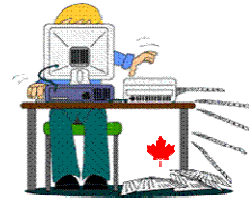


Media Watch...

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.

29 June Edition | Issue #103



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by **Barry R. Ashpole**

Hospice and the economy: Representative sample of recent reports from the news media in North America and Europe are highlighted (i.e., boxed).

Canada

Home care

Crisis on the doorstep

ONTARIO | *Ottawa Citizen* – 28 June 2009 – The region's \$120-million home-care program is being stretched to the limit. The demand is being fuelled by increasing numbers of elderly people, who make up more than half of this region's home-care clients and who require day-to-day medical and physical assistance to stay at home when their health begins to fail. In most cases, home care supplements the support provided by family and friends. The shortage of home-care workers has created a ripple effect across the health-care system as patients who could stay at home, if only they had a little more help, languish, instead, in expensive nursing homes or overburdened hospitals. <http://www.ottawacitizen.com/Crisis+doorstep/1740983/story.html>

Pediatric palliative care

At a hospice, my grandson died a peaceful death

B.C. | *Globe & Mail* (Essay) – 25 June 2009 – At Canuck Place, I would no longer see Ryder undergo his many painful injections, nor hear of more invasive tests and surgeries with unpronounceable names. No more ventilator to take over the role of his lungs. No more heartache after ineffective surgeries that vainly took parts of him away to make him whole. There were times Ryder had in and on him so many tubes, wires and monitoring devices, I was not able to hold him. I was helpless to protect him from all the procedures and interventions to keep him alive and my heart cried out, "Enough, let him go." Ryder was admitted to Canuck Place four times in the last six weeks of his life, yet somehow he always seemed to rally on his own. Inevitably, he had his final relapse and returned for the last time. After a short life filled with struggle, Ryder was finally living and dying on his terms, with no ventilator, no tests, no injections. <http://www.theglobeandmail.com/life/facts-and-arguments/at-a-hospice-my-grandson-died-a-peaceful-death/article1197334/>

Decision making at the end of life

Make 'another time' now

NATIONAL POST | Online OpEd – 24 June 2009 – It is never easy to talk about end-of-life matters ... about issues that might need to be dealt with after one dies. However, sometimes the most difficult things to do are the most important. Being proactive about these issues ensures appropriate reactions later. In this way, the focus can be on making the right resolutions before and after the loss of a loved one – choices that will be consistent with his or her expressed wishes. <http://www.nationalpost.com/arts/story.html?id=1726901>

Hospice and the economy

ONTARIO (SARNIA) | *The Observer* (Letter) – 25 June 2009 – **'We need to protect palliative care unit.'** Many community members are angry that the government has put money into the hospice when the hospital attempts to balance a budget. Health professionals see the hospice as taking nursing jobs away from the community as proposed staffing at the hospice is filled by a high percentage of trained volunteers. It is hoped that this strategy does not let the government (the Local Health Integrated Networks) off the hook for funding for health care in this community. <http://www.theobserver.ca/ArticleDisplay.aspx?e=1629089>

Informing potential users of Canada's Compassionate Care Benefit

SOCIAL SCIENCE & MEDICINE | Online article – 18 June 2009 – Implemented in 2004, the Compassionate Care Benefit (CCB) program aims to provide income assistance and job security to caregivers who ... take temporary leave from their employment to care for a terminally ill family member. Reports have cited numerous challenges with respect to the benefit's successful uptake, including the major obstacle of a general lack of awareness regarding the program's existence.

N.B. For a link to an abstract of the published study, scroll down to [Specialist Publications](#) and *Social Science & Medicine*, **'Informing potential users of Canada's Compassionate Care Benefit.'**

CCB website: http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO (KINGSTON) | *Whig-Standard* (OpEd) – 26 June 2009 – **'Should we have the right to choose death with dignity, peace and care?'** I think many of us fear that our last moments are not going to be happy ones. I think we anticipate pain, depression, discomfort and a sense of foreboding as we await death's call. Painlessly dying in our sleep is often said to be the best way to go; Jewish tradition, my father tells me, has even given this a name – a rabbi's death – symbolizing the value placed on it. <http://www.thewhig.com/ArticleDisplay.aspx?e=1630769>

U.S.A.

Catholics take a new view on a one-time death-bed ritual

PENNSYLVANIA | *Valley News Dispatch* – 29 June 2009 – Roman Catholics are being asked to view the sacrament, once thought only to be a death-bed ritual, in a new light. The educational process is ongoing, though changes ... came decades ago during the historic Vatican II sessions of the 1960s. Not only isn't it necessary to be on one's death bed to receive that strength, but (the) faithful are encouraged to take advantage of other opportunities to receive the sacrament. http://www.pittsburghlive.com/x/pittsburghtrib/ae/s_631428.html

Obama talks about end-of-life planning as hospice providers lobby against funding cuts

ILLINOIS | McKnights.com – 29 June 2009 – President Barack Obama suggested at a town hall meeting at the White House last Wednesday that some end-of-life education and planning could help save on medical expenses. A day later, hospice care organizations asked the president to halt funding cuts for their programs. Hospice and palliative care organizations on Thursday sent the president a letter urging him to stop Bush Administration-approved cuts to Medicare hospice programs set to take effect 1 October.¹ The more than 3,500 organizations pointed to a recent Robert Wood Johnson Foundation study that found hospice programs save \$2,300 per patient for Medicare – up to \$2 billion per year. The cuts in question would reduce hospice rates by eliminating a portion of the hospice wage index calculation called the Budget Neutrality Adjustment Factor.
<http://www.mcknights.com/Obama-talks-about-end-of-life-planning-as-hospice-providers-lobby-against-funding-cuts/article/139198/>

1. National Hospice & Palliative Care Organization letter to President Obama:
http://www.nhpco.org/files/public/public_policy/Open_Letter_to_President_Obama.pdf

Funeral planning assistance is a new perk at workplaces

TEXAS | *Dallas Morning News* – 29 June 2009 – Employees at a small but growing number of companies are gaining access to funeral planning services. With the help of a funeral concierge, they're able to make arrangements years in advance or at a moment's notice. Insurers such as The Hartford and ING have begun to offer the end-of-life services to employers as part of their group life insurance coverage.
http://www.dallasnews.com/sharedcontent/dws/bus/stories/DN-funeralplanning_29bus.ART0.State.Edition1.3cf2e90.html

Hospice and the economy

MISSISSIPPI | *Clarion-Ledger* – 27 June 2009 – **'Tough choices for state hospices.'** Hospice owners complain that a federal cap on Medicare payments is forcing them to choose between limiting patient care or going out of business.
<http://www.clarionledger.com/article/20090627/NEWS/906270334/Tough+choice+for+state+hospices>

NEW YORK | *Capital News 9* – 26 June 2009 – **'Hospice house struggling.'** St. Joseph's House of Grace helps people fighting life's last battles. Now the hospice itself is fighting its own battle.
<http://www.capitalnews9.com/content/headlines/475751/hospice-house-struggling/?RegionCookie=12>

ALABAMA | *Montgomery Advertiser* – 25 June 2009 – **'Funding woes may hit Alabama next.'** A recent report critical of national hospice care trends said Alabama is actually faring better than most states. But it's only a matter of time before Alabama is hit harder by the same problems.
<http://www.montgomeryadvertiser.com/article/20090625/NEWS01/906250322>

CALIFORNIA | *Centre Daily Times* – 25 June 2009 – **'Economy makes roommates of elders and their adult children.'** When she moved in with her daughter Moehr became one of the 3.6 million older parents sharing living quarters with their adult children, a number that has increased 55% since 2000.
<http://www.centredaily.com/living/story/1365272.html>

NORTH DAKOTA | *Associated Press* – 25 June 2009 – **'Hospice lays off 11 people, cites poor economy.'** Susan Fuglie, executive director of the Fargo-based Hospice of the Red River Valley says the cuts represent about 3% of the non-profit agency's 231 employees.
<http://wcco.com/health/hospice.lays.off.2.1058797.html>

VIRGINIA | *United Press International* – 25 June 2009 – **'Obama urged to stop Medicare hospice cuts.'** U.S. hospice providers are urging President Barack Obama to stop cuts to the nation's Medicare hospice benefits.
http://www.upi.com/Science_News/2009/06/25/Obama-urged-to-stop-Medicare-hospice-cuts/UPI-31851245947174/

Medicaid hospice benefit

NHPCO comments on *NEJM* article and emphasizes position of hospice community

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Press release – 25 June 2009 – An article appearing in the current issue of the *New England Journal of Medicine* draws attention to hospice care in the U.S., the Medicare hospice benefit, growth in the field, and includes comments from recent Medicare Payment Advisory Commission reports.¹ The organization ... restate(s) beliefs shared by the hospice community and involving hospice care in the U.S.

- All eligible patients should have access to quality hospice care and the field supports the preservation and enhancement of the Medicare hospice benefit.
- High-quality care for patients and families facing life-limiting illness is provided by non-profit, for-profit, and government owned organizations throughout the nation.
- All providers should follow quality standards for care.
- Transparency and fair regulatory scrutiny in the field is called for and endorsed.
- Increased access and awareness to quality hospice and palliative care should be promoted through collaboration and expansion.

These points were agreed upon ... by the American Academy of Hospice & Palliative Medicine, the Hospice & Palliative Nurses Association, the National Association for Home Care & Hospice, the National Hospice Work Group, Visiting Nurses Association of America, and the National Hospice & Palliative Care Organization. <http://www.nhpc.org/i4a/pages/index.cfm?pageID=5933>

1. For a link to the journal article scroll down to [Specialist Publications](#) and *New England Journal of Medicine*, 'A new era of for-profit hospice care – the Medicare benefit.'

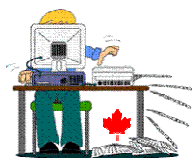
Family caregiving on contract

NEW YORK | *New York Times* – 25 June 2009 – The elderly mother wanted to avoid a nursing home and remain in her house in Kansas City, but she needed hands-on help. The daughter, a nurse at a local hospital, was willing to shoulder responsibility for her mother's care but couldn't afford to lose income by substantially scaling back her work schedule. So elder law attorney Craig Reaves drew up a care contract, specifying that the daughter would help her mother a certain number of hours each week and perform particular duties, for which her mother would pay the same hourly wage her daughter would have earned at the hospital. The whole family agreed. <http://newoldage.blogs.nytimes.com/2009/06/25/caregiving-on-contract/>

From Media Watch dated 12.22.08.

- *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-careagreements-canada-and-united-states>

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.

Expressions of grief

The power of telling your story

COLORADO (DENVER) | *Examiner* – 23 June 2009 – The need to "tell our story" is rarely as strong as it is when we are facing death – our own, or a loved one's. Women in particular immediately sense the need to tell the story of the loss of a child or other loved one. Weeping, they gather with others and begin to talk, to tell what happened, to examine each detail, each word and facial expression, that were part of the last days and hours. Each time the story is repeated, new details are recalled, and new understandings and insights are drawn from the telling. Support groups are formed largely to give a forum where others may recount their stories to a compassionate audience. The advantage of a support group is that tears, stories, and intense focus on the death of someone close is expected and encouraged, while even our closest and most supportive friends and relatives will probably tire of listening to "the same thing over again." And many bereaved parents have an innate sense of the important of their child's story, talking of writing a book recounting the short but precious life. <http://www.examiner.com/x-9432-Family-Grief--Bereavement-Examiner~y2009m6d23-The-power-of-telling-your-story>

Decision making at the end of life

Heart Failure Society of America applauds ... Senior Navigation & Planning Act

HEART FAILURE SOCIETY OF AMERICA | Press release – 22 June 2009 – As highlighted in the Senior Navigation & Planning Act, many patients with heart failure have advanced illness and are in need of end-of-life decision-making and care. Advanced directives and planning measures for care are crucial aspects of the management of patients with heart failure. Availability of skilled end-of-life care is essential to enhance the support and well-being of both patients and families, and to optimize patient quality-of-life and dignity through advanced stages of illness. <http://sev.prnewswire.com/health-care-hospitals/20090622/NE3621322062009-1.html>

(State) Senate OKs bill to allow refusal of health care

LOUISIANA | Associated Press – 22 June 2009 – The Louisiana Senate (has) agreed ... to a proposal that would shield doctors and pharmacists from penalties for refusing to provide health care because of religious or moral objections. The bill would protect health providers from civil or criminal penalties, job loss or demotion because they refuse to provide certain services based on religious or moral beliefs. http://www.wxvt.com/Global/story.asp?S=10576485&nav=menu1344_2

International

Doctors told to be more sensitive and listen to parents of very ill children

U.K. | *The Guardian* – 28 June 2009 – Doctors are being told to display greater sensitivity towards parents facing the agonising decision of whether to switch off the life support machine of their critically ill newborn baby. The General Medical Council is finalising new guidance for medics amid concern that some of them can seem high-handed, not explain complex medical procedures very well, unwittingly leave parents with false hopes about their child's chances of survival and exclude loved ones from crucial decisions. The advice is intended to help doctors support parents in coping with such emotionally charged situations and to avoid the tension that develops when clinicians and families disagree over the treatment of a very sick child, especially whether to prolong its life. It recognises that while some parents are happy to accept doctors' judgments, many want to be involved at every stage of a baby's care and to help make key decisions. <http://www.guardian.co.uk/society/2009/jun/28/doctors-sensitivity-life-support>

Quality at life's end

IRELAND | *Irish Times* (OpEd) – 25 June 2009 – As we plan for life, we should plan for death. Because although dying is part of life, it is often regarded as a peripheral event. And, as such, it has been treated as a poor relation within our health services and by the wider public as little more than a passing theme, generally ignored until the inevitable happens. However, there are encouraging signs of change. Among them is the endorsement by the Health Information & Quality Authority of the work of the Hospice Friendly Hospitals Programme in relation to the development of standards for end-of-life care in hospitals. A new consultation document has set a benchmark for best practice in relation to end of life care provision, allowing families – and those who are dying – to know what they can reasonably expect from hospitals in terms of service provision, support and quality of care. Most importantly, those who run hospitals and long-stay institutions – where 75% of us die – will know and, hopefully, will be trained to adhere to the standards and to respond to the needs of those who are dying and to their families.

<http://www.irishtimes.com/newspaper/opinion/2009/0625/1224249498431.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SWITZERLAND | The Christian Institute (U.K.) – 26 June 2009 – **'Swiss government to consider ban on assisted suicide.'** The Swiss Government is considering a proposal to ban assisted suicide facilities ... (that) would tighten restrictions on who could access assisted suicide, potentially limiting it to those who are close to death. <http://www.christian.org.uk/news/20090626/swiss-govt-to-consider-ban-on-assisted-suicide/>
- U.K. (SCOTLAND) | *Herald* (OpEd) – 24 June 2009 – **'These are vital questions of life and death.'** All the arguments for and against changes in the British law will be rehearsed again at the British Medical Association annual conference ... a debate which will include new statistics that some will find damning. For it seems that of those hundred-plus assisted deaths, around one-third involved cancer and one-fifth motor neurone disease, while some 17 involved multiple diseases. Very many of the rest had conditions that were not in themselves immediately life-threatening. http://www.theherald.co.uk/features/featuresopinon/display.var.2516072.0.These_are_vital_questions_of_life_and_death.php
- CHILE | Angus Reid Global Monitor online report – 23 June 2009 – **'Chileans overwhelmingly support euthanasia.'** Almost two-thirds of people in traditionally-conservative Chile agree with the practice of euthanasia in some cases, according to a poll by Ipsos. 64.5% of respondents support euthanasia or assisted death in cases of terminal or incurable diseases, while 32.3% oppose it. http://www.angus-reid.com/polls/view/33638/chileans_overwhelmingly_support_euthanasia
- SOUTH KOREA | Agence France-Presse – 22 June 2009 – **'South Korea hospital enforces 'right to die' ruling.'** A hospital has removed a life-support system from a comatose patient, upholding a court ruling which had approved a euthanasia request for the first time in the country. Local religious communities have been split on the subject of euthanasia (and) activists have warned against abuse of the ruling. Some Koreans still oppose mercy killing because of deep-rooted Confucianist beliefs ... (and) the Korea Medical Association (has) called for a new law to prevent abuse of the landmark ruling. http://www.google.com/hostednews/afp/article/ALeqM5ipM-NLZbb-OFRaKac5Gp9MLsU_Mg

Hospice and the economy

U.K. | BBC News – 22 June 2009 – **'No new cash for bank loss hospice.'** A ... children's hospice which invested £5.7m in one of the collapsed Icelandic banks has been told it will not receive government compensation. http://news.bbc.co.uk/2/hi/uk_news/england/hampshire/8112254.stm

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

Pharmacologic pearls for end-of-life care

AMERICAN FAMILY PHYSICIAN, 2009;79(12):1059-65 As death approaches, a gradual shift in emphasis from curative and life prolonging therapies toward palliative therapies can relieve significant medical burdens and maintain a patient's dignity and comfort. Pain and dyspnea are treated based on severity, with stepped interventions, primarily opioids. Common adverse effects of opioids, such as constipation, must be treated proactively; other adverse effects, such as nausea and mental status changes, usually dissipate with time. Parenteral methylnaltrexone can be considered for intractable cases of opioid bowel dysfunction. Tumor-related bowel obstruction can be managed with corticosteroids and octreotide. Therapy for nausea and vomiting should be targeted to the underlying cause; low-dose haloperidol is often effective. Delirium should be prevented with normalization of environment or managed medically. Excessive respiratory secretions can be treated with reassurance and, if necessary, drying of secretions to prevent the phenomenon called the "death rattle." There is always something more that can be done for comfort, no matter how dire a situation appears to be. <https://secure.aafp.org/login/>

Quality medical care in gastroenterology: Lessons from palliative medicine

AMERICAN JOURNAL GASTROENTEROLOGY, 2009;104(6):1352-1355. An emerging specialty ... palliative medicine arose to meet a need in caring for patients with incurable and often terminal disease. Symptom management, particularly for pain, was inadequate in traditional health-care delivery; moreover, patients and families had psychosocial and spiritual needs, among others, that were being overlooked or inadequately addressed. These unmet needs were adding to the burden of illness and adversely affecting symptom management. The goal of palliative care is to relieve suffering and improve quality of life by addressing all of these components of illness. Traditionally, our attention is focused on the disease process on the assumption that suffering will decrease and quality of life will benefit if the disease is effectively managed. While that may be true to some extent, these other aspects of illness often require specific attention. To achieve this goal, effective communication is sought with both patients and families, and a variety of medical and social services are brought into the mix. This is not something that is routine in community-based practice, much less in procedure-oriented disciplines such as gastroenterology. <http://www.nature.com/ajg/journal/v104/n6/full/ajg2009142a.html>

Patient-physician communication

Expressing humanism in each medical encounter

ARCHIVES OF INTERNAL MEDICINE, 2009;169(12):1095-1099. Humanistic behavior is considered an essential component of professional medical care. However, the evidence shows that it is often neglected. Many barriers to the expression of sensitivity to the patient's concerns and empathy and compassion in the clinical encounter can be identified. Time constraints, poor continuity of care, appearance of alienating factors between patients and physicians, and the "hidden curriculum" are just a few in a long list. To overcome them, personal adoption of the CAPTURES mnemonic technique is suggested. It includes curiosity about the patient's personal aspects, finding something to admire, trying to see things from the patient's perspective, touching and using body language to convey caring, reacting to the patient, and stressing any positive or encouraging aspects to provide support, reassurance, and hope. <http://archinte.ama-assn.org/cgi/content/extract/169/12/1095>

From Media Watch dated 01.26.09.

- *ACADEMIC MEDICINE*, 2009;84(1):117-125. 'A good clinician and a caring person: Longitudinal faculty development and the enhancement of the human dimensions of care.' http://journals.lww.com/academicmedicine/Abstract/2009/01000/A_Good_Clinician_and_a_Caring_Person_Longitudinal.32.aspx

Palliative care for older people: Exploring the views of doctors and nurses from different fields in Germany

BMC PALLIATIVE CARE | Online article – 23 June 2009 – Providing appropriate palliative care for older people is a major task for health care systems worldwide, and up to now it has also been one of the most neglected. Focusing on the German health care system, the authors sought to explore the attitudes of health professionals regarding their understanding of palliative care for older patients and its implementation. General practitioners are the central health professionals in the delivery of palliative care for older people. They should however be encouraged to involve specialized services such as palliative care teams where necessary. With the German health care reform of 2007, a legal framework has been created that allows for this. As far as its realization is concerned, it must be ensured that the spotlight remains on the needs of the patients and not on policy conflicts and rivalries between health care professionals. Older people might particularly benefit if "talking" medicine and time-consuming care were properly catered for, financially and organizationally, in the health care system. <http://www.biomedcentral.com/content/pdf/1472-684x-8-7.pdf>

End of life care: Key skills for care staff defined

COMMUNITY CARE (U.K.) | Online report – 26 June 2009 – Skills for Care & Skills for Health today defined a "baseline" set of skills for all staff working with people approaching the end of their lives. The two sector skills councils have laid out a series of core competences and principles, designed to achieve a "cultural shift in attitudes and behaviour related to end of life care" in the workplace. They are designed to apply to all staff across care homes, hospitals and other settings, not just specialists in end of life or palliative care, and supplement current occupation-specific training standards. They have been produced on the back of the government's End of Life Care Strategy, published last July, and will be followed next year by a suite of e-learning resources for staff and the launch of a communication skills programme. <http://www.communitycare.co.uk/Articles/2009/06/26/111940/end-of-life-care-key-skills-for-care-staff-defined.html>

Decision making at the end of life

The saga of Eluana Englaro: another tragedy feeding the media

INTENSIVE CARE MEDICINE, 2009;35(6):1129-1131. This article focuses on issues concerning end-of-life care in medicine in Italy. It discusses the case of Eluana Englaro, a 36-year-old woman with persistent vegetative state at the age of 19 (who) continued to live through the use of (a) feeding tube. It depicts the controversy of the case ... regarding the family's proposal to remove the life support. It presents the contradicting theories of both the religion and the law regarding euthanasia. <http://www.springerlink.com/content/p3546048v851335w/>

From Media Watch dated 04.20.09.

- ITALY | OneNewsNow – 15 April 2009 – **'Italy passes end-of-life legislation.'** Italy's Senate passed an end-of-life bill that prohibits withdrawing food and water from patients in response to the case of Eluana Englaro, who died last month after her family had her food and water removed. <http://www.onenewsnow.com/Politics/Default.aspx?id=489286>

Quotable Quotes

It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has. William Osier (1849-1919)

States explore shared decision making

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2009;301(24):2539-2541. Health officials in Washington State are probing whether more actively involving patients in decision making will help improve patient care and satisfaction and perhaps lower costs associated with certain elective medical procedures. In 2007, the state passed legislation that officially recognized shared decision making as a high standard of informed consent. The law also required a demonstration project, which is now under way, to gauge the effects of this model of informed consent for treating patients with "preference-sensitive conditions" that have multiple options for care. <http://jama.ama-assn.org/cgi/content/extract/301/24/2539>

Assisted (or facilitated) death

Dying and choosing

THE LANCET (OpEd), 2009;373(9678):1840-1841. "I have never seen such a clear cut case for euthanasia" were the general practitioner's words when he referred to me a young man with a fungating malignant spinal tumour. The patient's distress was palpable and compounded by neuropathic pain. But, most of all, he hated losing control through creeping paraplegia and through his increasing dependence on his young wife, who was struggling to cope with their two children and 7-week-old baby. He asked me to end it for him, and his request persisted for several weeks. He would have passed all the tests about mental competence that euthanasia campaigners suggest and appeared to fulfil all the criteria in legislation from other countries: he was terminally ill with a short predicted prognosis, suffering unbearably, persistent in his competent request, fully informed, and had no psychiatric condition. That was 1991. In 2001, he telephoned me to say that his beautiful wife had been diagnosed with pancreatic cancer. She died some months later, and he has brought up their children alone, aware that the law in Britain had saved them from being orphaned. Yet the media campaign for legalising what is euphemistically called "assisted dying" rarely shows this side of the coin.

<http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2809%2961012-6/fulltext>

Differentiating states of impaired consciousness

Frequent misdiagnoses and inconsistent standards in Europe pose ethical problems

MEDICAL NEWS TODAY (U.K.) | Online report – 23 June 2009 – "Latest research raises important ethical issues concerning ... care for patients with chronic consciousness disorders," said Professor Gustave Moonen, past president of the European Neurological Society. "This is all the more important as studies have shown that more than a third of patients given an initial diagnosis of vegetative state or persistent vegetative state show minimal signs of consciousness under more detailed examination." <http://www.medicalnewstoday.com/articles/154886.php>

A new era of for-profit hospice care – the Medicare benefit

NEW ENGLAND JOURNAL OF MEDICINE, 2009;360(26):2701-2703. To ensure that a reluctant medical community would embrace Medicare at its inception in 1965, Congress declared that any willing provider could participate. Since that time, the vast majority of physicians and hospitals have come to rely on Medicare as a major source of revenue. But as additional Medicare benefits have been created, they have increasingly been provided by for-profit companies that find doing business with government, though sometimes frustrating, a worthwhile commercial venture. Perhaps the most untraditional Medicare service offered by such organizations is hospice care. The hospice benefit was created in 1982 to offer terminally ill patients an alternative to conventional care, but "there was also a strong expectation that hospice services would result in lower costs to the Medicare program than conventional medical interventions at the end of life," according to the Medicare Payment Advisory Commission (MedPAC), which advises Congress. <http://content.nejm.org/cgi/content/full/360/26/2701>

Patients need to be provided with real choice in end-of-life care

NURSING TIMES (U.K.) | Online OpEd – 26 June 2009 – While there is now greater emphasis on helping patients choose where they might want to die, the details of some of the practical issues when that choice is at home need to be addressed. By scrupulous assessment, healthcare professionals, care planners and commissioners can help patients achieve their choice. Last year, a striking advert in a magazine caught my eye. The caption was: 'You've got your own bed. So why die in someone else's?' This was part of Marie Curie Cancer Care's Delivering Choice Programme. It seemed to touch at the very heart of end-of-life care in a non-sentimental, practical way. Rarely are these details of how and where one might die raised in public in such a way. It made me reflect on three issues that are a core part of my working life and have been for many years. <http://www.nursingtimes.net/nursing-practice-clinical-research/primary-care/patients-need-to-be-provided-with-real-choice-in-end-of-life-care/5003225.article>

Techniques for framing questions in conducting family meetings in palliative care

PALLIATIVE & SUPPORTIVE CARE, 2009;7(2):163-170. Family therapy has developed several approaches to framing questions within family meetings, but few of these techniques have been adapted for palliative care. The authors focus on the application of questioning techniques from systemic family therapy to palliative care (and) ... highlight ... a model of questioning styles. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=5867644&fulltextType=RA&fileId=S1478951509000212>

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE*, 2009;7(2):171-179. **'Conducting family meetings in palliative care: Themes, techniques, and preliminary evaluation of a communication skills module.'** Although (family) meetings can be challenging, the communication skills module (discussed) is effective in increasing the confidence of participants in conducting a family meeting. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=5867656&fulltextType=RA&fileId=S1478951509000224>

Palliative care: A need for a family systems approach

PALLIATIVE & SUPPORTIVE CARE, 2009;7(2):235-243. A Family Systems Theory (FST) framework can be useful in helping health care providers deliver optimal care to ... patients and their families and standardize the way research is done by providing an appropriate framework with which to study the family. FST will provide consistency for future studies ... presently lacking. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=5867752&fulltextType=RV&fileId=S1478951509000303>

Informing potential users of Canada's Compassionate Care Benefit

SOCIAL SCIENCE & MEDICINE | Online article – 18 June 2009 – Implemented in 2004 by the Canadian government, the Compassionate Care Benefit (CCB) program aims to provide income assistance and job security to caregivers who decide to take temporary leave from their employment to care for a terminally ill family member at risk of dying. Reports have cited numerous challenges with respect to the benefit's successful uptake, including the major obstacle of a general lack of awareness regarding the program's existence. Results (of this study) indicate that targeted dissemination efforts undertaken outside of urban cores are likely to be most efficient in reaching potential or current CCB-eligible family caregivers. This strategy should be implemented through multiple formats and venues via two information pathways: 1) from key professionals to family caregivers; and, 2) from the community to the general public. http://www.ncbi.nlm.nih.gov/pubmed/19540645?ordinalpos=8&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum

Worth Repeating

Preparing patients and families for future emotional journey

Controlling death: The false promise of advance directives

ANNALS OF INTERNAL MEDICINE, 2007;147(1):51-57. Advance directives promise patients a say in their future care but actually have had little effect. Many experts blame problems with completion and implementation, but the advance directive concept itself may be fundamentally flawed. Advance directives simply presuppose more control over future care than is realistic. Medical crises cannot be predicted in detail, making most prior instructions difficult to adapt, irrelevant, or even misleading. Furthermore, many proxies either do not know patients' wishes or do not pursue those wishes effectively. Thus, unexpected problems arise often to defeat advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning should emphasize not the completion of directives but the emotional preparation of patients and families for future crises. The existentialist Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying. <http://www.annals.org/cgi/content/abstract/147/1/51>

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 an abstract or introductory paragraph. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced and 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.

Links to Sources

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

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca