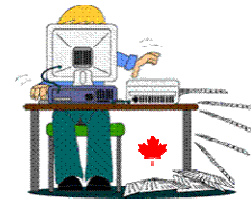


Media Watch...

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 ©

Compiled & Annotated by Barry R. Ashpole

Palliative sedation: Scroll down to [U.S.A.](#) and the *New York Times* and an article titled 'Hard choice for a comfortable death...' (p.2)

Canada

John Seely 1937-2009

Researcher, professor, physician and author known for caring, generous spirit

ONTARIO | *Ottawa Citizen* – 21 December 2009 – In the end, Dr. John Seely benefited from one of his many, and perhaps his most important, legacies. The Ottawa researcher, professor, physician and author of more than 40 scientific papers was a pioneer in the field of palliative care. And he died, as so many of his patients did, in the comfort and care of palliative specialists at the Hospice at Maycourt. Gerard Yetman, executive director at Maycourt, told Seely's four children several times that day that none of the services their dad had accessed in the last three months of his life would have been possible without his research and practical work in palliative care. Seely's long career began when he studied medicine at McGill University. He worked as a nephrologist at the Royal Victoria Hospital and served as professor of medicine and director of nephrology at McGill. He was then physician-in-chief at The Ottawa Hospital and, later, dean of the faculty of medicine at the University of Ottawa. Before he retired, he was director of the University of Ottawa Institute of Palliative Care and a palliative care physician at The Ottawa Hospital. <http://www.ottawacitizen.com/health/Doctor+created+palliative+legacy/2365803/story.html>

Specialist Publications

Of particular interest:

'Canadian Alzheimer's disease caregiver survey: baby-boomer caregivers and burden of care.' Scroll down to p.9 for the findings of the survey published in the *International Journal of Geriatric Psychiatry*.

'Quebec to establish \$200Million fund for family caregivers.' Scroll down to p.8 for a recent report published in *The Medical Post*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Toronto Star* – 23 December 2009 – **'Park bench stickers could get folks talking about euthanasia, and the need for living wills.'** Two Toronto advertising veterans have come up with park bench plaques – actually stickers – meant to draw attention to the fact that death can be excruciatingly difficult and to stir up debate about euthanasia and the need for living wills. <http://www.thestar.com/living/article/742101--giving-dignity-to-bad-deaths>

U.S.A.

Hard choice for a comfortable death: Sedation

NEW YORK TIMES | Online article – 26 December 2009 – In almost every room people were sleeping, but not like babies. This was not the carefree sleep that would restore them to rise and shine for another day. It was the sleep before – and sometimes until – death. In some of the rooms in the hospice unit at Franklin Hospital ... the patients were sleeping because their organs were shutting down, the natural process of death by disease. But at least one patient had been rendered unconscious by strong drugs. The patient, Leo Oltzik, an 88-year-old man with dementia, congestive heart failure and kidney problems, was brought from home by his wife and son, who were distressed to see him agitated, jumping out of bed and ripping off his clothes. Now he was sleeping soundly with his mouth wide open. "Obviously, he's much different than he was when he came in," Dr. Edward Halbridge, the hospice medical director, told Mr. Oltzik's wife. "He's calm, he's quiet." <http://www.nytimes.com/2009/12/27/health/27sedation.html>

Life in a year: Saying goodbye to the cycle of life

CALIFORNIA | *Mercury News* – 25 December 2009 – In Western culture, we celebrate the "miracle of birth," but death – the subject of this final installment in the *Mercury News*' 12-part series, 'Life in a Year' – more often is viewed as a malevolent adversary. The Grim Reaper, armed only with his killing scythe, has been a formidable metaphor for death since the Middle Ages. It's an image that modern doctors, armed with high-tech weaponry, sometimes boast to patients that they can "beat." And they're not the only ones. Most of the world's religions promise some form of eternal life – reincarnation for believers in Hinduism and Jainism, everlasting life in heaven for Christians – reducing death to a sort of transformational stage: The body perishes, but the spirit becomes immortal. http://www.mercurynews.com/search/ci_14070282?IADID=Search-www.mercurynews.com-www.mercurynews.com

Hospice offers patients free care for their pets

OREGON | *The Oregonian* – 23 December 2009 – The Banfield Charitable Trust has awarded Mt. Hood Hospice a grant to initiate a Pet Peace of Mind program ... [which] will provide in-home pet care such as dog-walking, litter box maintenance, transportation to and from vet appointments and financial assistance with pet food, grooming and routine veterinary care for small animals. http://www.oregonlive.com/clackamascounty/index.ssf/2009/12/sandy_hospice_offers_patients.html

Of related interest:

- ALABAMA | *Tuscaloosa News* – 26 December 2009 – **'University of Alabama music therapy students work with hospice patients.'** Playing music for someone dying is not something University of Alabama senior Sarah Pitts ever thought she would do. But it's something she said has opened her eyes not only to her perception of death but also to how her musical skills can help others, from calming patients who are stressed or agitated to helping them breathe easier. <http://www.tuscaloosaneews.com/article/20091226/NEWS/912259977/1007>

Unclaimed corpses push up urban morgue body counts

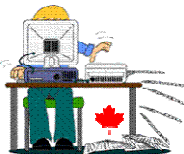
MICHIGAN | Associated Press – 22 December 2009 – Forgotten in death or abandoned by loved ones, Dewanda McNeil, Maurice Webber and Alan Jones were laid to rest in pauper's graves, their names left to be recognized by a half-dozen strangers at a service in a small Detroit funeral chapel. Times are tough for the living in Detroit and unforgiving for dozens ... dying alone and poor in the economically distressed city. Taxpayers increasingly are paying to dispose of unclaimed bodies in cities and towns throughout the U.S., but the problem appears more acute in Detroit, where nearly a third of working adults are without a job and the poverty rate has reached 33.8%. McNeil, Webber and Jones were recognized at the once-a-month Celebration of Friends service at Perry Funeral Home, started last year by Paul Betts after he heard about the unclaimed dead. Those who attend light candles, say prayers and sing hymns to recognize the deceased. <http://www.google.com/hostednews/ap/article/ALeqM5ia91Z4jlc5JOeuU3win88Ao7aKNwD9COG8M80>

From Media Watch dated 31 August 2009

- OREGON | KGW News (Portland) – 28 August 2009 – '**Cost of dying leads to more unclaimed bodies in Oregon.**' Death and taxes may be the two things in life that can't be escaped. But in this tough economy, more people are avoiding paying for the cost of dying. According the state medical examiner's office, the high cost of funerals is resulting in an increase in "unclaimed bodies." http://www.kgw.com/news-local/stories/kgw_082809_news_unclaimed_bodies.124db8302.html

Hospice set up at state prison

MISSISSIPPI | *Clarion Herald* – 22 December 2009 – A special medical unit at the Mississippi State Penitentiary at Parchman is providing dying prisoners a bit of comfort in their final days. "For the inmates, it offers assistance and serenity for the end of life for prison population," said Lawrence Kelly, superintendent of the prison. The six-bed ward provides hospice care to inmates. The unit opened 9 December and has two patients. The concept allows inmates to die in a less institutional setting, Corrections Commissioner Chris Epps said. The ward has clouds painted on the ceilings, soothing paint colors on the walls and a waiting area for visiting family members. Epps said 36 inmates are trained in hospice care and will assist the medical staff in providing 24-hour care. <http://www.clarionledger.com/article/20091222/NEWS/912220347/1001/Hospice-set-up-at-state-prison>



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.

Media Watch posted on Prison Terminal website

Prison Terminal is a feature length documentary following the final months in the life of a prisoner, from his initial terminal diagnosis to his eventual death in an Iowa prison-based hospice program. In production and seeking funds to complete the documentary, Edgar Baren's film demonstrates the holistic benefits a prison-based hospice program has on those involved on both sides of the wall and will reveal the complexities of end-of-life care in the correctional environment.

Media Watch, including supplements highlighting prison hospice, is posted on *Prison Terminal's* website at: <http://www.prisonterminal.com/news%20media%20watch.html>

Prison Terminal homepage: <http://www.prisonterminal.com/index.html>

Last call on reforming health reform bill

NEW YORK TIMES | Online OpEd – 22 December 2009 – I recently sat in on the daily meeting of a palliative care team at a hospital – doctors, nurses, a social worker, a chaplain and others, all working with seriously ill patients in extreme pain. One of the patients was a middle-aged man whose advanced cancer had destroyed a major bone in his leg. His wife had already done heroic work caring for him, and more was going to be needed in the months ahead. But she had a problem: she was on the verge of using up her medical leave time. To continue caring for her husband, she would have to quit her job. If she quit her job, the couple would eventually lose their health insurance. Both the health care bill passed by the House of Representatives and the one that the Senate seems set to pass on Christmas Eve would begin to do away with such terrible choices, by making health insurance available to most everyone. That ... would be a grand achievement. It's not enough, though. Our health care system ... also suffers from soaring costs and uneven quality. For health reform to be a success, it needs to make major progress on those problems, too. http://www.nytimes.com/2009/12/23/business/economy/23leonhardt.html?_r=1

Of related interest:

- *NEW YORK TIMES* | Online report – 22 December 2009 – **'Weighing medical costs of end-of-life care.'** The Ronald Reagan UCLA Medical Center ... has earned a reputation as a place where doctors will go to virtually any length and expense to try to save a patient's life. "If you come into this hospital, we're not going to let you die," said Dr. David T. Feinberg, the ... chief executive. Yet that ethos has made the medical center a prime target for critics in the Obama administration and elsewhere who talk about how much money the nation wastes on needless tests and futile procedures. <http://www.nytimes.com/2009/12/23/health/23uc-la.html>

Aren't we enjoying all this celebrity death a little too much?

ESQUIRE | Online OpEd – 21 December 2009 – Statistically, no more celebrities died this year than any other, but from what we're seeing across television and the Web, you'd think the whole of "Who's Who" had vanished in a single gigantic puff of glittery smoke. You can't really blame CNN or TMZ[.com] or the army of loggers who host these elaborate public wakes: They're simply giving us what we want. We don't just grieve for celebrities anymore; we indulge in orgies that turn the dead into the people we need them to be so we can assuage our anxieties about death, both our own and America's. <http://www.esquire.com/features/thousand-words-on-culture/dead-celebrities-2009-1209>

[Specialist Publications](#)

Of particular interest:

'A survey of family members' satisfaction with the services provided by hospice palliative care volunteers.' Scroll down to p.6 for the findings of the survey published in the *American Journal of Hospice & Palliative Medicine*.

'Expensive cancer drugs: A comparison between the U.S. and the U.K.' Scroll down to p.9 for the findings of a recent study published in *Milbank Quarterly*.

[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/>

International

Cancer specialists cast doubt on prayer power

THE AUSTRALIAN | Online report - 22 December 2009 – Cancer experts say prayer should not take priority over conventional treatments. David Goldstein, senior staff specialist in the department of medical oncology at Sydney's Prince of Wales Hospital, said spontaneous remission of cancer happened in about one or two cases in every 1000. "It would be a brave person that used prayer instead of conventional treatment for a curable cancer – it's a complementary practice," Dr Goldstein said. Dr Goldstein said it was "impossible to dissect out" whether improvements seen in patients who pray were due to these and other explainable phenomena, such as the fact people who attended church also tended to live more healthily. A review of 10 previous trials by the international Cochrane Collaboration found when patients were prayed for by others, they enjoyed no significant improvement in outcomes compared to others who were not prayed for.¹ <http://www.theaustralian.com.au/news/health-science/doubts-cast-on-prayer-power/story-e6frg8y6-1225812593562>

1. *THE COCHRANE LIBRARY*, 2009, Issue 4. '**Intercessory prayer for the alleviation of ill health.**' The authors found 10 studies, in which more than 7000 participants were randomly allocated to either be prayed for, or not. Most of the studies show no significant differences in the health related outcomes of patients who were allocated to be prayed for and those who allocated to the other group. http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD000368/pdf_fs.html

Of related interest:

- *SOUTHERN MEDICAL JOURNAL*, 2009;102(12):1218-21. '**Prayers in the clinic: how pediatric physicians respond.**' Physicians and researchers have recently paid increased attention to prayer in physician-patient interactions. Research focuses more on attitudinal questions about whether physicians and/or patients think prayer is relevant than on actual data about when and how prayer comes up in the clinic and how physicians respond. Asking how prayer actually came up in clinical situations rather than how patients and/or physicians thought it should be raised better informs ongoing conversations about the significance of prayer in physician-patient interactions. http://www.ncbi.nlm.nih.gov/pubmed/20016427?itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum&ordinalpos=1

National audit on end-of-life care

Affording dignity to the dying

IRISH TIMES | Online report – 22 December 2009 – The Hospice Friendly Hospitals programme is currently undertaking a national audit on end-of-life care in hospitals in Ireland.¹ It is the first such audit of its kind in the country and the most sophisticated baseline survey to be undertaken in Europe. The first phase included 24 acute and 19 community hospitals. The initial results ... indicate that "end-of-life care in Irish hospitals is probably as good as elsewhere, but the results suggest, it's not good enough." Privacy in the latter stages of life is one of the things highlighted in the initial findings of the first phase of the programme. While nursing staff go to a substantial amount of effort to ensure dying people are afforded some privacy in their final hours, in practice privacy often falls short. About 56% of deaths occur in wards where five or six other people are present. This is partially due to the small number of single rooms available. Another finding of the report is that, while most people wish to die at home, the vast majority are dying in hospitals. Yet in 20% of cases the diagnosis of death in Irish hospitals occurs five to six days before death occurs. <http://www.irishtimes.com/newspaper/health/2009/1222/1224261097819.html>

1. The Hospice Friendly Hospitals website: <http://www.hospicefriendlyhospitals.net/>

Withdrawal of treatment

Doctors who withdrew respirators from 7 patients avoid murder indictment

JAPAN | *Mainichi Daily News* – 22 December 2009 – Prosecutors will not pursue charges against two doctors for the death of seven patients under their care. A medical expert consulted by police stated three of the patients would have died within two to three hours even if artificial respiration had continued, while another three had a life expectancy of 12-24 hours. The remaining patient may have survived for some days, but recovery was an impossibility. Prosecutors concluded "the act of attaching and withdrawing the artificial respirators does not exceed measures to prolong life or their suspension" and "it cannot be proven that the two doctors hastened the death of" their patients. <http://mdn.mainichi.jp/mdnnews/national/news/20091222p2a00m0na002000c.html?inb=s>

Cameron says Tory government would double funding for hospices

U.K. | *Guardian* – 21 December 2009 – Funding for hospices would be doubled under a Conservative government, David Cameron said today as he spoke of how his family had been "blown away" by the excellent care provided for his late son Ivan. Children's hospices, which receive around £100million in public and private funds, would see that amount doubled under a system that would make payments on a per patient basis. The same system would be established for hospices for adults. <http://www.guardian.co.uk/politics/2009/dec/21/conservatives-health>

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

Current practices for withdrawal of life support in intensive care units

AMERICAN JOURNAL OF CRITICAL CARE | Online article – 21 December 2009 – Nurses are present at the bedside of patients undergoing withdrawal of life support more often than any other member of the health care team, yet most publications on this topic are directed at physicians. This article describes the training, guidance, and support related to withdrawal of life support received by nurses in intensive care units in the U.S., how the nurses participated, and how the withdrawal of life support occurred. To improve their practice, intensive care nurses should receive formal training on withdrawal of life support, and institutions should develop best practices that support nurses in providing the highest quality care for patients undergoing this procedure. <http://ajcc.aacnjournals.org/cgi/content/abstract/ajcc2009796v1>

A survey of family members' satisfaction with the services provided by hospice palliative care volunteers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 18 December 2009 – A total of 22 family members, whose deceased loved ones had used the services of a hospice palliative care volunteer, responded to a brief survey designed to assess the importance of the different kinds of support offered to them (family members) by the volunteer, their impressions of the volunteers' personal qualities/characteristics, their general experiences with the volunteer, and their overall satisfaction with the volunteer services. The kind of support that received the highest importance rating from family members was the opportunity to take a much-needed break from the demands of caring for their loved one, closely followed by emotional support, the volunteer spending time with them, and the volunteer providing them with information. Family members rated volunteers highly on a list of qualities/characteristics that exemplify individuals who are effective in this role. In all, 85% of the family members felt that their volunteer was well trained and 95% did not feel that their or their loved one's privacy had been invaded by having a volunteer. Overall, family members were very satisfied with the volunteer support they received. <http://ajh.sagepub.com/cgi/content/abstract/1049909109350207v1>

Royal Society panel to study physician-assisted death

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 8 December 2009 – The Royal Society of Canada has launched a one-year exercise to assess the pros and cons of permitting physician-assisted death. To that end, the society has appointed a six-member Expert Panel on End-of-Life Decision Making, chaired by Udo Schuklenk, professor of philosophy and Ontario research chair in bioethics at Queen's University in Kingston, Ontario. The expert panel has decided to "focus squarely on the questions of whether or not physician-assisted suicide and/or voluntary euthanasia ought to be decriminalized in Canada," Schuklenk stated, adding that the panel plans widespread consultations. "We will tackle these questions by means of an in-depth review of the legal situation in the country, as well as a review of the situation clinicians, as well as terminally ill patients, face on the ground in Canada on a daily basis."
<http://www.cmaj.ca/cgi/content/full/181/12/E293>

From Media Watch dated 2 November 2009:

- ONTARIO | *Exchange* – 28 October 2009 – '**Queen's professor to head international end-of-life panel.**' The Royal Society of Canada panel will investigate key aspects of voluntary euthanasia and physician-assisted suicide and prepare a public report, which is expected to be published in 2011. <http://www.exchangemagazine.com/morningpost/2009/week44/Wednesday/102821.htm>

Of related interest:

- *JOURNAL OF MEDICAL ETHICS*, 2010;36(1):24-29. '**Physicians' labelling of end-of-life practices: a hypothetical case study.**' Similar cases are not uniformly labelled. However, a physicians' label is strongly associated with their willingness to report their acts. Differences in how physicians label similar acts impede complete societal control. Further education and debate could enhance the level of agreement about what is physician-assisted dying, and thus should be reported, and what is not. <http://jme.bmj.com/content/36/1/24.abstract>

Alleviating existential distress of cancer patients: can relational ethics guide clinicians?

EUROPEAN JOURNAL OF CANCER CARE, 2010;19(1):30-38. Most people have a heightened awareness of death at the moment they receive a cancer diagnosis. Medical treatment attempts to demystify and manage death, yet surprisingly, care that alleviates existential distress is the least provided psychosocial care. This paper summarizes clinicians' experiences with cancer patients who face the threat of mortality. Given that the majority of literature was found to be in nursing, emphasis in this paper tends to be on nurses' experiences. However, findings are suggested to have implications for other clinicians who deal with similar concerns.
<http://www3.interscience.wiley.com/journal/122681643/abstract>

Of related interest:

- *ANNALS OF ONCOLOGY*, 2010;21(1):3-5. '**Cultural competence in oncology: where do we stand?**' Demographic shifts in recent decades have rendered most of today's industrialized countries multiethnic and multicultural. Yet cultural pluralism remains a moral and social quandary as the coexistence of multiple cultures within countries is at the same time a source of enrichment, stress and potential conflicts. <http://annonc.oxfordjournals.org/cgi/content/short/21/1/3>

Quotable Quotes

Spiritual care lies at the heart of hospice. It says we are here. We will be with you in your living and your dying. We will free you from pain and give you the freedom to find your own meaning in your own life – your way. We will comfort you and those you love – not always with words, often with a touch or a glance. We will bring you hope – not for tomorrow but for this day. We will not leave you. We will watch with you. We will be there. Dorothy Ley (1924-1994)

Internet-based interventions for complicated grief

GRIEF MATTERS, 2009;12(2):44-47. Over the last few years, research has shown that internet-based psychotherapeutic interventions are effective in a number of areas. Based on a cognitive-behavioural treatment protocol for post-traumatic stress disorder, an internet-based treatment for complicated grief was developed and evaluated. The contact between therapist and patient was exclusively via email during a five-week period of 10 writing assignments. The participants in the treatment group improved significantly on grief-related symptoms and general psychopathology. A preventive internet-based bereavement program for individuals who are at high risk to develop complicated grief (e.g., bereaved parents or individuals bereaved by sudden, unexpected, or violent death) is evaluated. Treatment protocols and results of both interventions are presented. <http://search.informit.com.au/documentSummary;dn=168858653345963;res=IELHSS>

Of related interest:

- *PSYCHO-ONCOLOGY* | Online article – 21 December 2009 – '**Bereavement care: some clinical observations.**' The Yale Bereavement Study has revealed a specific syndrome, prolonged grief disorder. The diagnostic criteria of this disorder are outlined and several clinical illustrations are presented. Preliminary evidence suggests that cognitive-behaviour therapy (CBT) can be effective in the management of prolonged grief disorder. An example of the use of CBT is provided together with some useful clinical guidelines. <http://www3.interscience.wiley.com/journal/123221241/abstract>
- ROUTLEDGE | Publisher's online posting – Accessed 24 December 2009 – '**A Good Death: Conversations with East Londoners.**' The voices in the book are those of people who have managed to cope despite being under the shadow of impending death. *A Good Death* is intended for people who are dying, for their lay and professional carers and for student doctors, nurses and social workers. <http://www.informaworld.com/smpp/title~db=all~content=t737085207>

Quebec to establish \$200Million fund for family caregivers

THE MEDICAL POST (Canada) | Online report – 18 December 2009 – Quebec is establishing a support fund of \$200 million over 10 years to assist caregivers of aging parents and relatives. A draft law to establish the fund ... was approved thanks largely to research done by the University of Montreal Desjardins chair in geriatric and family nursing care. Francine Ducharme, a professor at the faculty of nursing and a researcher at the Research Centre of the University Institute of Geriatrics of Montreal, led the study. Quebec has more than a million people voluntarily supporting and caring for elderly family members, according to *UdMNouvelles* (the University of Montreal newsletter).¹ The research found that family members caring for their elderly at home, as well as their budgetary constraints, constitutes a burden that sometimes threatens their own health. A portion of the funds injected by the government will be aimed at creating support hubs for caregivers throughout the province. These will provide caregivers with evaluation of needs, references, psycho-educational activities, counselling and protection of their rights, among other things. <http://www.canadianhealthcarenetwork.ca/physicians/news/qc-to-establish-200m-fund-for-family-caregivers-6198>

1. '**To help caregivers of elderly,**' *UdMNouvelles*, December 2009. http://translate.google.ca/translate?hl=en&sl=fr&u=http://www.nouvelles.umontreal.ca/&ei=DjKxS5vXNtL0IAfDz4SeBw&sa=X&oi=translate&ct=result&resnum=1&ved=0CBAQ7gEwAA&prev=/search%3Fq%3DUdM%2BNouvelles%26hl%3Den%26rlz%3D1T4DACA_en-GBCA284CA284%26sa%3DX

Factors determining the cost of end of life care

Expensive cancer drugs: A comparison between the U.S. and the U.K.

MILBANK QUARTERLY, 2009;87(4). This article describes British and American coverage, access, and cost-sharing policies with regard to expensive cancer drugs and then compares the costs of eleven such drugs to British patients, American Medicare beneficiaries, and American patients purchasing the drugs in the retail market. In both the British and American health care systems, not all patients who might benefit from or desire access to expensive cancer drugs have access to them. The popular characterization of the U.S., where all cancer drugs are available for all to access as and when needed, and that of the British National Health System, where top-down population rationing poses insurmountable obstacles to British patients' access, are far from the reality in both countries. Key elements of the British system are fairer than the American system, and the British system is better structured to deal with difficult decisions about expensive end-of-life cancer drugs. Both systems face common ethical, financial, organizational, and priority-setting challenges in making these decisions. <http://www.milbank.org/870402.html>

Of related interest:

- *JOURNAL OF MEDICAL ETHICS*, 2010;36(1):61-62 '**Rights, respect for dignity and end-of-life care: time for a change in the concept of informed consent.**' Current concepts of autonomy, surrogate autonomy and informed consent often lead to futile and expensive care at the ends of life. They may impinge on the dignity of the patient as well as subject society to unwarranted expense. In order to provide affordable healthcare for all, these concepts are in need of modification. <http://jme.bmj.com/content/36/1/61.abstract>

Villains and victims: Normative settings in the home care of the terminally ill

MORTALITY, 2009;14(4):325-337. The article reflects how we construct normative settings for acceptable behaviour on the part of dying people and their relatives. Dying people have to behave according to preconceived standards for a 'good family member,' e.g., they should not be too demanding; they have to cooperate on terms set by healthcare professionals by accepting their interventions. For relatives, the normative settings dictate that they have to accept the autonomy of the dying person; they must be modest and humble, obliging towards healthcare professionals and trusting that the professionals are doing the right thing. Such settings stand in complete contrast to the recent development in the Danish healthcare system, which stresses the importance of acknowledging autonomy, integrity and user involvement. <http://www.informaworld.com/smpp/content~db=all~content=a916382747>

Of related interest:

- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online article – 22 December 2009 – '**Canadian Alzheimer's disease caregiver survey: baby-boomer caregivers and burden of care.**' Caregivers of persons with Alzheimer's or related dementia face important social, physical, psychological and financial pressures. These negatively affect the quality of life of caregivers with a significant increased burden being placed on live-in caregivers versus caregivers who do not co-reside with their care recipients. <http://www3.interscience.wiley.com/journal/123210376/abstract>

The breadth of hopes

NEW ENGLAND JOURNAL OF MEDICINE (OpEd), 2009;361(24):2306-2307. Hoping is a fundamental human activity. As a pediatrician who cares for children with life-threatening, complex chronic conditions, I hear the word "hope" on a daily basis: "I hope we can come up with the definitive diagnosis"; "I hope the treatment makes the disease go away"; "I hope we can relieve his pain"; "I hope we can go home today." Indeed, the word is uttered so frequently in clinical medicine that the underlying phenomenon is widely presumed to be well understood, a shared point of reference. Our understanding of hope, however, is not based on much empirical evidence. <http://content.nejm.org/cgi/content/extract/361/24/2306>

Worth Repeating

Personal reflections

Hospice, Day 1

JOURNAL OF PALLIATIVE MEDICINE, 1999;2(1):99. After rounds, I chatted with one of the nurses at the front desk, talking about the movies and the weather. Our conversation flowed easily, the two of us veterans in the practiced kind of small talk that is necessary to survive in medicine. I remember that we both were smiling as a gentleman approached us. Eyes wide and face drawn, he asked if someone could come see his mother. "I . . . I think she's passed away." A quick unspoken exchange passed between the nurse and I. I volunteered to check on his mother. I rose quietly and moved with him toward her room, unsure of what to say. I felt very conscious of my facial expression. The walk to the room was long, 50 or 75 yards. There's no medical school preparation for the long-walk-with-someone-you-don't-know-to-see-if-their-loved-one-has-passed-away situation. I put a hand on his shoulder and we walked silently to the room. His mother was dead, of course. He knew intuitively, but as much for my sake as for his, I put my stethoscope in my ears and gingerly listened for a heartbeat. I heard only silence. I didn't feel her chest moving to pull in air or hear the gurgling of moving bowels in her belly. I did see the blue tinge to her lips and the pallor of her skin. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.1999.2.99>

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Something Missed or Overlooked?

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

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