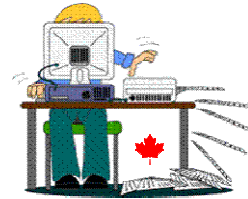


## Media Watch...

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 and research.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012 ©

Compiled & Annotated by Barry R. Ashpole

Skill development: Scroll down to [Specialist Publications](#) and 'Integrating palliative care into comprehensive cancer care' (p.8), in *Journal of the National Comprehensive Cancer Network*.

## Canada

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Toronto Star* – 21 October 2012 – **'Death's midwife helps terminally ill Canadians end their lives.'** Whether [Ruth] von Fuchs is breaching Canadian criminal law prohibiting "assisted suicide" is a question mired in the complexities of legislative language and the mysteries of human desire. Here's what is clear: an underground movement of death facilitators has emerged to help Canadians execute their final wish despite threats of arrest and imprisonment. In interviews, eight Canadians who have attended hastenings, ranging from an atheist physician to a retired United Church minister, were all careful to say they "support" – not "assist" – people they call "clients." The practical distinction may be subtle. But it holds tremendous legal consequence. While "assisting" a death is a criminal offence, "supporting" appears to be a sufficiently muddled concept to escape prosecution. Police have questioned most of the eight, but no charges were pursued. <http://www.thestar.com/news/gta/article/1274588--death-s-midwife-helps-terminally-ill-canadians-end-their-lives>
- SASKATCHEWAN | *Star Phoenix* (Saskatoon) – 20 October 2012 – **'Taking the Pulse: The new social consensus.'** A decade into the 21st Century, Saskatchewan's social views are turning sharply towards the progressive, according to a new social attitudes survey.<sup>1</sup> Many traditional conservative values held for generations in Saskatchewan have slipped, giving way to more permissive metropolitan views. The survey found that a majority now support gay marriage, medical marijuana use, abortion and doctor-assisted suicide. <http://www.thestarphoenix.com/news/social+consensus/7420346/story.html>
  1. 'Taking the Pulse of Saskatchewan,' University of Saskatchewan, Social Sciences Research, October 2012, <http://www.usask.ca/research/news/read.php?id=1115&newsid=1>

### Specialist Publications

Of related interest:

**'Controversial policies and the usefulness of non-profit, private and public sector partnerships: Introducing an assisted suicide service in Ontario'** (p.11), in *Canadian Review of Social Policy*.

## U.S.A.

### No matter the species

#### **Hospice for pets comforts owners, too**

CALIFORNIA | *San Francisco Chronicle* – 17 October 2012 – Now, as a provider of pet hospice, [Shea Cox] shepherds her patients through death, tending to their needs and those of their guardians, relieving animals' pain so they can live out their final days surrounded by loved ones, not in the sterile confines of a veterinary clinic. Modeled on human hospice, the growing field of pet hospice offers palliative care to animals in their homes. It ushers in a profound shift in how people care for dying and elderly pets, providing an option that falls between aggressive medical intervention and immediate euthanasia. For pet owners, in-home care gives solace as they make painful end-of-life decisions. <http://www.sfgate.com/business/article/Hospice-for-pets-comforts-owners-too-3958378.php>

### POLST: Physician Orders for Life-Sustaining Treatment

#### **End-of-life medical care initiative prompts worries about abuse**

WISCONSIN | *Milwaukee Journal-Sentinel* – 16 October 2012 – A statewide pilot program aimed at getting more people to document their wishes for end-of-life medical care is modeled in part on a successful La Crosse program that has been touted as a national example. But the new initiative will exclude one key feature of the La Crosse plan, a bright yellow document that directs emergency caregivers – paramedics and emergency room doctors – to provide or withhold lifesaving treatment in accordance with a patient's wishes. Advocates consider the POLST, or Physician Orders for Life-Sustaining Treatment, an important tool that gives chronically and terminally ill patients greater control of their care in the final moments of their lives. Critics ... fear it can be abused to expedite death and advance euthanasia. The debate raises moral and ethical questions that lie at the heart of end-of-life care, including what constitutes living, what medical care is normal and what is extraordinary, and who decides how and when life should end. They are questions that strain and often estrange family members who confront them at the bedsides of elderly relatives, and they will only grow more ur-

gent as the nation's elderly population nearly doubles by 2030, according to projections.

<http://www.jsonline.com/features/health/endoflife-medical-care-initiative-prompts-worries-about-abuse-pv71jc9-174491051.html>

#### **Should we ration end-of-life care?**

NATIONAL PUBLIC RADIO | Online report – 16 October 2012 – A big driver of U.S. health care expenditure is what's spent in the last year of life. Those who argue in favor of rationing that care say the country cannot afford to provide unlimited health care – either the government or insurance companies have to ration end-of-life care as a policy response. Others argue that that kind of care should be the subject of a discussion between the doctor, the patient and the patient's family. A panel debated the pros and cons of both sides in the latest edition of Intelligence Squared U.S. Forty-three percent of the audience started out in favor of the motion while 22% were against it and 35% undecided. After the debate, 12% were against the motion and 81% were for it – making those arguing for the motion the winners. <http://www.npr.org/2012/10/12/162831800/should-we-ration-end-of-life-care>

#### **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/owner/MediaWatch>

## International

### Palliative care in Australia

#### **Palliative care admissions rise 50% in a decade**

AUSTRALIA | Australian Institute of Health & Welfare – 19 October 2012 – The number of palliative care hospital admissions in Australia rose by more than 50% between 2001 and 2010, according to a report released by the Australian Institute of Health and Welfare. The report ... shows that there were almost 56,000 palliative care admissions reported in public and private hospitals in 2009-2010. The average age of people being admitted to palliative care was 71.9 years. Most palliative care admissions in Australia were to public hospitals (85%), particularly in New South Wales (92%) and Victoria (89%). In Western Australia, however, most palliative care admissions were to private hospitals (61%). Among all general practice encounters in 2010-2011 about 1 in 1,000 were palliative care-related. <http://aihw.gov.au/publication-detail/?id=10737423073>

Of related interest:

- AUSTRALIA | ABC News – 18 October 2012 – **'National laws needed for living wills.'** Some leading doctors and ethicists are calling for uniform national laws to guarantee a dying person's right to what they call "a good death." <http://www.abc.net.au/lateline/content/2012/s3613951.htm>

### Quality Care Commission

#### **Care Commission boost for Peace Hospice**

U.K. (ENGLAND) | *Watford Observer* (Hertfordshire) – 18 October 2012 – The Peace Hospice received a major boost after an independent audit by the Quality Care Commission reported that the Hospice's standard of care is "exceptional." The Quality Care Commission which regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in England, spent time at the hospice observing how people were being cared for, looked at records of people who used the hospice's services, talked with staff and patients about the care provided and reviewed information from key stakeholder groups. The report also commended the hospice on the way in which people's views and experiences were taken into account in the way the hospice delivers its services. The report complimented the hospice on ensuring that it had enough qualified and experienced staff who were able to keep people safe and meet their health needs. [http://www.watfordobserver.co.uk/news/9993831.Hospice\\_care\\_exceptional\\_says\\_report/](http://www.watfordobserver.co.uk/news/9993831.Hospice_care_exceptional_says_report/)

Of related interest:

- U.K. | Department of Health – 16 October 2012 – **'End of Life Care Strategy: Fourth Annual Report.'** The Department has published the fourth annual report on progress in delivering the End of Life Care Strategy, which was published in 2008. <http://www.dh.gov.uk/health/2012/10/end-of-life-care-fourth/>

#### 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>



## Palliative care in Singapore

### **Pain management more "valuable" than extending life span: Survey**

SINGAPORE | Channel News Asia – 17 October 2012 – A survey on end-of-life care has found that Singaporeans prefer to manage their pain than to extend their life span. The survey findings were presented by the Lien Centre for Palliative Care at a recent conference. A first-of-its-kind study has shed some light on the end-of-life care preferences among Singaporeans. The survey included scenarios where respondents could trade off some factors against others. Researchers then pegged a monetary value to various factors by seeing how people would change their course of treatment if the cost differed. As a result, on average, management of severe pain was valued at SGD\$24,000 a year, while quality healthcare was valued at SGD\$21,600 a year. An additional year of life was only worth an average

of SGD\$9,100 to older Singaporeans, if they were critically ill. This was much lower than the SGD\$50,000 benchmark used by some countries ... when deciding whether to subsidise or introduce life-extending treatments. <http://www.channelnewsasia.com/stories/singaporelocalnews/view/1231839/1.html>

#### **Specialist Publications**

Of related interest:

**'Exploring the experience of dignified palliative care in patients with advanced cancer and families: A feasibility study in Singapore'** (p.10), in *Progress in Palliative Care*.

Of related interest:

- SINGAPORE | *Today* – 20 October 2012 – **'New home palliative scheme for young launched.'** Called Star PALS (Paediatric Advanced Life Support), the programme aims to improve the patients' quality of life with support from a team of doctors, nurses and counsellors. The three-year pilot costs some SGD\$3.1 million with 80% covered by the Tote Board Community Healthcare Fund. <http://www.todayonline.com/Focus/Health/EDC121020-0000069/New-home-palliative-scheme-for-young-launched>

## Elder, home and end-of-life care

### **Failure to legislate on home care 'may harm elderly'**

IRELAND | *Irish Times* (Dublin) – 16 October 2012 – A continuing failure to legislate for standards governing home care and home help services may expose older people to abuse and serious harm, a new report warns.<sup>1</sup> Reductions in Health Services Executive budgets mean older people have less say in how their care is provided, with the time available increasingly determining how the care is given. A separate report on end-of-life care in hospitals highlights the impact of spending cutbacks on such care.<sup>2</sup> Staff have less time to implement improvements in end-of-life care, it is more difficult to release staff from day-to-day work for training and staff have less time to spend with those who are dying. "Cuts in capital budgets are likely to have a negative impact on the prospect of more single rooms in hospi-

tals, or viewing rooms in mortuaries – both issues that need to be addressed to improve the quality of end-of-life care and the experience of the bereaved." Almost 30,000 people die in Ireland each year, 75% of them in hospitals, but end-of-life care is not seen as a core hospital activity, says the report. <http://www.irishtimes.com/newspaper/health/2012/1016/1224325290794.html>

#### **Specialist Publications**

Of related interest:

**'Call to protect palliative funding'** (p.8), in *Irish Health*.

Cont.

1. 'Quality and Standards in Human Services in Ireland: Home Care for Older People,' National Economic & Social Council, October 2012. <http://www.nesc.ie/en/publications/publications/nesc-reports/quality-and-standards-in-human-services-in-ireland-home-care-for-older-people/>
2. 'Quality and Standards in Human Services in Ireland: End-of-Life Care in Hospitals,' National Economic & Social Council, October 2012. <http://www.nesc.ie/en/publications/publications/nesc-reports/quality-and-standards-in-human-services-in-ireland-end-of-life-care-in-hospitals/>

### **Social care cuts 'could lead to higher National Health Service bills'**

U.K. | *The Telegraph* – 16 October 2012 – The Nuffield Trust, a think tank, has found that good social care tends to keep the terminally ill out of hospital until they really need it. Their report looked at the usage that 73,000 people made of council social services and hospitals in the last months of their lives. Dr. Martin Bardsley, at the Nuffield trust, said: "Our study suggests how social care might be effectively substituting for hospital care for this group of people. The worry is that if funding for social care is cut back, people may have no option but to use hospital care. This may not be the best care for people who wish to be at home in

their last months of life, as well as cost far more for the National Health Service." <http://www.telegraph.co.uk/health/healthnews/9610213/Social-care-cuts-could-lead-to-higher-NHS-bills.html>

#### **Specialist Publications**

Also on the Nuffield Trust report::

**'Social care keeps people out of hospital at end of life, finds study'** (p.7), in *Community Care*.

#### **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.

## Care? No, this is a pathway to killing people that doctors deem worthless

U.K. | *Daily Mail* (Commentary) – 14 October 2012 – For relatives anxious about a frail loved one in hospital, few things could surely sound more reassuring than a 'care pathway.' It sounds like a well-worked-out schedule for providing the best possible approach to treating a patient. Accordingly, when relatives have been asked to sign up to the Liverpool Care Pathway (LCP), that's precisely what they thought they were agreeing to. And, in theory, that's what it is supposed to be. Devised by the Marie Curie Palliative Care Institute in the Nineties and adopted nationwide in 2010, its aims are laudable and appropriate. For its objective is to ensure that a dying person is treated in his or her last days with as much dignity and comfort as possible. Accordingly, it rules out potentially distressing interventions aimed at prolonging the dying process. Certainly, it is an important principle of medical ethics that dying should not be artificially prolonged, since this is as pointless as it is degrading and even cruel. In practice, however, the LCP has turned into something quite different. <http://www.dailymail.co.uk/debate/article-2217748/Care-No-pathway-killing-people-doctors-deem-worthless.html>

**N.B.** Royal College of General Practitioners statement in response to the *Daily Mail* article. <http://www.rcgp.org.uk/news/rcgp-response-to-end-of-life-care-media-stories-this-week.aspx>

Of related interest:

- U.K. | *Daily Mail* – 16 October 2012 – **'Put 1 in 100 patients on death list, GPs told: Frailest to be asked to choose 'end-of-life' care.'** GPs have been asked to select one in every 100 of their patients to go on a list of those likely to die over the next 12 months. The patients will be singled out for 'end-of-life care,' potentially saving the National Health Service more than £1billion a year. The listed patients may be asked to say where they would prefer to die and should be told they can draw up a 'living will' by which they can instruct doctors to withdraw life-saving treatment if they become incapacitated in hospital. The 'toolkit' giving doctors and health and social workers new guidance on how to select candidates was launched by Liberal Democrat Care Minister Norman Lamb at a conference on end-of-life care. <http://www.dailymail.co.uk/health/article-2218790/Put-1-100-patients-death-list-GPs-told-Frailest-asked-choose-end-life-care.html?openGraphAuthor=%2Fhome%2Fsearch.html%3Fs%3D%26authname%3DSteve%2BDoughty>

### The Liverpool Pathway: Noted in Media Watch

U.K. (ENGLAND & WALES) | *Daily Mail* – 1 October 2012 – **'Two doctors must agree to use of controversial 'death pathway' for patients in their final days.'** <http://www.dailymail.co.uk/news/article-2211484/Two-doctors-agree-use-controversial-death-pathway-patients-final-days.html>

*BMC RESEARCH NOTES* | Published online – 26 September 2012 – **'Why is the Liverpool Care Pathway used for some dying cancer patients and not others?'** <http://www.biomedcentral.com/content/pdf/1756-0500-5-524.pdf>

U.K. | National Council for Palliative Care – 25 September 2012 – **'Consensus Statement: Liverpool Care Pathway for the Dying Patient.'** <http://www.ncpc.org.uk/sites/default/files/user/LCP%20Consensus%20Statement.pdf>

U.K. | *Daily Telegraph* – 24 July 2012 – **'Advance refusal' cards for patients fearing 'death pathway.'** <http://www.telegraph.co.uk/health/elderhealth/9420794/Advance-refusal-cards-for-patients-fearing-death-pathway.html>

U.K. | *Daily Telegraph* – 8 July 2012 – **'Hospitals 'letting patients die to save money.'** <http://www.telegraph.co.uk/health/healthnews/9385674/Hospitals-letting-patients-die-to-save-money.html>

*JOURNAL OF PALLIATIVE MEDICINE* | Published online – 13 April 2012 – **'Staff perceptions of end-of-life care following implementation of the Liverpool Care Pathway ... in the acute care setting.'** <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0375>



## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | BBC News – 20 October 2012 – '**Assisted suicide: 10 years of dying at Dignitas.**' While euthanasia and assisted suicide are illegal in the UK, other countries, like Switzerland, do permit assisted suicide in specific circumstances – and Dignitas is the only Swiss facility to accept foreigners. <http://www.bbc.co.uk/news/health-19989167>
- U.K. | *The Economist* – 20 October 2012 – '**Over my dead body.**' Helping the terminally ill to die, once taboo, is gaining acceptance. <http://www.economist.com/news/international/21564830-helping-terminally-ill-die-once-taboo-gaining-acceptance>

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

### An evaluation of two online advance directive programs

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Published online – 18 October 2012 – [In this study] the authors show that increasingly people are finding advance directive information on the Internet, completing directives to be prepared and to have control, and that the attraction of these websites is their ease of use. Users report where they keep their documents, with whom they have end-of-life conversations, and what medical care requests they make. <http://ajh.sagepub.com/content/early/2012/10/17/1049909112463116.abstract>

### Social care keeps people out of hospital at end of life, finds study

*COMMUNITY CARE* (U.K.) | Online report – 16 October 2012 – A government-funded Nuffield Trust study found a statistically significant inverse relationship between spending on social and hospital care for people in the last year of life: the higher the social care spending, in all age groups, the lower the spending on hospital care.<sup>1</sup> The same was true of measures of activity, with higher levels of social care use associated with lower inpatient admissions, inpatient bed-days, outpatient attendances and A&E [accident and emergency department] visits. The results are significant because, while over half of annual deaths take place in hospitals, just 1% of palliative care patients would choose to die in hospital. "Our study suggests how social care might be effectively substituting for hospital care for this group of people," said report co-author ... Dr. Martin Bardsley. "The worry is that if funding for social care is cut back, people may have no option but to use hospital care. "This may not be the best care for people who wish to be at home in their last months of life, as well as cost far more for the NHS." The report also found that, while hospital care costs per person

rose sharply in the last months of life, social care costs only rose gradually, which it said meant the economic risks of introducing free end-of-life social care were not great. <http://www.communitycare.co.uk/Articles/16/10/2012/118604/social-care-keeps-people-out-of-hospital-at-end-of-life-finds-study.htm>

#### Key findings of the Nuffield Trust report:

27.8% of people used council-funded social care and 89.6% hospital care in the last year of life.

There were considerable variations in rates of social care use between areas.

Total hospital costs for the sample were double total social care costs.

But for those who use a service, unit social care costs were £12,500 in the last year compared with £7,400 for hospital care.

Hospital costs per person rose sharply in the last few months of life while social care costs rose gradually.

1. 'Understanding patterns of health and social care at the end of life,' Nuffield Trust, October 2012. <http://www.nuffieldtrust.org.uk/publications/understanding-patterns-health-and-social-care-end-life>

## Palliative care in Ireland

### **Call to protect palliative funding**

*IRISH HEALTH* | Online report – 15 October 2012 – Hospice workers are appealing to the government not to cut funding to palliative care services in the next budget. According to the Irish Hospice Foundation (IHF), last year's palliative care budget was cut by almost 4%, to €78 million. This happened at a time when demand for these services was increasing. Over 6,700 deaths in 2010 were aided by specialist palliative care services. These are services which attempt to meet the needs of complex cases both in the home and in hospitals. This accounted for one in four of all deaths and almost three in four of all cancer deaths in Ireland during that year. However currently, no hospice service in the country is fully funded by the State. "The modern hospice movement has not reached a level of maturity that it can absorb any further cuts. Last year's budget cuts took place as the numbers seeking hospice support continue to increase. Local communities are the backbone of their local hospice service, but caring for people at end of life should be a national healthcare priority," insisted IHF's Sharon Foley. She added that the contribution of older people to society must be recognised and that they should be able to access 'the care that they need to live and die with dignity and respect.' <http://www.irishhealth.com/article.html?id=21175>

### **The Rose of Sharon: What is the ideal timing for palliative care consultation versus ethics consultation?**

*JOURNAL OF CLINICAL ETHICS*, 2012;23(3):231-233. Ethics committees and palliative care consultants can function in a complementary fashion, seamlessly and effectively. Ethics committees can "air" and help resolves issues, and palliative care consultants can use a low-key, longitudinal approach. [http://www.clinicalethics.com/single\\_article/949diaglecA.htm](http://www.clinicalethics.com/single_article/949diaglecA.htm)

**N.B.** Rose of Sharon is a common name that applies to several different species of flowering plants that are highly valued throughout the world. The name's colloquial application has been used as an example of the lack of precision of common names, which potentially causes confusion. (Source: Wikipedia)

### **Integrating palliative care into comprehensive cancer care**

*JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK*, 2012; 10(10):1192-1198. While there are operational, financial, and workforce barriers to integrating oncology with palliative care, part of the problem lies in ourselves, not in our systems. First, there is oncologists' "learned helplessness" from years of practice without effective medications to manage symptoms or training in how to handle the tough communication challenges every oncologist faces. Unless they and the fellows they train have had the opportunity to work with a palliative care team, they are unlikely to be fully aware of what palliative care has to offer to their patients at the time of diagnosis, during active therapy, or after developing advanced disease, or may believe that, "I already do that." The second barrier to better integration is the compassion fatigue many oncologists develop from caring for so many years for patients who, despite the oncologists' best efforts, suffer and die. The cumulative grief oncologists experience may go unnamed and unacknowledged, contributing to this compassion fatigue and burnout, both of which inhibit the integration of oncology and palliative care. Solutions include training fellows and practicing oncologists in palliative care skills (e.g., in symptom management, psychological disorders, communication), preventing and treating compassion fatigue, and enhancing collaboration with palliative care specialists in caring for patients with refractory distress at any stage of disease. As more oncologists develop these skills, process their grief, and recognize the breadth of additional expertise offered by their palliative care colleagues, palliative care will become integrated into comprehensive cancer care. <http://www.jnccn.org/content/10/10/1192.abstract>

Cont.



Of related interest:

- *CANCER NURSING* | Published online – 9 October 2012 – **'Making sense of receiving palliative treatment: Its significance to palliative cancer care communication and information provision.'** [In this study] making sense was revealed as a phenomenon constructed narratively, through patients' searching for knowledge and understanding, approached by a dialectic pattern of living in wait and in the present, and finally, as a process of human learning through being and becoming, which transforms the experience and results in a changed personal experience. [http://journals.lww.com/cancernursingonline/Abstract/publishahead/Making\\_Sense\\_of\\_Receiving\\_Palliative\\_Treatment\\_.99674.aspx](http://journals.lww.com/cancernursingonline/Abstract/publishahead/Making_Sense_of_Receiving_Palliative_Treatment_.99674.aspx)
- *JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK*, 2012;10(10):1284-1309. **'Palliative care.'** These guidelines were developed and updated by an interdisciplinary group of experts based on clinical experience and available scientific evidence. The goal of these guidelines is to help patients with cancer experience the best quality of life possible throughout the illness trajectory by providing guidance for the primary oncology team for symptom screening, assessment, palliative care interventions, reassessment, and after death care. Palliative care should be initiated by the primary oncology team and augmented by collaboration with an interdisciplinary team of palliative care experts. <http://www.jnccn.org/content/10/10/1284.short>

### The child's voice in pediatric palliative and end-of-life care

*PROGRESS IN PALLIATIVE CARE* | Published online – 15 October 2012 – Although much is asked clinically and emotionally of children and adolescents who are receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. Without their subjective reports (the 'child's voice'), the treatment risk/benefit ratio cannot be fully known. [In this literature review] many children ages 5-7 years and most children 8 years of age and older in treatment for cancer or receiving end-of-life care were able to validly report their symptoms, treatment experiences, and quality of life through qualitative and quantitative measures. Although relevant literature is limited, research findings indicate that a majority of ill children and adolescents are able to report on their treatment-related symptoms and quality of life. The absence of the child's voice in palliative and end-of-life care jeopardizes best care efforts. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Noted in Media Watch, 15 October 2012:

- *U.S. NEWS & WORLD REPORT* | Online report – 9 October 2012 – **'Teens want voice in end-of-life decisions.'** Teens and young adults who are seriously ill should have a chance to be involved in end-of-life decisions, and a new planning guide – developed especially for this age group – can help, researchers say. <http://health.usnews.com/health-news/news/articles/2012/10/09/teens-want-voice-in-end-of-life-decisions>

Of related interest

- *PROGRESS IN PALLIATIVE CARE* | Published online – 15 October 2012 – **'Advances in pediatric palliative medicine in the U.S.'** Over the past decade, pediatric palliative medicine in the U.S. has advanced to a remarkable degree. This article situates these changes in the general context of the growth of adult-focused palliative medicine, and enumerates several landmark reports, studies, programmatic initiatives, and professional developments that serve as milestones marking the progress of the field, while also underscoring the continuing need to better educate families and health care providers about what pediatric palliative care can offer patients, to expand the evidence base regarding specific pediatric palliative care interventions, and to further our abilities to finance and improve these services. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000038>

**Exploring the experience of dignified palliative care in patients with advanced cancer and families: A feasibility study in Singapore**

*PROGRESS IN PALLIATIVE CARE* | Published online – 15 October 2012 – The aim of the study was to conduct a feasibility study to explore the experience of dignity in palliative care in Singapore. The preliminary findings showed that the experience of dignity in Singapore context consists of three factors, which reflected 12 themes: 1) social factor, which comprised of family, friends, relatives, and employers; 2) organizational factor, which comprised of the healthcare system, voluntary welfare organization, and private sector; and, 3) spiritual factor, which was associated with existential values, cultural and religious belief systems of the patients, and their families. The preliminary findings suggest similarity to the Western findings: dignity can be preserved by holistic care that focuses on psychosocial, physical, and spiritual aspects. Dignified patient care should encompass the knowledge and sensitivity to the multi-cultural and multi-ethnic practices and health beliefs of the patients and their families. The preliminary findings suggest that using systems perspective, it is feasible to conduct a study to develop an empirical model on dignified palliative care in the Singapore context. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000041>

**An overview and evaluation of the oncology family caregiver project: Improving quality of life and quality of care for oncology family caregivers**

*PSYCHO-ONCOLOGY* | Published online – 14 October 2012 – With changes in health care, oncology family caregivers (FCs) provide the vast majority of patient care. Yet, FCs assume their role with little or no training and with limited resources within the cancer setting to support them. The purpose of this project is to develop and implement a curriculum to improve the quality of life and quality of care for FCs by strengthening cancer care settings in this area. To date, three courses have been presented to 154 teams representing 39 states. Course evaluations were positive, and participants have initiated institutional FC support goals. Although the goals are diverse, the broad categories include support groups, staff/FC/community education, resource development, assessment tools, and institutional change. There is a critical need to improve support for cancer FCs. This FC training course for professionals is a first step in addressing this need. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3198/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

**Family matters in health care delivery**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Published online – 17 October 2012 – The relevance of family, broadly defined as encompassing blood relatives as well as trusted friends and partners, influences health and health care across the life span. The considerable economic value conferred by families to patients and the health system is also widely acknowledged. According to a Congressional Budget Office report, "The value of donated care probably exceeds that of any other category of long-term care financing but is difficult to quantify in dollar terms." According to an Institute of Medicine report ... "the entire health care workforce, including both formal and informal caregivers need to have the requisite data, knowledge, and tools to provide high-quality care." <http://jama.jamanetwork.com/article.aspx?articleid=1383241>

Noted in Media Watch, 15 October 2012:

- *FORBES* | Online commentary – 12 October 2012 – **'We need better ways to train and support family caregivers.'** <http://www.forbes.com/sites/howardgleckman/2012/10/12/we-need-better-ways-to-train-and-support-family-caregivers/>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *ADULTSPAN JOURNAL*, 2012;11(2):89-96. **'Ethical guidelines for counselors when working with clients with terminal illness requesting physician aid in dying.'** In 2005, the American Counseling Association (ACA) introduced a new ethical standard for counselors working with clients with terminal illness who are considering hastened death options. The authors' purpose is to inform counselors of the Death with Dignity Act and explore relevant ethical guidelines in the ACA Code of Ethics. <http://onlinelibrary.wiley.com/doi/10.1002/j.2161-0029.2012.00008.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *ADVANCES IN EXPERIMENTAL MEDICINE & BIOLOGY*, 2013;755(1):349-356. **'Toward the clarification of ideas: Medical futility, persistent/obstinate therapy and extra/ordinary means.'** Despite reluctance of a part of medical society to accept the moral and/or legal permission to euthanasia, there is seemingly a common agreement on the need to resolve the problem of excessive therapy. Several ethical concepts are used to justify decisions to withhold/withdraw such treatment. Three of them are of particular value. The ordinary-extraordinary means distinction has a long tradition deeply-rooted in the Catholic medical ethics. During the last decades the concept of futile (or pointless) treatment has reached popularity within bioethical discourse. Also, slightly less common in use, the term 'obstinate therapy' and the relative concept seems to provide interesting insights into ethical debate. What is however to be emphasized is the ambiguity of meanings attached to these terms/concepts which prompt many bioethicists to reject these terms in favor of other concepts. [http://rd.springer.com/chapter/10.1007/978-94-007-4546-9\\_44](http://rd.springer.com/chapter/10.1007/978-94-007-4546-9_44)
- *CANADIAN REVIEW OF SOCIAL POLICY*, 2012, No. 67. **'Controversial policies and the usefulness of non-profit, private and public sector partnerships: Introducing an assisted suicide service in Ontario.'** This article addresses whether a partnership between the public, non-profit, and private sectors represents a feasible solution for dealing with contentious and symbolic public policy issues in the provision of assisted suicide service in Ontario. The first section outlines key characteristics of mature and integrated relationships among the three sectors. The second determines the parameters of acceptable policy by exploring the intersection between economic drivers and public opinion on assisted suicide: the Ontario government is intent on reducing health care expenditures, while public opinion increasingly favours end-of-life options but is wary of state pressure upon individuals to choose an early death in order to save on costly medical interventions. The third section demonstrates how a trisectoral partnership could build a model of an assisted suicide policy and service in Ontario by incorporating design elements from the Dignitas Clinic in Switzerland. <http://pi.library.yorku.ca/ojs/index.php/crsp/article/view/35307>

## Worth Repeating

### The rhetoric of death and dying

*PHILOSOPHY AND PRACTICE OF MEDICINE AND BIOETHICS*, 2011;47:497-535. Medicine aims at preventing death, yet it is not clear how we may understand what death is. "Death" is a word too familiar to us to be understood. The "metaphorical method" helps us to make death extraordinary. The rhetoric about death is a contribution to philosophy of medicine and to narrative medicine, as how to deal and to communicate death against the incommunicable and to avoid being silenced and isolated as a dying patient and his relatives. It is to enable healthcare-workers to develop an attitude open to communication with dying patients and their significant others. Because thought is mainly language use, careful attention should be paid to the metaphors and models the dying patient lives by. The criteria to bring about an appropriate death are: 1) conflict reduction; 2) proper understanding of the patient in terms of the image he has of one-self; 3) restoration of important social relationships; and, 4) satisfaction of his wishes as much as possible. <http://www.springerlink.com/content/r60qk771270600t2/>

## Media Watch Online

### **Canada**

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:  
<http://www.hnhbpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County):  
<http://www.hpcconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

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

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

### **Europe**

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

### **Asia**

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'What's New: Reading List Update')

### **International**

Australasian Palliative International Link: <http://www1.petermac.org/apli/links.htm> (Scroll down to 'Media Watch')

Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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

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

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