battles debilitating disease, bureaucracy

ONTARIO | *The Record* (Waterloo) – 3 September 2011 – Over 5,900 Canadians received compassionate care benefits ... last year, a payment that lasts six weeks, according to Human Resources & Skills Development Canada. Most people with ALS, however, can survive for years before succumbing to the disease, so the death-within-six-months criteria doesn't appear to make them eligible. "How am I supposed to be able to know when he will die?" Allison [Allensen, whose husband Sean is living with ALS] said. "I don't have a crystal ball." The family is receiving some assistance from the Canada Pension Plan Disability benefit, but says it's not enough to pay their bills. Sean also has life insurance that covers the mortgage payments in the event of a medical crisis, but that's capped at two years. If he survives past that, he worries they won't be able to afford their house and may have to sell. It seems wrong the family's financial straits can be fixed only if he dies, he said. <http://www.therecord.com/news/local/article/588949--family-battles-debilitating-disease-bureaucracy>

From Media Watch dated 23 May 2011:

- *BMC PUBLIC HEALTH* | Online article – 18 May 2011 – '**Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care?**' The Compassionate Care Benefit (CCB) is not living up to its full potential in sustaining informal palliative/end-of-life caregivers. Effort is required to transform the CCB so that it may fulfill the potential it holds for serving as one public health response to caregiver burden. <http://www.biomedcentral.com/content/pdf/1471-2458-11-335.pdf>

N.B. Employment Insurance Compassionate Care Benefit website:
http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *GLOBE & MAIL* | Online interview – 11 September 2011 – **'The assisted suicide dilemma.'** Professor Udo Schuklenk, a philosopher from Queen's University, talked to Marina Jimenez of the *Globe & Mail* editorial board. He is chair of the Royal Society's committee on end-of-life decision-making in Canada. The committee, which will release a lengthy report this fall, spent two years studying this issue, and the experience of other countries which have decriminalized assisted suicide. <http://www.theglobeandmail.com/news/opinions/editorials/the-assisted-suicide-dilemma/article2161476/>
- *GLOBE & MAIL* | Online editorial – 11 September 2011 – **'Make the right to die legal, with protections.'** Canadians want to live good, long lives. And for most people, that includes an ending-of-life that is as dignified, peaceful and comfortable as possible. Time and again, opinion polls show a large majority of Canadians support the idea that the terminally ill should be able to decide when and how they die. <http://www.theglobeandmail.com/news/opinions/editorials/make-the-right-to-die-legal-with-protections/article2161475/>

U.S.A.

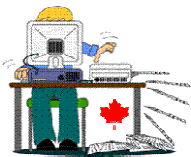
Overriding patients' end-of-life wishes

Merger impact on Jewish Hospital questioned

KENTUCKY | *Courier-Journal* (Louisville) – 10 September 2011 – A merger that would put Jewish Hospital under the control of Catholic Health Initiatives has raised questions in the Jewish community. The proposal would create the state's largest health care system by merging Jewish Hospital & St. Mary's HealthCare and University Hospital in Louisville with St. Joseph Health System of Lexington, which is owned by Denver-based Catholic Health Initiatives. The hospitals have agreed to follow Catholic health care directives. Those directives have created controversy because the merger includes University Hospital, the main teaching facility for the University of Louisville and the recipient of millions of dollars from the government for its treatment of the poor. <http://www.chron.com/news/article/Merger-impact-on-Jewish-Hospital-questioned-2164400.php>

From Media Watch dated 25 July 2011:

- KENTUCKY | *Courier-Journal* (Louisville) – 21 July 2011 – **'University Hospital merger stirs end-of-life care fears.'** A growing chorus of protest from local residents, doctors and others has erupted over the fact that Catholic doctrine could override patients' end-of-life wishes under a pending merger of three Kentucky hospitals. <http://www.courier-journal.com/article/20110723/BUSINESS/307240044/University-Hospital-merger-stirs-end-life-care-fears?odyssey=tab%7Ctopnews%7Ctext%7CHome>



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Florida ranks 44th for long-term care

FLORIDA | *Herald-Tribune* (Sarasota) – 8 September 2011 – A new national rating indicates that Florida's elderly and disabled residents would be best off moving to Minnesota, Washington or Oregon, based on measurements of the quality and availability of help for people who need long-term care. On a "scorecard" released by American Association for Retired Persons and two national foundations,¹ Florida ranked a dismal 44th among 50 states and the District of Columbia. The rating ... is meant to nudge states to improve their long-term care services by gauging four categories: affordability and access, choice of setting and provider, quality of life and

support for family caregivers.

<http://www.heraldtribune.com/article/20110908/ARTICLE/110909674/-1/news?Title=Florida-ranks-44th-for-long-term-care>

Specialist Publications

Of particular interest:

'The intersection of long-term care and end-of-life care' (p.12), published in *Medical Care Research & Review*.

1. 'Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers,' American Association for Retired Persons, September 2011. <http://www.longtermscorecard.org/>

5 Steps to a Family Caregiving Agreement

U.S. TODAY & WORLD NEWS | Online article – 6 September 2011 – More than 65 million Americans provide more than \$375 billion a year in uncompensated care to friends and family members. Now, with older populations growing rapidly, the need for caregiving is rising, just as a brutal economic downturn is making money increasingly tight. In response, some family caregivers are being paid for their work, usually by an aging parent. And while authoritative numbers aren't available, family-care attorneys and consultants say they're seeing more families creating caregiver agreements. <http://money.usnews.com/money/blogs/the-best-life/2011/09/06/5-steps-to-a-family-caregiving-agreement>

From Media Watch dated 22 December 2008:

- *CANADIAN JOURNAL OF ELDER CARE* | Online article – 15 December 2008 – **'Formalizing the informal: Family care agreements in Canada and the U.S.'** In both Canada and the U.S., family caregiving agreements are increasingly being used to formalize the responsibilities that family caregivers undertake when providing in-home assistance for their (typically) older relatives. <http://www.bcli.org/cjel/projects/formalizing-informal-family-care-agreements-canada-and-united-states>

Putting a price on prolonging a doomed life

CALIFORNIA | *Los Angeles Times* (OpEd) – 1 September 2011 – In the harsh light of pure statistics, it's clear that we have to do more to bring down healthcare costs and expenditures. One way to do that would be through the efficiencies of extending Medicare to all Americans and more strictly regulating how much can be charged for medical procedures and insurance. Another would be to limit how much of our healthcare resources should be devoted to ... lost causes. Do we really want to spend hundreds of thousands of dollars extending the life of a person with a terminal illness? Clearly there are limits to how much can and should be done to prolong the lives of the terminally ill. But this is a matter for medical experts, not insurance bean counters, to address. <http://articles.latimes.com/2011/sep/01/business/la-fi-lazarus-20110902>

Cont.

Of related interest:

- *MCKNIGHT'S LONG TERM CARE & ASSISTED LIVING* | Online report – 1 September 2011 – **'Higher regulatory demands, money for hospice providers.'** When others were sweating out funding threats or declines, hospice providers were able to enjoy the announcement of a 2.5% rise in Medicare payments for fiscal 2012. The Center for Medicare & Medicaid Services released a final rule for it that was published in the Aug. 4 Federal Register. <http://www.mcknights.com/higher-regulatory-demands-money-for-hospice-providers/article/211620/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | WMAC Radio – 9 September 2011 – **'Campaigns ramping up for Massachusetts ballot initiatives including physician assisted suicide...'** Massachusetts Attorney General Martha Coakley announced the certification of 23 ballot initiative petitions ... setting the stage for advocates to begin campaigning to get their proposals on the ballot next year. State law requires that petitioners must now gather the signatures of almost 70,000 registered voters by the first week of December. Any initiative passed would become the equivalent of state law; meaning voters could get the chance to enact proposals on several policies which have garnered national attention, including ... physician assisted suicide. The "Massachusetts Death with Dignity Act," one of the initiatives vying for a ballot spot, would allow terminally ill patients whose doctors have determined will likely die within six months to self administer a lethal dose of medication. <http://www.publicbroadcasting.net/wamc/news.newsmain/article/0/0/1850041/WAMC.N ew.England.News/Campaigns.ramping.up.for.Massachusetts.ballot.initiatives.including.physician-assisted.suicide..medical.marijuana..and.expanded.bottle.deposits>

International

Help the dying to 'live'

AUSTRALIAN AGEING AGENDA | Online report – 8 September 2011 – Health care staff do not place enough focus on helping the dying to live well until the moment that they die. This statement was made by Peninsula Health's senior occupational therapist, Deidre Morgan, at the 'Diversity 2011 – 11th Australian Palliative Care Conference.' Ms. Morgan said that medical professionals, hospital, aged and community care mistakenly consider palliative and terminal care to be interchangeable terms, only associate palliation with the last days of someone's life, and identify palliative care with the "black vans that take people away." What's more, she added, the delivery of palliative care in hospital and aged care settings is currently delivered in an "ad hoc way, if at all." However, she stated, differentiation between the two terms is essential because an accurate definition will influence funding, care provision and how others see the palliative care discipline. <http://www.australianageingagenda.com.au/2011/09/08/article/Looking-at-death-differently/LPWECSIXZN.html>

Of related interest:

- AUSTRALIA (VICTORIA) | *Ararat Advertiser* – 9 September 2011 – **'Funding for palliative care in Ararat.'** The Baillieu Government has allocated an extra \$8.6 million to palliative care agencies across the State in 2011-12 as the first part of its election commitment to boosting services for people with a terminal illness. <http://www.araratadvertiser.com.au/news/local/news/general/funding-for-palliative-care-in-ararat/2286426.aspx>
- AUSTRALIA (NEW SOUTH WALES) | *AUSTRALIAN AGEING AGENDA* – 6 September 2011 – **'Triumph for palliative care at home.'** Hammond Care has had a welcome win with the government with the recent restoration of much needed funding for its community palliative care services in northern Sydney. Following a two year battle, the Premier ... Barry O'Farrell announced the decision ... to restore over a million dollars taken away from these services as part of cost-saving measures in 2009. <http://www.australianageingagenda.com.au/2011/09/06/article/Triumph-for-palliative-care-at-home/BQDPLRZYEG>

Advance care directives

It's just a piece of paper

AUSTRALIAN AGEING AGENDA | Online report – 6 September 2011 – Advance care directives are "helpful" but they do not guarantee that a person will die the way they want or in their location of choice, a palliation expert and advocate told the audience at 'Diversity 2011, the 11th Australian Palliative Care Conference.' President of Palliative Care New South Wales, Peter Cleasby, said although advance care documents are essential, they alone are just a piece of paper. Directives, by themselves, do not ensure that a person's end-of-life care wishes are carried out, nor do they prevent individuals from spending their last hours traumatised in the back of an ambulance or emergency department. Advance care plans, Mr. Cleasby said, "will not prevent all inappropriate hospital admissions." To make an advance care directive effective, it must therefore go hand-in-hand with a series of family-wide conversations about ... an individual's palliative and end-of-life care wishes. <http://www.australianageingagenda.com.au/2011/09/06/article/lts-just-a-piece-of-paper/RJQKEZZPCZ.html>

Of related interest:

- AUSTRALIAN AGEING AGENDA | Online report – 6 September 2011 – **'Choice and control over life and death.'** The Productivity Commission [PC] has taken up the palliative care cause, recommending that the aged care system "should aim to be consumer-directed, allowing older Australians to have choice and control over their lives and to die well." Behind those words – "to die well" – is a much greater emphasis placed on palliative care in the final version of the PC's report. ¹ <http://www.australianageingagenda.com.au/2011/08/16/article/Choice-and-control-over-life-and-death/PCZVWNMNLJ.html>
1. Caring for Older Australians. Productivity Commission, 2011. <http://pc.gov.au/projects/inquiry/aged-care/report>

Do not resuscitate: They're the fateful words meaning doctors won't try to save you if you collapse in hospital. But could they go on YOUR file without you being asked?

U.K. | *Daily Mail* – 6 September 2011 – Throughout England and Wales, bereaved relatives have discovered that the decision not to resuscitate had been taken without either the patient or their family being consulted. Indeed, it is doctors who have the final say about whether resuscitation is in the patient's best interest. This has led to accusations that doctors are 'playing God' and ignoring vulnerable patients' right to life by not consulting them about what should happen in the event of a collapse. As hospitals face deeper budget cuts, some even fear that not resuscitating patients will become a cost-cutting option to help cash-strapped hospitals save money and prevent 'bed blocking.' It is thought that a staggering 80% of those who die in hospital are the subject of 'do not resuscitate' orders. <http://www.dailymail.co.uk/health/article-2034160/Do-resuscitate-Theyre-fateful-words-meaning-doctors-wont-try-save-you-collapse-hospital.html?ito=feeds-newsxml>

N.B. The issue of do not resuscitate orders has in recent weeks generated significant media attention in the U.K. (see Media Watch dated 5 September and 29 August 2011, p.5 and p.2, respectively).

'Do not resuscitate' tattooed on Norfolk pensioner

U.K. | BBC News – 6 September 2011 – An 81-year-old woman from Norfolk has had "Do Not Resuscitate" tattooed across her chest in case she falls ill and attempts are made to revive her. <http://www.bbc.co.uk/news/uk-england-norfolk-14802369>

Specialist Publications

Of particular interest:

'Palliative medicine and decision science: The critical need for a shared agenda to foster informed patient choice in serious illness' (p.11), published in the *Journal of Palliative Medicine*.

Give quality service to patients: Minister

INDIA | *The Hindu* – 6 September 2011 – Formally inaugurating the first palliative medicine clinic started by the department of community medicine at the Medical College Hospital [in the city of Thiruvananthapuram, capital of the State of Kerala, Health Minister Adoor] Prakash said that compassion should mark the relationship between a doctor and a patient. M.R. Rajagopal, chairman of Pallium India, who has been spearheading a silent revolution in palliative care in the State, said that while the palliative movement had grown by leaps and bounds, the State should improve the quality of care offered to palliative care patients. The palliative movement should go hand in hand with the existing health system so that it had better reach and accessibility, Dr. Rajagopal said. <http://www.thehindu.com/news/cities/Thiruvananthapuram/article2428914.ece>

N.B. The palliative care initiative in Kerala has in recent months generated significant international media attention (see Media Watch dated 5 September and 29 August 2011, p.7 and p.2, respectively).

Study: What Doctors Say About Care Of The Dying

Subsidy dearth for end-of-life home care

SINGAPORE | *Straits Times* – 6 September 2011 – 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 study¹ [conducted by the National University of Singapore's Centre for Biomedical Ethics and commissioned by the Lien Foundation]. Doctors noted that the system is largely based on the assumption that hospital care is likely to cost the most, and therefore requires the most subsidy and help. This ... is true in 'the more traditional model of illness,' such as when someone gets a heart attack and is hospitalised, and either dies or recovers. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_709910.html

- SINGAPORE | *Straits Times* – 6 September 2011 – **'Doctors say 'no' to helping patients end their lives.'** While doctors in Singapore generally have no problems with the concept of withholding and withdrawing treatment from dying patients, some have qualms about doing so for food and water. A study found that the latter proved much more difficult for doctors, morally and emotionally. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_709902.html
- SINGAPORE | *Today* – 5 September 2011 – **'Dying patients have less say in care and treatment than their families do.'** Doctors here are caught between a rock and a hard place when it comes to the treatment and care of people who are dying, according to an inaugural study on end-of-life care. As a result, tensions flare between doctors and families "when Western-based laws come into conflict with the Asian practice of collective decision-making in families, local values and cultural norms." <http://www.todayonline.com/Singapore/EDC110905-0000183/Dying-patients-have-less-say-in-care-and-treatment-than-their-families-do>

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. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Debunking the 'death house' myth about hospices

SINGAPORE | *Straits Times* – 5 September 2011 – With demand for better quality end-of-life care expected to spike with Singapore's ageing population, there is a need to increase awareness about hospice care. That is why Dr. Seet Ai Mee, of the Singapore Hospice Council, is heading a task force to do just that and also debunk the myth that hospices are merely death houses. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_709598.html

N.B. There are eight hospices in Singapore.

1. *What Doctors Say About Care Of The Dying*, Lien Foundation, September 2011. http://www.lienfoundation.org/pdf/news/What_Doctors_Say_About_Care_of_the_Dying.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (SOUTH AUSTRALIA) | Law Fuel (New Zealand) – 12 September 2011 – **'Australian doctors and lawyers oppose 'End of Life' Bill.'** Peter Sharley, of the AMA(SA) and Ralph Bonig, of the Law Society of South Australia have jointly stated opposition to the proposed amendments to the Criminal Consolidation Act which will make it easier for doctors to provide treatment which shortens a persons' life. <http://www.lawfuel.co.nz/releases/release.asp?NewsID=2744>
- THE NETHERLANDS | Dutch News – 7 September 2011 – **'Doctors should always deal with euthanasia: KNMG.'** Doctors with moral objections to euthanasia should always refer patients to another doctor for help, according to new guidelines¹ drawn up by the national doctors' association KNMG [Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst – the Royal Dutch Medical Association]. Euthanasia requests should always be taken seriously, even if someone has simply had enough of life without being terminally ill, the KNMG says. A string of complaints relating to old age, for example, could be grounds for mercy killing, even if they are not terminal. But no-one should be helped to die simply because they are old or fed up with living. http://www.dutchnews.nl/news/archives/2011/09/doctors_should_always_deal_wit.php
 1. KNMG Position paper: The role of the physician in the voluntary termination of life (2011). <http://knmg.artsennet.nl/Diensten/knmgpublicaties/KNMGpublicatie/Position-paper-The-role-of-the-physician-in-the-voluntary-termination-of-life-2011.htm>
- U.K. | *Daily Telegraph* – 3 September 2011 – **'44 assisted suicide cases since Crown Prosecution Service guidelines published.'** The police have passed a total of 44 files to the Crown Prosecution Service (CPS) since 2009 in which firm evidence was found which could have led to a prosecution for helping someone end their lives. The crime remains punishable by up to 14 years' imprisonment. However, a landmark court case brought by a right-to-die campaigner that year led to the publication of guidelines which made it clear that suspects would not be charged unless it was thought that they forced the victim into killing themselves or sought to profit from their death. Nobody has been prosecuted since the guidelines were produced early in 2010, following a handful of previous criminal cases, although a small number of files are still being reviewed. The official figures ... are the first official evidence of the scale of assisted suicide in Britain. <http://www.telegraph.co.uk/news/uknews/law-and-order/8738415/44-assisted-suicide-cases-since-CPS-guidelines-published.html>

Crown Prosecution Service defends assisted suicide policy

U.K. | Press Association – 6 September 2011 – The Crown Prosecution Service [CPS] has not implemented a "blanket policy" banning the prosecution of cases of assisted suicide, its head has insisted. The Director of Public Prosecutions Keir Starmer admitted that no prosecutions had been brought for the offence since new CPS guidelines were issued 18 months ago. But he said after personally overseeing all the "unique" cases since then, none have involved an individual who was "motivated by the prospect of gaining from the victim's death." http://www.google.com/hostednews/ukpress/article/ALeqM5iN_fqEpb6eE-ILrmiALw9EgoT-Pg?docId=N0213081315284850926A

N.B. Director of Public Prosecutions interim policy on prosecuting assisted suicide, September 2009. http://www.cps.gov.uk/news/press_releases/144_9/



8 October 2011

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

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

Bereavement and depression

Bereavement-related depressive episodes

ARCHIVES OF GENERAL PSYCHIATRY, 2011;68(9):920-928. The DSM-IV [*Diagnostic & Statistical Manual of Mental Disorders-IV*] criteria for major depressive episodes exclude brief episodes that are better accounted for by bereavement. However, a proposal has been made to remove this exclusion from the DSM-IV. Compared with participants [in this longitudinal, community-based, epidemiologic study] with other types of depression, those with bereavement-related, single, brief depressive episodes were more likely to experience later onset and to be black but less likely to have had impairment in role functioning, co-morbid anxiety disorders, or a treatment history at baseline. Participants with bereavement-related, single, brief episodes were less likely than those with bereavement-unrelated, single, brief episodes to experience fatigue, increased sleep, feelings of worthlessness, and suicidal ideations. The risk of new depressive episodes during the follow-up period among participants with bereavement-related, single, brief episodes was significantly lower than among participants with bereavement-unrelated, single, brief episodes and other types of depression but similar to the risk among the participants from the general population with no baseline history of depression. The findings support preserving the DSM-IV bereavement exclusion criterion for major depressive episodes. <http://archpsyc.ama-assn.org/cgi/content/abstract/68/9/920>

From Media Watch dated 22 August 2011:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2011;63(3):199-220. **'Possible changes to the Diagnostic & Statistical Manual of Mental Disorders: A report from the Scientific Advisory Committee of the Association for Death Education & Counseling.'** The exclusionary criterion states that within the first two months of onset of bereavement a person should not be diagnosed as having major depression unless certain symptoms uncharacteristic of a normal grief reaction are present. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue_1_5;journal_1_250;linkingpublicationresults_1:300329_1;

Of related interest:

- *JOURNAL OF CHILD & ADOLESCENT TRAUMA*, 2011;4(3):233-257. **'Complicated grief reactions in children and adolescents.'** An understanding of complicated grief in youth is incomplete, because the full range of observed, theorized, and studied symptoms and reactions has not yet been examined in different age groups. Until recently, scales to assess complicated grief in youth were based on adult constructs of complicated grief and did not include many of the symptoms and reactions proposed for post trauma grief. Much can be learned from adult theories and findings. <http://www.tandfonline.com/doi/abs/10.1080/19361521.2011.599358>

Rwanda moving to provide "good deaths" for terminally ill

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 8 September 2011 – "Go home and die." Until recently, that advice constituted the extent of end-of-life care that patients with incurable diseases could expect in Rwanda. As in much of the developing world, palliative care was virtually non-existent in the tiny Africa nation, condemning those with terminal illnesses to meet their end in isolation and pain. Now, however, the country has committed to provide all Rwandans living with incurable illnesses, as well as their families and caregivers, with high-quality, affordable palliative care services to meet their physical, psychological, social and spiritual needs by 2020 – one of the first such policies in sub-Saharan Africa and the developing world. http://www.cmaj.ca/site/earlyreleases/8sept11_rwanda-moving-to-provide-good-deaths-for-terminally-ill.xhtml

Withdrawal of life support

Physicians appeal Rasouli ruling to Supreme Court

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 6 September 2011 – Arguing that lower court decisions would "require physicians to breach the applicable medical standard of care," a pair of Ontario physicians have appealed to the Supreme Court of Canada to overturn a ruling that life support cannot be withdrawn without the consent of a substitute decision maker. Brian Cuthbertson and Gordon Rubinfeld, physicians at the Sunnybrook Health Sciences Centre in Toronto, Ontario, sought leave to appeal from the Supreme Court in August to overturn lower court decisions that prohibit them from withdrawing mechanical ventilation from a 59-year-old mechanical engineer in a persistent vegetative state. The patient, Hassan Rasouli, has been in a coma since he contracted bacterial meningitis following brain surgery at Sunnybrook in October 2010. Cuthbertson and Rubinfeld want to withdraw life support to prevent Rasouli from dying a slow death from complications of being bedridden. But Rasouli's family has refused their consent, arguing that his religious beliefs should be respected and that, as a devout Shia Muslim, he should be kept alive on mechanical support "until all signs of life are gone." Ontario's Superior Court of Justice, and subsequently the Court of Appeal for Ontario, have ruled that the withdrawal of life support constitutes a form of "treatment" under the province's Health Care Consent Act and therefore, the consent of Rasouli's wife is required. "If her consent is not forthcoming, the appellants' proposal must be referred" to the province's Consent & Capacity Board, jointly wrote Justices Michael Moldaver and Janet Simmons. Cuthbertson and Rosenfeld argue the case raises several critical questions of law. <http://www.cmaj.ca/site/earlyreleases/4theRecord.xhtml>

N.B. The Rasouli case has in recent months generated significant media attention in Canada (see Media Watch dated 25, 11 & 4 July 2011, p.1 in each issue, and 23 May and 11 April 2011, p.2 and p.7, respectively).

From Media Watch dated 6 June 2011:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online article – 2 June 2011 – '**Legal ambiguities surround authority to make end-of-life decisions.**' Should physicians have to seek consent from patients, substitute decision-makers or an independent tribunal in order to pull the plug on life-sustaining treatments they deem futile? An informal survey of Canadian case law indicates that courts have been all over the map on the issue, which has recently resurfaced in the headlines. <http://www.cmaj.ca/content/early/2011/06/06/cmaj.109-3910.full.pdf+html?sid=0ead2a3c-d25b-41fc-ad7b-59269d552615>

Informing medical training

Centre for Workforce Intelligence report on the medical workforce [in the U.K.]...

CENTRE FOR WORKFORCE INTELLIGENCE | Online report – 5 September 2010 – The report makes recommendations to inform the future recruitment to medical training over the medium term. The recommendations include a view on: the nature of any change needed; the pace of this change; geographical imbalances that need to be addressed; and, a year for the next review. The report is supported by medical specialty recommendations, presented as fifty-seven combined fact and summary sheets

containing more detailed analyses for each specialty. <http://www.cfw.org.uk/intelligence/projects/shape-of-the-medical-workforce-informing-medical-training-numbers>

Medical Specialty Workforce Summary Sheet (Palliative Medicine): <http://www.cfw.org.uk/intelligence/shape-of-the-medical-workforce-informing-medical-specialty-training-numbers/palliative-medicine>

The influence of race/ethnicity and socioeconomic status on end-of-life care in the ICU

CHEST, 2011;139(5):1025-1033. There is conflicting evidence about the influence of race/ethnicity on the use of intensive care at the end of life, and little is known about the influence of socio-economic status. The authors examined patients who died in the ICU in 15 hospitals. Race/ethnicity was assessed as white and non-white. Socioeconomic status included patient education, health insurance, and income by zip code. To explore differences in end-of-life care, they examined the use of 1) advance directives; 2) life-sustaining therapies; 3) symptom management; 4) communication; and, 5) support services. The authors found numerous racial/ethnic differences in end-of-life care in the ICU that were not influenced by socio-economic status. <http://chestjournal.chestpubs.org/content/139/5/1025.abstract>

Supporting organ donation through end-of-life care: Implications for heart-beating donation

CLINICAL ETHICS, 2011;6(3):122-126. New protocols have been developed for donors after circulatory death involving early assessment of donor status and pre-mortem supporting treatment in appropriate cases where there is evidence that the patient wished to be an organ donor. These donors are now making an increasingly marked impact on overall deceased donor numbers in the U.K. Donors after brainstem death, on the other hand, are much less buoyant yet require the same flexibility in approach in order to improve rates of donation and to realize the wishes of potential deceased organ donors to the proper requisite extent. <http://ce.rsmjournals.com/content/6/3/122.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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
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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.

Hospitalists see value in palliative care

THE HOSPITALIST (U.S.) | Online report – 7 September 2011 – Hospital medicine groups looking for a new revenue stream would be well served to keep an eye on the explosive growth of palliative care, according to a former Society for Hospital Medicine president who also runs a palliative service. Steven Pantilat, of the Palliative Care Leadership Center at the University of California ... says data ... show that 63% of hospitals have palliative-care teams, up from 24.5% in 2000. But growth is lagging in both smaller hospitals and hospitals in the South. "Hospitals that are looking to improve the systems of care, hospitals that are looking to be more cutting-edge, looking to be adopters of new models of care are going to pursue both hospital medicine and palliative care," he says. [American Academy of Hospice and Palliative Medicine. http://www.the-hospitalist.org/details/article/1338921/Hospitalists See Value in Palliative Care.html](http://www.the-hospitalist.org/details/article/1338921/Hospitalists%20See%20Value%20in%20Palliative%20Care.html)

From Media Watch dated 8 August 2011:

- U.S. | *Florida Trend* – 1 August 2011 – '**Hospices in Florida: From cause to commerce.**' In the 1970s, hospices began to grow in the U.S. as a grassroots effort by those who believed that terminally ill people should be able to die with dignity. Advocates set up non-profit organizations called hospices on shoestring budgets to care for the emotional, social and spiritual needs of dying people and their families. The programs relied almost entirely on charitable contributions and volunteers. Providers of hospice services grew to meet the demand. Many non-profits got bigger, but the Medicare reimbursement system was generous enough to attract for-profit providers, too. <http://www.floridatrend.com/article.asp?aID=55369&mostread=true>

N.B. Several articles on trends in for-profit hospices in the U.S. are noted in Media Watch dated 1 August 2011 (p.5).

Palliative medicine and decision science: The critical need for a shared agenda to foster informed patient choice in serious illness

JOURNAL OF PALLIATIVE MEDICINE | Online article – 6 September 2011 – Assisting patients and their families in complex decision making is a foundational skill in palliative care; however, palliative care clinicians and scientists have just begun to establish an evidence base for best practice in assisting patients and families in complex decision making. Decision scientists aim to understand and clarify the concepts and techniques of shared decision making (SDM), decision support, and informed patient choice in order to ensure that patient and family perspectives shape their health care experience. Patients with serious illness and their families are faced with myriad complex decisions over the course of illness and as death approaches. If patients lose capacity, then surrogate decision makers are cast into the decision-making role. The fields of palliative care and decision science have grown in parallel. There is much to be gained in advancing the practices of complex decision making in serious illness through increased collaboration. The purpose of this article is to use a case study to highlight the broad range of difficult decisions, issues, and opportunities imposed by a life-limiting illness in order to illustrate how collaboration and a joint research agenda between palliative care and decision science researchers, theorists, and clinicians might guide best practices for patients and their families. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0032>

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online report – 8 September 2011 – '**Royal College of General Practitioners launches guide to managing long term conditions.**' The Royal College of General Practitioners is urging family doctors in England to let patients with long term conditions take an active role in managing their own healthcare. The college has issued guidance setting out how GPs can "provide active support" to ensure that patients are in charge of their own care, amid a reluctance among doctors to relinquish control. <http://www.bmj.com/content/343/bmj.d5623.extract>

Cont.

- *JOURNAL OF NURSING CARE QUALITY*, 2011;26(4):350-357. **'Encouraging patients and families to influence change on a palliative care unit: Value of patient satisfaction surveys.'** This article describes how a series of patient satisfaction surveys ... were used to help influence the care provided to patients and their families. Innovative interventions aimed at addressing areas of lower satisfaction identified in the initial survey are described. The results from a follow-up survey provided the opportunity to evaluate whether our interventions were effective in improving patient satisfaction. http://journals.lww.com/jncqjournal/Abstract/2011/10000/Encouraging_Patients_and_Families_to_Influence.9.aspx
- *PACESETTERS*, 2011;8(3):34-39. **'Advanced care planning: How does current practice compare with best practice?'** An audit of highlighted that although every resident had an advance care plan, they were not always completed correctly, had conflicting information, or were incomplete. http://journals.lww.com/jbipacesetters/Abstract/2011/07000/Advanced_Care_Planning_How_does_current_practice.10.aspx

Place of death

In-region versus out-of-region hospitalizations at the end of life among older rural residents: The relationship between personal and system-related factors

JOURNALS OF GERONTOLOGY | Online article – 3 September 2011 – Even though a large segment of the population lives in rural areas, relatively little attention has been paid in the literature to date to hospital use at the end of life among rural residents. [In the hospital population included in this study] 20% of hospitalizations and 21% of hospital deaths occurred in a hospital that was out of older adults' region of residence. Compared with decedents aged 65-74, those aged 75-84 and even more so those aged 85+ had reduced odds of being hospitalized out of region or dying in an out-of-region hospital. Those 85+ years old also had reduced odds of being hospitalized in a (out-of-region) tertiary hospital. Higher hospital bed rates and physician rates were associated with reduced odds of out-of-region hospitalization and hospital death. <http://biomedgerontology.oxfordjournals.org/content/early/2011/09/03/gerona.glr161.abstract>

The intersection of long-term care and end-of-life care

MEDICAL CARE RESEARCH & REVIEW | Online article – 8 September 2011 – High-quality end-of-life care is an important component of high-quality long-term care, yet many elderly individuals receiving long-term care services do not obtain good care as they approach death. This study provides a systematic review of articles that describe care received at the nexus of long-term care and end-of-life care. They identified three primary types of barriers to high-quality end-of-life care in long-term care settings: delivery system barriers intrinsic to long-term care settings, barriers related to features of coverage and reimbursement, and barriers resulting from the current regulatory approach for long-term care providers. Recommended are areas for future research ... to support progress on public policy that governs the provision of care at this important intersection. <http://mcr.sagepub.com/content/early/2011/08/19/1077558711418518.abstract>

U.S. National Institutes of Health Summit

Palliative care becoming more fully integrated into oncology

ONCOLOGY TIMES | Online report – 4 September 2011 – One sign that end-of-life and palliative care are coming of age in oncology and other medical specialties is the fact that the federal Agency for Healthcare Research & Quality (AHRQ) announced in June that it has requested a systematic review of end-of-life and hospice care as part of its 'Closing the Quality Gap: Revisiting the State of the Science' series. That review – which will cover the lifespan – will address pain management and the variation in quality in hospice programs, and determine how well the needs of family members whose loved one is at the end of life due to cancer or another illness are being met. <http://journals.lww.com/oncology-times/blog/onlinefirst/pages/post.aspx?PostID=286>

Cont.

From Media Watch dated 4 July 2011:

- AGENCY FOR HEALTHCARE RESEARCH & QUALITY (AHRQ) | Online posting – 27 June 2011 – **'Closing the quality gap: End-of-life and hospice care.'** The AHRQ [an agency of the U.S. Department of Health & Human Services] has requested a systematic review on end-of-life and hospice care as part of the 2011 'Closing the Quality Gap: Revisiting the State of the Science (CQG)' series. <http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?productid=717&pageaction=displayproduct>

Of related interest:

- *HEALTH DATA MANAGEMENT* | Online report – 2 September 2011 – **'New data quality reporting programs for hospices, long-term care.'** The Affordable Care Act requires establishment of a quality data reporting program for hospices and long-term care hospitals, with reduced Medicare payments beginning in fiscal year 2014 for those that do not participate. <http://www.healthdatamanagement.com/news/medicare-quality-hospice-long-term-43137-1.html>

Caring for the dying in emergency departments

SOCIAL SCIENCE & MEDICINE | Online article – 1 September – In an ageing society, like the U.K., where long-term illness dominates healthcare, there has been a change in the way that the end-of-life is approached and experienced. Advancing technology, inadequate knowledge and inconsistency in palliative care services have complicated the ability to recognise imminent dying, and many people access emergency services at the end-of-life. The authors examine the spaces of dying and death, which are created in a place designed to save life, and not necessarily to provide supportive and palliative care. Despite the high need for attention in an emergency crisis, this study shows that the approach taken to care for someone at the end-of-life, and consequently the space in which they are cared for, often falls short of the expectations of the dying patient and their relatives. It is argued that the dying body is seen as dirty and polluted in the sterile, controlled, clinical environment and is therefore 'matter out of place.' Attempts are made to conceal or remove the dying patient, the bereaved relatives and the deceased body protecting the natural order of the emergency department (ED). Consequently, the individual supportive and palliative care needs of the dying are often overlooked. This paper highlights the needs of patients as death nears in the ED and argues that the critical decisions made in the ED have a significant impact on the quality of care experienced by patients, who spend the last few hours of their life there. <http://www.sciencedirect.com/science/article/pii/S0277953611005132>

From Media Watch dated 8 August 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 30 July 2011 – **'Does palliative care have a future in the emergency department?'** Providers [i.e., study participants] acknowledged many benefits of palliative care presence in the ED [emergency department], including provision of a specialized skill set, time to discuss goals of care, and an opportunity to intervene for seriously ill or injured patients. Providers believed that concerns about medico-legal issues impaired their ability to forgo treatments where risks outweigh benefits. Additionally, the culture of emergency medicine ... was sometimes at odds with the culture of palliative care. <http://www.sciencedirect.com/science/article/pii/S0885392411002727>

From Media Watch dated 25 July 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 18 July 2011 – **'The palliative care model for emergency department patients with advanced illness.'** Although some data on pilot programs are available, optimal models of delivery of emergency department-based palliative care have not been rigorously studied. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0011>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online report – 6 September 2011 – '**Prosecutors have taken no action over cases of suspected assisted suicide since new guidance was issued.**' Since the introduction of new guidance in February 2010 around 30 people who were suspected of assisted suicide have been referred to the Crown Prosecution Service, but no prosecutions have so far followed. Figures ... show that 19 cases of suspected assisted suicide were referred from the police in 2009-2010, all of which, apart from one case that was withdrawn, resulted in no further action. <http://www.bmj.com/content/343/bmj.d5668.extract>
 - *BC MEDICAL JOURNAL*, 2011;53(7):318. '**Physicians assisting suicide.**' The legal argument [for legalizing assisted suicide] is straightforward: if suicide itself is legal then assisting suicide should be legal as well. Otherwise, the law against assisted suicide is the only one on the books that makes assisting a legal act illegal. This I can understand, although the legal nuances escape me. What I have difficulty understanding is the assumption by several groups supportive of assisted suicide that physicians would be the ones to assist. While assisting someone to commit suicide can result in a decrease of suffering for the individual, it certainly contradicts the tenet "above all else, do no harm," which surely is the underlying principle of the practice of medicine. There can be no more harmful and irrevocable act done to an individual than killing that person, even though the person requests it. <http://www.bcmj.org/editorials/physicians-assisting-suicide>
 - *JOURNAL OF MEDICAL ETHICS*, 2011;37(9):573-576. '**Mario Monicelli's Grande Guerra: The right of living and the choice of dying.**' Monicelli's suicide [20 November 2010] has reawakened [in Italy] a political and legal dispute about the medical role in end-of-life decisions, allowing us to discuss medical, ethical, legal, religious and political debate in various paradigmatic conscious and unconscious cases of end-of-life decision. The authors analyse the uncertainty about the 'a priori' choice between different specific legislative systems, highlighting the need for a unifying model, dictated by the existing trust in the critical relationship between patient and doctor, whose primary mission should be not only 'to cure' but also 'to care.' <http://jme.bmj.com/content/37/9/573.abstract>
- N.B.** 'La grande guerra' ('The Great War') is a 1959 Italian film directed by Monicelli. It tells the story of an odd couple of army buddies in World War I.

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.hpconnection.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%20watch.html>

International

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/all/>

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>

Worth Repeating

Evaluation of hospital palliative care teams: Strengths and weaknesses of the before-after study design and strategies to improve it

PALLIATIVE MEDICINE, 2009;23(1):23-28. Hospital palliative care teams (HPCTs) are well established as multi-professional services to provide palliative care in an acute hospital setting and are increasing in number. However, there is still limited evaluation of them, in terms of efficacy and effectiveness. The gold standard method of evaluation is a randomised control trial, but because of methodological (e.g., randomisation), ethical and practical difficulties such trials are often not possible. HPCT is a complex intervention, and the specific situation in palliative care makes it challenging to evaluate (e.g., distress and cognitive impairment of patients). The quasi-experimental before-after study design has the advantage of enabling an experimental character without randomisation. But this has other weaknesses and is prone to bias, for example, temporal trends and selection bias. As for every study design, avoidance and minimisation of bias is important to improve validity. Therefore, strategies of selecting an appropriate control group or time series and applying valid outcomes and measurement tools help reducing bias and strengthen the methods. Special attention is needed to plan and define the design and applied method. <http://pmj.sagepub.com/content/23/1/23.abstract>

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