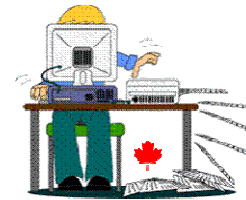


Media Watch...

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

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Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

Barriers to dying at Home: Scroll down to [Specialist Publications](#) and 'The impact of poor co-ordination of community service provision for patients with cancer' published in *Health & Social Care in the Community* (p.7)

Canada

Conference opens eyes to treatments

"Treatment for dying patients in Canada and China are worlds apart"

SASKATCHEWAN | *Leader Post* (Regina) – 28 December 2009 – Whether you're Canadian or Chinese, no one likes using the "p" word. "How many people accept that they're going to die?" registered nurse Barb Hale asks. "People hear the "p" word – palliative – and they think, 'That's the end of the road ... That's it, I'm done.'" The clinical consultant in palliative care – a specialty of hers for 15 years. Because of her expertise, she was invited to join a contingent of Canadian physicians and nurses on a 10-day trip to Beijing and Xi'an last month. The trip was organized by the Canadian Hospice Palliative Care Association so that Canadian health-care professionals could exchange information about palliative and end-of-life care with their Chinese counterparts.

<http://www.leaderpost.com/technology/Conference+opens+eyes+treatments/2385117/story.html>

Assisted (or facilitated) death

- PARLIAMENTARY NOTE: Suspension of the parliament until 3 March will delay second reading of Bill C-384. The private member's bill, which would decriminalize assisted suicide, was introduced by Parti Québécois MP Francine Lalonde. Her previous attempts to amend the law, Bill C-407 (2005) and Bill C-562 (2008), died on the Order Paper with the dissolution of parliament in the fall of both years. A private member's bill receives two hours of debate in parliament before it is voted on at second reading. Transcript of the first hour of debate (2 October 2009) is available at: <http://www2.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=40&Ses=2&DocId=4122372#OOB-2876558>

Specialist Publications

Of particular interest:

'Construction of palliative care training contents in China.' Scroll down to p.6 for the findings of a recent study published in *Cancer Nursing*.

'Perspectives of Vancouver Island hospice palliative care team members on barriers to communication at the end of life.' Scroll down to p.8 for the findings of a preliminary study published in the *Journal of Hospice & Palliative Nursing*.

U.S.A.

New Catholic mandate on comatose patients

CALIFORNIA | *San Francisco Chronicle* – 3 January 2010 – The nation's Catholic hospitals ... face a new religious mandate in the new year: to provide life-sustaining food, water and medicine to comatose patients who have no hope of recovery. The U.S. Conference of Catholic Bishops issued the directive 17 November to the more than 1,000 church-affiliated hospitals and nursing homes in the U.S. and to all Catholic doctors and nurses. Invoking a 2004 speech by Pope John Paul II, the bishops said Catholics must provide nutritional assistance to patients with "presumably irreversible conditions ... who can reasonably be expected to live indefinitely if given such care." A previous directive let Catholic hospitals and doctors decide whether the burdens on the patient outweighed the benefits of prolonging life. The bishops said the new policy was guided by "Catholic teaching against euthanasia" and by John Paul's observation that providing food and water "always represents a natural means of preserving life, not a medical act."
<http://www.sfgate.com/cgi-bin/article.cgi?f=/c/a/2010/01/03/BA321BC2R1.DTL>

Palliative sedation

National Hospice & Palliative Care Organization response to *New York Times* article

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION
| Press release – 30 December 2009 – Whenever the media focuses on issues involving end-of-life care, there are sure to be different points of view, nowhere is this better understood than within the hospice and palliative care provider community. When such an article appears in the press, there is always value in the conversations that follow among individuals and families, and between healthcare providers. That said, there is concern regarding the *New York Times* article by Anemona Hartcollis, 'Hard choices for a comfortable death: Sedation.' While the large majority of the nearly 500 responses posted to the *New York Times* web site in response to this article reflect favorably on hospice care and the personal experiences of many readers, there is concern that others may draw inaccurate conclusions about hospice and care of the dying. Intractable pain at the end of life is never a simple issue. A decision to use sedation near the end of life should be made carefully and thoughtfully, with adequate support from knowledgeable and skilled healthcare providers. <http://www.nhpco.org/i4a/pages/index.cfm?pageID=6167>

From Media Watch dated 28 December 2009:

- *NEW YORK TIMES* | Online article – 26 December 2009 – **'Hard choice for a comfortable death: Sedation.'** In almost every room people were sleeping, but not like babies. This was not the carefree sleep that would restore them to rise and shine for another day. It was the sleep before – and sometimes until – death.
<http://www.nytimes.com/2009/12/27/health/27sedation.html>

N.B. The *New York Times* article was widely syndicated.

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

Ontario | Hamilton Niagara
Haldimand Brant Hospice
Palliative Care Network:
<http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation
Services:
<http://www.hpcconnection.ca/newsletter/inthenews.html>

U.S.A.

Prison Terminal:
<http://www.prisonterminal.com/news%20media%20watch.html>

International

Palliative Care Network:
<http://www.pcn-e.com/community/>

Terminally ill pets get hospice care

ALABAMA | *Birmingham News* – 29 December 2009 – Jim Elrod has worked for nearly 20 years as a hospice minister, helping terminally ill people find peace and comfort at the end of life. So when the Vestavia Hills resident's cat, Roxie, became sick with no hope of recovery, he sought an alternative to treatment at a veterinary clinic before the inevitable act of euthanasia. Elrod set about researching pet hospice, but found while it is offered in other areas of the country, there are no pet hospice clinics in Alabama. http://blog.al.com/birmingham-news-stories/2009/12/terminally_ill_pets_get_hospic.html

From Media Watch dated 10 August 2009:

- *HEALTHDAY NEWS* | Online report – 6 August 2009 – 'Hospice care eases the end for loyal pets.' <http://www.ajc.com/health/content/sharedauto/healthnews/dead/629040.html>

Hospice: Acceptance and availability

New study shows that American public is willing to accept major reforms in Medicare program

CONCORD COALITION | Online news release – 29 December 2009 – Encouraging hospice care instead of heroic measures at the end of life is supported by 85% of participants in a recent dialogue on health reforms, according to a new study.¹ Although Americans see Medicare as a key part of the country's social contract ... they are willing to consider significant changes in the program to hold down its costs as the U.S. population ages. If additional money is needed to maintain Medicare ... Americans would rather see the government raise taxes than increase the federal debt. <http://www.prnewswire.com/news-releases/new-study-shows-that-american-public-is-willing-to-accept-major-reforms-in-medicare-program-80284302.html>

1. *Medicare: It's Not Just Another Program*, Concord Coalition, December 2009. http://www.concordcoalition.org/files/uploaded-pdfs/Medicare_Report_Dec09_PRINT.pdf

Indigent burials, and cost to public, on rise

MINNESOTA | *Star Tribune* (Minneapolis-St. Paul) – 27 December 2009 – It's a grim but necessary county job that, unlike building roads or jailing bad guys, usually escapes notice: burying the dead when no one else can. In some Minnesota localities ... indigent and county-assisted burials have been on the rise in the last couple of years as economic conditions have worsened. State law requires counties to pay basic funeral expenses to bury or cremate those who die alone and destitute, or to provide those services for families who can't afford a basic coffin and burial for a relative. In Hennepin County, there are hundreds of indigent funerals every year. <http://www.startribune.com/politics/local/80182062.html?elr=KArksLckD8EQDUoaEyqyP4O:DW3ckUiD3aPc:Yyc:aUUsA>



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.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *OREGON BUSINESS REPORT* | Online article – 4 January 2010 – **'Estate tax and Oregon assisted suicide.'** Opponents to the physician-assisted suicide laws have long felt there is a moral hazard to granting a person the right to choose when to die. Will the person make that choice merely because of their personal suffering, or are they going to feel obligated to do so to relieve their children of the need to care for them or because they are a financial burden. Add to the mix the possibility that by dying in 2010 they could become a financial "windfall" for their heirs and the risk of a "moral" hazard to the law rises. <http://oregonbusinessreport.com/2010/01/estate-tax-and-oregon-assisted-suicide/>
- MONTANA | *New York Times* – 31 December 2009 – **'Montana ruling bolsters doctor-assisted suicide.'** The Montana Supreme Court ruled ... that state law protects doctors in Montana from prosecution for helping terminally ill patients die. But the court, ruling with a narrow majority, sidestepped the larger landmark question of whether physician-assisted suicide is a right guaranteed under the state's Constitution. <http://www.nytimes.com/2010/01/01/us/01suicide.html>

International

Profile: Ilora Finlay

"As a junior doctor, I saw people dying appallingly badly ... I was so angry"

U.K. (WALES) | *Western Mail* – 2 January 2010 – Like other junior doctors before her, Ilora Finlay saw her fair share of patients dying. But rather than pursue any number of different careers in medicine, after training as a GP she decided to move into the often ignored specialty of palliative care. The spectre of those patients dying, often in pain, left an indelible mark on the woman who would later become Baroness Finlay of Llandaff. Today, Professor Finlay, who regularly shuttles between Velindre Cancer Centre, in Cardiff, and the House of Lords, is fronting a campaign to encourage families to share their experiences of palliative care and the last months of a loved one's life in a bid to improve NHS [National Health Service] services. In many respects the dying well matters campaign is a culmination of all that she has tried to achieve during her working career to date. <http://www.walesonline.co.uk/news/wales-news/2010/01/02/as-a-junior-doctor-i-saw-people-dying-appallingly-badly-i-was-so-angry-91466-25508291/>

Gap analysis of specialist palliative care in New Zealand

NEW ZEALAND | Ministry of Health online report – December 2009 – This gap analysis confirmed the anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care at both local and regional levels. Hospital services particularly are generally limited to nursing and medical services only. There are opportunities for sharing resources between services, such as between the hospice and the hospital-based palliative care service in the same region, to increase the level of access to specialist palliative care, particularly in terms of support for grief, loss and bereavement, for patients, families and whānau [Māori word for extended family]. [http://www.moh.govt.nz/moh.nsf/pagesmh/9843/\\$File/palliative-care-gap-analysis-09.pdf](http://www.moh.govt.nz/moh.nsf/pagesmh/9843/$File/palliative-care-gap-analysis-09.pdf)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | Dutch News – 3 January 2010 – **'More cases of euthanasia in 2009.'** The number of registered cases of euthanasia rose by 200 to some 2,500 in 2009, according to new figures. http://www.dutchnews.nl/news/archives/2010/01/more_cases_of_euthanasia_in_20.php
- U.K. (SCOTLAND) | *Scotsman* – 3 January 2010 – **'Bid to block assisted suicide bill.'** Pro-life campaigners have launched a legal bid to prevent MSPs [Members of the Scottish Parliament] from debating plans for a new law which would permit assisted suicide in Scotland. <http://news.scotsman.com/scotland/Bid-to-block-assisted-suicide.5952080.jp>
- U.K. (SCOTLAND) | *Scotsman* – 3 January 2010 – **'When pain becomes a matter of life and death.'** Margo MacDonald's bill to legalise assisted suicide is due to come before the Scottish Parliament this month, but opinion on the subject is still sharply polarised. <http://scotlandonsunday.scotsman.com/health/When-pain-becomes-a-matter.5952067.jp>

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

Pediatric nurses' perceptions of obstacles and supportive behaviors in end-of-life care

AMERICAN JOURNAL OF CRITICAL CARE | Online article – 21 December 2009 – Each year 55,000 children die in the U.S. Most of these deaths occur in hospitals. The object of this survey was to determine pediatric intensive care unit nurses' perceptions of sizes, frequencies, and magnitudes of ... obstacles and helpful behaviors in providing end-of-life care to children. The two items with the highest perceived obstacle magnitude scores for size and frequency means were language barriers and parental discomfort in withholding and/or withdrawing mechanical ventilation. <http://ajcc.aacnjournals.org/cgi/reprint/ajcc2009497v1?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&author1=Beckstrand&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT>

Cardiopulmonary resuscitation and do-not-resuscitate orders: A guide for clinicians

AMERICAN JOURNAL OF MEDICINE, 2010;123(1):4-9. The do-not-resuscitate order, introduced nearly a half century ago, continues to raise questions and controversy among health care providers and patients. In today's society, the expectation and availability of medical interventions, including at the end of life, have rendered the do-not-resuscitate order particularly relevant. The do-not-resuscitate order is the only order that requires patient consent to prevent a medical procedure from being performed; therefore, informed code status discussions between physicians and patients are especially important. Epidemiologic studies have informed our understanding of resuscitation outcomes; however, patient, provider, and institutional characteristics account for great variability in the prevalence of do-not-resuscitate orders. Specific strategies can improve the quality of code status conversations and enhance end-of-life care planning. In this article, the authors review the history, epidemiology, and determinants of do-not-resuscitate orders, as well as frequently encountered questions and recommended strategies for discussing this important topic with patients. [http://www.amjmed.com/article/S0002-9343\(09\)00714-1/abstract](http://www.amjmed.com/article/S0002-9343(09)00714-1/abstract)

Rapid spread of complex change: A case study in inpatient palliative care

BMC HEALTH SERVICES RESEARCH | Online article – 29 December 2009 – Based on positive findings from a randomized controlled trial, Kaiser Permanente's national executive leadership group set an expectation that all Kaiser Permanente and partner hospitals would implement a consultative model of interdisciplinary, inpatient-based palliative care (IPC). Within one year, the number of IPC consultations program-wide increased almost ten-fold from baseline, and the number of teams nearly doubled. The authors report results from a qualitative evaluation of the IPC initiative; their purpose was to understand factors supporting or impeding the rapid and consistent spread of a complex program. <http://www.biomedcentral.com/content/pdf/1472-6963-9-245.pdf>

Construction of palliative care training contents in China

CANCER NURSING, 2009;32(6):446-455. There is a growing emphasis on improving the quality of ending life in China today; however, Chinese professional nursing education in palliative care is limited and inconsistent, and there are no standardized formal training contents. The 6-module integrated training mode achieved in this study represents the core knowledge and skill that a nurse who provides palliative care in China needs to know; then the nurse can choose any module to get training according to his or her practical needs and availability, totally or separately. http://journals.lww.com/cancernursingonline/Abstract/2009/11000/Construction_of_Palliative_Care_Training_Contents.6.aspx

Integrated versus standard palliative care in patients with advanced non-small cell lung cancer

CLINICALTRIALS.GOV (U.S.) | Online posting – 22 December 2009 – The main purpose of this study is to compare two types of treatment-standard palliative care (which usually is given towards the end of life) and integrated palliative care (which is given soon after diagnosis) to see which is better for improving quality of life of participants with advanced non-small cell lung cancer. Palliative care is care that tries to lessen the symptoms of a disease. Although many people with advanced lung cancer receive palliative care or hospice toward the end of their disease, the entire course of their disease is often complicated by physical and emotional difficulties. Palliative care may be useful when it is started soon after diagnosis. <http://clinicaltrials.gov/ct2/show/NCT01038271>

Physician-assisted suicide: A perspective from advocates for people with disability

DISABILITY & HEALTH JOURNAL, 2010;3(1):1-70. This special edition examines the issues related to assisted suicide and disability, legal considerations, and the Oregon and Washington experiences. Manuscripts were solicited from disability advocates and disability scholars, most of whom ... oppose assisted suicide; however, the varied approaches of the authors broadens the discussion and each article contains a literature review. The authors include scientists, lawyers, scholars and disability rights advocates. Overview of the contents (i.e., editorial): [http://www.disabilityandhealthjnl.com/article/S1936-6574\(09\)00190-3/fulltext](http://www.disabilityandhealthjnl.com/article/S1936-6574(09)00190-3/fulltext)

N.B. Contents page with links to each article: <http://www.disabilityandhealthjnl.com/current>

Of related interest:

- *BIOETHICS*, 2010;24(2):78-86. **'Living to the bitter end? A personalist approach to euthanasia in persons with severe dementia.'** In this article, the authors discuss some practical and ethical dilemmas regarding euthanasia in persons with severe dementia based on an advance euthanasia directive. <http://www3.interscience.wiley.com/journal/122204941/abstract>

Improving quality of life for patients with terminal respiratory disease

EXPERT REVIEW OF RESPIRATORY MEDICINE, 2009;3(6):597-605. Care for patients with terminal respiratory diseases has historically focused on disease-modifying therapies, many of which have little impact on life expectancy. This exclusive focus can detract from attention to patient-physician communication, advance care planning and palliative treatment strategies. Such shortcomings are exacerbated by the prognostic uncertainty inherent in many non-cancer diagnoses. With relatively indeterminate prognosis, many clinicians are reluctant to address goals of care and to consider palliative strategies. Unfortunately, the symptom burden caused by terminal respiratory diseases is high, particularly with regard to dyspnea, pain and psychiatric symptoms such as depressed mood and anxiety. <http://www.expert-reviews.com/doi/abs/10.1586/ers.09.47>

Measuring end-of-life care processes in nursing homes

THE GERONTOLOGIST, 2009;49(6):803-815. The objectives of this study were to develop measures of end-of-life (EOL) care processes in nursing homes and to validate the instrument for measuring them. A survey of directors of nursing was conducted in 608 eligible nursing homes in New York State. Four EOL process domains were identified – assessment, delivery, communication and coordination of care among providers, and communication with residents and families. Facilities with more EOL quality assurance or monitoring mechanisms in place and greater emphasis on EOL staff education had better scores on EOL care processes of assessment, communication and coordination among providers, and care delivery. Facilities with better registered nurse and certified nurse aide staffing ratios and those with religious affiliation also scored higher on selected care process measures. This study offers a new validated tool for measuring EOL care processes in nursing homes. <http://gerontologist.oxfordjournals.org/cgi/content/abstract/49/6/803>

Barriers to dying at home

The impact of poor co-ordination of community service provision for patients with cancer

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online article – 22 December 2009 – A qualitative study, using two audio tape-recorded focus group interviews, with a purposive sample of district nurses and community specialist palliative care nurses was undertaken across two primary care trusts in the north west of England. Data were analysed using a thematic analysis approach. From a service provision perspective, the results reveal that poor discharge planning and co-ordination, difficulty in establishing additional equipment and services together with inadequate out of hours medical provision were all factors contributing to hospital admissions for patients with cancer in the last hours and days of life, and thus were barriers to dying at home. <http://www3.interscience.wiley.com/journal/123220774/abstract>

Next-of-kin's perspectives of end-of-life care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2010;12(1):41-50. The quality of end-of-life (EOL) care from the next-of-kin's perspective given to their loved one needs further study in the context of a community setting focus. Qualitative content analysis of 186 next-of-kin responses revealed two themes: 1) communication; and, 2) family values and preferences including three sub-themes of having a supportive environment to secure a peaceful death with dignity and respect, the desire to be present at the time of death, and attending to the needs and wishes of the dying individual and family. The need for palliative care services in institutionalized settings, continuity of provider care (physician and nurse), family presence, and support for caregiver and financial concerns with hospice services was identified. Communication remains an essential component in all aspects of EOL care with further examination involving the loved one's perspectives. http://journals.lww.com/jhpn/Abstract/2010/01000/Next_of_Kin_s_Perspectives_of_End_of_Life_Care.12.aspx

Perspectives of Vancouver Island hospice palliative care team members on barriers to communication at the end of life

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2010;12(1):59-68. A survey of barriers and difficulties in communicating with patients, families, and team members was distributed via e-mail to 138 palliative care health professionals. Four major areas of difficulty were identified: 1) communication with patients and their families; 2) communication with team members; 3) lack of skills; and, 4) related to the system in which the HCPs were working. Difficulties most frequently mentioned included information sharing about transitions to palliative care, inefficient team communication processes, role issues, frustration with lack of availability of GPs, need for specialized skills in communication, lack of time, and lack of coordination of information between agencies. Recommendations include interdisciplinary training, palliative care guidelines, organizational support for interdisciplinary delivery of care, specific communication protocols for teams, assigned team-meeting time, and training opportunities to help members function as a team. http://journals.lww.com/jhpn/Abstract/2010/01000/Perspectives_of_Vancouver_Island_Hospice.14.aspx

Do not resuscitate: A case study from the Islamic viewpoint

JOURNAL OF THE ISLAMIC MEDICAL ASSOCIATION OF NORTH AMERICA, 2009;41(3):109-113. From an Islamic standpoint, there are no clear guidelines on DNR orders for a Muslim patient in a setting of a non-terminal illness. A literature review on this topic was carried out, including a search of religious texts on the subject. It resulted in the following conclusion: It is imperative to seek remedy in life-threatening situations. When treatment benefit is doubted, seeking remedy becomes optional. If the treatment is futile, then it is not recommended to continue such treatment. It is encouraged for Muslim patients to have a living will, but they are discouraged from putting in a DNR order that covers all situations. In other words, they should be full code if there is a reasonable chance of recovery. http://jima.imana.org/article/view/4477/41_3-109

From Media Watch dated 6 April 2009:

- U.K. | *New Statesman* – 3 April 2009 – '**Death and Islam.**' For Muslims, life decides the afterlife. Death is divinely willed and when it arrives it should be readily accepted. There should, therefore, be no reasoning by the bereaved as to why they have lost their loved one. <http://www.newstatesman.com/blogs/the-faith-column/0000/00/holy-qur-muslims-life-death>
- THE NETHERLANDS | *Islam in Europe* – 31 March 2009 – '**Muslims refusing pain management treatment.**' Palliative care for Muslims is often hindered by cultural barriers and prejudices. <http://islamineurope.blogspot.com/2009/03/netherlands-muslims-refusing-pain.html>

Practical model for psychosocial care

JOURNAL OF ONCOLOGY PRACTICE, 2010;6(1):1-2. The Institute of Medicine (IOM) recognizes the provision of psychosocial care to patients with cancer as the first of 10 newly developed standards of care. Since 2004, a team of psychology graduate students and their supervisor/professor have provided counseling services to patients and families in a regional, medical school-affiliated cancer center that serves a large catchment area of rural and semi-rural communities. The team began working in the outpatient clinic, infusion area, radiation area, and bone marrow transplantation unit. Additions to the services have included increased coverage of clinics, provision of consultation services to staff, and three Grand Rounds presentations on aspects of patient-health care provider communication. Research has shown that counseling services collocated with medical services are the most used and effective, so a trans-disciplinary approach has been taken throughout. In addition, assessment, intervention, and follow-up as well as effective communication between patients, families, and care providers have characterized the counseling team. <http://jop.ascopubs.org/er/JOP091066.pdf>

True to the principles of palliative care

Politics and Policy

JOURNAL OF PALLIATIVE MEDICINE | Online roundtable discussion – 31 December 2009 – My message is that we have to be careful about how we explain ourselves, not only to our patients and families and to our colleagues, but to the public at large and that we need to keep our focus on palliative care as a means of matching medical care to patient and family goals. It is not about anybody's agenda other than that of the patient and family, and I think we must keep saying that. We should stop saying we want people to have a good death or that we want to be more efficient or we want to stop those other doctors from doing the wrong thing. If we keep our focus on the patient and the family in front of us and help them come to an understanding of their situation and help them identify the priorities that are meaningful for them, we are true to the principles of palliative care. I think that it is something that the public not only can understand but will embrace. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9852>

Kidney end-of-life coalition expands online resources for dialysis patients

RENAL BUSINESS TODAY (U.S.) | Online report – 29 December 2009 – The Kidney End-of-Life Coalition has updated its Patient & Family Education web site to include a new section, 'Choosing Not to Start and Choosing to Stop Dialysis.' This section, which includes resources from the U.S., the U.K. and Canada, is intended to assist dialysis patients and their families in making informed decisions about treatment options, including the option of no dialysis, according to the Coalition. <http://www.renalbusiness.com/hotnews/keol-coalition-expands-website.html>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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.

Worth Repeating

Truth may hurt but deceit hurts more: Communication in palliative care

PALLIATIVE MEDICINE, 202;16(4):297-303. Healthcare professionals often censor their information giving to patients in an attempt to protect them from potentially hurtful, sad or bad news. There is a commonly expressed belief that what people do not know does not harm them. Analysis of doctor and nurse-patient interactions reveals that this well-intentioned but misguided assumption about human behaviour is present at all stages of cancer care. Less than honest disclosure is seen from the moment that a patient reports symptoms, to the confirmation of diagnosis, during discussions about the therapeutic benefits of treatment, at relapse and terminal illness. This desire to shield patients from the reality of their situation usually creates even greater difficulties for patients, their relatives and friends and other members of the healthcare team. Although the motivation behind economy with the truth is often well meant, a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion not one of calm and equanimity. Ambiguous or deliberately misleading information may afford short-term benefits while things continue to go well, but denies individuals and their families opportunities to reorganize and adapt their lives towards the attainment of more achievable goals, realistic hopes and aspirations. In this paper, some examples and consequences of accidental, deliberate, if well-meaning, attempts to disguise the truth from patients, taken verbatim from interviews, are given, together with cases of unintentional deception or misunderstandings created by the use of ambiguous language. The authors provide evidence from research studies showing that although truth hurts, deceit may well hurt more. <http://pmj.sagepub.com/cgi/content/short/16/4/297>

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