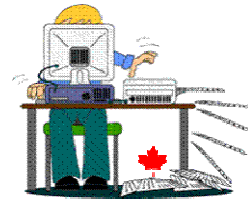


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Paediatric palliative care: Scroll down to [Specialist Publications](#) and 'A learning and development strategy for children's hospices across London [England]' (p.8), published by the Children's Hospices across London (CHaL) Learning & Development Group.

## Canada

### Grief and mourning

#### **Sometimes, life is just really sad**

*NATIONAL POST* | Online article – 27 April 2011 – Grief over the loss of a loved one is a universal phenomenon. But grief's expression and attendant rituals vary greatly according to individual circumstances and cultural tradition. The stiff upper lip and discrete silent tear is the norm amongst my WASP [White Anglo-Saxon Protestant] friends, while a West Indian acquaintance of mine took comfort from the histrionic style... Mourning is a more complex matter. Some people recover quickly from bereavement, or make a point of pretending to, and get on with their lives; others not so much. Queen Victoria never stopped mourning the death of her beloved Prince Albert. Considering their loving union, the perfection of their working partnership, the loneliness of solitary reign and the culture of her era, her emotional withdrawal seems understandable... But according to the *Diagnostic & Statistical Manual of Mental Disorders* (DSM) ... Victoria was suffering from a mental disorder. The fifth version of the DSM (DSM-5) is due out in 2013. In DSM-4, grief used to occupy a special category: One could suffer depression from grief longer than from other stressors and still be considered "normal." But in DSM-5, grief is likely to be lumped in with other triggers for depression, such as job loss, divorce or any other life stressor. <http://www.nationalpost.com/opinion/columnists/Sometimes+life+just+really/4680226/story.html>

From Media Watch dated 7 March 2011:

- QUEBEC | *THE MCGILL DAILY* (University of McGill, Montreal) | Online article – 3 March 2011 – **'To medicalize mourning.'** Over the past 25 years in the *Diagnostic & Statistical Manual of Mental Disorders* (DSM) has expanded to allow room for a number of "new" disorders. Included in this growing group is "Complicated Grief," or "Prolonged Grief Disorder," which is being considered for a spot in the DSM-V, due out in 2013. <http://www.mcgilldaily.com/2011/03/to-medicalize-mourning/>

**N.B.** This issue of Media Watch lists several articles on the proposed change to *Diagnostic & Statistical Manual of Mental Disorders*.

## Deadliest cancers in research funding gap: Report

CBC NEWS | Online report – 26 April 2011 – Research on some of the deadliest cancers in Canada is underfunded relative to their toll in lives taken, according to a new report.<sup>1</sup> Charity Intelligence Canada, an Ontario-based non-profit that analyzes charities, released its report ... to highlight four cancers it says most desperately need donor support – pancreatic, stomach, lung and colorectal. Charity Intelligence believes people should think strategically about their donations, aiming to transform these often terminal cancers into something that can be prevented or lived with as a chronic condition. To reach its conclusions, the group described the magnitude of a cancer's impact in terms of cases, deaths and potential years of life lost to cancer,

calculated based on deaths by age and life expectancy. <http://www.cbc.ca/news/health/story/2011/04/25/cancer-charity-intelligence.html>

### Extract from *Cancer in Canada*

As Canada's population ages, more Canadians will get cancer. Not all will survive. Palliative care will help cancer victims live out their lives in the greatest possible comfort, while reducing the burden on their loved ones and mitigating the escalation in Canada's health care costs. Palliative care is a huge, growing, and currently unmet need that applies to all cancers. Funding palliative care is a key way for donors to make an immediate and measurable difference.

1. *Cancer in Canada: Framing the Crisis and Previewing the Opportunity for Donors*, Charity Intelligence Canada, April 2011. <http://www.charityintelligence.ca/?page=24>
- CTV | Online report – 27 April 2010 – **'Donations vary among cancer charities.'** "It's a great report, and we're grateful for it," said Dan Halinda [executive director of the Canadian Cancer Society's Alberta/North West Territories Division]. "We've been trying for years to get a much more comprehensive and strategic funding of cancers and we're hoping to get more dollars to the underfunded cancers named in the report." Currently there are over 270 cancer charities in Canada. [http://calgary.ctv.ca/servlet/an/local/CTVNews/20110427/CGY\\_charity\\_cancer\\_110427/20110427/?hub=CalgaryHome](http://calgary.ctv.ca/servlet/an/local/CTVNews/20110427/CGY_charity_cancer_110427/20110427/?hub=CalgaryHome)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | CBC News (Vancouver) – 26 April 2011 – **'Lawsuit to legalize assisted suicide filed in B.C.'** A B.C. woman who escorted her ill 89-year-old mother on a trip to end her life in Switzerland last year is challenging the law that makes the same act a criminal offence in Canada. <http://www.cbc.ca/news/canada/british-columbia/story/2011/04/26/bc-assisted-suicide-lawsuit.html>
- BRITISH COLUMBIA | *Globe & Mail* – 26 April 2011 – **'B.C. civil liberties group sues to legalize euthanasia in Canada.'** Grace Pastine, the ... [B.C. Civil Liberties Association's] executive director, said Criminal Code provisions against physician-assisted death are unconstitutional because they deny individuals the right to make choices fundamental to their physical, emotional and psychological dignity. <http://www.theglobeandmail.com/news/national/british-columbia/bc-civil-liberties-group-sues-to-legalize-euthanasia-in-canada/article1999454/>

From Media Watch dated 11 April 2011:

- BRITISH COLUMBIA | *Vancouver Sun* – 8 April 2011 – **'B.C. group trying to legalize assisted suicide files constitutional challenge.'** A B.C. group fighting to legalize assisted suicide has filed a constitutional challenge in B.C. Supreme Court. The Farewell Foundation for the Right to Die is challenging a section of the Criminal Code which makes aiding and abetting suicide an offence punishable by up to 14 years in prison. <http://www.vancouversun.com/news/group+trying+legalize+assisted+suicide+files+constitutional+challenge/4584334/story.html>

**N.B.** Available is **'Assisted (or Facilitated) Death: The Debate in Canada,'** which summarizes notable developments (as reported in past issues of Media Watch) – highlighting also those in other countries – that inform discussion of the issue in Canada. Contact information at foot of (p.10).

## U.S.A.

### Help patients and doctors discuss end-of-life care

MASSACHUSETTS | *Boston Globe* (OpEd) – 30 April 2011 – As long as doctors and patients alike find it difficult to talk about end-of-life issues, patients with terminal illnesses may be denied the kind of death they would prefer. All too often, patients with terminal illnesses tell family members they don't want to be hooked up to machines when they are dying. Sometimes, though, relatives are reluctant to carry out wishes that aren't put in writing. More often, patients don't explain their wishes to their doctors, who then – in the absence of family members – put the patients on breathing or feeding devices. This would happen less often if the Massachusetts Department of Public Health were to promote state-wide adoption ... of a standardized form that helps make patients' wishes known. [http://articles.boston.com/2011-04-30/bostonglobe/29491366\\_1\\_end-of-life-care-patients-doctors](http://articles.boston.com/2011-04-30/bostonglobe/29491366_1_end-of-life-care-patients-doctors)

### Blacks facing cancer more likely than whites to drain resources to extend life

ALABAMA | *Los Angeles Times* (California) – 26 April 2011 – When faced with life-threatening cancer, minority patients may be more likely to drain their bank accounts to extend life than whites, according to a study published online ... in *Cancer*.<sup>1</sup> Researchers asked patients how willing they were to trade personal financial resources for life-prolonging cancer treatment, or would they rather receive treatment that would cost them less but not allow them to live as long. They found that 80% of blacks were willing to exhaust all resources to extend life, compared to 72% of Asians, 69% of Hispanics and 54% of whites. The biggest difference was between whites and blacks: Blacks were 2.4 times more likely than whites to exhaust personal finances to live longer. <http://www.latimes.com/health/os-minorities-money-health-20110425,0,1294744.story>

1. 'Racial variation in willingness to trade financial resources for life-prolonging cancer treatment,' *Cancer*, published online at: <http://onlinelibrary.wiley.com/doi/10.1002/cncr.25839/abstract>

### Official challenges criticism of hospices

IOWA | *Globe Gazette* (Mason City) – 26 April 2011 – Hospice of North Iowa is inspected every two or three years and is a licensed facility, a spokeswoman for the facility said. Dixie Kavars ... was responding to recent charges by Toby Edelman, a policy attorney at the Center for Medicare Advocacy, who told *The Des Moines Register* that most of Iowa's hospices are inspected once every 20 years. Edelman also said just eight of the state's 83 hospices are licensed. Iowa does not require licensing for its hospices, the *Register* reported. [http://www.globegazette.com/news/local/article\\_fc1c379c-7070-11e0-9569-001cc4c03286.html](http://www.globegazette.com/news/local/article_fc1c379c-7070-11e0-9569-001cc4c03286.html)

#### **New hospice regulations improve end-of-life care**

*CONNECTICUT POST* (Bridgeport) | Online report – 26 April 2011 – The state Department of Public Health has proposed new regulations for hospice facilities, including hospice residences such as the 12-bed Rosenthal Hospice Residence in Stamford. After 32 years, hospice regulations need to be updated. All of the hospices were asked to participate in the development of the new regulations. <http://www.ctpost.com/default/article/New-hospice-regulations-improve-end-of-life-care-1353404.php>

From Media Watch dated 25 April 2011:

- IOWA | *The Des Moines Register* – 24 April 2011 – '**Iowa hospices inspected only once every 20 years.**' Hospice providers that care for hundreds of Iowans in the final stages of a terminal illness are now being inspected by the state on a schedule of one visit every 20 years. Patient advocates say that sort of inspection cycle "doesn't even pass the laugh test," and puts Iowans at risk of sub-standard care. <http://www.desmoinesregister.com/article/20110424/NEWS10/104240335/iowa-hospices-inspected-only-once-every-20-years?Iowa%20Politics%20Insider>

## [Governor Peter] Shumlin administration opposes hospice waiver

VERMONT | Vermont Journalism Trust (Hinesburg) – 26 April 2011 – Increased use of hospice could play a crucial role in controlling health care expenses. Hospice care, which is typically delivered at home, costs significantly less than hospital care at the end of life, and that is when 77% of medical treatment and expenditures take place, according to the Vermont Program for Quality in Health Care, Inc. Proponents consider the waiver important because doctors are often reluctant to make a six-month prognosis, which Medicare now requires for hospice eligibility: Doctors say it's difficult to predict how rapidly many diseases will progress. And patients – especially young adults – are unwilling to give up searching for a cure even as they are dying. The enhanced hospice benefit waiver is one of the provisions that gives the hospice and palliative care bill "a lot of teeth and meat," said Cindy Bruzzese, executive director of the Vermont Ethics Network. <http://vtdigger.org/2011/04/26/shumlin-administration-opposes-hospice-waiver/>

### Dying behind bars: Documentary portrays humanity of prison hospice

ILLINOIS | *UIC News* (University of Illinois) – 20 April 2011 – The number of inmates in state and federal prisons over age 50 has grown by 172% since the early 1990s. Within the next 15 to 20 years, more than 20% of the U.S. prison population will be classified as elderly, says the U.S. Department of Justice, National Institute of Corrections. "Despite harsh public and political rhetoric about sending criminals to prison until they die, little is actually known about the death and dying process within prisons," says filmmaker Edgar Barens. Each year, more than 3,000 men and women die in U.S. prisons – most from illnesses such as cancer, hepatitis, chronic obstructive pulmonary disease and congestive heart failure, according to the U.S. Department of Justice, Bureau of Justice Statistics. Recently, one approach has gained momentum for meeting the needs of terminally ill prisoners: prison-based hospice programs. The community hospice model offers the dying person support from an interdisciplinary team that includes family members, physicians, nurses, social workers, counselors and clergy. The prison hospice model has an additional element: security, which must be maintained even in a hospice setting. It's all in the story of *Prison Terminal*, Barens' feature-length documentary scheduled for completion next fall. <http://www.uic.edu/htbin/cgiwrap/bin/uicnews/articleDetail.cgi?id=15276&emailsent=1>

**N.B.** Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of (p.10).

#### [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?media\\_watch=1](http://www.mhpcn.ca/Physicians/resources.htm?media_watch=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>

## International

### Breaking bad news

U.K. | *The Economist: Intelligent Life* – 26 April 2011 – Breaking bad news might seem straightforward. "It's not rocket science," said one surgeon I spoke to, "you've just got to be a half-decent person and give them the facts." But common sense tells us that those facts are an emotional bomb waiting to go off. And medical thinking now recognises this: receiving bad news ... "results in cognitive, behavioural, or emotional deficit in the person receiving the news that persists for some time after the news is received." News of a sudden death can prompt intense crying, anger or guilt. Some people appear calm and controlled; others are seized by a need to be busy – faced with overwhelming pain, some of us block it by going and doing the washing-up. But no one in such a predicament can be considered normal. We go into shock, which means we are unbalanced mentally and physically. Distress impairs circulation,

makes us cold, disrupts the endocrine, immune and cardiovascular systems, upsets rational thought, disturbs sleep.

<http://moreintelligentlife.com/content/ideas/breaking-bad-news>

#### What bad news looks like

U.K. | *The Economist* – 22 April 2011 – It wasn't an easy brief for an illustrator, but when the results landed on his desk ... [*The Economist's*] art director ... was raving about their subtlety. Even he was surprised to ... see just how many layers [Richard] Wilkinson went through, which was more like an Old Master painting. "What is amazing is the way Richard has managed to translate his painterly technique to the digital medium," Black says. "He builds layer upon layer ... to produce work of great depth and luminescence." [http://www.economist.com/blogs/osperso/2011/04/richard\\_wilkinsons\\_illustrations](http://www.economist.com/blogs/osperso/2011/04/richard_wilkinsons_illustrations)

Of related interest:

- *PSYCHO-ONCOLOGY* | Online article – 20 April 2011 – **'Whether, when, and who to disclose bad news to patients with cancer...'** There was poor or slight concordance in disclosure preferences between patients with cancer and their families [i.e., the participants in this study]. More patients than their families wanted to be informed completely, immediately, and directly by doctors. <http://onlinelibrary.wiley.com/doi/10.1002/pon.1979/abstract>

From Media Watch dated 23 August 2010:

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2010;16(2):61-65. **'BREAKS' protocol for breaking bad news.** Six-step SPIKES protocol is widely used for breaking bad news. The authors put forward another six-step protocol, the BREAKS protocol as a systematic and easy communication strategy for breaking bad news. <http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2010;volume=16;issue=2;spage=61;epage=65;aulast=Narayanan>

**N.B.** BREAKS = Background, Rapport, Explore, Announce, Kindling, Summarize; SPIKES = Setting, Perception, Invitation, Knowledge, Empathy, Summary.

#### Quotable Quotes

*How did it become normal, or for that matter even acceptable, to refer to medical patients as "consumers"? The relationship between patient and doctor used to be considered something special, almost sacred. Now politicians and supposed reformers talk about the act of receiving care as if it were no different from a commercial transaction, like buying a car – and their only complaint is that it isn't commercial enough. What has gone wrong with us? **Paul Krugman** (American economist, Nobel prize recipient and *New York Times* columnist)*

**Source:** 'Patients are not consumers,' *New York Times*, 21 April 2011. [http://www.nytimes.com/2011/04/22/opinion/22krugman.html?\\_r=2&hp](http://www.nytimes.com/2011/04/22/opinion/22krugman.html?_r=2&hp)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *Daily Mail* (London) – 28 April 2011 – **'Outrage as 'how-to-die helpline' is launched by euthanasia charity.'** A right-to-die pressure group provoked outrage yesterday over plans to sponsor the UK's first helpline aimed at speeding the terminally ill towards 'a good death.' The free phone line, to be set up by a charity called Compassion in Dying, will 'promote greater patient choice and control where possible.' The charity is an offshoot of euthanasia campaign Dignity in Dying and is led by the right-to-die group's chief executive Sarah Wootton, a former sex equality and abortion campaigner. <http://www.dailymail.co.uk/news/article-1381321/Euthanasia-charity-launches-die-helpline.html>
- AUSTRALIA (NORTHERN TERRITORY) | *NT News* (Darwin) – 26 April 2011 – **'Members moot euthanasia Bill.'** Former Chief Minister Marshall Perron said several Territory politicians were seriously considering introducing voluntary euthanasia legislation behind Chief Minister Paul Henderson's back. [http://www.ntnews.com.au/article/2011/04/26/227681\\_ntnews.html](http://www.ntnews.com.au/article/2011/04/26/227681_ntnews.html)
- U.K. | *Daily Express* (London) – 26 April 2011 – **'Row over real death film on BBC.'** The decision to film an 84-year-old cancer victim ... for 'Inside The Human Body' was taken knowing it would be offensive to many viewers. Film-maker Michael Mosley wrote in *Radio Times*: "I know there are those who feel that showing a human death on television is wrong, whatever the circumstances. Although I respect this point of view I think there is a case to be made for filming a peaceful, natural death – a view shared by many who work closely with the dying." But the Pro Life Alliance said: "It is trivialising death. It's unhealthy." The scene, the second time the BBC has screened a death, will go out on BBC One on 12 May. <http://www.express.co.uk/posts/view/242964/Row-over-real-death-film-on-BBC>

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

### Voluntary hospices in England: A viable business model?

*ACCOUNTING FORUM* (U.K.) | Online article – 20 April 2011 – This article is concerned with how the U.K. Government's End of Life Care Strategy seeks to draw upon the capacity and additional choice provided by voluntary charitable hospices in England. Analysis in this paper reveals how charitable income streams donated to voluntary hospices are significant relative to government funding but that this income is uncertain and volatile. The authors argue that this serves to recycle and amplify financial uncertainty at a time when the demand for palliative care will increase. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B7GWN-52NK38N-1&\\_user=10&\\_coverDate=04%2F20%2F2011&\\_rdoc=1&\\_fmt=high&\\_orig=gateway&\\_origin=gateway&\\_sort=d&\\_docanchor=&view=c&\\_searchStrId=1734362041&\\_rerunOrigin=scholar.google&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=1ea6ab246e589347a15b0579fdc0f8a4&searchtype=a](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B7GWN-52NK38N-1&_user=10&_coverDate=04%2F20%2F2011&_rdoc=1&_fmt=high&_orig=gateway&_origin=gateway&_sort=d&_docanchor=&view=c&_searchStrId=1734362041&_rerunOrigin=scholar.google&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=1ea6ab246e589347a15b0579fdc0f8a4&searchtype=a)

### Physicians don't always choose same treatment they'd recommend for patients

*AMERICAN MEDICAL NEWS* | Online article – 25 April 2011 – A new study finds that they select options with a higher death risk and fewer side effects for themselves. Primary care physicians recommend treatment with the lowest risk of mortality for patients more often than they choose it for themselves, a study shows. But such decisions leave patients with a greater risk of treatment-related side effects. The study's authors encourage primary care doctors to talk to patients about their treatment preferences and personal values before making a recommendation. Physicians also should explain to patients how they came to their decisions, said Peter A. Ubel, MD, lead author of the study and professor of public policy at Sanford School of Public Policy at Duke University in North Carolina. <http://www.ama-assn.org/amednews/2011/04/25/hlsb0425.htm>

1. 'Physicians recommend different treatments for patients than they would choose for themselves,' *Archives of Internal Medicine*, 2011;171(7):630-634.

## Clinical practice guidelines

### **Psychosocial and bereavement support of family caregivers of palliative care patients**

CENTRE FOR PALLIATIVE CARE (St. Vincent's Hospital of the University of Melbourne, Australia, and Queen's University, Belfast, U.K.) | Online document – Accessed 27 April 2011 – Support for family caregivers is a core function of palliative care. Most family caregivers will adequately respond to their role and even identify positive aspects associated with their experience. However, a considerable proportion of family caregivers will experience poor psychological, social, financial, spiritual and physical well-being and some will also suffer from prolonged grief. It is clear that many family caregivers have unmet needs and would like more information, education, preparation and personal support to assist them in the caregiving role. There is also a shortage of evidence-based strategies to guide health professionals to provide optimal support whilst the caregiver is providing care and after the patient's death. [The] research team [at the Centre for Palliative Care] has developed clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. The guidelines were developed for multi-disciplinary health care professionals and clinical services commonly involved in caring for adult patients receiving palliative care in

a variety of care sites throughout Australia. The guidelines may also prove valuable for the international palliative care community and for generalist health care providers who may occasionally care for palliative care patients. [http://www.centreforpalliativecare.org/assets/uploads/CP-Guidelines\\_web.pdf](http://www.centreforpalliativecare.org/assets/uploads/CP-Guidelines_web.pdf)

#### **Taking care of a dying grandparent: Case studies of grandchildren in the hospice caregiver role**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 26 April 2011 – This study aims to provide insight into the role of grandchildren as informal hospice caregivers. A researcher met regularly with family caregivers to discuss the problems or challenges during hospice caregiving. Although each caregiver presented unique individual experiences, several themes are common among the family caregivers including fatigue, stress, guilt, and loss of the "grandchild" identity. Grandchildren caregivers often take care of 3 generations (grandparents, parents, and children) and in many cases need additional assistance to help them overcome the challenges associated with managing a household, career, family, and caregiving roles. <http://ajh.sagepub.com/content/early/2011/04/26/1049909111405644.abstract>

Of related interest:

- *BMC PALLIATIVE CARE* | Online article – 24 March 2011 – **'The experience of palliative patients and their families of a family meeting utilised as an instrument for spiritual and psychosocial care: A qualitative study.'** This study explores the experience of palliative patients and their family members of a family meeting model, utilised as an instrument for the provision of spiritual and psychosocial care. In doing so the study embraces a broad understanding of spirituality which may or may not include formal religious practice and a concept of psychosocial care that includes: social and emotional well-being, communication, self esteem, mental health and adaptation to illness. <http://www.biomedcentral.com/content/pdf/1472-684X-10-7.pdf>



#### **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>

## A learning and development strategy for children's hospices across London [England]

CHILDREN'S HOSPICES ACROSS LONDON (CHaL) LEARNING & DEVELOPMENT GROUP | Online report – Accessed 26 April 2011 – This project lays the foundation for the development of a sustainable and unified approach to learning and development by bringing together policy, practice and evidence, and interfacing with regulatory requirements that have recently been strengthened for hospices and that are inspected by the Care Quality Commission (CQC). It commences with CHaL's vision for learning and development, follows with project description and methods, and summarises the initial scoping conducted to underpin the strategy. The subsequent analytical and conceptual development of the strategy is described, alongside a rationale for aligning thinking with the CQC essential standards that are inspected. The project had a unique opportunity to link in to a set of three

national workshops for hospices arranged by Children's Hospices UK (CHUK) and working with CQC that served to act as a consultation forum; this process is described [http://kar.kent.ac.uk/27698/1/CHAL\\_report\\_4th\\_april.pdf](http://kar.kent.ac.uk/27698/1/CHAL_report_4th_april.pdf)

### Glitter balls, bubble machines and rooms ringing with laughter: The hospice where children don't just come to die

U.K. | *Daily Mail* – 1 May 2011 – This is the type of place I imagine my own three children, aged three, five and six, would love. But, in reality, as wonderful as it is, I hope they never need to be here. For Little Bridge House is a hospice. And the families who stay here have children who are not expected to survive into adulthood. <http://www.dailymail.co.uk/health/article-1382268/Glitter-balls-bubble-machines-rooms-ringing-laughter---isnt-just-children-come-die.html>

Of related interest:

- *AMERICAN JOURNAL OF PREVENTIVE MEDICINE*, 2011;40(5):S208-S216. '**Pediatric palliative care and eHealth.**' Pediatric palliative care currently faces many challenges including unnecessary pain from insufficiently personalized treatment, doctor–patient communication breakdowns, and a paucity of usable patient-centric information. Recent advances in informatics for consumer health through eHealth initiatives have the potential to bridge known communication gaps, but overall these technologies remain under-utilized in practice. [http://www.ajpmonline.org/article/S0749-3797\(11\)00094-8/abstract](http://www.ajpmonline.org/article/S0749-3797(11)00094-8/abstract)
- *SOUTHERN AFRICAN JOURNAL OF HIV MEDICINE*, 2011;12(1):6-7. '**Children's palliative care in South Africa: An urgent need for an evidence base.**' There is an urgent need to develop and/or expand palliative care for children in South Africa, and this editorial emphasises the scarcity of an evidence base on which to base clinical and operational decisions. Children in Africa are more likely to face illness and death before the age of 5 years than anywhere else in the world. <http://www.sajhivmed.org.za/index.php/sajhivmed/article/viewFile/692/519>

## The challenges of providing palliative care for older people with dementia

*CURRENT ONCOLOGY REPORTS* | Online article – 19 April 2011 – Palliative care seems the right approach to dementia, except that it suggests a dichotomy between cure and care. As in cancer care, supportive care provides a broader framework, viewing dementia from the time of diagnosis until death and bereavement. The challenge is to find the right approach to the individual. This challenge arises in the person's own home, in long-term care homes, and in hospitals. <http://www.springerlink.com/content/e68776uw8p78704m/>

From Media Watch dated 8 November 2010:

- *JOURNAL OF ALZHEIMER'S DISEASE*, 2011;22(1):37-55. '**Dying with dementia: What we know after more than a decade of research.**' Although recent studies indicate encouraging trends of improved palliative care, little evidence supports effectiveness of specific treatments. <http://iospress.metapress.com/content/454w7g4vx7q48453/?p=0db5b21f4bff4a30a3177cc1c73a5c3f&pi=2>



## **Northwestern Asthma-COPD Program partners with palliative medicine to help patients cope with their disease**

*MEDICAL NEWS TODAY* (U.S.) | Online report – 27 April 2011 – When faced with a long-term illness, patients often retreat or are left feeling hopeless, a response that can negatively impact one's prognosis and impair their quality of life. When coping measures are offered however, the opposite can hold true. Patients can learn to accept their illness, take control of the situation and plan for the future. The Northwestern Asthma-COPD Program is pioneering a new approach to the treatment of patients suffering from Chronic Obstructive Pulmonary Disease ... that combines traditional care and palliative medicine. The forward-thinking approach is part of an emerging trend in medicine to bring palliative care into the equation earlier in order to improve disease management and enhance patient care. <http://www.medicalnewstoday.com/articles/223455.php>

## **How we involved bereaved family caregivers in palliative care education**

*MEDICAL TEACHER*, 2011;33(5):351-353. As palliative care coursework continues to proliferate within US medical education, novel curriculum approaches have included the use of cancer survivors and family caregivers. The authors included bereaved family caregivers in structured clinical teaching. First year students were exposed to a lecture about death and dying and then met with a bereaved caregiver in small groups of 10-15 for a presentation about the caregiving experience, bereavement, and question and answer period. Substantial pre-planning was involved to recruit caregivers and arrange for classroom space. Participation evoked caregiver anxiety but was resolved with adequate arrangement of the classroom and student introductions. Future implementation of bereaved caregivers in palliative coursework should include an appropriate follow-up phone call as well as recruiting more caregivers than necessary for the curriculum. <http://informahealthcare.com/doi/abs/10.3109/0142159X.2011.530318>

## **Home health care and discharged hospice care patients: U.S., 2000 and 2007**

*NATIONAL HEALTH STATISTICS REPORTS* (U.S.) | Online report – 27 April 2011 – This report presents national estimates on home health care patients and discharged hospice care patients. Information on characteristics, length of service, medical diagnoses, functional limitations, service use, advance care planning, and emergent and hospital care use are presented for home health care patients and hospice care discharges. A comparison of selected characteristics for 2000 and 2007 is also provided to highlight changes. <http://www.cdc.gov/nchs/data/nhsr/nhsr038.pdf>

## **End of life: A need for bowel care guidance**

*NURSING TIMES* (U.K.) | Online article – 30 April 2011 – Patients receiving end-of-life and palliative care often need help to manage their bowel care. Although several policies on palliative care have been introduced in recent years, there is a lack of guidance specifically on bowel management for patients approaching death. This article highlights the gaps in guidance, and discusses how nurses can alleviate patients' distress and best preserve their dignity while managing their bowel care. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/continence/end-of-life-a-need-for-bowel-care-guidance/5029189.article>

## **Assisted (or facilitated) death**

Representative sample of recent articles, etc:

- *AMERICAN JOURNAL OF HEALTH-SYSTEM PHARMACY*, 2011;68(9):846-849. 'Physician-assisted suicide: Ongoing challenges for pharmacists.' Abstract not available. <http://www.ajhp.org/content/68/9/846.full>

## Worth Repeating

### Quality of death, end of life care in America: Inside out

U.S. | National Public Radio – 13 August 2009 – Does a booming aging population in the U.S. combined with an endless array of medical treatments place too much stress on our healthcare budget and on older patients? When asked, most Americans say they would prefer to die at home, yet the majority of us die in hospitals and other institutions, often in pain. It would seem logical that the more healthcare a patient gets, the better that patient's care would be, but for people nearing the end of their lives, this is not always the case. Aggressive medical care at the end of life accounts for one third of all Medicare spending, yet such spending and extensive treatment can too easily decrease a patient's quality of life during this period, and thus, their quality of death. <http://insideout.wbur.org/documentaries/qualityofdeath/default.asp>

**N.B.** The U.S. was rated 9th in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

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#### 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.

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