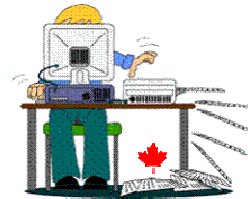


## Media Watch...

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.

16 May 2011 Edition | Issue #201



Compilation of Media Watch 2008, 2009, 2010, 2011 ©

Compiled & Annotated by Barry R. Ashpole

**Cancer pain management: Scroll down to [International](#) and 'Ukrainian cancer patients denied pain relief' (p.4) for an Associated Press article on a recent Human Rights Watch report.**

## Canada

### **Coping with death online**

ALBERTA | *Edmonton Journal* – 15 May 2011 – The complexities of imminent death intrude harshly into our lives, whether it's our own time that has come or that of our loved ones. Our minds are clouded by anxiety, yet we're forced to grapple with unwelcome information and medical decisions we don't feel qualified to make. Fearsome questions churn in our heads, particularly if we're reluctant to pose them directly to anyone. The [Canadian] Virtual Hospice website ... has emerged to answer those concerns. The continually evolving website offers articles on managing pain, talking to children about death, making medical decisions, hope and denial, coping with depression, and dozens of other topics, all written by health-care providers experienced in end-of-life care. 'When Death is Near' is the most frequently downloaded article on the site.<sup>1</sup> <http://www.edmontonjournal.com/health/Coping+with+death+online/4786189/story.html>

1. 'When Death is Near,' Canadian Virtual Hospice. [http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Topics/Topics/Final+Days/When+Death+Is+Near.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Final+Days/When+Death+Is+Near.aspx)

N.B. Canadian Virtual Hospice website: [http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx)

### **Patients less likely to pull own plug**

ALBERTA | *Toronto Star* (Ontario) – 14 May 2011 – Ideas concerning quality of life sometimes change as people near the end of theirs. That, coupled with the unpopularity surrounding advanced directive ... planning, are the driving forces behind the push for a review of how medical treatment preferences are determined ... as patients become incapable of making those decisions. At the University of Calgary, registered nurse and PhD candidate Murray Holtby has explored years' worth of research into advanced care plans, which exploded following the 1990 passage of the Patient Self-Determination ... Act in the U.S. What he found was that in spite of a massive push for patients to explicitly decide their end-of-life treatment options, few actually take that step. <http://www.torontosun.com/2011/05/14/patients-less-likely-to-pull-own-plug>

## **Ontarians to political parties, health care policy makers: Make home and community care services a funding priority**

ONTARIO | *Canadian Business* – 11 May 2011 – A new poll shows Ontarians support more public investment in home and community support services with six in ten agreeing new funding is better designated to these preventative care services rather than facilities and full-time nursing care. A majority of Ontarians (62%) also believe non-profit home and community support services deserve to be prioritized equally alongside long-term-care facilities and hospitals. This would represent a major shift in how non-profit home and community support services are financed, as these services currently receive a much smaller percentage of the health budget compared to hospitals and long-term-care facilities. One-in-five Ontarians think home and community support services should be the greater priority. <http://www.canadianbusiness.com/article/24770--ontarians-to-political-parties-health-care-policy-makers-make-home-and-community-care-services-a-funding-priority>

### **Derek Miller's last blog**

ONTARIO | CBC News – 11 May 2011 – This story is part of a series co-produced with the Graduate Program in Journalism at the University of Western Ontario called 'A Good Death.' <http://www.cbc.ca/news/health/story/2011/05/11/f-milestogo-cancer-blogging.html>

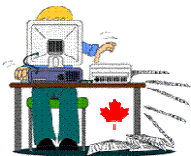
From Media Watch dated 18 April 2011:

- ONTARIO | *Western News* (University of Western Ontario) – 12 April 2011 – '**Journalism project reflects on death and dying.**' Western's Graduate Journalism Program and London palliative care providers are celebrating their innovative partnership in a groundbreaking journalism project addressing death and dying. 'Miles to Go' results from a first-ever journalism course on dying. [http://communications.uwo.ca/western\\_news/stories/2011/April/journalism\\_project\\_reflects\\_on\\_death\\_and\\_dying.html](http://communications.uwo.ca/western_news/stories/2011/April/journalism_project_reflects_on_death_and_dying.html)

## **U.S.A.**

### **Sensitive topic of futile medical care faces long road in Legislature**

TEXAS | *Statesman* (Austin) – 8 May 2011 – For the fourth consecutive session, Texas legislators are struggling with the delicate issue of how and when doctors can allow patients to die by withholding life-sustaining treatment against the wishes of family members. It's a nuanced, difficult question that can be ill-suited to the blunt-force nature of lawmaking. And true to form, tackling the issue this legislative session has split allies, produced odd political alliances and resulted, thus far, in a stalemate. <http://www.statesman.com/news/texas-politics/sensitive-topic-of-futile-medical-care-faces-long-1463003.html>



### **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. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

## International

### Dying Matters Coalition survey

#### **Palliative care: The way we die now**

U.K. | *The Guardian* – 16 May 2011 – A major survey<sup>1</sup> ... explores attitudes around the full arc of the grim reaper's scythe. Despite signs of some mortal taboos losing their grip, when it comes to chewing over the practicalities of breathing our own last, most of us are as inhibited as ever. Even business-like issues are often passed over in silence. More than a third of us say we have never asked any relative whether they have written a will. And the reticence is of another order entirely when it comes to more intimate expectations, concerning funeral arrangements, the final form of care we will want or where we would prefer to die. The six in 10 people who say they have never spoken to another soul about the last of these is striking, since this is one area where bottled up wishes reliably end up being wishes frustrated. Across the whole population, fully 70% tell strangers with clipboards they would rather die at home, and yet the official figures record that more than one death in every two ends up being

in a hospital bed. Some of this great gulf between what is wanted and what ends up happening, one might imagine, reflects a failure on the part of the healthy to think through where they will truly want to be when they are in an incomparably frailer condition. <http://www.guardian.co.uk/commentisfree/2011/may/16/palliative-care-way-we-die-editorial>

#### **Highlights of Dying Matters Coalition survey**

Just 15% of people would like to live forever and only 9% would like to live to over 100.

More people are scared of dying in pain (83%) than of being told they are dying (67%), dying alone (62%) or dying in hospital (59%). Women are more scared of dying than men.

The older people get the more likely they are to think that quality of life is more important than the age they live to.

1. Dying Matters Coalition Survey, ComRes, May 2011. <http://www.dyingmatters.org.uk/documents/NCPC%20Topline%20Findings%20May%203rd%202011%20FD3.pdf>

#### **Death an easier burden for believers**

NEW ZEALAND | *Sunday Star Times* (Wellington) – 15 May 2011 – The thought of loved ones dying makes most Kiwis [i.e., New Zealanders] uneasy, but those who believe in the afterlife are less troubled, a new survey shows. Hospice New Zealand commissioned the research, which looks at how Kiwis regard death and dying, and what they know about hospice services. Professor Rod MacLeod, of North Shore Hospice Trust palliative care development, said the results surprised them and showed hospices needed to do more to meet Kiwis' spiritual needs. More than a third of respondents rated spirituality as important in their lives. The ... survey found people made a distinction between spirituality and religion, and showed those under 40 were most likely to say religion was of low importance, while

40% of women rated spirituality as important compared to 28% of men.

<http://www.stuff.co.nz/life-style/5005607/Death-an-easier-burden-for-believers>

#### **Terminally ill choosing to spend final days at home**

NEW ZEALAND | TVNZ News – 16 May 2011 – Nine out of ten New Zealanders die from a chronic or terminal illness, and until recently they would have passed away in a hospice or hospital. But the pressure New Zealand's ageing population is putting on the health system means that some people may have to stay at home. <http://tvnz.co.nz/health-news/terminally-ill-choosing-spend-final-days-home-4174691>

## Terminally ill could get right to die faster under law approved by Spanish government

SPAIN | Associated Press – 13 May 2011 – The Spanish government has approved a law that gives terminally ill patients the right to hasten their deaths by halting medical treatment. Health Minister Leire Pajin said that the law would not affect bans on euthanasia or assisted suicide, which outlaw actions that lead to the deaths of those who otherwise would have lived. Halting medical treatment in terminal cases is common practice in Spanish hospitals but was never explicitly permitted. [http://www.washingtonpost.com/world/terminally-ill-could-get-right-to-die-faster-under-law-approved-by-spanish-government/2011/05/13/AF9N3g2G\\_story.html](http://www.washingtonpost.com/world/terminally-ill-could-get-right-to-die-faster-under-law-approved-by-spanish-government/2011/05/13/AF9N3g2G_story.html)

## A great leap forward for palliative care in Victoria, Australia

AUSTRALIA (VICTORIA) | *Health News* – 12 May 2011 – Victoria is now leading Australia in its commitment to optimal palliative care for people with a terminal illness and their families thanks to the injection of an extra \$34.4 million in the recent Victorian budget. "This is an unprecedented leap forward in funding for palliative care services," said Associate Professor Brian Le, Chairperson of Palliative Care Victoria, referring to the 38% increase in funding at a meeting today with the Premier, Hon. Ted Baillieu and the Minister for Health, Hon. David Davis. The new funding recognises the increasing need for palliative care for people with a terminal illness and their families due to population ageing and the increasing incidence of chronic diseases - such as cancer and dementia. <http://health.gresnews.com/ch/TopStories/cl/People/id/293301/A-Great-Leap-Forward-For-Palliative-Care-In-Victoria-Australia>

- AUSTRALIA (VICTORIA) | *The Age* – 12 May 2011 – '**Palliative plan no remedy, Labour.**' Encouraging dying patients to stay at home is the state government's only strategy to meet growing hospital demand. Budget documents show the Baillieu government has predicted that hospital admissions will grow by just 1.7% next financial year – compared with actual growth of 3.5% in 2010-2011. Asked by a parliamentary committee ... how he expected to halve hospital demand in the coming year, Health Minister David Davis cited a \$34.4 million palliative care package that would allow people to receive care at home. <http://www.theage.com.au/victoria/palliative-plan-is-no-remedy-says-labor-20110511-1ej0t.html>

## Ukrainian cancer patients denied pain relief

UKRAINE | Associated Press – 12 May 2011 – When his brain cancer pain became unbearable, Vlad Zhukovsky pleaded for a stronger dose of painkiller, but the doctors refused, citing Ukrainian health regulations. Unable to withstand the agony, he tried to jump out of a hospital window, but a fellow patient held him back. "He wanted to fall head down to be killed right away to stop the torture, that's how much his head hurt," his 50-year-old mother Nadezhda said sobbing. "He howled like a wolf." Hundreds of thousands of Ukrainians who suffer from terminal illnesses are denied proper pain relief, Human Rights Watch said in a report, urging Ukrainian authorities to adopt international guidelines for pain management.<sup>1</sup> "These people are crossed out from life even before death," said Viktor Paramonov, head doctor at the Cherkasy Regional Oncology Center in central Ukraine. Rooted in archaic Soviet-era restrictions and a government campaign to fight illegal drug use, Ukrainian regulations for the use of opioid-based analgesics are among the strictest in the world. <http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php>

1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. <http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0>

From Media Watch dated 4 April 2011:

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2011;25(1):25-28. '**Where is the evidence for pain, suffering, and relief – can narrative help fill the void?**' Eighty percent of global population has no access to pain relief or to palliative care. International organizations have repeatedly pointed out that access to pain relief and palliative care are basic human rights. <http://informahealthcare.com/doi/abs/10.3109/15360288.2010.549937>

## Assisted (or facilitated) death

- SWITZERLAND | Swiss.info – 16 May 2011 – **'Zürich voters reject ban on "suicide tourism."** A proposal to restrict access for foreigners to assisted suicide only to those living at least one year in the canton [of Zürich] was rejected by more than three-quarters of voters, according to provisional results. A second initiative seeking a national ban on assisted suicide was rejected by a greater majority. [http://www.swissinfo.ch/eng/politics/Zurich\\_voters\\_reject\\_ban\\_on\\_suicide\\_tourism.html?cid=30236234](http://www.swissinfo.ch/eng/politics/Zurich_voters_reject_ban_on_suicide_tourism.html?cid=30236234)
- UNITED ARAB EMIRATES (UAE) | Emirates 24/7 – 11 May 2011 – **'Dubai rejects demands to enforce euthanasia.'** Dubai health authorities have rejected demands by a group of local doctors for enforcing euthanasia, better known as mercy killing of dying patients, saying ending a human life is not permissible in the UAE. <http://www.emirates247.com/news/emirates/dubai-rejects-demands-to-enforce-euthanasia-2011-05-11-1.391592>
- U.K. | *Daily Telegraph* – 9 May 2011 – **'Allowing assisted suicide would 'pressurise disabled to kill themselves.'** A new poll found 70% of disabled people were concerned that such a reform would create pressure on vulnerable patients to "end their lives prematurely." The survey for [the charitable organization] Scope<sup>1</sup> ... also found 3% of the 500 disabled people questioned in the ComRes poll feared that they would personally come under pressure to commit suicide if the law were changed. <http://www.telegraph.co.uk/news/uknews/8501306/Allowing-assisted-suicide-would-pressurise-disabled-to-kill-themselves.html>

1. Scope Assisted Suicide Survey, 9 May 2011 <http://www.comres.co.uk/scopeassistedsuicidemay11.aspx>

### 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.

### Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/world/world/>

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

### **On patient autonomy and physician responsibility in end-of-life care**

*ARCHIVES OF INTERNAL MEDICINE*, 2011;171(9):849-853.

In current medical practice, excessive or reflexive deference to an unreflective concept of patient autonomy may inadvertently compromise patient autonomy by placing unwanted and unreasonable responsibility for technical medical decisions on patients or their surrogate decision makers rather than on their physicians. Such practices can harm patients by depriving them of the expert, professional advice they both need and deserve to make important decisions about their health care. The authors describe ... how the patient-physician relationship has evolved in recent decades as more life-sustaining and life-saving treatments, such as cardiopulmonary resuscitation, have become available. They then examine respect for patient autonomy and describe how patient autonomy can be promoted while the physician's responsibility for technical medical decisions is simultaneously affirmed. The patient is the expert on his or her values, goals, and preferences, while the physician is the expert on the medical means for honoring the patient's perspective. The authors conclude that an intervention, such as cardiopulmonary resuscitation, should not be offered when, based on the patient's own criteria, it promises no physical or psychosocial benefit or would be far more harmful than beneficial. <http://archinte.ama-assn.org/cgi/content/abstract/171/9/849>

From Media Watch dated 9 May 2011:

- *MEDICAL LAW REVIEW* | Online article – 4 May 2011 – **'Family involvement, independence, and patient autonomy in practice.'** The debate about patient autonomy focuses mainly on mental capacity and provision of information. The influence of the family on the decisions of the competent adult patient has scarcely been discussed in English medical law. The findings [of this qualitative study] reflect a relational approach to patient autonomy. When making decisions about treatment, patients needed to know that their relatives would support them no matter what they decided. <http://medlaw.oxfordjournals.org/content/early/2011/05/03/medlaw.fwr008.abstract>

From Media Watch dated 30 August 2010:

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2010;304(8):903-904. **'The shared decision-making continuum.'** During the 20th century, medical decision making shifted from a paternalistic approach to an autonomy-based standard in the U.S. Now ... the pendulum is swinging back and the medical community and the public are increasingly embracing shared decision making. <http://jama.ama-assn.org/cgi/content/extract/304/8/903>

**"In the last stages of irremediable disease": American hospitals and dying patients before World War II**

*BULLETIN OF THE HISTORY OF MEDICINE*, 2011;85(1):29-56. After a brief discussion of early- and mid-nineteenth-century hospitals, this article focuses on the years between 1880 and 1939, when those facilities underwent a major transformation and the proportion of hospital deaths steadily increased. During both periods, private hospitals refused admission to many seriously ill people and discharged others when death approached. City hospitals dumped poor patients with advanced disease on chronic care facilities and especially on almshouses [i.e., charitable housing]. With each transfer, the quality of care sharply declined. And trips from one institution to another often inflicted additional suffering; some accelerated death. [http://muse.jhu.edu/journals/bulletin\\_of\\_the\\_history\\_of\\_medicine/summary/v085/85.1.abel.html](http://muse.jhu.edu/journals/bulletin_of_the_history_of_medicine/summary/v085/85.1.abel.html)

## Discussions about palliation and end-of-life care

### Teaching physicians how to talk

*HEMONC TODAY* | Online article – 10 May 2011 – Studies have shown repeatedly that patients who make a plan for end-of-life care experience less pain, fear and stress; death is less stressful on the patient's family and costs less overall. However, surveys show that training is still poor and physicians are uncomfortable discussing death and dying with their patients. Part of the problem is that palliative care as a discipline only began appearing in medical school curricula in the past 15 years or so, said Anthony L. Back, MD, a professor of medical oncology at the University of Washington in Seattle and director of the Program in Cancer Communication at the Seattle Cancer Care Alliance. Accordingly, most physicians have never gone through any formal training to learn how to discuss end-of-life issues "so that they don't have a sense of how to bring up these difficult topics. (Palliative care is) a tricky skill. You need practice, you need feedback, you need supervision and many physicians haven't gotten that," Back said. "Many oncologists did their training before this movement of thinking of palliation happened and so many of them feel that they have to focus on anti-cancer treatment until they decide that the anti-cancer treatment isn't working. Then they make this big switch to move someone on to hospice, usually very near the end of life." <http://www.hemonctoday.com/article.aspx?rid=83457>

### Decision-making and outcomes of feeding tube insertion: A five-state study

*JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online article – 3 May 2011 – Of 486 family members surveyed, representing 9,652 relatives dying from dementia, 10.8% reported that the decedent had a feeding tube, 17.6% made a decision not to use a feeding tube, and 71.6% reported that there was no decision about feeding tubes. Of respondents for decedents with a feeding tube, 13.7% stated that there was no discussion about feeding tube insertion, and 41.6% reported a discussion that was shorter than 15 minutes. The risks associated with feeding tube insertion were not discussed in one-third of the cases, 51.8% felt that the healthcare provider was strongly in favor of feeding tube insertion, and 12.6% felt pressured by the physician to insert a feeding tube. Respondents whose loved ones died with a feeding tube were less likely to report excellent end-of-life care than those who were not. Based on the perceptions of bereaved family members, important opportunities exist to improve decision-making in feeding tube insertion. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03385.x/abstract>

### End-of-life care: A philosophical or management problem?

*JOURNAL OF LAW, MEDICINE & ETHICS*, 2011;39(2):114-120. End-of-life care became an important issue in the late 1960s and early 1970s. It was in great part driven by complaints about the care of the dying: lack of patient autonomy, indifferent or insensitive physicians, and inadequate pain control. The main task of those who worked to improve the situation centered on changing each of those variables, assuming that would do the job. But it has worked to a moderate extent only and the problem is not fully solved. The main omission has been a failure to confront the medical enterprise itself, which believes in endless progress and conducts a war against death. Only a change in those underlying values can bring about further significant change. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00581.x/abstract>

- *JOURNAL OF LAW, MEDICINE & ETHICS*, 2011;39(2):215-223. 'The value of life at the end of life: A critical assessment of hope and other factors.' Low opportunity cost, weak influence of quality of life in the face of death, the social value of life extension to others, shifting psychological reference points, and hope have been proposed as factors to explain why people apparently perceive marginal life extension at the end of life to have disproportionately greater value than its length. <http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00590.x/abstract>

**N.B.** The June 2011 issue of *Journal of Law, Medicine & Ethics* includes several articles related to end of life care. Publication contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jlme.2011.39.issue-2/issuetoc>

## Burnout in palliative care: A systematic review

*NURSING ETHICS*, 2011;18(3):317-326. Burnout is a phenomenon characterized by fatigue and frustration, usually related to work stress and dedication to a cause, a way of life that does not match the person's expectations. Although it seems to be associated with risk factors stemming from a professional environment, this problem may affect any person. Palliative care is provided in a challenging environment, where professionals often have to make demanding ethical decisions and deal with death and dying. This article reports on the findings of a systematic review aimed at identifying described burnout levels in palliative care nurses and physicians, and the related risks and protective factors. The main findings indicate that burnout levels in palliative care, or in health care settings related to this field, do not seem to be higher than in other contexts. <http://nej.sagepub.com/content/18/3/317.short>

## Pediatric palliative care patients: A prospective multicenter cohort study

*PEDIATRICS* | Online article – 9 May 2011 – This study describes demographic and clinical characteristics and outcomes of patients who received hospital-based pediatric palliative care (PPC) consultations [in the U.S. and Canada]. There were 515 new (35.7%) or established (64.3%) patients who received care from the 6 programs during the 3-month [the] enrollment interval [of the study]. Of these, 54.0% were male, and 69.5% were identified as white and 8.1% as Hispanic. Patient age ranged from less than one month (4.7%) to 19 years or older (15.5%). Of the patients, 60.4% lived with both parents, and 72.6% had siblings. The predominant primary clinical conditions were genetic/congenital (40.8%), neuromuscular (39.2%), cancer (19.8%), respiratory (12.8%), and gastrointestinal (10.7%). Most patients had chronic use of some form of medical technology, with gastrostomy tubes (48.5%) being the most

common. At the time of consultation, 47.2% of the patients had cognitive impairment; 30.9% of the cohort experienced pain. Patients were receiving many medications. During the 12-month follow-up, 30.3% of the cohort died; the median time from consult to death was 107 days. Patients who died within 30 days of cohort entry were more likely to be infants and have cancer or cardiovascular conditions.

<http://pediatrics.aappublications.org/content/early/2011/05/05/peds.2010-3225.abstract>

### Extract from *Pediatrics*

In contrast to the reported experience of adult-oriented palliative care teams, most pediatric palliative care patients are alive for more than a year after initiating pediatric palliative care.

Of related interest:

- ONMEDICA | Online report – 13 May 2011 – '**Guidance on palliative care for children.**' The charity ACT ... has launched online the free *Children's Palliative Care Handbook for GPs*, a practical and emotional guide to support GPs as they care for children who need palliative care, and their families. <http://www.onmedica.com/newsarticle.aspx?id=f852a255-8fec-4a36-a8e0-9b050faf78ac>
- *Pediatric Annals*, 2011;40(5):232-234. '**End-of-life treatment and palliative care.**' The definition of palliative care is difficult and subject to interpretation. "Palliative" comes from the Latin adjective, meaning "tending or serving to cloak" and "relieving or soothing the symptoms of a disease or disorder without effecting a cure." "Care" comes from the Latin noun, meaning "attentive assistance or treatment to those in need." <http://www.pediatricsupersite.com/view.aspx?rid=83393>

**N.B.** The June 2011 issue of *Pediatric Annals* includes several articles related to end of life care. Publication contents page: <http://www.pediatricsupersite.com/issue.aspx?pubid=pedann>



## Worth Repeating

### Is it stressful? Is it helpful?

#### **Talking with terminally ill patients and their caregivers about death, dying, and bereavement**

*ARCHIVES OF INTERNAL MEDICINE*, 2004;164(18):1999-2004. Discussing end-of-life issues with terminally ill patients is often considered distressing and harmful. This study was conducted to assess whether interviewing terminally ill patients and their caregivers about death, dying, and bereavement is stressful and/or helpful. At the end of the first interview, 1.9% of the patients reported having experienced a great deal of stress, 7.1% some stress, and 88.7% little or no stress from the interview. Among the caregivers, 1.5% reported a great deal of stress, 8.4% some stress, and 89.7% little or no stress. Slightly more stress was reported to have been caused by the re-interview. Overall, 16.9% of the patients reported the initial interview as very helpful, 29.6% as somewhat helpful, and 49.6% as offering little or no help. Among the caregivers, 19.1% reported the initial interview as very helpful, 34.3% as somewhat helpful, and 44.9% as offering little or no help. Patients experiencing pain, more personal meaning in dying, and less ease with talking about the end of life were significantly more likely to report stress. <http://archinte.ama-assn.org/cgi/reprint/164/18/1999?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=dying+and+death&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>

#### 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.hpconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

##### **U.S.A.**

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

##### **International**

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/world/world/>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

---

**Barry R. Ashpole**  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [barryashpole@bellnet.ca](mailto:barryashpole@bellnet.ca)