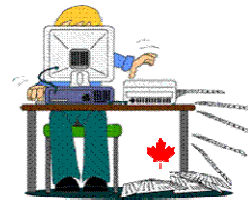


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Facing a diagnosis of terminal cancer: Scroll down to [U.S.A.](#) and 'Certain people have the skills to cope well and go gently into the night.'

Canada

Thousands ... 'suffer hideously,' palliative care report finds

NEWFOUNDLAND | CBC News – 2 June 2009 – A scathing report has found that few of the people who die in Newfoundland & Labrador have access to appropriate palliative care, and spend their final days in needless anguish. "Throughout Newfoundland & Labrador many of the most vulnerable, terminally ill and those with life-limiting illnesses continue to suffer hideously," says a not yet publicly released needs assessment report. "They struggle daily for medications and services and such as medical care, home care, nursing and medical care. They struggle through the bureaucratic roller-coaster of endless paperwork for admission to acute care, respite care, palliative care and long-term care facilities ... because of the lack of these same basic services in their individual communities." The report ... found that palliative care is currently a specialized service available to less than ten percent of the people who die in Newfoundland & Labrador. <http://www.cbc.ca/canada/newfoundland-labrador/story/2009/06/02/dying-pain-report-602.html>

- NEWFOUNDLAND | CBC News – 5 June 2009 – **'No one should die alone, Labrador palliative volunteer says.'** A woman who sits with patients as they die says Newfoundland & Labrador government officials should recognize they one day may need palliative care. <http://www.cbc.ca/canada/newfoundland-labrador/story/2009/06/05/palliative-care-605.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | LifeSiteNews.com – 28 May 2009 – **'Canadian private member's motion would make Internet counselling for suicide a criminal offense.'** M-388, tabled by Kitchener MP Harold Albrecht, proposes that the government should ensure that counseling, aiding or abetting a person to commit suicide is a Criminal Code offence "regardless of the means used to counsel or aid or abet including via telecommunications, the Internet or a computer system." The Motion follows the well-publicized case of Nadia Kajouji, the 18 year-old Carleton University student who committed suicide in 2008 after allegedly being coaxed to do so in an internet chat room. <http://www.lifesitenews.com/ldn/2009/may/09052801.html>

U.S.A.

Patient-physician communication

Body of lies: Patients aren't 100% honest with doctors

CALIFORNIA | *Los Angeles Times* – 7 June 2009 – Doctors know that at least some of the time, at least some of their patients overstate, understate, embellish, omit, or otherwise stray from a straight and thorough reporting. "Everybody lies at some point," says Dr. Sharon Parish, a professor of clinical medicine at Albert Einstein College of Medicine in New York City who practices at Montefiore Medical Center. They do it out of embarrassment, to please the doctor, to avoid a lecture. But doctors and patient advocates agree that in most cases, when patients lie, they're pretty much asking for trouble. Even when telling the truth is unappealing, "getting into a lying relationship with your physician is really far more perilous," says Peter Clarke, director of the Center for Health & Medical Communication at USC. http://www.latimes.com/features/health/la-he-lying8-2009jun08_0_2605423.story

- CALIFORNIA | *Los Angeles Times* – 8 June 2009 – '**How doctors can spot lies or head them off.**' If a physician can establish a rapport with a patient and phrase questions well, it's easier to elicit the truth. http://www.latimes.com/features/health/la-hew-lying-docs8-2009jun08_0_3888674.story

Facing a diagnosis of terminal cancer

Certain people have the skills to cope well and go gently into the night

U.S. NEWS & WORLD REPORT | Online article – 4 June 2009 – How people respond to a diagnosis of incurable cancer is very individualized, says Holly Prigerson, director of the Center for Psycho-oncology & Palliative Care Research at the Dana-Farber Cancer Institute in Boston. In her research, she's found that about 20% of terminally ill patients are both cognitively aware and emotionally accepting of their deaths. "Those are the resilient types," she says. "They appreciate their time is limited and choose not to freak out about it." Of course, everyone goes through a grieving process, the initial shock and numbness, the denial, anger, despair. But more resilient folks move through that to a state of acceptance in which they take on those life projects and have conversations with their kids, friends, and spouses about dying. They are more likely to spend their final days in hospice, getting pain relief and saying goodbye. Unfortunately, the majority of people don't fare so well, says Prigerson. They never come to terms with the fact that they're dying. Studies of terminally ill patients show that four months prior to their deaths, very few actually acknowledge that the end is near. The worst off, though, are the ones who understand that death is imminent but aren't emotionally accepting of it, fighting to stay alive at any cost. "They're at a much, much greater likelihood of spending their last days in pain, attached to a ventilator," says Prigerson. <http://health.usnews.com/articles/health/cancer/2009/06/04/facing-a-diagnosis-of-terminal-cancer.html>

Bill would provide for better end-of-life care

WASHINGTON | *Morgan Messenger* (West Virginia) – 3 June 2009 – U.S. Senators Jay Rockefeller and Susan Collins have reintroduced a more comprehensive version of their Advance Planning & Compassionate Care Act. The legislation would provide the resources to improve care at the end of life. Sen. Rockefeller chairs the Senate Finance Subcommittee on Health Care. http://74.95.82.237:591/mmonline/FMPro?-db=mmonline.fp5&-format=record_detail.html&-lay=allfields&lay=allfields&Category=Top%20Stories&ArticleStatus=Current&-max=20&-recid=12591725&-find

Professor examines making life and death decisions after Terry Schiavo

VIRGINIA | *News Leader* – 2 June 2009 – Every day, thousands of people quietly face end-of-life decisions as agonizing as those made famous in the Terri Schiavo case. Throughout that controversy, politicians, religious leaders and legal and medical experts made emphatic public statements about the facts and offered even more certain opinions about what should be done. In *If That Ever Happens to Me: Making Life and Death Decisions after Terri Schiavo* (Chapel Hill: University of North Carolina Press, 2009), University of Virginia professor Lois Shepherd details why simple answers were not right for Schiavo and are not right for end-of-life decisions today. Shepherd looks behind labels like "starvation," "care" and "medical treatment" to consider what care and feeding really mean, when feeding tubes might be removed, and why disability groups, the people of faith and even the dying themselves often suggest end-of-life solutions they might later regret. For example, Shepherd cautions against living wills as a pat answer. She provides evidence that attempting to create letter-perfect documents can actually weaken, rather than bolster, patient choice. <http://www.newsleader.com/article/20090602/NEWS01/90602002/1002>

Care at the end of life: A psychotherapist's perspective

In talks with a dying patient, affirming life

NEW YORK | *New York Times* (OpEd) – 1 June 2009 – We are in uncharted territory here; the rules of my profession no longer have meaning. The boundaries that govern our psychoanalytic relationship – the 50-minute hour at prescribed times within the confines of my office, the carefully choreographed dance of free association and interpretation – are stretched beyond recognition. Now the task is just a kind of witnessing, of being with her in any way she needs me to be. For her, I will travel an hour on public transportation, wipe her brow, dab her drool, fetch blankets, hold her hand, even sing a lullaby if that's what she wants. How did I get here? It's not part of my training; I am not a hospice nurse or a social worker. I am not a friend or family member. And even though I specialize in treating the medically ill, I've always been a bit skittish on the topic of death. http://www.nytimes.com/2009/06/02/health/02case.html?_r=1&ref=health

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.

The autopsy, a search for reassurance

NEW YORK | *New York Times* – 18 May 2009 – Unsettled feelings are not uncommon when there is uncertainty about a death, and autopsies apparently help some people resolve them, according to an article by doctors in The Netherlands who interviewed relatives of patients who had died.¹ Was something overlooked? Could they have done anything to prevent the death?
http://www.nytimes.com/2009/05/19/health/19seco.html?_r=2&partner=rssnyt&emc=rss

1. *Family Practice*, 2001;18(3):304-308. **'Family members' experiences of autopsy.**
<http://fampra.oxfordjournals.org/cgi/content/full/18/3/304>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON | *Peninsula Daily News* – 4 June 2009 – **'Olympic Medical Center amends death with dignity policy.'** Doctors working at Olympic Medical Center can counsel patients on the Death with Dignity Act, the hospital's commissioners have decided. The amended resolution approved in a 5-1 vote is a modification ... of a 4 March decision to 'opt out' of the voter-approved Initiative 1000. <http://www.peninsuladailynews.com/article/20090605/news/306059992>
- MONTANA | Associated Press – 1 June 2009 – **'Montana lawmakers line up in assisted suicide case.'** The assisted-suicide case before the Montana Supreme Court is drawing a barrage of briefs from legislators, physicians and groups, over an issue that sows controversy. The state of Montana has asked the court to reverse a lower court ruling that Montanans have a constitutional right to physician-assisted suicide. Before the deadline, at least 14 motions to participate in the case had been filed with the Supreme Court, which is likely to hear oral arguments later this year. <http://www.flatheadbeacon.com/articles/article/montana-lawmakers-line-up-in-assisted-suicide-case/10780/>

International

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Times* (Letter) – 6 June 2009 – **'Existing suicide law stops sinister deaths.'** It is naive to suppose that people who are helped to commit suicide are always 'loved ones.'
<http://www.timesonline.co.uk/tol/comment/letters/article6439753.ece>
- U.K. | *The Economist* – 4 June 2009 – **'Assisted suicide and the law.'** The law lords who heard Debbie Purdy's case are unlikely to publish their judgment for some weeks. Her hearing coincided with passage through the House of Lords of the Coroners & Justice Bill and provides an opportunity for lords sympathetic to Ms. Purdy's predicament to give her and others in a similar position the certainty they want. http://www.economist.com/world/britain/displaystory.cfm?story_id=13785065
- U.K. | Press Association – 2 June 2009 – **'Lords debating assisted suicide bid.'** The controversial legal action brought by multiple sclerosis sufferer Debbie Purdy to clarify the law on assisted suicide is moving to the House of Lords. Purdy has so far failed to secure a definitive court ruling that her husband, Cuban violinist Omar Puente, would not face prosecution if he helped her travel abroad to die in a country such as Switzerland where assisted suicide is legal. Under English law, aiding and abetting suicide is a criminal offence punishable by up to 14 years imprisonment. <http://www.google.com/hostednews/ukpress/article/ALeqM5jXXtRjOheD2umBbF9d63fum-n8DQ>
- CZECH REPUBLIC | *České Noviny* – 1 June 2009 – **'Czechs more tolerant of abortion than euthanasia – poll.'** Czechs have a more tolerant stance on abortion than on euthanasia, according to a poll conducted in May. <http://www.ceskenoviny.cz/news/zpravy/czechs-more-tolerant-of-abortion-than-euthanasia-poll/380089>

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

Dignity of dying man in world religions

ADVANCES IN PALLIATIVE MEDICINE, 2009;8(2):63-68. Attitudes towards death, preparations for it, and faith in life after death are the core of each religion and philosophical system. Death is the final ritual, the last chance to discover the ultimate meaning and aim of life. That is where the dignity of a dying human comes from, which is expressed by the rituals connected with a religion: preparations for death, accompanying the dying person, as well as the rituals of funeral and way of experiencing mourning. This article describes attitudes to death in Judaism, Islam, Hinduism and Buddhism (and) discusses the basic philosophical and existential ideas, as well as problems of preparation to death, handling a dead body and behaviour of the relatives during the period of mourning. <http://www.viamedica.pl/en/gazety/xgazEang/wydanie.phtml?VSID=0aa98011e62ec4387d8662a2c04385df>

New guidance for anaesthetists to help resolve dilemmas posed by DNAR orders

ANAESTHESIA (U.K.) | Online report – 3 June 2009 – The body that represents anaesthetists in the U.K. and the Republic of Ireland has issued new guidelines to help their members through the ethical and clinical maze of how to treat terminally ill patients with Do Not Attempt Resuscitation (DNAR) orders when they need an operation. Guidelines have been available in the U.S. since 1993 and Canada since 2002. In the U.K., a framework to support decisions relating to cardiac resuscitation was jointly published by the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing in 2007. <http://www.frca.co.uk/content.aspx?content=1120>

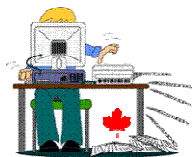
Of related interest:

- *JOURNAL OF MEDICAL ETHICS*, 2009;35:338-342. **'Code status discussions and goals of care among hospitalised adults.'** Code status discussions may fail to address patients' treatment-related goals and their knowledge of cardiopulmonary resuscitation. This study aimed to investigate patients' resuscitation preferences, knowledge of cardiopulmonary resuscitation, and goals of care. <http://jme.bmj.com/cgi/content/abstract/35/6/338>

Collaborated death: An exploration of the Swiss model of assisted suicide for its potential to enhance oversight and demedicalize the dying process

JOURNAL OF LAW, MEDICINE & ETHICS, 2009;37(2):318-330. Death, like many social problems, has become medicalized. In response to this medicalization, physician-assisted suicide (PAS) has emerged as one alternative among many at the end of life. And although the practice is currently legal in the states of Oregon and Washington, opponents still argue that PAS is unethical, is inconsistent with a physician's role, and cannot be effectively regulated. In comparison, Switzerland, like Oregon, permits PAS, but unlike Oregon, non-physicians and private organizations play a significant role in assisted death. Could the Swiss model be the answer? <http://www3.interscience.wiley.com/journal/122428853/abstract>

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.

Deep and continuous palliative sedation (terminal sedation): clinical-ethical and philosophical aspects

LANCET ONCOLOGY, 2009;10(6):622-627. Terminal sedation continues to fuel debate. When confronted with a patient for whom terminal sedation is considered a possible treatment option, decision making can be difficult. In this paper the authors focus on the clinical-ethical issues, with an aim to provide clinicians with ways of framing the issue from an ethical point of view. In addition to the clinical-ethical issues, terminal sedation touches upon interesting and complex questions of an essentially philosophical nature. What it means to be a "person" is one such question, and is a topic that is relevant to clinical, daily practice. Accordingly, in the latter part of this paper they draw briefly on selected philosophical positions to elucidate this question. A doctor's belief of what it means to be a "person" might well affect their actions. For example, if a doctor believes terminal sedation involves the destruction of the person, they might not be willing to proceed with it. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(09\)70032-4/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(09)70032-4/abstract)

From Media Watch dated 13 April 2009:

- *PALLIATIVE MEDICINE* | Online journal article – 7 April 2009 – '**Deciding about continuous deep sedation: physicians' perspectives.**' The authors conclude that physicians' decision-making about continuous deep sedation is characterized by balancing the interests of patients with their own feelings. Accordingly, the reasons for its use are not unambiguous and need further debate. <http://pmj.sagepub.com/cgi/content/abstract/0269216309104074v2>

Life-and-death scenarios lead to moral distress in nurses

NURSE (U.S.) | Online OpEd – 1 June 2009 – You know it's time to withdraw ventilator support from your unresponsive patient. The physician knows it's time. But the family doesn't. That's just one possible source of moral distress – when healthcare professionals feel their core personal values and ethical obligations are in conflict. "Moral distress is characterized by situations where you can't do what you believe you should morally do," says Ann Hamric, associate professor at the University of Virginia School of Nursing, who is also faculty affiliate for the Center for Biomedical Ethics & Humanities, and a researcher in moral distress. "It's nurses perceiving they're powerless." Moral distress jumped into public view with a *The New York Times* article that generated nearly 300 online comments from readers, many of them healthcare professionals.¹ <http://news.nurse.com/article/20090601/NATIONAL01/90529002/-1/frontpage>

1. '**When doctors and nurses can't do the right thing.**' <http://www.nytimes.com/2009/02/06/health/05chen.html>

Technology and home care: Implementing systems to enhance aging in place

NURSING CLINICS OF NORTH AMERICA, 2009;44(2):239-246. The national healthcare agenda to improve efficiencies, reduce costs, provide high quality evidence and performance based care while simultaneously meeting stricter legal and regulatory requirements, has forced home care and hospice staff to change the way they work. These pressures require a reliance on new technologies to meet these goals. Through the agency-wide introduction and implementation of a variety of technological systems; electronic medical record/ point of care devices, telehealth, telephony and e-learning the Norwell VNA and Hospice has been able to improve efficiencies for employees allowing the focus of services to remain solely on patients and patient care. [http://www.nursing.theclinics.com/article/S0029-6465\(09\)00010-3/abstract](http://www.nursing.theclinics.com/article/S0029-6465(09)00010-3/abstract)

Of related interest:

- *NURSING CLINICS OF NORTH AMERICA*, 2009;44(2):233-238. '**Hospice – organizational perspectives.**' Coverage of hospice care by Medicare and other insurers has helped it develop into an important part of today's health care system. Nevertheless, substantial barriers to its ideal use remain. [http://www.nursing.theclinics.com/article/S0029-6465\(09\)00003-6/abstract](http://www.nursing.theclinics.com/article/S0029-6465(09)00003-6/abstract)

Soins palliatifs et maladie d'Alzheimer

LA REVUE DE MÉDECINE INTERNE, 2009;30(6):475-562. Although end-of-life care is a relatively common option for patients with terminal cancer, it has become available only recently for patients with Alzheimer's disease. Alzheimer's disease is a chronic process of gradual deterioration of cognitive ability and the resulting deficits in activities of daily living. The chronic disease course of Alzheimer's disease gives to the clinician the opportunity to look ahead and plan for the final stages of care. This article presents a review of palliative care interventions for patients with Alzheimer's disease and other dementias. End-of-life care for individuals with end-stage Alzheimer's disease is increasingly important because of the increasing number of patients with this disease. However, there are barriers to providing high-quality end-of-life care. Currently, palliative care is not optimal for Alzheimer's patients. Health care systems and clinicians should make efforts to improve the suffering of patients with this disease and their caregivers. <http://www.sciencedirect.com/science/journal/02488663> N.B.

N.B. Scroll down to 'Soins palliatifs et maladie d'Alzheimer.' Text in French.

Specialist Publications ...but, without a link to an abstract or the article

- JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION, 2009;10(5):292-294. **'The medical director as a member of the hospice team.'** A logical, organized approach to the decision to become a medical director, along with a careful evaluation of the prospective hospice, will lead to the highest satisfaction for all parties. A comprehensive and clearly written contract will delineate the roles and responsibilities of the medical director and hospice. Effective negotiation techniques will assist the prospective medical director to attain highest satisfaction with the position. This article addresses these issues using a review of the literature and the authors' extensive experience as medical directors.

Worth Repeating ...and, a Quotable Quote

Effecting change in the illness experience

It is interesting to again participate in the birth of a new subspecialty. I can remember when all of the neonatal physicians gathered at a meeting in 1972 – there were less than 200 of us. Man we thought we were "hot." We realized we were at a frontier, doing new and exciting things and at the cusp of an information explosion. However, there is a huge difference in that "hot attitude." I remember then and the "heart attitude" so widely reflected among this new group of palliative medicine specialists. And while some of the same elements are present as in the birth of neonatology, no other specialty focuses so keenly on relational medicine, on the nature and meaning of suffering and requires so much plumbing of our own spiritual depths and returns such meaningful rewards. There is no other scientific meeting that has a session devoted to remembering our patients. We even sense an unspoken bond between all of us who do this work that goes beyond expertise. The glue that binds us together is much deeper, grounded in the fact that we know something about each other's heart I feel so privileged to be a part of this awesome group at this bookend point in my career. My deepest thanks to all of you who have worked so hard to make palliative medicine a real specialty. My hope is that it will bring about change in how all of medicine is practiced.

A recent website posting by Lawrence J. Fenton, MD, Professor Emeritus, Sanford School of Medicine, University of South Dakota where he serves as Chief of Section, Pediatric Palliative Care .

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