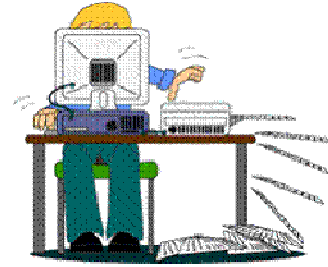


Media Watch

...is distributed weekly to colleagues active or with 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 inform discussion and encourage further inquiry. Following is an annotated listing of recent articles, reports, etc., with links to the original source.

26 January Edition | Issue #81



Compilation of Media Watch 2008, 2009 ©

Compiled & Annotated by Barry R. Ashpole

Does endlessly battling death begin to diminish life? Scroll down to **U.S.A.** and **'Dealing with modern culture's last taboo and medicine's greatest weakness.'**

Canada

Call to support family caregivers: Online poll

CANADIAN CAREGIVER COALITION | Online posting – 20 January 2009 – Of the nearly 3,000 members of the Canadian Association for Retired Persons (CARP) who responded to an online poll, 95.7% endorsed the idea of supporting the five million family caregivers in Canada who provide \$6-9 billion dollars of unpaid care every year.¹ Without the help of these informal caregivers, the responsibility of caring for older adults would fall on the health care system. CARP and the Canadian Caregiver Coalition are asking for budget measures to assist caregivers.

<http://www.ccc-ccan.ca/announce.php?annon=23>

1. CARP Economic Stimulus Survey (Scroll down to 'Family Caregiver assistance?'):
http://www.imakenews.com/eletra/mod_input_proc.cfm?XXDESXXsurvey.id=32778&mode=view&mod_name=surveyresults&XXDESXXbackto=http://www.imakenews.com/carp/index000325014.cfm&XXDESXXshow_votes=T&XXDESXXuser=carp

Euthanasia & Assisted Suicide Debate in Canada: Annotated Historical Perspective on End-of-Life Decisions

Summarized are notably "developments" – also highlighting those in other countries – that inform the euthanasia and assisted suicide debate in Canada.

Compiled & Annotated by Barry R. Ashpole

Updated and re-formatted: 26 January 2009

Canada: Provinces

Home care: Falling through the cracks of health-care protocol

Giving up can't be a solution

ONTARIO | *The Sudbury Star* (Editorial) – 24 January 2009 – The situation 42-year-old Minna Mettinen-Kekalainen faces is truly sad, but finger pointing is not the solution. Action is needed and plans to deal with difficult cases must be addressed. Mettinen-Kekalainen suffers from amyotrophic lateral sclerosis (ALS), a neurodegenerative disease that is usually fatal. She also has Asperger's syndrome, which is related to autism. It often results in poor communication skills, obsessive routines, physical clumsiness and difficulties with social adjustment. Mettinen-Kekalainen, who two years ago was still active with the adaptive rowing program in Sudbury she helped found, now finds herself in a wheelchair and in need of assistance to live at home. She has been identified as a palliative patient by her doctor, and she has sent her daughter to live with relatives in British Columbia to spare her the trauma of watching her mother's inevitable physical decline. <http://www.thesudburystar.com/ArticleDisplay.aspx?e=1403444>

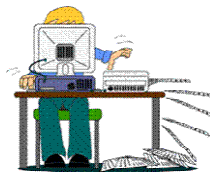
- CANADIAN PRESS | Newswire report – 25 January 2009 – '**Ontario woman in battle with Lou Gehrig's Disease also battles to get home care.**' Minna Mettinen-Kekalainen has not received home care since mid-November and survives day to day on the kindness of friends, but they have neither the time nor the training to replace the care of a registered nurse. <http://www.google.com/hostednews/canadianpress/article/ALeqM5gW3uEwTkrXw5O-OlxVSyCg9AqTtg>

U.S.A.

Hospital-wide palliative care program

Health center program uses holistic approach to ease pain

CONNECTICUT | *Advance* (University of Connecticut) – 26 January 2009 – A new initiative is underway at the John Dempsey Hospital to meet the physical, emotional, psychological, and spiritual needs of patients who are seriously ill or coping with persistent pain. The Pain & Palliative Care Program is a consultation service led by Nancy Baccaro, a nurse practitioner who also sees patients in the Carole & Ray Neag Comprehensive Cancer Center, working with a team of experts from areas including nursing, case management, social work, and pastoral care. The program was introduced in stages throughout the hospital. It began last fall on the fourth, sixth, and seventh floors, and within months, evolved into a hospital-wide service. <http://www.advance.uconn.edu/2009/090126/09012606.htm>



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 workshops for frontline care providers.

Choose with care: Your health-care representative will speak for you when you can't

OREGON | *Mail Tribune* – 23 January 2009 – If you couldn't make your wishes known during a medical emergency, who would you trust to speak for you? Oregon law allows each of us to appoint a health-care representative to speak for us when we can't. People need to make sure the person they choose really knows what they want, says a medical ethicist. The ideal health-care representative brings compassion and common sense to the task, says John Tuohey, of the Center for Health Care Ethics for Providence Health & Services. If you're going to pick a health-care representative, pick someone who's not in a hurry to get rid of you, but not unwilling to let you go. <http://www.mailtribune.com/apps/pbcs.dll/article?AID=/20090123/NEWS/901230328/-1/LIFE>

Inmates near death sent home

NORTH CAROLINA | *Charlotte Observer* – 22 January 2009 – Nine days before Christmas, state prison officials released Jeffery Cooke from McCain Correctional Hospital and sent him home to Currituck County to die. Cooke, a 41-year-old repeat drunken driver suffering from liver disease, was the first inmate released under a new state program that grants early parole to terminally ill, disabled and geriatric prisoners who qualify. North Carolina is among a majority of states that release inmates with high medical costs, but who officials believe pose no threat outside prison. A 2007 study showed that North Carolina spent \$34 million on health care for inmates age 50 and older out of a \$1.2 billion budget that year. That was a 35% increase over the previous year. <http://www.charlotteobserver.com/local/story/488186.html>

Representative sample of recent reports

Assisted suicide and euthanasia

- WASHINGTON | *Catholic Sentinel* – 22 January 2009 – **'Non-assisted suicide zones being sought.'** A coalition opposed to Washington's assisted-suicide initiative is trying to create zones in the state where the controversial practice would be banned. <http://www.sentinel.org/node/9759>
- MARYLAND | CitizenLink – 20 January 2009 – **'Maryland may force doctors to provide information on suicide.'** Legislation sitting in the Maryland House would require doctors to provide terminally ill patients who wish to die with information from groups that advocate physician-assisted suicide. <http://www.citizenlink.org/content/A000009130.cfm>
- NATIONAL REVIEW, 2009;61(1):20-22. **'Courts vs. Law.'** Citing Montana, where a judge declared its state constitution includes a right to physician-assisted suicide, the author opinions that court intervention on moral issues suggests "judicial activism" and insults democracy and the rule of law. <http://nrd.nationalreview.com/article/?q=Njg2NWY4YTUyYTRkNzAxN2VmNzU5YjRmMGYyZDU0Y2E=>

Links & Back Issues of Media Watch

Please alert this office if you encounter any difficulty. Every effort will be made to find an alternative means of access. Alternatively, copy/paste the URL into the address bar of your browser. All links are confirmed as being active before Media Watch is distributed; they remain active, however, for only a limited period of time.

Back issues of Media Watch are held on file for a limited time and available on request.

End of life decision making and quality care for American Indians

MONTANA STATE UNIVERSITY (MSU) | Press release – 20 January – Most hospitals funded by the Indian Health Service focus more on acute care treatment and services for the chronically ill. End-of-life services for patients on Indian reservations are often lacking, says Yoshiko Colclough, an assistant professor of nursing at MSU. Colclough recently received a grant from the Lance Armstrong Foundation to work with the Blackfeet Tribe focusing on end of life decision making and the quality of end of life care. <http://www.montana.edu/cpa/news/nwview.php?article=6712>

Related areas of research:

- ADVANCE (Speech-Language & Audiology Weekly) | Online report – 20 January 2009 – '**Palliative care in pediatrics.**' Researchers at Johns Hopkins plan to explore the ethical challenges health professionals face when caring for children and families affected by life-threatening neuromuscular diseases. <http://speech-language-pathology-audiology.advanceweb.com/editorial/content/editorial.aspx?cc=192412>
- CALIFORNIA | Stanford University School of Medicine press release – 23 January 2009 – '**New center at Stanford to study brain's role in compassion, altruism.**' A new Center for Compassion and Altruism Research & Education has been launched at the Stanford University School of Medicine, with the aim of doing scientific research on the neural underpinnings of these thoughts and feelings. http://media-newswire.com/release_1084911.html

Web grief: Funeral webcasts gain in popularity

ASSOCIATED PRESS | Online newswire report – 20 January 2009 – Schoedinger Funeral & Cremation Service has taken the business of grief high-tech. It's one of a growing number of funeral service providers to embrace the Web. Schoedinger – in central Ohio – is offering live Web streaming and archived online video for use by military personnel overseas and others who can't be present for a loved one's funeral. It's a way for mourners to take part in the experience without the time and expense of a long-distance trip, especially one arranged on short notice. <http://www.google.com/hostednews/ap/article/ALeqM5jOaE1JWbIBOdaHunxBgoJDWzaQcAD95QRAI00>

Of related interest:

- UTAH | *Herald Journal* – 25 January 2009 – '**The price of dying.**' One company sells huggable urns for \$99 to \$169, allowing family members to keep a loved one's or pet's remains in a stuffed animal they can hold onto forever. <http://hjnews.townnews.com/articles/2009/01/25/news/news01-01-25-09.txt>

Dealing with modern culture's last taboo and medicine's greatest weakness

TEXAS | *Dallas Morning Star* – 19 January 2009 – Nobody wants to die a slow, lingering death. But many do – in hospitals. Often, their last months of life are expensive, painful exercises in medical futility. Health care reformers around the nation are pushing for a better way to help people at the edge of life. Practitioners of "palliative care" combine traditional medicine with pain relief, spiritual counselling and practical advice for patients and families. Unlike hospice, palliative care can continue alongside aggressive, life-sustaining treatments. Palliative doctors, nurses and other clinicians guide patients and families through searingly painful choices, including decisions to avoid overly invasive care. They aim to help patients live as well as possible for as long as possible, and to help grieving families prepare for the inevitable. Research indicates that such "comfort care" sometimes can prolong life more effectively than aggressive surgical, chemical or radiation therapies. It also can reduce medical expenses; Medicare spends 28% of its annual budget on care given in the last year of life. The author of the article asks: Does endlessly battling death begin to diminish life? Is death always the enemy, or is it a mystery as profound and sacred as birth? http://www.vvdailypress.com/articles/care_10464_article.html/life_patients.html

Hospice rates protected in version of economic stimulus plan

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Press release – 16 January 2009 – The U.S. House of Representatives released its proposed American Recovery & Reinvestment Act, widely known as the "stimulus bill." The plan included a provision to halt the elimination of the budget neutrality adjustment factor for one year, retroactive to 1 October 2008. NHPCO, the Alliance for Care at the End of Life, and thousands of hospice advocates around the nation have been working since last April to get Congress to intervene with such a delay ... step one in a complicated legislative process. <http://www.nhpc.org/i4a/pages/index.cfm?pageid=5810>

N.B. Medicaid Hospice Benefit Q&A: http://www.medicareadvocacy.org/FAQ_Hospice.htm [Accessed 21 January 2009.]

Of related interest:

- *NEW YORK TIMES* | Online interview – 19 January 2008 – '**A front-row seat as a health care system goes awry.**' In *Life Worth Living: A Doctor's Reflections on Illness in a High-Tech Era*, Dr. Robert L. Martensen criticizes the American way of dying and is asked why he feels this aspect of health care is on the wrong track?" <http://www.nytimes.com/2009/01/20/health/policy/20conv.html>

International

Family caregiver issues

Family abuse of people with dementia common: study

U.K. | Reuters – 22 January 2009 – People caring for family members with dementia commonly abuse them with behaviour such as swearing and shouting, according to a study that shows a more widespread problem than previously thought.¹ "The study shows abusive behaviour is very common and not something doctors are regularly asking about and therefore finding," Claudia Cooper, a researcher at University College London, who led the study, said in a telephone interview. A third of family caregivers said their abuse of the person they were looking after was significant, including frequent insulting or swearing, and half said they occasionally screamed or yelled at the person. The researchers, who found few cases of physical abuse, say their study highlights the need for governments and health officials to widen efforts aimed at tackling elder abuse. "This is the strongest evidence so far about the prevalence of abusive behaviour from family carers of people with dementia," said Cooper. "These were the sons and daughters, and husbands and wives." <http://www.reuters.com/article/lifestyleMolt/idUSTRE50M0GH20090123>

1. *British Medical Journal*, 2009;338:b155. '**Abuse of people with dementia by family carers: representative cross sectional survey.**' Abusive behaviour by family carers towards people with dementia is common, with a third reporting important levels of abuse and half some abusive behaviour. http://www.bmj.com/cgi/content/full/338/jan22_2/b155

Media Watch Posted on Palliative Care Network-e Website

The 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. PCN-e provides a platform to foster teaching and interaction, and the exchange of ideas, information and materials.

Links: PCN-e <http://www.pcn-e.com/> | Media Watch: <http://www.pcn-e.com/MW.htm>.

Palliative Care Network has launched the first online networking community website exclusively for palliative care professionals at: www.pcn-e.com/alpha

Assisted suicide and euthanasia

Clinic backs down in Eluana Englaro case

ITALY | CathNews – 19 January 2009 – An Italian clinic that had offered to help end the life of 38-year-old Eluana Englaro, who is said to be in an irreversible coma, in accordance with a landmark "right to die" court ruling, has withdrawn its offer. The publicly-assisted clinic in the Friuli-Venezia Giulia region offered its services in December after the Lombardy region, where Englaro is cared for by nuns at a Lecco clinic, refused to offer clinics or health workers to help her die despite the right to die verdict from Italy's supreme court. <http://www.cathnews.com/article.aspx?aeid=11227>

- ITALY | ANSA – 20 January 2009 – **'Piedmont 'would let Eluana (Englaro) die.'** The governor of Piedmont said that the region would be prepared to allow Englaro to end her life in accordance with a landmark right-to-die ruling. http://www.ansa.it/site/notizie/awnplus/english/news/2009-01-20_120315583.html

Of related interest:

- U.K. | *Daily Telegraph* – 24 January 2009 – **'BBC accused of trying to influence assisted suicide debate ...'** As part of deliberations on the Coroners and Justice Bill, MPs will vote on whether to clarify the law so that it is clear that aiding and abetting suicide is illegal. <http://www.telegraph.co.uk/news/uknews/4326438/BBC-accused-of-trying-to-influence-assisted-suicide-debate-with-Julie-Walters-film.html>
- GERMANY | Spiegel – 21 January 2009 – **'Court expected to rule on assisted suicide case.'** Should police be permitted to stop a former Hamburg official who sells assisted suicide services? The issue is headed to court and may result in a fundamental German ruling on an issue that has divided people across Europe. <http://www.spiegel.de/international/germany/0,1518,602390,00.html>
- U.K. (Scotland) | *Press & Journal* – 21 January 2009 – **'Assisted suicide explored in exhibition.'** Personal experiences of death by assisted suicide are explored in a new art exhibition to be unveiled in Dundee this weekend. <http://www.pressandjournal.co.uk/Article.aspx/1039439?UserKey>

Journal Articles

Patient-physician communication

The total package: A skillful, compassionate doctor

ACADEMIC MEDICINE | University of Indiana press release – 22 January 2009 – Patients and their families want physicians who are gifted in diagnosis and treatment and who are caring individuals with the interpersonal skills needed to communicate complex information in stressful circumstances. A new study published in the January 2009 issue of *Academic Medicine* shows training physicians to be humanistic is feasible and produces measurably better communicators.¹ "Humanism in medicine ... is about taking the individual patient's concerns and values into account in his or her treatment," said co-author Richard Frankel. "Those values are clearly linked to higher quality of care and reduction of medical errors yielding safety improvement." The study was conducted at five different medical schools. http://www.eurekalert.org/pub_releases/2009-01/iu-ttp012209.php

1. *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

Managing grief and relationship roles influence which forms of social support the bereaved needs

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online journal article – 21 January 2009. Social support is important during the bereavement period and influences which form of social support the grieving person needs. This study shows two different strategies for coping with grief which also revealed which form of social support the grieving persons needed depend on what they found difficult to manage. Systematically monitoring the bereaved makes it possible to understand the strategies they use in the grieving process and to identify when these strategies are insufficient so professional support can be offered.
<http://ajh.sagepub.com/cgi/content/abstract/1049909108330034v1>

Implementation of ICU palliative care guidelines and procedures

CHEST, 2009;135(1):26-32. Ethical conflicts are commonly encountered in the course of delivering end-of-life care in the intensive care unit (ICU). Some ethical concerns have legal dimensions, including concerns about inappropriate hastening of death. Despite these concerns, many ICUs do not have explicit policies and procedures for withdrawal of life-sustaining treatments. The authors describe a U.S. Office of Inspector General (OIG) investigation of end-of-life care practices in their ICU. The investigation focused on care delivered to four critically ill patients with terminal diseases and an ICU nurse's concern that the patients had been subjected to euthanasia. The OIG investigation also assessed the validity of allegations that patient flow in and out of the ICU was inappropriately influenced by scheduled surgeries and that end-of-life care policies in our ICU were not clear. Although the investigation did not substantiate the allegations of euthanasia or inappropriate ICU patient flow, it did find that the policies that discuss end-of-life care issues were not clear and allowed for wide-ranging interpretations.
<http://www.chestjournal.org/content/135/1/26.abstract>

Dementia and dying: The need for a systematic policy approach

CRITICAL SOCIAL POLICY, 2009;29(1):146-157. In November 2006 a joint National Institute for Health & Clinical Excellence and Social Care Institute for Excellence guideline to improve the care of people with dementia was released. This influential policy document reflects both a medicalized approach to care (emphasizing pharmacological management and health services) as well as one characterized by professional dominance (an emphasis on professional authority and control). Despite the involvement of social sciences in its development the policy reflects common biases in other areas of policy and practice in the care of older people. Furthermore, the idea that people with dementia have complex end of life care needs is addressed only with the most cursory and clinically oriented approaches to palliative care. A critical commentary about this policy approach is supplemented with a brief description of an alternative policy vision that connects older people's care with a wider public health approach to end of life care for older people. <http://csp.sagepub.com/cgi/content/abstract/29/1/146>

Something Missed or Overlooked?

If you come across a media report, journal article, etc., relevant to hospice palliative care or end-of-life issues not mentioned in this edition of Media Watch, please alert this office so that it can be included in a future issue of the weekly report. Thank you.

Timing of hospice referral

HOME HEALTH CARE MANAGEMENT & PRACTICE, 2009;21(2):109-116. In general, satisfaction with timing of hospice referral was measured in mortality follow-back surveys of patients who died in hospice. In contrast in this study, investigators assessed timing of the hospice referral in patients enrolled in hospice for a minimum of two weeks. About one third of patients or families identified that it would have been easier if they had started hospice earlier. Barriers to early hospice access were associated primarily with access to the health care system. <http://hhc.sagepub.com/cgi/content/abstract/21/2/109>

Representative sample of (fairly) recent journal articles on the topic:

- *THE GERONTOLOGIST*, 2008;48:477-484. '**Referral and timing of referral to hospice care in nursing homes ...**' Residents received hospice for longer periods when staff believed hospice complemented (nursing home) care and when staff took the initiative in raising the option of hospice. <http://gerontologist.gerontologyjournals.org/cgi/content/abstract/48/4/477>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2007;34(2):120-125. '**Timing of referral to hospice and quality of care ...**' The majority of respondents surveyed believed that they were referred to hospice "at the right time," this despite a reported short length of stay. <http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392407003375.pdf>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2005;30(5):400-407. '**Late referral to hospice and bereaved family member perception of quality of end-of-life care.**' A survey of bereaved family members ... found that 13.7% of decedents were referred at a time too late for hospice. <http://www.journals.elsevierhealth.com/periodicals/jps/article/PIIS0885392405004720/abstract>
- *JOURNAL OF PALLIATIVE MEDICINE*, 2008;11(3):484-491. '**Ethnic variation in timing of hospice referral ...**' The length of hospice stay, as an indicator of timing of hospice referral, is an important outcome to examine in end-of-life care; it is relevant to the quality and cost efficiency of end-of-life care that patients receive. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2007.0149>
- *JOURNAL OF PALLIATIVE MEDICINE*, 2004;7(3):411-418. '**Barriers to hospice care and referrals ...**' The difficulty of predicting death to within six months was cited by 37% of physicians surveyed as a barrier to hospice. <http://www.liebertonline.com/doi/abs/10.1089/1096621041349518>

Dire deadlines: coping with dysfunctional family dynamics in an end-of-life care setting

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(1):34-41. The hospice triad – the patient, the staff member and the family member – forms the basis for communication and intervention in a hospice. Higher expectations and demands of younger, more well-informed patients and family members challenge hospice staff in terms of information and communication when planning for care. The inherent risk factors of working with patients in the terminal phase of life become a focal point in the prevention of the development of compassion fatigue among staff members. A series of coping strategies to more optimally manage dysfunctional families in a setting where time is of the essence are presented in an effort to empower the hospice team, to prevent splitting among staff members, and to improve quality of care. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=37951;article=IJPN_15_1_34_41

Quotable Quotes

We humans – we have got this idea that there is something wrong with dying, and oh my goodness is that a fountain of sorrow for us! Mark Gallagher, 'Approaching the End of Life,' 2008.

Nurses' experiences of delivering spiritual care to patients in an Irish hospice

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(1):42-48. This study describes nurses' experiences of delivering spiritual support in a palliative care setting. The authors conducted semi-structured interviews with 22 nurses working in the area of specialist palliative care. A content analysis of the transcriptions revealed five sub-themes: understanding spirituality; the art of nursing in spiritual care; education and learning; the challenge of spiritual caring; and the dimensions of time. The resulting creation of a spiritual tapestry provided an overall theme. Nurses in this study were spiritually self-aware and placed a high value on the spiritual element of their caring role. Nurses described their individual understanding of spirituality and discussed how they recognized and addressed a patient's spiritual needs. Time was described as essential to the provision of spiritual support and appeared to be a significant resource challenge to the provision of spiritual care. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=37952;article=IJPN_15_1_42_48

N. B. Of related interest: Scroll down to [Worth Repeating](#) and 'The caregiver's perspective on existential and spiritual distress in palliative care.'

Perspectives of healthy elders on advance care planning

JOURNAL OF THE AMERICAN ACADEMY OF NURSE PRACTITIONERS, 2009;21(1):18-23. This study explored the perspectives of healthy elders on advance care planning. Data reveal five major themes: advance care planning is strongly influenced by concern for others; elders assume that preferences are known to their trusted friends, family, and providers, even in the absence of explicit communication with these people; elders value a healthcare system that supports provider time, focus, and continuity; being "known" to a provider is critical to comfort that advance care planning preferences will be respected; and, elders are generally ready and eager to discuss advance care planning. Additional findings include: elders are better prepared for the event of death than the dying process; lawyers and financial planners play a prominent role in guiding elders through end-of-life decisions; and elders believe that the optimal time for advance care planning discussion is during periods of relative wellness. <http://www.ingentaconnect.com/content/bsc/jaan/2009/00000021/00000001/art00003>

From Media Watch dated 01.12.09.

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY*, 2009;57(1):31-39. 'A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers.' <http://www3.interscience.wiley.com/journal/121562572/abstract>

Arts & Entertainment

Contrasts in societal views of dying and death

The end can be a beginning

U.K. (SCOTLAND) | *The Herald* – 23 January 2009 – To Tracy Mackenna, a Scot, and Edwin Janssen, who is Dutch – collaborators in life, work and art since they first met in 1997 – communicating their responses to the death of their parents in two very different cultures, was as natural as breathing. Not long after the death of his father, Janssen's mother, who had been ill for a long while, also died. In the family home, almost in the manner of a Dutch still-life painter, he made a darkly mournful, yet beautiful series of slides using objects such as his father's watch, a glass and bottle of water, purple tulips and a changing series of highly personal photographs within a photographic frame. This series, 'Life, Death & Beauty: The Invisible Looks Back,' is just one of many segments in Mackenna and Janssen's new exhibition, 'Life is over! If you want it.' http://www.theherald.co.uk/features/features/display.var.2483779.0.The_end_can_be_a_beginning.php

Worth Repeating

The caregiver's perspective on existential and spiritual distress in palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2006;32(1):13-26. There is a paucity of research relating to how palliative caregivers conceptualize, identify and provide for spiritual and existential domains of care. Focus groups comprising experienced palliative care providers participated in three semi-structured interviews, which were transcribed and subjected to thematic analysis. Eight themes were revealed: conceptualization of spirituality; creating openings; issues of transference and counter transference; cumulative grief; healing connections; the wounded healer; sustaining a healing environment for the caregiver; and challenges and strengths for the spiritual and existential domains of palliative care. While the spiritual and existential domains were variously conceived by experienced care providers, their significance for both patient and caregiver was affirmed. Transference and counter transference issues, and the "wounded healer," concept were considered fundamental to effective care. Strategies for promoting therapeutic depth discussion were suggested and the importance of self-awareness and staff support emphasized. The spiritual and existential domains of palliative care may be viewed as being richly rewarding and essential for any thoughtful pursuit of optimal quality of life for both patient and caregiver. http://www.mcgill.ca/files/wholepersoncare/caregivers_perspective.pdf

Reader response:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2006;32(6):516-517. '**Caregivers and existential and spiritual distress.**' The ... benefits of spirituality in terms of mental health appear more mixed than Boston and Mount's paper appears to acknowledge, plus there are real difficulties in integrating spirituality into clinical practice and scientific research, which this paper ... appears to side step. [Referenced] [http://www.jpsmjournal.com/article/S0885-3924\(06\)00475-1/fulltext](http://www.jpsmjournal.com/article/S0885-3924(06)00475-1/fulltext)

Authors' response:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2006;32(6):517-518. We agree that the findings of much of the existing, largely American-based, research concerning "religion and health" cannot be generalized to other cultural and religious settings, and that there is a need for qualitative research to clarify the issues at play as we come to terms with the core existential issues that frame our lives (death, meaninglessness, loss of external structure, aloneness). [Referenced] [http://www.jpsmjournal.com/article/S0885-3924\(06\)00592-6/fulltext](http://www.jpsmjournal.com/article/S0885-3924(06)00592-6/fulltext)

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