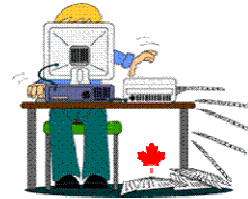


Media Watch...

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 and research.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Experiencing loss and separation: Scroll down to [Specialist Publications](#) and 'Bereavement in childhood: Risks, consequences and responses' (p.8), published in *BMJ Supportive & Palliative Care*.

Canada

Curing cancer: A reality check

CBC NEWS | Online report – 4 January 2012 – Cancer became the top killer of Canadians in 2011, yet people are often living longer after being diagnosed. Curing cancer often leads the most hoped-for list when you ask people what medical breakthroughs they would like to see. But trying to answer the question of whether the war on cancer is being won means stepping into a contradictory tangle of statistics, anecdotes, hopes and fears. Measuring progress in the fight depends on who you ask and how success is measured. There has been remarkable progress against some childhood cancers but very little change in mortality rates for some other forms.

<http://www.cbc.ca/news/health/story/2011/12/30/cancer-chasing-cures.html>

Extract from CBC News report

As a palliative care physician at Toronto General Hospital, Dr. James Downar isn't as focused on trying to extend the life of people with cancer. Instead, Downar works on making that person's quality of life as high as possible. "Unfortunately, our success in reducing the mortality from cancer over the past 60 years has been very, very modest," said Downar. "So I don't think, as I say, that it's realistic or even necessary to talk about curing cancer in order to make a big impact." He sees some downside in promoting unrealistic hope from a cure or positive prognosis for some patients with terminal cancer.

Many family caregivers wait a year or more before seeking help for Alzheimer patients

ONTARIO | *London Free Press* – 4 January 2012 – Canadians are far less likely to seek help for dementia than for other ailments, according to a new study released by the Alzheimer Society of Canada. The national survey ... showed 44% [of family caregivers] waited a year or more from the first signs of dementia to seek help. Seeking help early gives the patient and caregivers a chance to plan for the future, but even more importantly, early treatment can prolong quality of life. <http://www.lfpress.com/life/healthandfitness/2012/01/04/19199861.html>

Cont.

Of related interest:

- ONTARIO | *Toronto Star* – 4 January 2012 – **'Male caregivers are more practical.'** Are men from Mars and women from Venus when they're looking after parents with Alzheimer's? That wasn't precisely the question occupational therapist Nira Rittenberg had in mind when she collaborated on a study about male caregivers. She did suspect the masculine approach would be distinctive. <http://www.thestar.com/article/1110163--male-caregivers-are-more-practical>

[Specialist Publications](#)

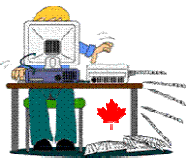
Of particular interest:

'Behavioral and psychological symptoms in moderate to severe Alzheimer's disease: A palliative care approach emphasizing recognition of personhood and preservation of dignity' (p.9), published in the *Journal of Alzheimer's Disease*.

[Navigating the health care system](#)

Hospice care out of reach for dying teen

ONTARIO | *Toronto Star* – 3 January 2012 – Wayne and Linda Rumsby spend most of their time in the tiny basement of their semi-detached Leslieville home, tending to their gravely ill son, Mark. The 17-year-old, who is not expected to live beyond a year, requires round-the-clock care, his father said. It's taking a huge emotional, physical and financial toll on the Rumsbys. But they have been struggling to navigate Ontario's healthcare system maze to get help for their son. After falling ill with pneumonia last November, Mark's condition drastically deteriorated, his father said. He started needing overnight nursing care, which he never had before. When it became clear Mark was not going to recover, the Rumsbys began looking for hospices where their son could live out his last days. But they said the hospices they approached turned Mark away, citing lack of resources and funding. <http://www.thestar.com/news/article/1110182--hospice-care-out-of-reach-for-dying-teen>



[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>

[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/pg/file/owner/MediaWatch>

Assisted (or facilitated) death

Representative sample of recent News Media coverage:

- ONTARIO | *Ottawa Citizen* – 8 January 2012 – **'What is your faith's view on euthanasia?'** Much depends on what is meant by the term "euthanasia." Anglicans actively support the best of palliative care to relieve the suffering of the terminally ill. For example, the late Dame Cicely Saunders was a pioneer in Britain of the palliative care hospice movement, work whose influence has spread worldwide. This work combines pain and symptom relief with comprehensive care for the psycho-logical, spiritual, physical, and social needs of patients and their families.
<http://www.ottawacitizen.com/health/What+your+faith+view+euthanasia/5963210/story.html>

U.S.A.

Hospice for profit: Business of dying is booming

FLORIDA | *Palm Beach Post* – 7 January 2012 – Three decades after becoming a Medicare benefit, hospice care has emerged as its fastest-growing cost – and more than one federal investigation is targeting the nation's largest provider. Vitas Healthcare, the only for-profit hospice licensed in Palm Beach County, denies wrongdoing. But its local patients average 40% longer stays on government-reimbursed care than those at non-profit competitors, records analyzed by the *Palm Beach Post* show. Hospice offers relief from pain, symptoms and stress for people who are diagnosed with six months or less to live and choose to forgo last-ditch attempts at a cure. Now a big question is whether providers like Vitas, a corporate kingpin in a field once dominated by non-profit groups, are billing the government for patients who are not really on a fast track to the great beyond.
<http://www.palmbeachpost.com/money/hospice-for-profit-business-of-dying-is-booming-2087926.html>

Hospice Care in America

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online posting – January 2012 – Facts & Figures: Hospice Care in America provides an annual overview of important trends in the growth, delivery and quality of hospice care across the country. http://www.nhpco.org/files/public/Statistics_Research/2011_Facts_Figures.pdf

From Media Watch dated 12 December 2011:

- BLOOMBERG NEWS | Online article – 6 December 2011 – **'U.S. hospice care revealed as \$14billion market.'** <http://www.bloomberg.com/news/2011-12-06/hospice-care-revealed-as-14-billion-u-s-market.html>

From Media Watch dated 7 November 2011:

- FLORIDA | *Miami Herald* – 2 November 2011 – **'Daughter's complaint puts focus on Medicare payment to for-profit hospice.'** <http://www.miamiherald.com/2011/10/09/2446620/daughters-complaint-puts-focus.html>

From Media Watch dated 10 October 2011:

- CALIFORNIA | *Sacramento Business Journal* – 7 October 2011 – **'End-of-life care ... for profit.'** <http://www.bizjournals.com/sacramento/print-edition/2011/10/07/first-health-care-story.html>

From Media Watch dated 8 August 2011:

- FLORIDA | *Florida Trend* (St. Petersburg) – 1 August 2011 – **'Hospices in Florida: From cause to commerce.'** <http://www.floridatrend.com/article.asp?aID=55369&mostread=true>

Discussing end-of-life care

Gingrich challenged at Dartmouth-Hitchcock Medical Center's Grand Rounds

NEW HAMPSHIRE | *Valley News* (Vermont) – 7 January 2012 – [Republican presidential candidate Newt] Gingrich in 2009 had backed Sarah Palin in her claim that a proposed clause, later removed, in Obama's health-care reform amounted to "death panels," but yesterday sought to clarify his position under questioning from Dr. Ira Byock, the director of palliative medicine at Dartmouth-Hitchcock Medical Center's and a national expert on hospice care. "Please tell me that you don't believe that those intimate conversations and advanced care planning in some ways represents coercion or a 'death panel,'" Byock said, noting that Gingrich had voiced support for such discussions prior to the health care reform debate. Gingrich said he was concerned about end of life directives that might be driven by statistical models and government officials, but supported "personalized" discussions that would be covered by Medicare. "Having that funded so it happens at a personal level is terrific. Having any Washington bureaucracy start recommending what should or should not be appropriate, and what they think statistically you should or should not allow people to die, I would fight to the end." <http://www.vnews.com/01072012/8272657.htm>

From Media Watch dated 17 October 2011:

- UTAH | *Salt Lake Tribune* (OpEd) – 13 October 2011 – '**End-of-life care: Patient Protection & Affordable Care Act.**' Sarah Palin's "death panels" must shoulder much of the blame for the elimination of a provision in the Patient Protection & Affordable Care Act that would have allowed Medicare to reimburse doctors for providing requested end-of-life counseling. Yes, that's Sarah Palin's death panels, not President Barack Obama's. The former Alaska governor was the one who coined the ridiculous phrase to frighten Americans and bolster criticism of the health care reform proposal. It worked. <http://www.sltrib.com/sltrib/opinion/52706949-82/care-medicare-patient-counseling.html.csp>

Texas prisoner burials are a gentle touch in a punitive system

TEXAS | *New York Times* – 4 January 2012 – Kenneth Wayne Davis died at 54 as not so much a man but a number: Inmate No. 327320. Mr. Davis was charged, convicted, sentenced and incarcerated for capital murder by the State of Texas after taking someone's life on 19 November 1977. But when he died in November 2011, Texas seemed his only friend. His family failed to claim his body, so the state paid for his burial. On a cold morning in this East Texas town [of Huntsville], a group of inmates bowed their heads as a prison chaplain led a prayer for Mr. Davis, his silver-handled black metal coffin resting on wooden planks above the grave the prisoners had dug for him. http://www.nytimes.com/2012/01/05/us/texas-prisoner-burials-are-a-gentle-touch-in-a-punitive-system.html?_r=1

How new Michigan group plans to help couples who are running out of time

MICHIGAN | *Grand Rapids News* – 3 January 2012 – A national non-profit that provides free weddings to couples struggling with a terminal illness is opening a chapter in Michigan. Wish Upon a Wedding will take applications ... after its launch event ... in Pontiac [later this month]. The group is also looking for ... wedding vendors willing to volunteer services, from photographers to wedding planners to florists. The organization, started in 2010 by a wedding planner in California, uses volunteer donors in the wedding industry, called "wish granters," to plan and provide weddings for couples facing terminal illness or "life-altering circumstances." There are 22 chapters of Wish Upon a Wedding in the U.S. http://www.mlive.com/news/grand-rapids/index.ssf/2012/01/how_new_michigan_group_plans_t.html

An Oregon study points to better end-of-life care planning

OREGON | *The Oregonian* – 3 January 2012 – In a cardiac arrest, Helen Hobbs says she doesn't want medics to attempt to revive her. Nor does the 93-year-old Portland resident want to be kept alive with a feeding tube or a breathing machine if it comes to that. "But I do want comfort care," she says. "And if there is something you can treat to get a person better, that's okay." Such nuances are not captured in "do not resuscitate" orders used in nursing homes and hospitals across the U.S. A new study¹ ... suggests DNR orders may prompt caregivers to forego treatments that patients would have wanted. "The risk is that you make assumptions about the patient because of their DNR, you assume they may not want this treatment or that treatment," says Dr. Erik Fromme, a palliative care specialist at Oregon Health & Science

University. A registry in Oregon allowed Fromme and colleagues to compare detailed treatment preferences of more than 25,000 people. Since 2009, Oregon has kept an electronic registry of preferences residents recorded with a document called Physician Orders for Life-Sustaining Treatment. http://www.oregonlive.com/health/index.ssf/2012/01/an_oregon_study_points_to_bett.html

Specialist Publications

Of particular interest:

'Handful of states promise physicians online access to advance directives' (p.7), published in *AMEDNEWS*.

1. 'POLST registry do-not-resuscitate orders and other patient treatment preferences,' *Journal of the American Medical Association*, 2011;307(1):34-35. <http://jama.ama-assn.org/content/307/1/34.2.extract?sid=c0d14c2c-00fa-4759-adc7-9469ac68565d>

International

Ministry of Health accepts national palliative care strategy report

SINGAPORE | *Straits Times* – 5 January 2012 – Recommendations for the national strategy ... have been accepted by the Health Ministry, and a taskforce will be set up to study it in greater detail. The national strategy report, coordinated by the Lien Centre for Palliative Care, makes three broad recommendations in the areas of service development, training and research, and public education and awareness. Key among the recommendations is for palliative care to be provided based on a regional health system model, so that patients enjoy seamless care from one setting to another. The report suggests incorporating palliative care training in relevant undergraduate and diploma courses, and for grassroots groups to help raise greater public awareness. http://www.straitstimes.com/BreakingNews/Singapore/Story/STIStory_752104.html

N.B. Singapore was rated 18th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

[Prime Minister] David Cameron orders merging of health and social care

U.K. | *The Guardian* – 5 January 2012 – At the moment, health and social care – the help given mainly to old or disabled patients to help them continue to live at home rather than in hospital or nursing homes – are different systems in England. NHS [National Health Service] medical treatment and domiciliary support, which is provided mainly by local councils, are usually not joined-up. But Cameron has told the health secretary, Andrew Lansley, to drive through changes that health policy experts claim will make life more convenient for patients, improve care and save the NHS money. <http://www.guardian.co.uk/politics/2012/jan/05/david-cameron-health-social-care>

Palliative Care Atlas in Latin America

LATIN AMERICAN ASSOCIATION FOR PALLIATIVE CARE | Online posting – Accessed 3 January 2012 – The Association has launched 'Palliative Care Atlas in Latin America' in cooperation with the International Association for Hospice & Palliative Care, the European Association for Palliative Care, Sociedad Española de Cuidados Paliativos, and the University of Navarra (Spain). The aim of the project is to identify the degree of development and provide an overview of palliative care across the region. The Atlas will help create a network to allow exchange of experience. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=8YGIFEqJU4o%3d>

Death matters exhibition

THE NETHERLANDS | Cultural Issues in End-of-Life Care – 3 January 2012 – The exhibition, at Amsterdam's Tropenmuseum, focuses mainly on material culture and the rituals of death and dying. Different perspectives about what occurs after death are also examined and contrasted, and visitors are encouraged to think about how they themselves would like to be remembered through a number of interactive activities. <http://cultureeol.wordpress.com/2012/01/>

Specialist Publications

Of particular interest:

'Outcomes 'Out of Africa': The selection and implementation of outcome measures for palliative care in Africa' (p.8), published in *BMC Palliative Care*.

Fresh bid to raise £750,000 for new Romanian hospices

ROMANIA | *Kent & Sussex Courier* (England) – 3 January 2012 – For decades, terminally ill people living in Eastern Europe were given no care and left to die in pain at home. Hospices of Hope has been working tirelessly to change that – bringing palliative care to 15,000 people in some of the poorest European countries. This month, the charity celebrates its 20th anniversary and the ... founder Graham Perolls has marked the occasion with a fresh appeal for £750,000 to build two new hospices in Romania. <http://www.thisiskent.co.uk/Fresh-bid-raise-pound-750-000-new-Romanian/story-14278816-detail/story.html>

From Media Watch dated 28 November 2011:

- ROMANIA | *Edinburgh Evening News* (Scotland) – 24 November 2011 – **'Hospices helping to banish images of suffering in Romania.'** Since the Casa Sperantei hospice in Brasov first opened its doors, 11,000 terminally ill adults and children have received medical, psychological and emotional care, as have their families. http://www.scotsman.com/edinburgh-evening-news/edinburgh/hospices_helping_to_banish_images_of_suffering_in_romania_1_1983437

N.B. Romania is profiled in *The Quality of Death: Ranking End-of-life-Care Across the World* (p.22), 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

European Association for Palliative Care white paper on standards and norms

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online posting – 3 January 2012 – The white paper, first published in the *European Journal of Palliative Care*, is available in translation. <http://www.eapcnet.eu/Themes/Organisation/EAPCStandardsNorms/Translations.aspx>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (ENGLAND & WALES) | *Daily Telegraph* – 5 January 2012 – **'Allow assisted suicide for those with less than a year to live.'** The independent Commission on Assisted Dying, whose members include several prominent peers and medics, wants GPs to be able to prescribe lethal doses of medication for dying people to take themselves. The report¹ ... calls for the "inadequate and incoherent" law against assisted suicide to be scrapped following a series of high profile cases where patients have used the Dignitas suicide clinic to take their own lives. Although helping someone to die is punishable by up to 14 years' imprisonment and police still investigate all cases, there have been no prosecutions since landmark guidelines were set out almost two years ago. The year-long inquiry admits legalisation would create a "real risk" of pressure on vulnerable people to end their lives, either from family members or a sense

that they were a burden on society. It says that to safeguard the vulnerable, disabled people and those suffering from dementia or depression would not qualify for help in killing themselves. <http://www.telegraph.co.uk/news/uknews/law-and-order/8992593/Allow-assisted-suicide-for-those-with-less-than-a-year-to-live.html>

Extract from Commission on Assisted Dying report

There needs to be better coordination of end of life care and the pooling of social care and health care resources to meet patients' needs and spread resources more effectively. Best practice needs to be communicated more broadly.

1. *The current legal status of assisted dying is inadequate and incoherent...*, Commission on Assisted Dying, January 2012. http://www.demos.co.uk/files/CoAD_-_web.pdf?1325710486

- U.K. | *The Guardian* – 5 January 2012 – **'Assisted suicide is never an autonomous choice.'** The arguments over assisted suicide are mostly conducted with obvious flaws on both sides. Defenders of the *status quo* are wrong about the sacredness of life; those people trying to change it are wrong about humanity. The actual, practical issue is tiny. No one wants either to prolong the life of the elderly into a grotesque torture, or to bump them off as soon as they become inconvenient... <http://www.guardian.co.uk/commentisfree/andrewbrown/2012/jan/05/assisted-suicide-autonomous-choice>

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

Handful of states promise physicians online access to advance directives

AMEDNEWS | Online report – 3 January 2012 – Virginia has become the latest state to launch an online registry for advance directives that eventually will be connected to a state-wide health information exchange. By connecting the advance directive to an information exchange, a physician could access it without having to contact family or caregivers, or find out a patient's login and password to current online registry programs. That connection would allow a physician to follow through on the patient's wishes without any obligation to contact anyone. When physicians will have that access depends on when each state has its information exchange up and running. Virginia recently launched a website open to any resident, allowing anyone to file and store documents, at no charge, to express end-of-life wishes. Virginia's registry will be tied to its state-wide information exchange, scheduled to launch in 2013. Several states have dedicated online registry programs, or are partnering with nationwide organizations such as the U.S. Living Will Registry, to offer advance directive filing and storage. While the documents are crucial to family members who must make decisions on a patient's behalf if they become incapacitated, they would have to know the document's whereabouts and the username and password to access it ahead of time. <http://www.ama-assn.org/amednews/2012/01/02/bise0103.htm>

Outcomes 'Out of Africa': The selection and implementation of outcome measures for palliative care in Africa

BMC PALLIATIVE CARE | Online article – 6 January 2012 – A central issue in research in end-of-life care is the measurement of effects and outcomes of care on patients and families. Little is known about the experiences of health professionals' selection and implementation of outcome measures (OM) in clinical care, research, audit, or teaching in Africa. Challenges to the use of tools were shortage of time and resources, lack of guidance and training for the professionals, poor health status of patients and complexity of OM [Outcome Measures]. Researchers also have problems analysing OM data. The ... African POS [Palliative care Outcome Scale] was the most common version of the POS used, and was reported as a valuable tool for measuring outcomes. Respondents indicated the ideal outcome tool should be short, multi-dimensional and easy to use. <http://www.biomedcentral.com/content/pdf/1472-684X-11-1.pdf>

Bereavement in childhood: Risks, consequences and responses

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 4 January 2012 – Varying mortality patterns by social class and geography affect the risk of bereavement. At birth, children who go on to be bereaved of a parent are less likely than their peers to have parents with some experience of extended education or a father in a professional or managerial occupation, and more likely to have a father not in work. Higher levels of disadvantage persist: greater proportions of children bereaved of a parent or sibling live in economically inactive or low-earning households than their peers. These children are also more likely to have experienced other stressful events including a parent having a physical illness, serious mental illness or financial crisis and the child spending time in public care. These add-

itional difficulties may precede or follow the death; some are linked to it while others are independent. <http://spcare.bmj.com/content/early/2012/01/03/bmjspcare-2011-000029.extract>

Extract from *BMJ Supportive & Palliative Care* article

...estimates suggest that, in fact, the majority of young people face the death of a close relative or friend by the time they are 16 years old. Five per cent of young people have been bereaved of a parent by this age. Around 1 in 29 school-aged children have been bereaved of a parent or sibling and 1 in 16 have experienced the death of a friend.

Recovery of cortical effective connectivity and recovery of consciousness in vegetative patients

BRAIN | Online article – 5 January 2012 – In patients in a vegetative state, who were open-eyed, behaviourally awake but unresponsive, transcranial magnetic stimulation triggered a simple, local response indicating a breakdown of effective connectivity, similar to the one previously observed in unconscious sleeping or anaesthetized subjects. In contrast, in minimally conscious patients, who showed fluctuating signs of non-reflexive behaviour, transcranial magnetic stimulation invariably triggered complex activations that sequentially involved distant cortical areas ipsi – and contralateral to the site of stimulation, similar to activations we recorded in locked-in, conscious patients. Longitudinal measurements performed in patients who gradually recovered consciousness revealed that this clear-cut change in effective connectivity could occur at an early stage, before reliable communication was established with the subject and before the spontaneous electroencephalogram showed significant modifications. Measurements of effective connectivity by means of transcranial magnetic stimulation combined with electroencephalography can be performed at the bedside while by-passing subcortical afferent and efferent pathways, and without requiring active participation of subjects or language comprehension; hence, they offer an effective way to detect and track recovery of consciousness in brain-injured patients who are unable to exchange information with the external environment. <http://brain.oxfordjournals.org/content/early/2012/01/01/brain.awr340.abstract>

Humour in health-care interactions: A risk worth taking

HEALTH EXPECTATIONS | Online article – 2 January 2012 – Patients [i.e., study participants] hold a broad appreciation of humour and recognize it as being evident in subtle and nuanced forms. Patients wish health-care staff to initiate and reciprocate humour. A chasm exists between what patients apparently want with regard to humour use in health-care interactions and what actually transpires. Initiating humour involves risk, and risk-taking requires a degree of self-esteem and confidence. Nurses are, arguably, risk-averse and have low self-esteem.
<http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2011.00758.x/abstract>

From the archives:

- *CANCER NURSING*, 2005;28(4):292-300. **'More than trivial: Strategies for using humor in palliative care.'** Hospice/palliative care emphasizes quality of life and the importance of human relationships. In this context, humor finds its place in authentic person-to-person connectedness.
<http://xa.yimg.com/kq/groups/20503861/1218652787/name/033105-humor-in-palliative-care.pdf>

Behavioral and psychological symptoms in moderate to severe Alzheimer's disease: A palliative care approach emphasizing recognition of personhood and preservation of dignity

JOURNAL OF ALZHEIMER'S DISEASE | Online article – 29 December 2011 – The assessment and management of behavioral and psychological symptoms of dementia (BPSD) in moderate to severe Alzheimer's disease (AD) can be challenging, and ethical dilemmas often arise. Clinicians often perceive a disconnect between evidence-based guidelines and the challenges of treating BPSD in moderate to severe AD. Reconciliation of salient ethical issues can help bridge this disconnect. In view of the fact that AD is a progressive and ultimately fatal disease, and given that there are often competing considerations when managing BPSD in moderate to severe AD, the authors propose a palliative care approach that prioritizes the recognition of personhood and the preservation of dignity. <http://iospress.metapress.com/content/1797172u35601461/>

End-of-life discussion in assisted living facilities

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2012;14(1):13-24. Residents were most concerned about practical matters such as decisions about inheritance, financial matters, and funerals. They expressed that they were ready to accept death but felt that their family members were resistant to discussion. Family members were most concerned about good care for their elderly relative. Staff members expressed confidence in providing end-of-life care and supporting families but less confidence in initiating discussion about end-of-life decisions.
http://journals.lww.com/jhpn/Abstract/2012/01000/End_of_Life_Discussion_in_Assisted_Living.5.aspx

Does palliative care have a future in the emergency department? Discussions with attending emergency physicians

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2012;43(1):1-9. Twenty emergency physicians participated [in semi-structured focus groups]. Providers acknowledged many benefits of palliative care presence in the 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 medicolegal issues impaired their ability to forgo treatments where risks outweigh benefits. Additionally, the culture of emergency medicine – to provide stabilization of acute medical emergencies – was sometimes at odds with the culture of palliative care, which balances quality of life with the burdens of invasive treatments. Some providers also felt it was the primary physician's responsibility, and not their own, to address goals of care. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00272-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00272-7/abstract)

Cont.

Of related interest:

- *CRITICAL CARE MEDICINE*, 2012;40(1):98-103. 'The role of the medical emergency team in end-of-life care: A multicenter, prospective, observational study.' Issues around end-of-life care and limitations of medical therapy arose in approximately one-third of calls, suggesting a mismatch between patient needs for end-of-life care and resources at participating hospitals. Calls frequently occur in elderly medical patients and out of hours. Many do not return home, and half die in hospital. http://journals.lww.com/ccmjournal/Abstract/2012/01000/The_role_of_the_medical_emergency_team_in.15.aspx

From Media Watch dated 19 December 2011:

- *EUROPEAN JOURNAL OF EMERGENCY MEDICINE* | Online article – 12 December 2011 – 'Palliative care in emergency departments: An impossible challenge?' The aim of this study was to investigate the care practices surrounding end-of-life patients and the scope for providing palliative care in two emergency department short-stay units. http://journals.lww.com/euro-emergencymed/Abstract/publishahead/Palliative_care_in_emergency_departments_an.99720.aspx

N.B. Footnoted are several recent articles on the topic of palliative care in the emergency department that have been included in past issues of Media Watch.

Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals

JOURNAL OF PALLIATIVE MEDICINE | Online article – 4 January 2012 – The objective of this study was to evaluate the effectiveness of a specialized pediatric palliative home care team (PPHCT) as experienced by parents and health care professionals (HCPs). Satisfaction with the PPHCT scored a median of 10 (numeric rating scale, 0–10). The child's death was predominantly experienced as very peaceful; 71% died at home. According to parents, involvement of the PPHCT led to highly significant improvements in the children's symptoms and quality of life, as well as in aspects of communication and administrative barrier reduction. Anxiety was detected in 25% of parents, depression in 19%, and prolonged grief disorder in 13%. Involvement of a PPHCT is experienced as a substantial improvement of care by parents and HCPs. Coordination ... during the last phase of life appears to be an important quality factor for the home care of dying children and their families. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0196>

American College of Physicians makes close watch on costs an ethical issue

MEDPAGE TODAY | online report – 3 January 2012 – A new ethics manual from the American College of Physicians recommends that physicians practice "parsimonious" care. The manual, a supplement to the ... *Annals of Internal Medicine*,¹ noted that a physician's first duty is always to the patient, but added, "Physicians have a responsibility to practice effective and efficient health care, and to use health care resources responsibly. Parsimonious care that utilizes the most efficient means to effectively diagnose a condition and treat a patient respects the need to use resources wisely and to help ensure that resources are equitably available." In an accompanying editorial,² Ezekiel Emanuel, MD, of the University of Pennsylvania, noted that not only were the words "efficient" and "parsimonious" used without any qualifications, but also that the paragraphs containing them were put into their own "call-out" box so they couldn't be missed. "Here is a professional society unafraid of advocating the principle of cost-effectiveness," he wrote. "These positions on efficiency, parsimony, and cost-effectiveness constitute an important shift, if not in ethics then in emphasis." <http://www.medpagetoday.com/PublicHealthPolicy/Ethics/30475>

1. *American College of Physicians Ethics Manual, Sixth Edition, Annals of Internal Medicine* (Part 2), 2012;156(1):73-104. http://www.annals.org/content/156/1_Part_2/73.abstract?aimhp
2. 'Review of the *American College of Physicians Ethics Manual, Sixth Edition*,' *Annals of Internal Medicine* (Part 1), 2012;156(1):56-57. http://www.annals.org/content/156/1_Part_1/56.extract

Philosophizing social justice in rural palliative care: Hayek's moral stone?

NURSING PHILOSOPHY, 2012;13(1):46-55. Increasingly, palliative care is being referred to as an essential programme and in some cases as a human right. Once it is recognized as such, it becomes part of the lexicon of social justice in that it can be argued that all members of society should have access to such care. However, this begs the question of how that care should be enacted, particularly in rural and remote areas. In this paper the authors draw upon data from an ethnographic study in rural palliative care to illustrate the potential misfit between the ethical ideal of palliative care as expressed by rural participants and the narratives of social justice.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1466-769X.2011.00519.x/full>

From Media Watch dated 30 May 2011:

- *RURAL & REMOTE HEALTH* | Online article – 19 May 2011 – '**Developing rural palliative care: Validating a conceptual model.**' The purpose of this research was to validate a conceptual model for developing palliative care in rural communities. The model has roots in concepts of community capacity development, evolves from collaborative, generalist rural practice, and utilizes existing health services infrastructure. <http://www.rh.org.au/articles/printviewnew.asp?ArticleID=1717>

From Media Watch dated 21 March 2011:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 14 March 2011 – '**A shared care model pilot for palliative home care in a rural area: Impact on symptoms, distress, and place of death.**' Shared care models build on family physician capacity and as such are promising in the development of palliative home care programs to improve access to quality palliative home care and foster health system integration. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00031-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00031-5/abstract)

The effect of policy on end-of-life care practice within nursing care homes: A systematic review

PALLIATIVE MEDICINE | Online article – 4 January 2012 – The number of older people in the U.K. is increasing. A significant proportion of end of life care for this population is currently provided and will increasingly be provided within nursing care homes. [The objective of this study was] to identify the impact of implementing end of life care policy with regard to the use of the Gold Standards Framework in Care Homes programme, the Liverpool Care Pathway (or an Integrated Care Pathway) and educational/training interventions to support the provision of end of life care within nursing care homes within the U.K. The studies [reviewed] provided limited evidence on improved outcomes following the implementation of these interventions. Further research is needed ... that measures the process and impact of implementing these initiatives.

<http://pmj.sagepub.com/content/early/2012/01/03/0269216311432899.abstract>

Caught between love and money: The experiences of paid family caregivers

QUALITATIVE SOCIOLOGY | Online article – 24 December 2011 – This paper considers the experiences of family home care providers, paid an hourly wage by California's In Home Supportive Services program to care for disabled or elderly relatives. Drawing on in-depth interviews and ethnographic observations of family home care providers, the authors find that providers perceive their paid caregiving as deviant behavior that violates social norms surrounding family care, i.e., that people should not be paid for the care of kin. Family caregivers manage the norm violation associated with their carework by offering "accounts" that 1) emphasize the tasks and skill associated with caregiving, and 2) by framing their carework as a public good that benefits the larger community. These accounts allow family providers to distance themselves from the norm violation of receiving a wage for care and to reconstruct their actions in a positive light. <http://www.springerlink.com/content/d25461886w842065/>

Cont.

From Media Watch dated 12 September 2011:

- *U.S. TODAY & WORLD NEWS* | Online article – 6 September 2011 – '**5 Steps to a Family Caregiving Agreement.**' <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>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BIOETHICS*, 2012;26(1):1-7. '**To thine own self be true': On the loss of integrity as a kind of suffering.**' One of the requirements in the Dutch regulation for euthanasia and assisted suicide is that the doctor must be satisfied 'that the patient's suffering is unbearable, and that there is no prospect of improvement.' In the notorious Chabot case, a psychiatrist assisted a 50 year old woman in suicide, although she did not suffer from any somatic disease, nor strictly speaking from any psychiatric condition. In *Seduced by Death*, Herbert Hendin concluded that apparently the Dutch regulation now allows physicians to assist anyone in suicide simply because he or she is unhappy. <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2010.01801.x/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.hpccconnection.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>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm> (Scroll down to 'International End of Life Roundup')

International

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

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

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

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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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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