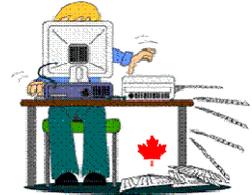


## Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Dying in a highly technological environment: Scroll down to [Specialist Publications](#) and 'Is dying in an ICU a sign of poor quality end-of-life care?' (p.9), in *American Journal of Critical Care*.

## Canada

### Palliative care: Toronto left with few residential hospice beds

ONTARIO | *The Toronto Star* – 13 May 2013 – Toronto has only two 10-bed residential hospices now that Perram House has closed. Some say more beds in the community are needed so Torontonians have a better place to die. Residential hospices are relatively new across Canada, but palliative care experts say they are a crucial option for patients who do not need to be in hospital and cannot die at home. There are about 193 palliative care beds in Toronto hospitals, but most have a vacancy rate of close to zero and limit stays to 15 days. Patients can stay in a residential hospice for three months or longer. Toronto Central Local Health Integration Network funds three visiting hospice programs. For patients with complex needs or without a family caregiver, it is only a short-term option. The vast majority of Canadians say they want to die at home or in a hospice, but about 70% die in hospitals. In the 2011 fiscal year, nearly 5,000 people died in an acute-care hospital in Ontario while receiving palliative care. Hospice patients receive care free-of-charge, but advocates say the savings are significant for a province trying to balance its books... [http://www.thestar.com/news/gta/2013/05/13/palliative\\_care\\_toronto\\_left\\_with\\_few\\_residential\\_hospice\\_beds.html](http://www.thestar.com/news/gta/2013/05/13/palliative_care_toronto_left_with_few_residential_hospice_beds.html)

Noted in Media Watch, 15 April 2013:

- ONTARIO | *The Toronto Star* – 10 April 2013 – '**Perram House hospice closing – staff got two days' notice.**' Perram House – one of the few hospices in the city providing end-of-life care to marginalized, homeless and drug-addicted people – will close on Wednesday. [http://www.thestar.com/life/health\\_wellness/2013/04/10/perram\\_house\\_hospice\\_closing\\_wednesday\\_staff\\_got\\_two\\_days\\_notice.html](http://www.thestar.com/life/health_wellness/2013/04/10/perram_house_hospice_closing_wednesday_staff_got_two_days_notice.html)

Of related interest:

- ONTARIO | *The Toronto Star* – 7 May 2013 – '**Scarborough Hospital braces for more cuts.**' The cuts continue at the Scarborough Hospital and the latest proposed targets include palliative care beds. An unspecified number of palliative beds could be closed [http://www.thestar.com/life/health\\_wellness/2013/05/07/scarborough\\_hospital\\_braces\\_for\\_more\\_cuts.html](http://www.thestar.com/life/health_wellness/2013/05/07/scarborough_hospital_braces_for_more_cuts.html)

## Quebec announces \$15M for palliative care

QUÉBEC | CBC News (Montreal) – 5 May 2013 – The Parti Québécois government is injecting \$15 million dollars to improve access to palliative care in the province. Premier Pauline Marois made the surprise announcement ... at an international congress of palliative care experts from around the French-speaking world [i.e., 2e Congrès International Francophone de Soins Palliatifs]. Québec Minister for Social Services Véronique Hivon said the new funding will help answer the needs of people who are sick and suffering, as well as their families. Out of the funding, \$4 million will go towards creating more beds in care centres. The remaining \$11 million will be used to improve palliative care at home. Some of that money is expected to help train family members to care for their terminally ill relatives in the comfort of their own homes. The investment will also help fund projects to support spouses and children who are dealing with the hardship of a dying loved one. <http://www.cbc.ca/news/canada/montreal/story/2013/05/05/quebec-palliative-care-funding-parti-quebecois.html>

Noted in Media Watch, 21 January 2013:

- QUÉBEC | *The Globe & Mail* – 16 January 2013 – **'Quebec leading the way in end-of-life issues.'** In 2010, the National Assembly of Quebec appointed an all-party committee to examine end-of-life issues. The committee published its report, 'Dying with Dignity,' in 2012.<sup>1</sup> <http://www.theglobeandmail.com/life/health-and-fitness/health/andr-picard-quebec-leading-the-way-on-end-of-life-issues/article7447929/>

1. French language edition [Noted in Media Watch, 26 March 2012]: <http://www.assnat.qc.ca/fr/actualites-salle-presse/nouvelle/actualite-25939.html>.  
English language edition [Noted in Media Watch, 27 August 2012]: [http://www.dyingwithdignity.ca/database/files/library/Quebec\\_death\\_with\\_dignity\\_report.pdf](http://www.dyingwithdignity.ca/database/files/library/Quebec_death_with_dignity_report.pdf)

## U.S.A.

### Medicare lags in project to expand hospice

KAISER HEALTH NEWS | Online – 9 May 2013 – Despite a three-year-old order from Congress, Medicare has yet to begin an experiment to expand hospice services to allow beneficiaries to continue potentially lifesaving treatments to see if it would save money while improving the patients' quality of life. The demonstration project would eliminate one major reason that people are reluctant to take up Medicare's hospice benefit: they have to first agree to forgo curative treatments such as chemotherapy. The 2010 health law required Medicaid to pay for joint hospice and curative treatments, called concurrent care, for children. More than half the states have taken steps to implement that in the joint federal-state program for low-income residents. It also instructed the secretary of Health & Human Services to select up to 15 sites to test concurrent care for patients in Medicare, which provides health coverage to seniors and disabled people. That test is to last for three years, but Medicare has yet to take any concrete steps toward beginning it. <http://www.kaiserhealthnews.org/stories/2013/may/09/medicare-delays-experiment-on-hospice-and-curative-care.aspx>

Noted in Media Watch, 24 May 2010:

- *AMERICAN MEDICAL NEWS* | Online – 24 May 2010 – **'Medicare to test allowing more than palliative care in hospice.'** The health reform law enacted in March directs state Children's Health Insurance Programs and Medicaid plans to immediately cover "concurrent care" – a combination of curative efforts and hospice care – for children with terminal illnesses. The law also calls on the Health & Human Services secretary to conduct a three-year, budget-neutral demonstration project of concurrent care for Medicare patients at 15 hospice-care sites. <http://www.ama-assn.org/amednews/2010/05/24/prsb0524.htm>

## Religious support tied to intensive end-of-life care

REUTERS | Online – 7 May 2013 – People with advanced cancer tend to get more aggressive care at the end of life and spend more time in the intensive care unit if they receive spiritual support from their religious communities, according to a new study.<sup>1</sup> The report's lead researcher said that finding was "quite the opposite" of what her team was expecting – in part because of evidence that spiritual support coming from within a patient's medical team leads to less aggressive care and more use of hospice. In the new study, spiritual patients who reported high levels of support from their religious communities were two to three times more likely to receive aggressive end-of-life treatment than those who got less support. However, spiritual support from doctors, nurses and chaplains was tied to a 77% drop in aggressive interventions, consistent with past research. "The spiritual supporters that are integrated into the medical team, knowing the diagnosis of the patient and where things are, are much more able to see the bigger picture of where someone's illness is heading," said Dr. Tracy Balboni, from the Dana-Farber Cancer Institute in Boston. She told Reuters the new findings point to a need for more collaboration between religious communities and medical teams – so a patient's religious supporters understand the "medical realities" of terminal cancer. <http://www.reuters.com/article/2013/05/07/us-religious-intensive-idUSBRE9460IP20130507>

1. 'Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life,' *JAMA Internal Medicine*, 6 May 2013. Patients [i.e., study participants] reporting high spiritual support from religious communities (43%) were less likely to receive hospice, more likely to receive aggressive end of life measures, and more likely to die in an ICU. <http://archinte.jamanetwork.com/article.aspx?articleid=1685898>

From the archives (noted under 'Worth Repeating' in Media Watch, 10 December 2012):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2009;301(11):1140-1147. '**Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer.**' To the author's knowledge, this is the first study to examine the influence of any religious factor on medical care received near death, and it is novel in demonstrating that positive religious coping is associated with receipt of aggressive end-of-life care. <http://jama.jamanetwork.com/article.aspx?articleid=183578>



### [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>

### [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>

## Susan Sontag, William F. Buckley, Jr. and care at the end of life

*THE HUFFINGTON POST* | Online – 6 May 2013 – Perhaps the medical system is beginning to feel the earliest stirrings of a shift in generational attitude. Baby boomers comprise the first generation to have witnessed, en masse, the indignities and miseries that can accompany medical efforts to extend life ... when it's in its final months. Among those miseries: severe pain, drugs with toxic side effects, delirium, and tubes – as the physician Atul Gawande puts it – "in most natural orifices and a few artificial ones."<sup>1</sup> Desperate to do everything they could for their parents at the time, boomers might well have pushed for such care. But now, as more and more have come to see with their own eyes what such treatment can entail, will fewer and fewer want it for themselves? If so, then as boomers take their place in the ranks of the elderly, the demand for expensive and aggressive interventions to extend life might fall over time. Demand for palliative and hospice care, which allows

for a more comfortable and conscious end-of-life experience, may rise. And this shift might ease cost pressures on the system in years to come. But in an online survey of 5,002 American adults under the age of 65 conducted recently by the RIWI Corporation, those expectations were upended. Of the 28% who indicated they had witnessed hospital-based end-of-life care to prolong a sick relative's life, 49% said that they would want such care for themselves in their own end-of-life situation, while only 35% would not. [http://www.huffingtonpost.com/andrew-stark/end-of-life-care\\_b\\_3223460.html](http://www.huffingtonpost.com/andrew-stark/end-of-life-care_b_3223460.html)

### Specialist Publications

**'Is dying in an ICU a sign of poor quality end-of-life care?'** (p.9), in *American Journal of Critical Care*.

1. 'What should medicine do when it can't save your life?' *The New Yorker*, 2 August 2010. Budget hawks urge us to face the fact that we can't afford everything. Demagogues shout about rationing and death panels. Market purists blame the existence of insurance: if patients and families paid the bills themselves, those expensive therapies would all come down in price. But they're debating the wrong question. [Noted in Media Watch, 2 August 2010] [http://www.newyorker.com/reporting/2010/08/02/100802fa\\_fact\\_gawande?currentPage=all](http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?currentPage=all)

## Psychiatry's guide is out of touch with science, experts say

*THE NEW YORK TIMES* | Online – 6 May 2013 – Just weeks before the long-awaited publication of a new edition of the so-called bible of mental disorders, the federal government's most prominent psychiatric expert has said the book suffers from a scientific "lack of credibility." Dr. Thomas R. Insel, of the National Institute of Mental Health, said ... that his goal is to reshape the direction of psychiatric research to focus on biology, genetics and neuroscience so scientists can define disorders by their causes, rather than their symptoms. While the *Diagnostic & Statistical Manual of Mental Disorders [DSM-5]* ... is the best tool now available for clinicians treating patients and should not be tossed out ... it does not reflect the complexity of many disorders, and its way of categorizing mental illness should not guide research. <http://www.nytimes.com/2013/05/07/health/psychiatrys-new-guide-falls-short-experts-say.html?ref=health&r=0>

### **DSM-5: Removal of bereavement exclusion**

Individuals meeting criteria for a major depressive episode were excluded from a diagnosis of major depressive disorder if symptoms occurred within two months of the death of a loved one. However, the implication that bereavement ends in only two months or that major depression and bereavement cannot co-occur appears false. Depression related to bereavement can share many of the same symptoms as non-bereavement-related depression and can accordingly respond to treatment.

Cont.

Noted in Media Watch, 1 April 2013:

- *CLINICAL PSYCHOLOGICAL SCIENCE* | Online – 18 March 2013 – **'Remembering the past and envisioning the future in bereaved adults with and without complicated grief.'** Complicated grief (CG) is associated with impairment in the ability to retrieve specific autobiographical memories. However, previous research suggests that this impairment may not occur for memories related to the deceased. Individuals with CG [i.e., study participants] were no less specific than bereaved comparison subjects when generating events that included the deceased. <http://cpx.sagepub.com/content/early/2013/03/14/2167702613476027.abstract>

Noted in Media Watch, 1 October 2012:

- *PSYCHOTHERAPY IN AUSTRALIA*, 2012;18(4):53-54. **'Considerations of difference: Is 'complicated grief' a viable new diagnosis in DSM-5?'** Mental health professionals working in the area of grief and loss have long agreed that the grieving individual should be allowed to mourn for a period of time, and not be subjected to diagnosis, medicalisation or "treatment." <http://search.informit.com.au/documentSummary;dn=736644127461028;res=IELHEA>

Noted in Media Watch, 24 September 2012:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;65(4):251-155. **'A call to the field: Complicated grief in the DSM-5.'** While complicated grief has been addressed in part through some recommendations for modifications in the upcoming ... *DSM-5*, there remain reasons for substantial concern about its scope therein and within clinical practice. The authors reiterate complicated grief is complicated and cannot be confined to just one syndrome or disorder. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,8;journal,1,259;linkingpublicationresults,1:300329,1>

**N.B.** Footnoted in this issue of Media Watch (p.10) is a list of articles, etc., on complicated grief and the DSM-5 that have been noted in past issues of the weekly report.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | *USA Today* – 9 May 2013 – **'Vermont Senate OKs end-of-life legislation.'** A revised bill that would allow terminally ill Vermonters to legally hasten their own deaths survived some roller-coaster twists and turns and appears likely to become the third physician-assisted death law in the country. The Senate voted 17-13 for an altered version of the Patient Choice & Control at End of Life Act that is a hybrid of Oregon's first-in-the-nation law and something less restrictive. The fewer restrictions helped win over key swing votes to break a deadlock in the Senate while retaining the support of those who wanted the original bill. <http://www.usatoday.com/story/news/politics/2013/05/09/vermont-physician-assisted-death-bill/2146617/>
- MONTANA | Associated Press – 8 May 2013 – **'Fight over assisted suicide moves back to court.'** The fight over physician-assisted suicide in Montana is moving back to the courtroom after the Legislature failed this session to clarify that the practice is specifically legal or illegal. A Helena judge has scheduled oral arguments for next month in the case. The lawsuit was filed in December. Since then, the Montana Legislature failed in efforts to either clarify that the practice is specifically legal or illegal. It was the second straight session where lawmakers couldn't agree on which direction to take the state. The procedure has been surrounded by various interpretations since the Supreme Court ruled in 2009 nothing in state law prohibits physician-assisted suicide - but it did not rule on whether the practice is a constitutionally protected right. The decision said nothing in state law, or precedent, makes the procedure illegal. [http://helenair.com/news/legislature/fight-over-assisted-suicide-moves-back-to-court/article\\_35bbe460-b819-11e2-a78f-0019bb2963f4.html](http://helenair.com/news/legislature/fight-over-assisted-suicide-moves-back-to-court/article_35bbe460-b819-11e2-a78f-0019bb2963f4.html)

## International

### **Hospice charity sets age limit on services for young people**

U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 10 May 2013 – A hospice charity that works with children affected by life-limiting illnesses has warned families it will have to withdraw its services from young people who are surviving much longer than ever expected. The Children's Hospice Association Scotland (CHAS) provides end-of-life care for children who are terminally ill, and respite breaks for children with life-limiting conditions. While it does not usually start working with young people of 16 or above, it has never had an age limit on how long existing users can carry on going to its hospices... However, children suffering from conditions such as muscular dystrophy, who were not expected to live past their teens when they were diagnosed, are now often living into their 20s and even 30s. CHAS chief executive Maria McGill ... said there was a lack of suitable services for people aged 25-45, with adult hospice services set up largely to cater for much older adults suffering from cancer and other terminal illnesses. However, she said CHAS was talking to other hospices and care providers to see if some could provide facilities for young adults. The charity will also work with politicians and civil servants to highlight the gaps in services, she said. <http://www.heraldsotland.com/news/health/hospice-charity-sets-age-limit-on-services-for-young-people.21041823>

### **End-of-life care in Australia**

#### **End-of-life plans go online nationally**

AUSTRALIA | *Herald Sun* (Melbourne) – 9 May 2013 – Federal Health Minister Tanya Plibersek says funding to help the sick communicate their dying wishes to health carers will provide comfort for the terminally ill. The \$10.8 million will put advance care directives on the national eHealth record system, so doctors across the states and territories can follow the predetermined wishes of their patients. Ms. Plibersek, speaking at the recent International Society of Advance Care Planning & End of Life Care Conference,<sup>1</sup> said the funding would

ensure peace of mind for the terminally ill. <http://www.heraldsun.com.au/news/breaking-news/end-of-life-plans-of-elderly-to-go-online/story-e6frf7kf-1226638084306>

#### **Specialist Publications**

'Considering Aboriginal palliative care models: The challenges for mainstream services' (p.16), in *Rural & Remote Health*.

1. Abstracts of the papers presented at the conference are published in *BMJ Supportive & Palliative Care*. [Noted in Media Watch, 6 May 2013] <http://spcare.bmj.com/content/3/2/239.2.short>

#### **MP calls for answers on "rushed" home care visits**

U.K. (ENGLAND) | *The Oxford Times* – 8 May 2013 – One in five visits by care staff to the elderly and frail is for 15 minutes or less in Oxfordshire – about double the national average. Questions were being raised about whether the home visits were long enough to provide the proper level of care because of the disparity with other areas around the country. In a five-week period leading up to the end of March, 21.7% of home visits to help the elderly or frail was of the shortest time slot of 0-15 minutes. Forty-three per cent of visits were of 16-30 minutes. The national average last year in comparison was 10% and 63% respectively. The Oxfordshire figures for March are the latest available, although Oxfordshire County Council said the general average could rise to 25%. [http://www.oxfordtimes.co.uk/news/10404419.MP\\_calls\\_for\\_answers\\_on\\_rushed\\_home\\_care\\_visits/](http://www.oxfordtimes.co.uk/news/10404419.MP_calls_for_answers_on_rushed_home_care_visits/)

## Doctors criticise bishops' report into Liverpool Care Pathway

U.K. (ENGLAND & WALES) | *Catholic Herald* – 8 May 2013 – Senior Catholic doctors have said that a bishops' conference report about the Liverpool Care Pathway (LCP) "borders on the disingenuous" adding that it "goes to extreme lengths to align support for the LCP with Catholic teaching." In response to the report,<sup>1</sup> issued by a department of the Bishops' Conference of England & Wales, Professor Patrick Pullicino, Dr. Anthony Cole and Dr. Philip Howard said in a joint statement: "The sufferings of patients who have been put on the LCP and their relatives is the first thing the Church should be reacting to in order to understand the great depth of anguish that this pathway has caused and the reasons for this." An independent inquiry into the LCP, chaired by Baroness Neuberger ... was announced by the Department of

Health in February, following mounting criticism from families of patients who were placed on the pathway. The bishops' Department of Christian Responsibility & Citizenship commissioned Professor David Albert Jones to write their report, which has been submitted to the independent inquiry. <http://www.catholicherald.co.uk/news/2013/05/08/doctors-criticise-bishops-report-into-liverpool-care-pathway/>

### Specialist Publications

'Controversy around The Liverpool Care Pathway – the fundamental issue is consent' (p.11), in *European Journal of Palliative Care*.

1. 'Liverpool Care Pathway Review Submission,' Bishops' Conference of England & Wales, May 2013. <http://www.catholic-ew.org.uk/Home/News/Liverpool-Care-Pathway>

### 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 and research tool.

### 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.

## End-of-life care in Russia

### St. Petersburg's children's hospice

RUSSIA | Aid to the Church in Need News Service – 6 May 2013 – Over the course of the past 10 years no fewer than 7 million children have died in Russia from a range of different illnesses – an unimaginably vast number of individual tragedies. Sadly, the hospitals are in many cases still insufficiently prepared in caring for terminally ill children and their families. Once a child is diagnosed as terminally ill, he is discharged from hospital and sent home. Hence the parents are left alone, to deal not only with all their pain and fear, but also with innumerable practical and organisational problems. Many families live in so-called communal apartments that are shared by several families. Caring day and night for a child in such circumstances is sometimes well-nigh impossible, and families often fall apart under the strain. On top of this, friends and relations often tend to draw back, partly out of fear of infection, but also from a sense of helplessness and inadequacy. The situation also impacts heavily on the healthy brothers and sisters, who still need parental care themselves; often they cannot cope and suffer greatly from the situation because their parents are entirely taken up with caring for the sick brother or sister. On top of this, these children also have to look on and see the sufferings of their sibling, a suffering that can often drag on for years. An Orthodox priest in Saint

Petersburg, Father Aleksandr Tkachenko, who had previously studied in the U.S. on a special course as a hospital chaplain, realised that in Russia too something needed to be done in this field as soon as possible. <http://members4.boardhost.com/acnaus/msg/1367826608.html>

#### Specialist Publications

'The development of an instrument that can identify children with palliative care needs: The paediatric palliative screening scale – A qualitative study approach' (p.14), in *BMC Palliative Care*.

'Helping the angels: A review of understanding and helping dying children' (p.14), in *Innovations in Clinical Neuroscience*.

#### Quotable Quotes

*It's still unclear who needs whom more, whether sick children need us more, or whether we need them most. They help us to compare our trivial trials with true suffering; to see what is really important, and what is ephemeral and of no value at all. Patriarch Kirill Gundryaev of Moscow and all the Russias, November 2010.*

**N.B.** Children's hospice, St. Petersburg: <http://www.youtube.com/watch?v=IK7NL7k8hFY>

Noted in Media Watch, 23 July 2012:

- *PALIAȚIA*, 2012;5(3). '**Palliative care for children in Russia: Some steps forward.**' Pioneering programmes have been introduced in a number of cities. These programmes involve collaboration between state and non-governmental organizations and have grown up primarily through the inspiration of local leaders. There is evidence of wide-ranging initiatives designed to create the organization, workforce, and policy to develop capacity for hospice-palliative care services for children. <http://www.paliatia.eu/modules/publisher/item.php?itemid=46>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ESTONIA | Estonian Public Broadcasting – 10 May 2013 – '**Euthanasia is a euphemism for death sentence, says ethics chairwoman.**' In Estonia there is no major legal precedent on the matter, although experts point out that the Constitution declares: "Everyone has the right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his or her life." <http://news.err.ee/health/959a8d79-8ef5-4e13-bb1b-78e585ffa737>

Cont.

- AUSTRALIA (NEW SOUTH WALES) | Parliamentary Library Issues Backgrounder – May 2013 – **'Euthanasia.'** This updated version (of an October 2010 backgrounder) takes account of the recent introduction of the Rights of the Terminally Ill Bill in New South Wales. Recent cases in Australia are canvassed as are proposed reforms and recommendations in selected jurisdictions – South Australia, Tasmania and the U.K. Sections on Canada and New Zealand are also included in this update and recent journal articles and media reports have been added. [http://www.parliament.nsw.gov.au/Prod/parlament/publications.nsf/0/CE101BFEE296DA17CA257B6000049EF3/\\$File/Euthanasia+Issues+Backgrounder+update.pdf](http://www.parliament.nsw.gov.au/Prod/parlament/publications.nsf/0/CE101BFEE296DA17CA257B6000049EF3/$File/Euthanasia+Issues+Backgrounder+update.pdf)

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

### Is dying in an ICU a sign of poor quality end-of-life care?

*AMERICAN JOURNAL OF CRITICAL CARE*, 2013;22(3):263-266. Many patients want to avoid high intensity treatment if dying, but also want to survive if possible. The main reason given to support the argument that death in an ICU is poor quality end-of-life care is data that indicate home is the preferred site of death for many patients. Although there are some concerns that, all other things be equal, the overwhelming majority of patients do not wish to die attached to invasive life support in a highly technological environment. However, there is another relevant consideration: many patients have a powerful desire to survive if survival with an acceptable quality of life is possible. In the context of acute, potentially reversible critical illness, there is a conflict between preference for a non-technological death and the preference to receive treatments that maximise the chance of surviving an acute episode, which may require ICU treatment. <http://ajcc.aacnjournals.org/content/22/3/263.extract>

#### **The Hastings Center calls on health care professionals and organizations to meet standards for good care near the end of life**

*MEDICAL EXPRESS* | Online – 7 May 2013 – People with chronic or life-threatening illnesses often experience problems with their care, including confusion and conflict over how to make good decisions, poor communication with care providers, inadequate pain and symptom relief, and treatments with little or no benefit. Poor care decreases patients' quality of life, increases family stress, and adds cost but not value to health care, often with heartbreaking financial consequences for families. A new set of consensus guidelines produced by The Hastings Center can help health care professionals improve care near the end of life.<sup>1</sup> The guidelines clarify what is ethically and legally permissible in the U.S. regarding the use life-sustaining technologies, provide in-depth guidance on talking with patients and surrogates, and offer recommendations about how to improve the delivery of care. <http://medicalxpress.com/news/2013-05-hastings-center-health-professionals-standards.html>

Of related interest:

- *ANASTHESIOLOGIE*, 2013;48(4):216-223. **'Definitions, decision-making and documentation in end of life situations in the intensive care unit.'** The present work provides assistance for physicians concerning decision making in clinical borderline situations in the intensive care unit. Based on a structured checklist the two fundamental aspects of any medical decision, the medical indication and the patient's preference are queried in a systematic way. Four possible steps of withholding and/or withdrawing therapy are discussed. Finally, recommendations regarding appropriate documentation of end of life decisions are provided. <http://europepmc.org/abstract/MED/23633250/reload=0;jsessionid=M8SkRxvB6RcWSuK86KM.P.6>

Noted in Media Watch, 10 September 2012:

- *CURRENT OPINION IN CRITICAL CARE* | Online – 29 August 2012 – **'From persistence to palliation: Limiting active treatment in the ICU.'** This narrative review describes recent studies on how to improve palliative care and surrogate decision-making in ICUs and compares the results with previously published literature on this topic. [http://journals.lww.com/criticalcare/Abstract/2012/12000/From\\_persistence\\_to\\_palliation\\_limiting\\_active.20.aspx](http://journals.lww.com/criticalcare/Abstract/2012/12000/From_persistence_to_palliation_limiting_active.20.aspx)

## **Therapeutic values clarification and values development for end-of-life patients: A conceptual model**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 May 2013 – The social, emotional, cognitive, and spiritual challenges that may be a major concern for a certain category of end-of-life patients are the focus of a conceptual counseling model. The intervention that was developed as a result of several years of practice is referred to as *therapeutic values clarification and values development*. This article outlines 4 phases of this intervention. This therapeutic process is illustrated by a case vignette with explanation of the key concepts. This model is suggested for use with end-of-life patients that are self-aware, emotionally and cognitively competent, and have adequate verbal skills. It may be useful as an optional tool for hospice workers, social workers, and clergy who render services to terminally ill patients and their families. <http://ajh.sagepub.com/content/early/2013/05/07/1049909113486337.abstract>

## **Caregivers have boundaries when speaking for patients**

*AMERICAN MEDICAL NEWS* | Online – 6 May 2013 – The physician is allowed ... to determine whether a patient lacks decision-making capacity regarding medical matters, and guidelines have been established to help physicians make this determination. The first role the physician gives the caregiver in such a situation is that of informant. The physician may need to hear from the caregiver the circumstances that produced the patient's current condition, the medications the patient is taking, the patient's medical conditions, the patient's baseline functional abilities and other necessary information. The caregiver also may know about the prearranged designation of a surrogate through a durable power of attorney for health care, and there may be an advance directive that the caregiver can help locate. If there is no such prearrangement, the informant role of the caregiver usually expands, and the physician may support the caregiver in the role of surrogate decision-maker as well, depending on other aspects of the caregiver's relationship with the patient. The laws of the jurisdiction (or customary practice in the community if the law is silent on the matter) determine who should have authority to serve as patient surrogate. If the caregiver is the patient's spouse, he or she usually is the surrogate decision-maker. Others next in line, such as the reasonably available adult children of the patient, should get the opportunity to act as surrogate decision-makers if the spouse declines, is unavailable or is otherwise unable to serve. <http://www.amednews.com/article/20130506/profession/130509994/5/>

Of related interest:

- *CRITICAL CARE MEDICINE* | Online – 8 May 2013 – '**The effect of emotion and physician communication behaviors on surrogates' life-sustaining treatment decisions: A randomized simulation experiment.**' The authors sought to explore the effect of emotional state and physician communication behaviors on surrogates' life-sustaining treatment decisions. [http://journals.lww.com/ccmjournals/Abstract/publishahead/The\\_Effect\\_of\\_Emotion\\_and\\_Physician\\_Communication.97857.aspx](http://journals.lww.com/ccmjournals/Abstract/publishahead/The_Effect_of_Emotion_and_Physician_Communication.97857.aspx)

## **Palliative care in Japan: A review focusing on care delivery system**

*CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE*, 2013;7(2):207-215. Palliative care units and hospital palliative care consultation teams are the two main specialized palliative care services. The number of palliative care units is 215, and there are approximately 500 hospital palliative care teams. Conversely, specialized home care services are one of the most undeveloped areas. However, the government has been trying to develop more efficient home care services through modifying laws, healthcare systems, and multiple educational and cooperative projects. The numbers of specialists are increasing across all disciplines. Multiple structure and process evaluation, bereaved family surveys in palliative care units, and patient and family evaluation in the regional palliative care program indicate many improvements. [http://journals.lww.com/supportiveandpalliative-care/Abstract/2013/06000/Palliative\\_care\\_in\\_Japan\\_a\\_review\\_focusing\\_on.14.aspx](http://journals.lww.com/supportiveandpalliative-care/Abstract/2013/06000/Palliative_care_in_Japan_a_review_focusing_on.14.aspx)

Cont.

Noted in Media Watch, 7 January 2013:

- *JAPANESE JOURNAL OF CLINICAL ONCOLOGY* | Online – 4 January 2013 – **'What influences the willingness of community physicians to provide palliative care for patients with terminal cancer? Evidence from a nationwide survey.'** The majority of respondents expressed a willingness (92.4%) to provide palliative care if they encountered patients with terminal cancer. However, they would limit their services to consultation (83.4%) and referral (86.8%), and were less likely to see patients and prescribe medicine (62.0%), to provide phone follow-ups (45.6%), to provide home visits (42.2%) or to offer bereavement care for the family (35.1%). <http://jjco.oxfordjournals.org/content/early/2013/01/03/jjco.hys222.abstract>

Noted in Media Watch, 26 November 2012:

- *JAPANESE JOURNAL OF CLINICAL ONCOLOGY* | Online – 19 November 2012 – **'Past, present, and future of palliative care in Japan.'** Palliative care in Japan has developed through a number of transition stages. <http://jjco.oxfordjournals.org/content/43/1/17.abstract>

### **Twenty-first century palliative care: A tale of four nations**

*EUROPEAN JOURNAL OF CANCER CARE* | Online – 6 May 2013 – In this paper, the evolution of palliative care practices in four developing nations (Nigeria,<sup>1</sup> Georgia,<sup>2</sup> Ethiopia and Tanzania) is described. By highlighting common problems as well as the unique individual perspectives of each country's practice, this paper aims at increasing global awareness of palliative care in the developing world. While the call for palliative care to become a fundamental human right is sustained, it is also hoped that this article will stimulate a global discussion on the best possible way to encourage the establishment and growth of palliative care services in other developing countries where hitherto it has not been in existence, with policymakers and healthcare professionals taking the lead through the institution of sound national policies to promote and provide palliative care to all citizenry. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12064/abstract>

- 'Experts identify lapses in health care delivery in Nigeria,' *The Tribune* (Ibadan), 14 October 2011. Dr. Israel Kolawole of the University of Ilorin Teaching Hospital ... said the Nigeria medical setting only emphasised quest to achieve cure and/or prolongation of life at all cost, adding "our healthcare package does not fully address the emotional, spiritual and psychology suffering faced by patients with life-threatening illnesses." [Noted in Media Watch, 17 October 2011] <http://www.tribune.com.ng/index.php/community-news/29644-experts-identify-lapses-in-health-care-delivery-in-nigeria>
- Georgia was one of 11 countries featured in the documentary 'Life Before Death,' which explores a diverse range of cultural perspectives on pain, death and dying. The project, presented by the Singapore-based Lien Foundation, includes a series of short films themed around pain control and end of life issues. [Noted in Media Watch, 8 August 2011] 'Life Before Death' website: <http://www.lifebeforedeath.com/movie/short-films.shtml>; 'Pain Control in Georgia' video: <http://www.lifebeforedeath.com/movie/short-films/14-paincontrollingeorgia.html>

### **Controversy around The Liverpool Care Pathway – the fundamental issue is consent**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):109. The furore around the Liverpool Care Pathway (LCP) continues. The publicity about it has been noxious. Despite the fact that over 20 reputable organisations have pledged their support to the LCP, the media appear to persist in the publication of misconceptions and inaccurate facts. And the public remains concerned and confused. How has it all gone so horribly wrong? Why has it come to this? What can we learn from it? Perhaps some of the answers to these questions lie in today's world of healthcare, where the emphasis is on patient-centric and evidence-based care. Working within this world requires managing expectations. And managing expectations requires good communication.

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Historically, hospice care delivered in U.K. hospices was considered the gold standard. The public never used to question the quality or clinical effectiveness of the care delivered in our hospices, because they were obvious; the care was exemplary. But times have changed. The public is more informed, outcome data are lacking, and the days of paternalism are over. In this issue, Professor John Ellershaw and colleagues outline why the LCP was adopted in the first place and open an international perspective with the widening of its use abroad.<sup>1</sup> Their article is preceded by a piece from Dr. Carol Davis, who, with her colleague Chrissie Guyer, systematically deconstructs the myths and rectifies the misinformation that have been circulated by the media recently.<sup>2</sup>

1. 'Care of the dying and the LCP in England: An international perspective.' Controversy surrounding care of the dying and The Liverpool Care Pathway for the Dying Patient in England has the potential to set back progress made in recent years. However, as the debate continues in public policy and the media in England, the LCP's country of origin, could an international perspective provide the next steps in improving care of the dying?
2. 'Integrated care pathways for dying patients – myths, misunderstandings and realities in clinical practice.' Over the last nine months, there has been a mixture of positive and negative publicity about the use of the Liverpool Care Pathway for the Dying Patient in England. Most coverage in the lay media (newspapers, television, chat rooms and blogs) has been negative as well as very emotive, while the converse is true of that aimed at a readership of health- and social care professionals.

**N.B.** Access to the *European Journal of Palliative Care* requires a subscription. Contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2013&Edition=474](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2013&Edition=474). The Liverpool Care Pathway is currently subject to a review commissioned by the Department of Health, England (<https://www.gov.uk/government/news/review-of-liverpool-care-pathway-outlined>).

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 7 May 2013 – '**The Liverpool Care Pathway for cancer patients dying in hospital medical wards: A before-after cluster phase II trial of outcomes reported by family members.**' These results provide the first robust data collected from family members of a preliminary clinically significant improvement, in some aspects, of quality of care after the implementation of the Italian version of Liverpool Care Pathway programme. The poor effect for symptom control suggests areas for further innovation and development. <http://pmj.sagepub.com/content/early/2013/05/03/0269216313487569.abstract>

### **Challenges in increasing regional equity in palliative care service provision in Ireland**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):130-133. Ireland has a long tradition of hospice and palliative care. In Dublin, Cork and Limerick, centres for the dying are long established, having been founded by religious orders in the late 19th and early 20th century. Nationally, service expansion to hospitals, inpatient hospices and home care services began in the mid-1980s, heavily influenced by the modern hospice movement. Local activism resulted in voluntary sector-initiated fundraising for, and provision of, specialist home care services in all parts of the country. Service development and dedicated training were followed, in the 1990s, by official recognition of palliative care as a specialty, a growing profile within health policy and rising government spending. However, despite considerable advances by the turn of the century, long-standing regional disparities in terms of capital facilities, staff numbers and organisational expertise remained. Quality and availability of care were still primarily determined by where a patient lived. This article reports on this regional inequity after a decade of funding and policy changes. It arose out of a larger study funded by The Atlantic Philanthropies, whose 'End of Life' programme has contributed significantly to hospice and palliative care in the Republic of Ireland.<sup>1</sup> The full study's aims were to evaluate the 'End of Life' programme and capture wider learning from a decade of intensive policy implementation and service development.

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1. *Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report*, The Atlantic Philanthropies, 2013. This report presents the findings of a five-phased evaluation of the programme, which assessed the progress and impact of the programme to date, and the strategic learning for the field. [Noted in Media Watch, 21 January 2013] [http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation\\_Programme\\_Support\\_Palliative\\_and\\_Hospice\\_Care\\_%20Republic\\_of\\_Ireland.pdf](http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf)

Of related interest:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):140-145. 'Core competencies in palliative care: White Paper on palliative care education – part 2.'<sup>1</sup> In the second part of this consensus issued by the European Association for Palliative Care, the authors describe in more detail the ten core interdisciplinary competencies in palliative care

1. *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(2):86-91. 'Core competencies in palliative care: White Paper on palliative care education – Part 1.' [Noted in Media Watch, 4 March 2013]

**N.B.** Access to the *European Journal of Palliative Care* requires a subscription. Contents page: [http://www.haywardpublishing.co.uk/year\\_search\\_review.aspx?JID=4&Year=2013&Edition=474](http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2013&Edition=474)

### End-of-life care in the U.K.

#### **Redesigning end of life care in the community**

*HEALTH SERVICE JOURNAL* (U.K.) | Online – 8 May 2013 – The challenges for the health and social care system in our rapidly ageing society and the pressure associated with ongoing public spending constraints are clear for all to see. Faced with these twin challenges, we can either stand by and oversee a gradual decline in the quality of care provided or we can seize the opportunity to fundamentally change the way we do things. Our task is to find new ways to deliver better care for a greater number of people with fewer resources. Marie Curie's latest report ... argues that by examining how the health and social care system can meet the needs of people who are dying, we can learn a lot about the future scope and focus of other services.<sup>1</sup> It says that in order to break with the current overreliance on hospitals in caring for people in the last weeks of life, we need to improve end of life care in all health and social care settings. The clear message to emerge ... is that hospitals are not the best places to care for people who are dying. The VOICES survey, which collated the views of people who had recently lost a relative, found that there were very different experiences of care depending on whether the deceased person had died in a hospital, hospice, care home or their own home.<sup>2</sup> Hospitals scored worst across almost all measures. The ... report shows the significant differences in perceptions of care between different settings: 32.6% of respondents whose loved one died in hospital said the care was excellent or outstanding, compared to 53.7% at home, 51.3% for care homes and 59.1% for hospices. <http://www.hsj.co.uk/home/innovation-and-efficiency/redesigning-end-of-life-care-in-the-community/5057553.article?blocktitle=Resource-Centre&contentID=8630>

1. 'Dying & Death,' Marie Curie Cancer Care, February 2013. [Noted in Media Watch, 18 February 2012] [http://www.mariecurie.org.uk/Documents/press-and-media/Death-dying-Exec-Summary\\_FINAL\\_web.pdf](http://www.mariecurie.org.uk/Documents/press-and-media/Death-dying-Exec-Summary_FINAL_web.pdf)
2. 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012. [Noted in Media Watch, 9 July 2012] [http://www.ons.gov.uk/ons/dcp171778\\_269914.pdf](http://www.ons.gov.uk/ons/dcp171778_269914.pdf)

## The digital remains: Social media and practices of online grief

*THE INFORMATION SOCIETY*, 2013;29(3):190-195. This article analyzes comments posted in response to articles and blog posts discussing Facebook's policies on the pages of deceased site members. These virtual discourses reflect the socio-cultural importance of social media policies in everyday life that is increasingly a blend of online and offline interaction. Analysis reveals themes of contested ownership of online identities, resistance to unilateral institutional policies, and social media site users' complex relationship to the preservation of virtual content. As a still-evolving phenomenon, virtual grief elucidates wider cultural trends at work in the construction of identity and community online. <http://www.tandfonline.com/doi/abs/10.1080/01972243.2013.777311>

**N.B.** This issue of *The Information Society* focuses on death, afterlife, and immortality of bodies and data. Journal contents page: <http://www.tandfonline.com/toc/utis20/current>

Noted in Media Watch, 1 April 2013:

- NATIONAL PUBLIC RADIO | Online – 28 March 2013 – **'Why more patients should blog about illness and death.'** Blogging empowers patients to talk about illness outside the typical frame of "the battle," Christian Sinclair says and reading the stories helps family members, too. <http://www.npr.org/blogs/health/2013/03/26/175383540/why-more-patients-should-blog-about-illness-and-death>

Noted in Media Watch, 5 March 2012:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;64(4):275-302. **'Does the Internet change how we die and mourn?'** This article outlines issues the Internet presents to death studies. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,6;journal,1,255;linkingpublicationresults,1:300329,1>

## Helping the angels: A review of understanding and helping dying children

*INNOVATIONS IN CLINICAL NEUROSCIENCE*, 2013;10(3):31-34. Helping a child face death can be a stressful and daunting challenge for a clinician. We must remember that each child is unique. To help a child cope with fears and anxieties that surround illness and death, we must treat each child on an individual basis. A clinician must be sensitive and tuned to a child's feelings, thoughts, and actions. Any work with the dying child should be crafted as compassionate and palliative care with child's best interests foremost in mind. The goal should be to add life to the child's years, not simply years to the child's life. It is impossible to find a comprehensive answer that will be universally valid for all children. The authors attempt to alert clinician to special needs of dying children and offer some measures for effectively helping to reduce the suffering in these children and their families. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3638843/>

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 8 May 2013 – **'The development of an instrument that can identify children with palliative care needs: The paediatric palliative screening scale – A qualitative study approach.'** This preliminary phase of development and validation of the instrument revealed five domains relevant to identifying children with life-limiting diseases who could benefit from palliative care: 1) trajectory of disease and impact on daily activities of the child; 2) expected outcome of disease-directed treatment and burden of treatment; 3) symptom and problem burden; 4) preferences of patient, parents or healthcare professional; and 5) estimated life expectancy. Where palliative care seems to be necessary, it would be introduced in a stepwise or graduated manner. <http://www.biomedcentral.com/content/pdf/1472-684X-12-20.pdf>

Cont.

Noted in Media Watch, 29 April 2013:

- *ISSUES IN COMPREHENSIVE PEDIATRIC NURSING* | Online – 19 April 2013 – **'Parent and professional perspectives on care for children at the end of life.'** Six issues were identified across professional groupings as particularly challenging within the context of caring for children at the end-of-life: truth telling; symptom management; communication with, and relationships between families and professionals; emotional impact, the withdrawal of feeding or treatment and sibling support. <http://www.ncbi.nlm.nih.gov/pubmed/23600569>

Noted in Media Watch, 22 April 2013:

- *JOURNAL OF PALLIATIVE MEDICINE*, 2013;16(4):334-336. **'Pediatric palliative care research comes of age: What we stand to learn from children with life-threatening illness.'** This issue of the journal includes three articles to inform the provision of palliative care for children with life-threatening illness and their families. They highlight innovative strategies to reduce suffering and improve the well-being of seriously ill children and families. Journal contents page: <http://online.liebertpub.com/toc/jpm/16/4>

### Communication in end-of-life care

#### **The best place for bare-knuckled ethics**

*JOURNAL OF CLINICAL ETHICS*, 2013;24(1):3-10. In the documentary 'Boston Med,<sup>1</sup> patients, their family members, and their care providers agree to be filmed in real medical situations. Why would they do this? The possible answers to this question may help us to make sense of the paradoxical results of a recent study, in which patients with terminal illness ranked their care providers highly for communication, even though the patients had failed to learn that they had a fatal illness. Based on this analysis, the author offers care providers a practical approach they can use to improve communication with patients, particularly to help patients to feel less alone. [http://www.clinicalethics.com/single\\_article/9rlachlu5IA.html](http://www.clinicalethics.com/single_article/9rlachlu5IA.html)

1. An eight-episode, U.S. television documentary series chronicling the life and drama of staff, nurses, patients and their families at three major hospitals.

#### **Why shared decision making is not good enough: Lessons from patients**

*JOURNAL OF MEDICAL ETHICS* | Online – 9 May 2013 – A closer look at the lived illness experiences of medical professionals themselves shows that shared decision making is in need of a logic of care. This paper underlines that medical decision making inevitably takes place in a messy and uncertain context in which sharing responsibilities may impose a considerable burden on patients. A better understanding of patients' lived experiences enables healthcare professionals to attune to what individual patients deem important in their lives. This will contribute to making medical decisions in a good and caring manner, taking into account the lived experience of being ill. <http://jme.bmj.com/content/early/2013/05/08/medethics-2012-101215.abstract>

#### **Latent classes of prognosis conversations in palliative care: A mixed-methods study**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 May 2013 – Prognosis conversations are complex phenomena of substantial importance to palliative care (PC), yet these remain poorly understood. This study empirically identifies and describes major types of prognosis conversations that occur in the natural setting of PC consultation. The authors observed three discrete types of prognosis conversations, each placing different communication demands upon all participants for achieving goal-concordant care: navigating options and goals (56% of consultations), facilitating new goals (23%), and preparing for end-of-Life (21%). This study provides the first step for developing educational and clinical prognosis communication interventions that are tailored to common decision-making contexts facing seriously ill patients, their families, and PC clinicians. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0381>

## Engage, empower, and enlighten: Art therapy and image making in hospice care

*PROGRESS IN PALLIATIVE CARE*, 2013;21(2):83-88. When art therapy exists as part of an interdisciplinary hospice team, it can enhance the holistic continuum of end of life comfort care. One case study is discussed that illustrates the art therapy journey for a hospice patient and the ensuing benefits including: using imagery and symbolism to communicate challenging emotions; gaining self-empowerment through the engagement of making art and reflecting on the resulting product; and, offering a non-threatening means to explore thoughts and feelings. Recommendations are made for further advocacy on the efficacy of art ther-

apy as a complementary intervention that can have a positive impact on the holistic well-being of the palliative care patient. <http://www.ingentaconnect.com/content/maney/ppc/2013/00000021/00000002/art00004>

### Quotable Quotes

*The process of art therapy is based on the recognition that man's most fundamental thoughts and feelings, derived from the unconscious, reach expression in images rather than words.*  
Margaret Naumberg (1890-1983)

Noted in Media Watch, 20 August 2012:

- *INTERNATIONAL JOURNAL OF ART THERAPY* | Online – 7 August 2012 – **'Working with loss: An examination of how language can be used to address the issue of loss in art therapy.'** This article will examine the ubiquity of loss and how this can influence the manner in which art therapists work with clients facing a life threatening illness or a significant bereavement. <http://www.tandfonline.com/doi/abs/10.1080/17454832.2012.707665>

Noted in Media Watch, 17 May 2010:

- *JOURNAL OF HOLISTIC NURSING*, 2008;26(2):147-154. **'Children's wishes.'** The language of children is unsophisticated; however, they speak meaningfully through their drawings. Children use symbols and images to represent elements in circumstances they are trying to understand. <http://jhn.sagepub.com/cgi/content/abstract/26/2/147>

## Considering Aboriginal palliative care models: The challenges for mainstream services

*RURAL & REMOTE HEALTH* | Online – 8 May 2013 – Aboriginal people in Australia account for a very small proportion of the population, have poorer health outcomes and their culture demonstrates a clear resistance to accessing mainstream health services which are viewed as powerful, isolating and not relevant to their culture, way of life, family and belief systems. Aboriginal people regard their land as spiritual and their culture dictates that an Aboriginal person needs to know their origins, emphasising the value placed on kin and also demonstrating a strong desire to remain within their own country. Currently Aboriginal people tend to not access palliative care services in mainstream facilities; and there is very little data on Aboriginal admissions to palliative care centres. Over the last two decades only two models of palliative care focusing on and developed in Aboriginal communities have been implemented. The seminal contribution to Aboriginal Palliative Care was in the form of a resource kit developed to support palliative care providers to examine their practice for cultural appropriateness for Aboriginal and Torres Strait Islanders. The "living model" coming from this project is adaptive and flexible, enabling implementation in different Aboriginal country as a participative process with community input. The Australian government's National Indigenous Palliative Care Needs Study similarly indicated that Australian empirical research on Aboriginal palliative care service provision is in its infancy, and comprehensive data on the rates of Aboriginal access to palliative care services did not exist.<sup>1</sup> <http://www.rrh.org.au/articles/subviewaust.asp?ArticleID=2339>

1. 'National Indigenous Palliative Care Needs Study,' Department of Health & Ageing, 2003. [http://www.health.gov.au/internet/main/publishing.nsf/Content/5619BFE763995E17CA256F410011C5C3/\\$File/needall.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/5619BFE763995E17CA256F410011C5C3/$File/needall.pdf)

## Media Watch Online

### Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

### Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

### Canada

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

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpconnection.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>

### 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>

### International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online – 2 May 2013 – **'Most religious followers support assisted suicide for the dying.'** A large survey in the U.K. has found that a majority of those people who said that they followed a religion – 64% – think that there should be a change in the law to allow assisted suicide for people who are terminally ill. Only among Baptists and Muslims was there a majority against such a change. The survey of nearly 4500 adults, 3000 of whom were religious, found that the greatest support for a legislative change was among those who did not have a religion... <http://www.bmj.com/content/346/bmj.f2855>

Noted in Media Watch, 6 May 2013:

- U.K. | *The Daily Telegraph* – 30 April 2013 – **'National Health Service fears fuelling support for assisted suicide, poll suggests.'** Fears about standards care for terminally ill people are fuelling support for the legalisation of assisted suicide, a study suggests. <http://www.telegraph.co.uk/health/healthnews/10026314/NHS-fears-fuelling-support-for-assisted-suicide-poll-suggests.html>

Cont.

- *HEALTH CARE ANALYSIS*, 2013;21(2):85-104. **'Organised assistance to suicide in England?'** Guidelines provided by the Director of Public Prosecutions suggest that anyone assisting another to commit suicide in England & Wales, or elsewhere, will not be prosecuted provided there are no self-seeking motives and no active encouragement. This paper explores the legitimacy of the current restrictive position adopted towards assisted suicide in England. It argues that the provisions within the guidelines prohibiting organisations that assist suicides, leaves some without the help they need. While legislative decriminalisation of assisted suicide and the establishment of state-sponsored suicide centres would represent the most permissive regime, this paper proposes that this would be a step too far. The preference here is for decriminalisation but adopting a 'middle way' between the two extremes: the more permissive approach provided by the 'Swiss model' is one that could be employed here, albeit within a more robust regulatory regime. <http://link.springer.com/article/10.1007/s10728-011-0191-y>

## Worth Repeating

### **Return home at the end of life: Patients' vulnerability and risk factors**

*PALLIATIVE MEDICINE*, 2011;25(2):139-147. Although most of the people in good health questioned about the subject said they would like to die at home, in the western world between 60-80% of deaths occur in hospital. Most authors consider that the indispensable conditions for a return home are the patient's desire and presence of the family and caregivers with the appropriate skills. The assessment of other factors predictive of a return home is inadequate. The aim of this study is to clarify how the return home is influenced by the vulnerability of the patient at the end of life, and by that of the family and caregivers. The authors carried out a ... study (with three months follow-up), including 146 patients hospitalized at the end of their life and desiring to return home. For these patients the caregivers respected their freedom to choose to die at home in over half the cases (56%). Their overall vulnerability (personal, family context, and caregivers) had a significant influence on the return home. This overall vulnerability was in fact identified as applying in 40% of the clinical situations, and made the possibility of a return home 50% less likely. <http://pmj.sagepub.com/content/25/2/139.abstract>

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