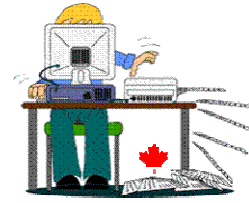


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Directing care at the end of life: 'Ask a different question, get a different answer: Why living wills are poor guides to care preferences at the end of life.' Scroll down to [Specialist Publications](#) for a study published in the *Journal of Palliative Medicine* and several related journal articles (p.6).

Canada

Long-term care plan is short-sighted

ONTARIO | *London Free Press* (OpEd) – 7 April 2010 – Alternate Level of Care patients – those who are chronically ill and need long-term care – are being told they can't stay in hospital and must move to a long-term facility that may be hours from friends and family. Kenora-Rainy River MPP [Member of the Provincial Parliament] Howard Hampton says Local Health Integration Networks are being told to get chronically ill patients out of hospitals and into long-term facilities. Without enough beds though, patients are being forced into neighbouring communities ... or wherever a vacancy occurs. New Democrat health critic France Gelinis says she has been dealing with this issue in her ... riding for the past five years. Now, it's spreading across the province. http://www.lfpress.com/comment/columnists/christina_blizzard/2010/04/07/13497616.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *Montreal Gazette* – 6 April 2010 – **'There's a big difference between euthanasia and pulling the plug.'** The issue ... is not if we die – we all eventually die. The issue is how we die and whether some means of dying, such as euthanasia and physician-assisted suicide, should remain legally prohibited. To maintain that they should, we need to be able to show how currently accepted practices, such as respect for patients' refusals of treatment, are not euthanasia and differ from it... <http://www.montrealgazette.com/health/There+difference+between+euthanasia+pulling+plug/2766905/story.html>

Quotable Quotes

I think the best physician is the one who has the providence to tell to the patients according to his knowledge the present situation, what has happened before, and what is going to happen in the future.
Hippocrates (460-370 B.C.)

U.S.A.

Conscience law: Can it override patients' end-of-life wishes?

IDAHO STATE JOURNAL | Online OpEd – 11 April 2010 – In 2005, the Idaho Legislature enacted the Natural Death & Medical Consent Act. The statute allows patients with an incurable or irreversible condition to forego life-sustaining treatment. The Act provides for citizens to fill out an "advanced directive" or legally-binding document, such as a living will, regarding matters such as refraining from artificial life-sustaining procedures and designating someone to communicate their wishes in the event the patient is incapacitated. But a new Idaho law that goes into effect on 1 July may confuse the issue and allow the moral dictates of caregivers to conflict and potentially override the wishes of patients. http://www.idahostatejournal.com/news/local/article_238b1d2a-4539-11df-bf05-001cc4c002e0.html

Long goodbye of the elderly can create crises for family caregivers

WASHINGTON POST | Online article – 6 April 2010 – The long goodbye is a predictable chapter in our lives. Giving care – and receiving care – is what to expect when you're expecting to live a long life. Longevity has brought new opportunities to men and women as they get older. It has also created the national caregiver crisis. "We hear a lot today about the joys of our longevity revolution. And we all look forward to the bonus years," said author and social chronicler Gail Sheehy, 72, at the joint annual conference of the National Council on Aging and the American Society on Aging in Chicago. "But there is another side to the longevity revolution. It affects just about everyone – but it's not the subject of public conversation. Family caregiving has become a predictable crisis for Americans in midlife and later life." It's time to rev up the public conversation about long-term care and the role of those who provide care for an increasingly older population. <http://www.washingtonpost.com/wp-dyn/content/article/2010/04/05/AR2010040503811.html>

Palliative care programs continue rapid growth in U.S. hospitals becoming standard practice throughout the country

CENTER TO ADVANCE PALLIATIVE CARE | Online report – 5 April 2010 – U.S. hospitals continue to implement palliative care programs at a rapid pace, according to a new analysis released by the Center to Advance Palliative Care.¹ Researchers report that the number of programs in U.S. hospitals with 50 or more beds increased from 658 (24.5%) to 1,486 (58.5%) – a 125.8% increase from 2000-2008. <http://www.capc.org/news-and-events/releases/04-05-10>

1. *Analysis of U.S. Hospital Palliative Care Programs: 2010 Snapshot.* http://www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file_view

From Media Watch dated 22 March 2010:

- TEXAS | M.D. Anderson Cancer Center (University of Texas) press release – 17 March 2010 – **'Study shows strong interest in palliative care programs, services and integration vary across nation.'** A recent study ... 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 http://www.eurekalert.org/pub_releases/2010-03/uotm-sss031710.php
1. *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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ASSOCIATED PRESS | Newswire report – 8 April 2010 – '**Advocates: At least 1 assisted suicide in Montana.**' Doctors in Montana have helped at least one patient commit suicide since a state court ruled late last year it wasn't illegal ... but authorities have no way of knowing how many others there may be, who is doing it or even how it is being done. The state Supreme Court ruled [31 December 2009] that nothing in state law prevents a doctor from prescribing the lethal drugs to mentally competent, terminally ill patients, making Montana the third state to allow physician-assisted suicide. But the court didn't determine whether the state Constitution guarantees the right to physician-assisted suicide, raising fears among doctors that they could still be prosecuted. <http://www.google.com/hostednews/ap/article/ALeqM5gQwmBJyYS4t1ZFpE2E3bAPIIViQD9EVP9001>

International

Investigation launched into elderly care

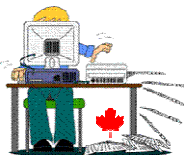
NEW ZEALAND | TV3 News – 8 April 2010 – An investigation into elderly care in New Zealand ... follows damning reports from both the Auditor General and the Health & Disability Commissioner. There are concerns the quality of aged care is declining at a time when the elderly population is growing. The final report is expected in September. <http://www.3news.co.nz/Investigation-launched-into-elderly-care/tabid/423/articleID/150110/Default.aspx>

Of related interest:

- AUSTRALIA | *Sydney Morning Herald* – 12 April 2010 – '**PM comes to rescue of elderly parked in hospitals.**' [Prime Minister] Kevin Rudd will unveil today a \$739 million plan for a federal takeover of aged care in a strategy aimed at ending disjointed services and elderly patients' costly and unnecessary stays in hospital. <http://www.smh.com.au/national/pm-comes-to-rescue-of-elderly-parked-in-hospitals-20100411-s0wf.html>

Holistic approach to introducing organised comprehensive palliative care

SLOVENIA | Government Office for Development & European Affairs press release – 8 April 2010 – The [proposed] programme ... contains guidelines for establishing ... nation-wide, comprehensively organised palliative care. In addition to making legislative amendments and securing the necessary funding, the programme calls for establishing a ... network with specially trained staff. Slovenia has no palliative care system or specific policy dealing with the issue. As a result of longer life expectancy and increasing number of chronic diseases ... there is a pressing need for organised palliative care. Research shows as many as 60% of people at the end of life and 80% of patients with advanced cancer require palliative care. On average, two family members per patient require ... treatment that is encompassed by the palliative care definition. http://www.vlada.si/nc/en/news/press_releases/press_release/article/5/8937///PType/95/



[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.

When a sibling dies, children's grief often goes unnoticed

GERMANY | Deutsche Welle – 6 April 2010 – When the greatest tragedy occurs – the death of a child – there's often support for parents, but siblings tend to be overlooked. Several groups in Germany are reaching out to young people who've lost a brother or sister. One of the ... main goals is to work alongside schools to explain to students and teachers what grieving siblings are going through and how they can be helped. <http://www.dw-world.de/dw/article/0,,5437067,00.html>

Of related interest:

- U.K. | *The Independent* – 6 April 2010 – **'How we learnt to grieve.'** For decades, a stiff upper lip was how Britons were expected to deal with the death of loved ones. As a society, we're finally starting to let our feelings show. <http://www.independent.co.uk/life-style/health-and-families/features/how-we-learnt-to-grieve-1936509.html>
- U.S. | *New York Times* – 5 April 2010 – **'The pain of losing a spouse is singular.'** As my husband of 43 years approached the end of his life and the anguish within me welled like a dam ready to burst, I realized something both simplistic and profound – losing a spouse is nothing like losing a parent. <http://www.nytimes.com/2010/04/06/health/06cases.html>

I'm a lot funnier now I know I'm dying

U.K. | *Times* – 4 April 2010 – Tony Judt is dying, cruelly. Eighteen months ago the British historian – a professor of European history at New York University and the author of *Postwar*, a bravura history of the continent since 1945 – was diagnosed with amyotrophic lateral sclerosis (ALS). Known in the U.S. as Lou Gehrig's disease, ALS is a motor neurone disorder. It is a hideous condition. Imagine the human body is a house, filled with lit rooms. ALS turns off the electricity, switch by switch. First you lose the use of your fingers, then your limbs, then the muscles in your torso and so on. "It is," Judt says, "like being in a prison which is shrinking six inches every day." http://www.timesonline.co.uk/tol/life_and_style/health/article7086639.ece

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

End of life care: The importance of culture and ethnicity

AUSTRALIAN FAMILY PHYSICIAN, 2010;39(4):210-213. This article discusses how cultural diversity may impact care and provides some strategies for the general practitioner when considering the provision of end of life care. This article does not attempt to provide GPs with a prescriptive approach to multicultural care, as this would run the risk of stereotyping individuals. Rather, it discusses the barriers to end of life care among different cultural and ethnic groups, and suggests ways in which to improve understanding of different cultural needs in end of life care. <http://www.racgp.org.au/afp/201004/201004clark.pdf>

Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium

BMC PUBLIC HEALTH | Online article – 9 April 2010 – Although the incidence of the use of life-ending drugs without explicit patient request has been estimated in several studies, in-depth empirical research on this controversial practice is non-existent. The authors investigated the clinical characteristics of the patients, the decision-making process, and the way the practice was conducted. They conclude that the practice of using life-ending drugs without explicit patient request ... mainly involves non-competent patients experiencing persistent and unbearable suffering whose end-of-life wishes can no longer be ascertained. GPs do not act as isolated decision-makers and they believe they act in the best interests of the patient. Advance care planning could help to inform GPs about patients' wishes prior to their loss of competence. <http://www.biomedcentral.com/content/pdf/1471-2458-10-186.pdf>

Facing our mortality: Transforming our suffering

INTERNATIONAL JOURNAL OF APPLIED PSYCHOANALYTIC STUDIES | Online article – 25 March 2010 – Are love and life stronger than death? Is the inevitability of our mortality the ultimate source of existential suffering? Or ... how do we live knowing that we shall die? Love may be the most powerful force in the universe but it cannot stop death. In the course of living, we all will experience the pain of losing our most beloved relationships. The degree to which our own mortality affects our living is incontestable. While every cell in our being desperately wants to live, the only inevitable reality is that one day we shall all die. In moments of profound loss or when our own mortality is threatened, it would seem that death is the greatest source of suffering in life. <http://www3.interscience.wiley.com/journal/123329060/abstract>

Movement urged on children's palliative care

IRISH MEDICAL TIMES | Online report – 5 April 2010 – It is essential that a national committee for children's palliative care is appointed as soon as possible to advance the recommendations in the new national policy document on palliative care for children with life-limiting illnesses, the Irish Association for Palliative Care has stated.¹ Approximately 1,400 children in Ireland are living with a life-limiting condition and in the region of 350 childhood deaths from such conditions occur per year. http://www.imt.ie/news/2010/04/movement_urged_on_childrens_pa.html

1. *Palliative Care For Children With Life-Limiting Conditions In Ireland – A National Policy*, Department of Health & Children, Government of Ireland, December 2009 http://www.dohc.ie/publications/pdf/palliative_care_en.pdf?direct=1

Of related interest:

- *JOURNAL OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS* | Online editorial – 7 April 2010 – '**Charlotte's Web: Lessons learned from a pig and a spider.**' Approximately 50,000 children younger than 19 years die each year in the U.S. from trauma, lethal congenital conditions, extreme prematurity, heritable disorders, or acquired illness. At any one time, an estimated 10 million children in the U.S. are living with chronic and life-threatening conditions. Many people are affected for every child with a serious or terminal illness. A grim diagnosis is like a pebble tossed into the pond of a child's life. http://media.jaapa.com/documents/13/editorialcombo0410_3147.pdf

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>

Ask a different question, get a different answer: Why living wills are poor guides to care preferences at the end of life

JOURNAL OF PALLIATIVE MEDICINE | Online article – 9 April 2010 – Living wills have a poor record of directing care at the end of life, as a copious literature attests. Some speculation centers on the questionable correspondence between the scenario described in living wills versus the real-life circumstances that typically arise at the end of life. Associations between responses to the standard living will question and preferences for treatment ... in six specific scenarios were statistically significant but modest in size, accounting for 23% of variance at most. The association for the worse-case scenario ... was significantly stronger than for any other association. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0311>

Of related interest:

- *AMERICAN JOURNAL OF BIOETHICS*, 2010;(10)4:3. **'Too soon to give up: Re-examining the value of advance directives.'** In the face of mounting criticism against advance directives, the authors describe how a novel, computer-based decision aid addresses some of these important concerns. This decision aid ... translates an individual's values and goals into a meaningful advance directive that explicitly reflects their healthcare wishes and outlines a plan for how they wish to be treated. http://www.bioethics.net/journal/j_articles.php?aid=2202&display=abstract
N.B. This issue of the *American Journal of Bioethics* includes several articles on decision making. Journal contents page: <http://www.bioethics.net/journal/>
- BMC PALLIATIVE CARE | Online article – 9 April 2010 – **'Implementing advance care planning: A qualitative study of community nurses' views and experiences.'** This study reveals some important areas for practice and educational development to enhance nurses' use and understanding of advance care planning. <http://www.biomedcentral.com/content/pdf/1472-684x-9-4.pdf>
- COMMONWEALTH FUND (U.S.) | Online article – Accessed 9 April 2010 – **'International developments in self-directed care.'** Self-directed care is an alternative way of delivering services that seeks to empower participants by expanding their degree of choice and control in selecting services. Over the last decade, it has been widely adopted internationally in home and community-based long-term care for people with physical and cognitive disabilities and for seniors. http://www.commonwealthfund.org/~media/Files/Publications/Issue%20Brief/2010/Feb/1370_Alakeson_intl_devel_selfdirected_care_ib_v2.pdf

A model for successful nursing home-hospice partnerships

JOURNAL OF PALLIATIVE MEDICINE | Online article – 9 April 2010 – This research aimed to characterize the partnerships of successful nursing home-hospice collaborators. While successful collaborators were organizational aligned, hospice leaders' acknowledgement that palliative care provision in nursing homes is complex and unique was important to success. Accordingly, the prevalent partnership model was a product of strategic efforts by leaders aimed at matching their staffing to the nursing home environment and promoting good communication and skills needed for problem solving. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2009.0296>

Of related interest:

- *BRITISH JOURNAL OF COMMUNITY NURSING*, 2010;15(4):170-176. **'Palliative care provision for older people in care homes.'** The aim of this study was to demonstrate the current involvement of District Nurses (DNs) in adult care homes and identify the potential implications for future practice in providing palliative care in this setting. The findings suggested that even experienced DN's, wanted support and education about when to commence palliative care. http://www.bjcn.co.uk/cgi-bin/go.pl/library/article.html?uid=47353;article=BJCN_15_4_170_176

End-of-life care in the neonatal intensive care unit: A family-centered approach

NEOREVIEWS, 2010;11(4):e194. Quality end-of-life care is a process that requires clear and consistent communication delivered by a compassionate multidisciplinary team within a framework of shared decision-making. The knowledge and communication skills of the interdisciplinary team can greatly influence the ability of the parents to cope effectively with their loss around the time of death and after they return home. Structured bereavement follow-up and staff support programs provide ongoing support for families and caregivers.

<http://neoreviews.aappublications.org/cgi/content/abstract/neoreviews;11/4/e194>

What evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions?

PALLIATIVE MEDICINE, 2010;24(3):268-285. Relatively little is known about the type of physical environment which is needed and preferred by patients aged 65 and over, with a prognosis of one year or less, who are receiving care in hospitals, care homes and hospices, and their families and staff. A narrative literature review was conducted to identify and analyse evidence on this issue, with twenty-nine papers meeting the inclusion criteria. The patients were found to have a wide range of views on their environment, but there was some variation between the views of patients and those of their families and staff. Four main themes emerged: the physical environment should be 'homely'; it should support patients' need for social interaction and privacy; it should support the caring activities of staff, family members and patients; and, it should allow opportunities for spiritual expression. <http://pmj.sagepub.com/cgi/content/abstract/24/3/268>

End-of-life issues in acute stroke care: A qualitative study of the experiences and preferences of patients and families

PALLIATIVE MEDICINE, 2010;24(2):146-153. [In this U.K., qualitative study] communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke care. Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information. Where decisions had been made to shift the focus of care from active to more passive support, families, and where possible patients, still wished to be included in ongoing dialogue with professionals. Where patients were thought to be dying, family members were keen to ensure that the death was peaceful and dignified. Families reported few opportunities for engagement in any form of choice over place or style of end-of-life care. No family member reported being offered the possibility of the patient dying at home.

<http://pmj.sagepub.com/cgi/content/abstract/24/2/146?etoc>

From Media Watch dated 4 May 2009:

- EMAXHEALTH (U.S.) | Online report – 27 April 2009 – **'Heart failure patients, caregivers have unmet care needs.'** This study helps define a role for palliative care in addressing the needs of heart failure patients and their caregivers." <http://www.emaxhealth.com/2/80/30657/heart-failurepatients-caregivers-have-unmet-care-needs.html>

End-of-life issues in U.S. veterinary medicine schools

SOCIETY & ANIMALS, 2010;18(2):152-162. The average number of hours students devote to end-of-life issues [in the 28 veterinary medicine schools in the U.S.] is 14.64, about the same as for U.S. medical and baccalaureate nursing schools. Topics covered most often are "euthanasia" and "communication with owners of dying animals." Veterinary schools overwhelmingly note that dying, death and bereavement are important topics. It might be helpful to veterinary medicine students if their own feelings regarding dying and death were addressed early in the curriculum and throughout class activities and clinical work. Veterinarians would likely relate better to animal guardians and to non-human animals themselves if they felt more comfortable with dying and death. <http://www.ingentaconnect.com/content/brill/saa/2010/00000018/00000002/art00004>

Worth Repeating

"It was just out of the question"

Dealing with conflict in caring for the seriously ill

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2005;293(11):1374-1381. Physicians often assume that conflict is undesirable and destructive, yet conflict handled well can be productive, and the clarity that results can lead to clearer decision making and greater family, patient, and clinician satisfaction. The authors review the course of Mrs B, an 84-year-old woman with advanced dementia and an advance directive stating no artificial hydration or nutrition. Over the course of her illness, her family and physicians had conflicting opinions about the use of short-term tube feeding and intravenous hydration in her care. They describe the conflicts that arose between her physicians and family and a typology of conflicts common in care of patients who are seriously ill (family vs. team, team member vs. team member). Drawing from the business, psychology, and mediation literature, the authors describe useful communication tools and common pitfalls. They outline a step-wise approach that physicians can use to deal with conflicts and the use of treatment trials as a strategy to address conflicts about the use of life-sustaining medical interventions. <http://www.hadassah-med.com/NR/ronlyres/7170BB53-8E1E-4DF0-93EC-DCFD71877065/6618/05CommunicationtohandleolconflictsJAMA.pdf>

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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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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