# 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-oflife care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

# 15 July 2013 Edition | Issue #314



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

Compiled & Annotated by Barry R. Ashpole

In the context of limited resources: Scroll down to <u>Specialist Publications</u> and 'Evidence on the cost and cost-effectiveness of palliative care: A literature review' (p.10), in *Palliative Medicine*.

# <u>U.S.A.</u>

# Hassan vetoes bill to form end-of-life study committee

NEW HAMPSHIRE | *The Union Leader* (Manchester) – 12 July 2013 – Governor Maggie Hassan issued her first veto of her term, rejecting as unnecessary legislation that created a committee to study "end-of-life decisions." House Bill 403 was passed by the House in February and by the Senate in May. But Hassan cited existing statute and a new bill she signed into law regarding "advance directive" life-sustaining treatment in her veto message. She said, "With any discussion of the complex and emotional issues related to end-of-life decisions, our focus must always be first and foremost on helping all of those in our society to fully live their lives with the dignity that they deserve. We have approached these issues very seriously and thoughtfully, always seeking to include the input of those who understand these issues best: doctors, patients, advocates for the elderly and those who experience chronic conditions or disabilities, and the people of New Hampshire." http://www.unionleader.com/article/20130712/NEWS06/130719713

# Aging prisoners' costs put systems nationwide in a bind

LOUISIANA | KSDK TV News (St. Louis, Missouri) – 11 July 2013 – The fiscal, legal, social and political challenges of housing this country's graying inmates have arrived with full force at precisely the time when states, and the federal government, are looking to rein in spending. A problem swelling for decades has become "a national epidemic," according to a 2012 report by the American Civil Liberties Union [ACLU].<sup>1</sup> Yet efforts to address an issue that will only worsen with time have largely floundered, ensuring that even incapacitated inmates ridden with tumors or paralyzed by Parkinson's disease live their last days in prison hospitals. The enormous medical costs required to maintain this status quo will inevitably sap money from other areas of government that affect residents who will never set foot near these penitentiaries. Nearly a quartermillion inmates in state and federal prisons – enough to fill the Rose Bowl nearly three times – are classified as "elderly" or "aging," according to the ACLU report. The designation applies to inmates age 50 and older whose aging process, according to the National Institute of Corrections, is often accelerated by general poor health before entering prison and the stress of confinement once there. <a href="http://www.ksdk.com/news/article/387777/28/Aging-inmates-taxing-America">http://www.ksdk.com/news/article/387777/28/Aging-inmates-taxing-America</a>

1. *At America's Expense: The Mass Incarceration of the Elderly*, American Civil Liberties Union, June 2012. [Noted in Media Watch, 18 June 2012, #258 (p.4)] <u>http://www.aclu.org/criminal-law-reform/report-americas-expense-mass-incarceration-elderly</u>

Noted in Media Watch, 18 June 2012, #258 (p.9):

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 14 June 2012 – 'Aging in correctional custody: Setting a policy agenda for older prisoner health care.' The authors convened a meeting of experts in correctional health care, academic medicine, nursing, and civil rights to identify knowledge gaps and to propose a policy agenda to improve the care of older prisoners. Nine priority areas were identified: definition of the older prisoner, correctional staff training, definition of functional impairment in prison, recognition and assessment of dementia, recognition of the special needs of older women prisoners, geriatric housing units, issues for older adults upon release, medical early release, and prison-based palliative medicine programs.http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2012.300704?prevSearch=priso ners&searchHistoryKey=

**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.17.

### Senate Special Committee on Aging

### Making sure your end-of-life wishes are followed

U.S. NEWS & WORLD REPORT | Online -11 July 2013 - Advanced directives and surrogates are needed if end-of-life wishes are to be followed, several experts recently testified at a U.S. Senate Special Committee on Aging hearing. Simply having these directives in place does not guarantee good outcomes for patients or their families. Without express and binding instructions about when to withhold care, hospitals and health care professionals generally have their own moral and legal obligations to keep a person alive as long as possible. When consumers are asked about their preferred end-of-life care, the committee was told, it turns out that they strongly favor less care, particularly if such care would be unlikely to lead to a cure and if it saddles the family with heavy health care expenses. Slowly, more and more families are "having the conversation" about end-of-

Noted in Media Watch, 1 July 2013, #312 (p.2):

life preferences and care. Such discussions also are likely to lead to the development of formal documents. The documents may carry different names in different states, but the good ones share two attributes: they explain the type of care people want if they are seriously ill, and they name a health care surrogate to make medical decisions on their behalf should they be incapacitated. http://money.usnews.com/money/blogs/thebest-life/2013/07/11/making-sure-your-endof-life-wishes-are-followed

# Specialist Publications

'Avoiding a "death panel" redux' (p.7), in The Hastings Report.

ASSOCIATION OF MATURE AMERICAN CITIZENS | Online – 27 June 2013 – 'Advanced care planning.' In a hearing entitled 'Renewing the Conversation: Respecting Patient's Wishes and Advanced Care Planning,' Senators and experts who specialize in end-of-life care testified to current trends among older Americans and shared their recommendations for responsible health care planning. <a href="http://amac.us/advanced-care-planning">http://amac.us/advanced-care-planning</a>

# Disability ramps up in last months of life

HEALTH 24 | Online – 9 July 2013 – People who live long are much more likely to be disabled and require caregiving during their last months of life, two new studies found.<sup>1,2</sup> A national study of more than 8,200 older Americans revealed more than one of every three seniors can expect to experience disability within their last year of life that will affect their ability to handle daily activities such as dressing, bathing, eating, getting in or out of bed, walking across the room or using the toilet. A smaller survey of 491 seniors in New Haven, Connecticut, found disability ramps up quickly in the last few months of life. Five months before death, about 27% of the seniors surveyed needed help due to disability; that number increased rapidly to 57% in the month prior to death. <u>http://www.health24.com/Medical/Palliative-care/News/Disability-ramps-up-in-the-lastmonths-of-life-20130709</u>

- 'Restricting symptoms in the last year of life: A prospective cohort study,' JAMA Internal Medicine, 8 July 2013. Restricting symptoms are common during last year of life, increasing substantially approximately five months before death. The authors' highlight the importance of assessing and managing symptoms in older patients, particularly those with multi-morbidity. <u>http://archinte.jamanetwork.com/article.aspx?articleid=1710124</u>
- 2. 'Disability during the last two years of life,' *JAMA Internal Medicine*, 8 July 2013. Those who live to an older age are likely to be disabled, and thus in need of caregiving assistance, many months or years prior to death. Women have a substantially longer period of end-of-life disability than men. <u>http://archinte.jamanetwork.com/article.aspx?articleid=1710125</u>

# **International**

### The Liverpool Care Pathway

### Review for end-of-life regime in Scotland

U.K. (SCOTLAND) | The Scotsman (Edinburgh) – 14 July 2013 – Scottish ministers are to consider the future of a controversial end-of-life regime north of the Border. The move came after it emerged yesterday that a review of the regime in England was expected to recommend it should be phased out. The Liverpool Care Pathway, which recommends in some circumstances doctors withdraw treatment, food and water from sedated patients in their final days, is under intense scrutiny. Reports have suggested doctors have been establishing "death lists" of patients to be put on the pathway, and that hospitals might be employing the method to cut costs and save bed spaces. However, medics have argued the pathway has transformed end-of-life care, saving it can offer peaceful, pain-free deaths when used properly. The Department of Health in England said an independent review ... was likely to recommend the programme be phased out over the next six to 12 months, and replaced with a new system. The Scottish Government said the recommendations would be considered by its Living & Dying

Well National Advisory Group "so any learning for Scotland can be taken forward." <u>http://www.scotsman.com/news/health/revie</u> <u>w-for-end-of-life-regime-in-scotland-1-</u> <u>3001009</u>

# Liverpool care pathway for dying patients to be scrapped after review

U.K. (ENGLAND) | The Guardian – 13 July 2013 - The Liverpool Care Pathway for dying patients is to be scrapped, ministers are expected to announce next week after an independent review. The regime was originally developed to allow terminally ill patients a peaceful and dignified death. But it came under intense criticism amid claims that it was being used to hasten deaths, clear beds and save money. An independent review of the system ... is expected to recommend the pathway is phased out ... [and] ... to say incentive payments for staff who put patients on end-of-life treatment plans should be banned, describing them as "totally unacceptable." http://www.guardian.co.uk/politics/2013/jul/13/live rpool-care-pathway-scrapped

### End-of-life care in Lebanon

### Palliative care recognition seen as boon to field

LEBANON | *The Daily Star* (Beirut) – 12 July 2013 – A recent decision to recognize palliative care as a medical specialization in Lebanon is expected to help encourage students interested in the field to stay in the country. Caretaker Health Minister Ali Hasan Khalil made the decision to make palliative care ... an official medical specialty in the country late last month. To date, few groups offer palliative care in Lebanon and in the region. Batlouni voiced hope that the move would encourage local hospitals to offer palliative care centers and education programs. "This announcement has many implications for the future; hospitals will be encouraged to open palliative care centers and education programs, medical students will be able to specialize in this domain, and the National Social Security Fund would cover palliative services," said Loubna Batlouni, an outreach coordinator from Balsam, one of the few non-governmental organizations that provide palliative care in the country. <u>http://www.dailystar.com.lb/News/Local-News/2013/Jul-13/223512-palliative-care-recognition-seen-as-boon-to-field.ashx#axzz2Z0y1tq2x</u>

### <u>End-of-life care in Japan</u>

### 70% don't want life-prolonging treatments

*THE JAPAN NEWS* | Online – 10 July 2013 – About 70% of Japanese said they do not wish to undergo life-prolonging treatments such as gastrostomy or artificial ventilation if they are suffering from terminal cancer or dementia, according to a survey conducted by the Health, Labor & Welfare Ministry. When asked about terminal cancer, 61% of respondents said they wanted to receive drip infusions for fluid replacement. However, 72% said they did not wish to have a gastrostomy. Sixty-seven percent also said they did not want to undergo artificial ventilation. When asked about preparing a document in advance specifying their wishes on medical treatments, 70% said they supported the idea. However, only 3% said they had actually prepared such documents. <a href="http://the-japan-news.com/news/article/0000354735">http://the-japan-news.com/news/article/0000354735</a>

N.B. Articles on end-of-life care in Japan are noted in Media Watch, 13 May 2013, #305 (pp.10-11).

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

### End-of-life care patients forced to choose between home and pain relief

U.K. | The Press Association – 9 July 2013 – Many people are having to make "unacceptable trade-offs" between passing away in their own home and receiving pain-free care at the end of their life, a new report has warned.<sup>1</sup> The report ... suggests that too many people are willing to go without pain relief in order to die at home with their family around them. The statistics indicate many people are compromising and not making positive decisions about how they will spend the end of their lives. <u>http://www.nursingtimes.net/nursing-practice/clinical-</u> zones/end-of-life-and-palliative-care/end-of-life-care-patientsforced-to-choose-between-home-and-painrelief/5060843.article?blocktitle=News&contentID=4385

# **Specialist Publications**

"Focus on dying at home has inhibited development of end-of-life care" (p.7), in *Community Care* (for additional perspective on the Sue Ryder report).

1. A Time and a Place: What People Want at the End of their Life, Sue Ryder, July 2013. http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isntworking/~/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx Of related interest:

- U.K. | National Council for Palliative Care 11 July 2013 'National Bereavement Survey (VOICES) published.' The second National Bereavement Survey on the quality of end-of-life care in the last three months of life, has been published.<sup>1,2</sup> Overall quality of care across all services in the last three months of life was rated by 44% of respondents as outstanding or excellent. Staff in hospices was more likely to show dignity and respect than those in hospitals. http://www.ncpc.org.uk/news/National%20Bereavement%20Survey%20%28VOICES%29%20 %20published
  - 1. 'National Bereavement Survey (VOICES), 2012,' Office for National Statistics, July 2013. http://www.ons.gov.uk/ons/dcp171778\_317495.pdf
  - 'National Bereavement Survey (VOICES), 2011,' Office for National Statistics, July 2012. [Key findings and summary noted in Media Watch, 9 July 2012, #261 (p.4)] <u>http://www.ons.gov.uk/ons/dcp171778 269914.pdf</u>

### Reflective practice and empathy

### The difference between looking and seeing

AUSTRALIA | The Age – 8 July 2013 – At first glance a crisp white doctor's coat may look slightly out of place in the quiet calm of an art gallery, but an innovative partnership program at the University of Melbourne is drawing a new picture of teaching and learning, particularly in the medical arena. Led by Dr. Heather Gaunt, Curator of Academic Programs (Research) at the Ian Potter Museum of Art, a team of academics and professionals is exploring ways to incorporate visual observation, reflection and interpretation into the learning process. It all started just over a year ago when Dr. Natasha Michael, a palliative care consultant with the Peter MacCallum Cancer Centre put in a call to the Museum. She was interested in exploring opportunities for her students to de-

Financial aspects of terminal illness

velop their visual observation skills in an art context. Michael's own medical training was strongly influenced by the humanities – literature, visual arts, music and theatre – areas she considers helpful for reflective practice and empathy development in doctors. http://www.theage.com.au/national/educatio n/voice/the-difference-between-looking-andseeing-20130704-2peev.html

# Specialist Publications

**'Empathy in palliative care: A biological inheritance'** (p.6), in *British Journal of Community Nursing.* 

### Terminally ill woman questions superannuation early release laws

AUSTRALIA (QUEENSLAND) | *The Financial Standard* (Sydney, New South Wales) – 8 July 2013 – A Queensland woman diagnosed with terminal cancer has said she will have to sell her home after she found that she could not access her superannuation. Donna Penny had been given between one and five years to live. Penny said she wanted to spend her last years with her family rather than working. However, federal legislation will only allow early release of superannuation on the grounds of terminal illness if the member has been given less than a year to live. Penny's super fund, HESTA [Health Employees Superannuation Trust Australia], said it has no discretion to release funds early if the member does not meet these requirements. HESTA deputy chief executive Debby Blakey said, "Every super fund in Australian has the same conditions of release." http://www.financialstandard.com.au/news/view/33296449

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

### Understanding the complex role of a hospice spiritual counselor

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 July 2013 – Hospice's professional roles in end-of-life care can be widely misunderstood by physicians, patients, and family members as well as others who do not work directly with them. The role of the spiritual counselor may be the most misunderstood due to the nature of this professional title. Hospice care at the end of life is holistic in that it is important to meet physical, emotional, and spiritual needs of the patient and their family. In order to provide the most complete and beneficial end-of-life care, it is important to understand the complexity and the importance of the role of the spiritual counselor. <a href="http://ajh.sagepub.com/content/early/2013/06/19/1049909113494746.abstract">http://ajh.sagepub.com/content/early/2013/06/19/1049909113494746.abstract</a>

Articles on spirituality and end-of-life care noted in past issues of Media Watch:

- JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2013;9(2-3):111.
   'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.' This issue of the journal gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care.<sup>1</sup> [Noted in Media Watch, 24 June 2013, #311 (p.12)] <u>http://www.tandfonline.com/doi/full/10.1080/15524256.2013.793988</u>
  - 1. Journal contents page: <u>http://www.tandfonline.com/toc/wswe20/current</u>
- ARCHIVE FOR THE PSYCHOLOGY OF RELIGION, 2012;34(1):63-81. 'Six understandings
  of the word 'spirituality' in a secular country.' Spirituality ... is often poorly defined and
  one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It
  is concluded that a common understanding of the term spirituality does not exist, at least in a
  modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)]
  http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005

**N.B.** This issue of the *Archive for the Psychology of Religion* focuses on spirituality. Journal contents page: <u>http://booksandjournals.brillonline.com/content/15736121</u>.

# Empathy in palliative care: A biological inheritance

BRITISH JOURNAL OF COMMUNITY NURSING, 2013;18(7):358. Community nurses play a crucial role in the provision of palliative care throughout the U.K. Among many other important components of their role, empathy, which involves providing emotional care and support to dying patients and those important to them, is a central and sensitive aspect of their work. Empathy is a critical component of the social intelligence needed for such support and is popularly associated with the ability to identify with the emotional experiences of others. When offered appropriately, empathy can help others to continue living their lives with enhanced quality of life and dignity in dying. http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=99489



### 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

# "Focus on dying at home has inhibited development of end-of-life care"

COMMUNITY CARE (U.K.) | Online – 9 July 2013 – A preoccupation with where people die – rather than what they want at the end of life – has inhibited personalisation and informed choice for patients and families, according to recently published research.<sup>1</sup> People are being forced to make unacceptable trade-offs between dying in the place of their choosing or being free from pain and discomfort. Researchers found 78% said their main priority at the end of their lives was a pain-free death. This was followed by being surrounded by loved ones (71%), having privacy and dignity (53%), and being in familiar, peaceful surroundings (45%). However, while 63% of people wanted to die at home, only 27% felt that home was a place where they would be free from pain during their final days. The report concluded: "This focus on where people die – rather than what they want at the end of life – has inhibited personalisation and informed choice for patients and their families. It has led to a lack of proper scrutiny of the experience of dying at home and left other settings neglected when it comes to developing them as good places for people to die." <a href="http://www.communitycare.co.uk/articles/09/07/2013/119316/focus-on-dying-at-home-has-inhibited-development-of-end-of-life.htm">http://www.communitycare.co.uk/articles/09/07/2013/119316/focus-on-dying-at-home-has-inhibited-development-of-end-of-life.htm</a>

1. A Time and a Place: What People Want at the End of their Life, Sue Ryder, July 2013. http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/Dying-isntworking/~/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx

### Avoiding a "death panel" redux

THE HASTINGS REPORT, 2013;43(4):20-28. If engaging in end-of-life conversations and advance care planning not only is desired by many Americans but also might significantly improve patient care at the end of life, then why was a provision that provided reimbursement for physicians to engage in end-of-life planning through Medicare removed from legislation? If ... reimbursements under Medicare "would have been a start" for encouraging these conversations, then why was the Advance Care Planning Consultation [ACPC] provision in the 2008 health reform effort so vehemently opposed by politicians and citizens alike? The heated and misleading rhetoric employed against the ACPC undoubtedly contributed to intractable polarization surrounding this portion of the health reform bill and assured its failure. But the ACPC's emphasis on "checklists" and regulation may also have served as fodder for these fiery critiques. If that's right, legislation that focuses squarely on the broader and more fundamental goals of endof-life consultations and deemphasizes administrative and documentary concerns may have a greater chance for success in years to come, as reform is implemented and the battle over the ACPC fades from memory. http://onlinelibrary.wiley.com/doi/10.1002/ha st.190/abstract

# What's not being shared in shared decision-making?

THE HASTINGS REPORT, 2013;43(4):13-16. What's not to like about shared decision-making? These programs employ specially crafted decision aids to educate patients about their treatment options and then merge the newly informed patient preferences, both general and treatmentspecific, with guidance from physicians to optimize medical decisions. Sounds great, right? Even better, recent evidence indicates that shared decision-making programs may also help bend the proverbial cost curve by reducing the use of medical interventions that patients, now properly educated about their options, often say they do not want. The notion that programs to inform and elicit patient choice might also help to align health care delivery with patient preferences for less invasive and therefore less costly treatment options seems the rarest of mutual wins in health care, in which what is best for the individual might also benefit the whole. Yet there has been scant attention to how the goals of patient care and cost-containment, and perhaps even coincide profitability. or conflict. http://onlinelibrary.wiley.com/doi/10.1002/hast.18 8/abstract

Of related interest:

- THE HASTINGS REPORT, 2013;43(4):29-30. 'Cuing "the conversation.'' In 'Avoiding a "death panel" redux,' the author describes how she tried to fire palliative care after first refusing to let it and any mention of death, from any source into her dying mother's room. One way to read this is as a familiar human story about the profound difficulty of facing death, a story that, too often, is reduced to the word "denial." If advance care planning had been part of the structure all along, if everyone oncologists, patients, loved ones talked about prognosis, preferences, benefits, burdens, and goals from the time a life-threatening disease was diagnosed, as a normal part of good care, would the author have understood her own role as care-giver and advocate differently? <a href="http://onlinelibrary.wiley.com/doi/10.1002/hast.191/abstract">http://onlinelibrary.wiley.com/doi/10.1002/hast.191/abstract</a>
- THE HASTINGS REPORT, 2013;43(4):30-32. 'The "good planning panel.'' In 'Avoiding a "death panel" redux,' the authors make the argument the ACPC provision during the health care reform debate collapsed both because the language in the provision was deliberately misread and because some features of the language could in fact be misleading. We [i.e., the authors of this article] agree on both counts. [They] add that the cost-effectiveness provisions of the bill make us face difficult decisions we as a nation would rather avoid, but can and must face squarely and together. <a href="http://onlinelibrary.wiley.com/doi/10.1002/hast.192/abstract">http://onlinelibrary.wiley.com/doi/10.1002/hast.192/abstract</a>

### End-of-life care in Ireland

### Inequity crises in hospice care

IRISH MEDICAL NEWS | Online - 12 July 2013 - The 2001 report of the National Advisory Committee on Palliative Care (NAPC) found that there was "wide variation in the type and level of service provision within each health board area," and it made a number of recommendations to "ensure the equitable delivery of palliative care services in all health board areas."<sup>1</sup> Again, in 2009, a Health Services Executive (HSE) report found there was "a wide regional and intraregional variation in the availability of specialist palliative care in a specialist inpatient unit."<sup>2</sup> In 2013, 12 years on from the NAPC report and four years since the HSE report, a new publication from the Irish Hospice Foundation (IHF) has revealed there has been little progress in relation to the availability of inpatient hospice beds.<sup>3</sup> In fact it revealed that an estimated 2,500 patients a year here are denied access to much needed inpatient hospice care. According to the report "results in regional inequity in resource allocation, approximately 2,470 patients being denied admission to hospice beds in Ireland each year. The 2001 NAPC report, which was adopted as Government policy, recommended that there should be one hospice bed per 10,000 people. However, the most recent IHF report found that just two regions ... came close to fulfilling this quota. According to the IHF report, there should currently be 450 hospice beds in the country. However, currently, there are just 155 such beds available with another 44 ready but not vet operational. http://www.imn.ie/index.php?option=com content&view=article&id=5314:inequity-crisis-inhospice-care&catid=57:clinical-news&Itemid=3

- 1. *Report of the National Advisory Committee on Palliative Care*, Department of Health & Children, 2001. <u>http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1</u>
- 2. *Palliative Care Services Five Year/Medium Term Development Framework*, Health Care Executive, 2009. <u>http://www.hse.ie/eng/services/Publications/corporate/palcareframework.pdf</u>
- Access to Specialist Palliative Care Services and Place of Death in Ireland: What the data tells us, Irish Hospice Foundation, May 2013. [Noted in Media Watch, 1 July 2013, #312 (p.6)] <u>http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf</u>

# Estimating the potential life-shortening effect of continuous sedation until death: A comparison between two approaches

JOURNAL OF MEDICAL ETHICS | Online – 11 July 2013 – In some cases, physicians estimate that continuous sedation until death may have a life-shortening effect. The accuracy of these estimations can be questioned. The aim of this study is to compare two approaches to estimate the potential life-shortening effect of continuous sedation until death. According to the direct approach, sedation might have had a life-shortening effect in 51% of the cases and according to the indirect approach in 84%. The intrarater agreement between both approaches was fair. In 10% of all cases, the direct approach yielded higher estimates of the extent to which life had been shortened; in 58% of the cases, the indirect approach yielded higher estimates. The results show a discrepancy between different approaches to estimate the potential life-shortening effect of continuous sedation until death. <u>http://jme.bmj.com/content/early/2013/07/10/medethics-2013-101459.abstract</u>

Noted in Media Watch, 20 May 2013, #306 (pp.10-11):

CURRENT OPINION IN ONCOLOGY | Online – 9 May 2013 – 'Palliative sedation in end-oflife care.' A number of authors have published interesting new findings ... [on] ... prevalence, indications, monitoring, duration and choice of drugs. In particular, a clear definition of palliative sedation and of its more pronounced form, deep continuous sedation, has emerged. It has been confirmed that, when performed in the correct way and with the right aims, palliative sedation does not have a detrimental impact on survival. <u>http://journals.lww.com/cooncology/Abstract/publishahead/Palliative sedation in end of life\_care.99618.aspx</u>

**N.B.** Several articles on palliative sedation that have been noted in past issues of Media Watch are listed in this issue of the weekly report.

# Do afterlife beliefs affect psychological adjustment to late-life spousal loss?

JOURNALS OF GERONTOLOGY (Series B) | Online – 29 June 2013 – Bleak or uncertain views about the afterlife [in this analysis] are associated with multiple aspects of distress post loss. Uncertainty about the existence of an afterlife is associated with elevated intrusive thoughts, a symptom similar to post-traumatic distress. Widowed persons who do not expect to be reunited with loved ones in the afterlife report significantly more depressive symptoms, anger, and intrusive thoughts at both 6 and 18 months post loss. Beliefs in an afterlife may be maladaptive for coping with late-life spousal loss, particularly if one is uncertain about its existence or holds a pessimistic view of what the afterlife entails. Findings are broadly consistent with recent work suggesting "continuing bonds" with the decedent may not be adaptive for older bereaved spouses. http://psychsocgerontology.oxfordjournals.org/content/early/2013/06/28/geronb.gbt063.abstract

Noted in Media Watch, 28 March 2011, #194 (p.9):

 JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 March 2011 –'Perspectives on death and an afterlife in relation to quality of life, depression, and hopelessness in cancer patients without evidence of disease and advanced cancer patients.' When there was no evidence of disease, negative emotions played the most important role, whereas in the advanced cancer situation, attitudes toward death and an afterlife ... became more prominent. http://www.jpsmjournal.com/article/S0885-3924(11)00013-3/abstract

### Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.17.

# Good practice in helping people cope with terminal illnesses

*LEARNING DISABILITY PRACTICE*, 2013;16(6). The 'Confidential Inquiry into Premature Deaths of People with Learning Disabilities' reviewed the deaths over a two-year period of all people with learning disabilities living in five primary care trusts [in the U.K.].<sup>1</sup> It aimed to identify good practice in the care of people with learning disabilities, and to contribute to learning and recommendations about what might have been done differently. This article presents a case study about end-of-life planning and palliative care. It discusses how a multidisciplinary team collaborated to support an individual with a terminal condition. Examples are given of the good practice recognised by the confidential inquiry investigation, and learning points arising from the case are highlighted. <a href="http://learningdisabilitypractice.rcnpublishing.co.uk/archive/article-good-practice-in-helping-people-cope-with-terminal-illnesses">http://learningdisabilitypractice.rcnpublishing.co.uk/archive/article-good-practice-in-helping-people-cope-with-terminal-illnesses</a>

1. Confidential Inquiry into Premature Deaths of People with Learning Disabilities, Department of Health, March 2013. <u>http://www.bris.ac.uk/cipold/fullfinalreport.pdf</u>

# Utilising feedback from patients and their families as a learning strategy in a Foundation Degree in palliative and supportive care: A qualitative study

NURSE EDUCATION TODAY | Online – 9 July 2013 – In the U.K., support workers provide much of the care that palliative care patients receive, and a novel Foundation Degree was developed to enhance their skills. Feedback on performance is a recognised educational tool that reinforces good practice, and gives insight into areas of weakness, but its use with this workforce has not been described. Positive feedback [among students enrolled in the Foundation Degree in Palliative & Supportive Care] helped to increase confidence, and negative feedback allowed students to look critically at their practice and identify areas of weakness. Some experienced challenges in approaching patients/families due to having a small number of suitable patients/families; a reluctance to burden patients; high patient turnover and brevity of care relationships. The tutors enjoyed delivering feedback, recognising its benefits as an educational strategy. Some concern was expressed about how to balance delivering negative feedback while continuing to provide tutorial support throughout the Foundation Degree. <a href="http://www.nurseeducationtoday.com/article/S0260-6917(13)00212-8/abstract">http://www.nurseeducationtoday.com/article/S0260-6917(13)00212-8/abstract</a>

Of related interest:

 NURSE EDUCATION TODAY | Online – 9 July 2013 – 'End-of-life care education, past and present: A review of the literature.' This review highlights issues with end-of-life care education and suggests that end-of-life care simulation is an innovative strategy that may help to prepare undergraduate nursing students to provide quality end-of-life care. http://www.nurseeducationtoday.com/article/S0260-6917(13)00209-8/abstract

### Evidence on the cost and cost-effectiveness of palliative care: A literature review

PALLIATIVE MEDICINE | Online – 9 July 2013 – Evidence on costs and cost-effectiveness of alternative methods of delivering health-care services is increasingly important to facilitate appropriate resource allocation. Palliative care services have been expanding worldwide with the aim of improving the experience of patients with terminal illness at the end of life through better symptom control, coordination of care and improved communication between professionals and the patient and family. 46 papers met the criteria for inclusion in the review, examining the cost and/or utilisation implications of a palliative care intervention with some form of comparator. The focus of these studies was on direct costs with little focus on informal care or out-of-pocket costs. The overall quality of the studies is mixed, although a number of cohort studies do undertake multivariate regression analysis. Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant. http://pmj.sagepub.com/content/early/2013/07/05/0269216313493466.abstract

Articles on the cost and cost-effectiveness of palliative care noted in past issues of Media Watch:

- U.S. (VERMONT) | *The Valley News* (OpEd) 16 June 2013 'End-of-life care and cost: Dartmouth Atlas' puzzling findings.' What's puzzling about the Dartmouth Atlas report is that despite more use of hospice and less dependence on hospitalization at the end of life, "Medicare spending per patient during the last two years of life rose from \$60,694 to \$69,947, a 15.2% increase during a period when the consumer price index rose only 5.3%."<sup>1</sup> [Noted in Media Watch, 24 June 2013, #311 (p.2)] <u>http://www.vnews.com/home/7036218-95/editorialend-of-life-care-and-cost-dartmouth-atlas-puzzling-findings</u>
  - Tracking Improvement in the Care of Chronically III Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life, June 2013. [Noted in Media Watch, 17 June 2013, #310 (p.4)] <u>http://www.dartmouthatlas.org/downloads/reports/EOL\_brief\_061213.pdf</u>
- THE COCHRANE LIBRARY (Cochrane Pain, Palliative & Supportive Care Group) | Online 6 June 2013 – 'Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers.' The authors reviewed all known studies that evaluated home palliative care services. [Noted in Media Watch, 10 June 2013, #309 (p.13)] <u>http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/abstract</u>
- PROGRESS IN PALLIATIVE CARE | Online 25 January 2013 'Capturing activity, costs, and outcomes: The challenges to be overcome for successful economic evaluation in palliative care.' The challenges for the palliative care community are to a) demonstrate the cost effectiveness of its interventions in comparison to other health services; and, b) provide evidence that the resources currently allocated are being used efficiently. In this paper different economic approaches to evaluating health care services are introduced. [Noted in Media Watch, 28 January 2013, #290 (p.13)] <a href="http://www.ingentaconnect.com/content/maney/ppc/preprints/1743291X12Y.000000046">http://www.ingentaconnect.com/content/maney/ppc/preprints/1743291X12Y.000000046</a>

### Palliative care for Parkinson's disease: A summary of the evidence and future directions

PALLIATIVE MEDICINE | Online – 9 July 2013 – Convention recognises a final "palliative phase" in Parkinson's disease, while qualitative studies suggest the presence of palliative care need in Parkinson's disease from diagnosis. Clinical tools to quantify palliative symptom burden exist and have helped to identify targets for intervention. Dementia is highly prevalent and influences many aspects of palliative care ... with particular implications for end-of-life care and advance care planning. The "palliative phase" [however] represents a poor entry point for consideration of palliative care need. An alternative, integrated model of care, promoting collaboration between specialist palliative and neurological services, is discussed, along with some specific palliative interventions. Limited evidence exists regarding timing of palliative interventions, triggers for specialist referral and management of terminal care. Research examining access to palliative care and management of terminal symptoms will assist development of sustainable, integrated palliative care services. http://pmj.sagepub.com/content/early/2013/07/05/0269216313495287.abstract

Articles on palliative care and Parkinson's disease noted in past issues of Media Watch:

- PARKINSONISM & RELATED DISORDERS | Online 6 August 2012 'Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD.' The Edmonton Symptom Assessment System Scale for Parkinson's disease is a quick, effective scale for assessment of late stage PD symptoms. [Noted in Media Watch, 13 August 2012, #266 (p.9)] <u>http://www.prd-journal.com/article/S1353-8020(12)00251-9/abstract</u>
- PARKINSONISM & RELATED DISORDERS | Online 9 July 2012 'The conceptual framework of palliative care applied to advanced Parkinson's disease.' Recently our understanding of advanced Parkinson's disease has led to the question of whether palliative care approaches would be complementary to the care of these patients. [Noted in Media Watch, 16 July 2012, #262 (p.12)] <a href="http://www.prd-journal.com/article/S1353-8020(12)00250-7/abstract">http://www.prd-journal.com/article/S1353-8020(12)00250-7/abstract</a>

NATIONAL COUNCIL FOR PALLIATIVE CARE (U.K.) | Online – 6 February 2012 – 'New guide to manage last days of life in Parkinson's disease.' Parkinson's and the last days of life has been developed by the Neurological Conditions Group following a survey of Parkinson's disease experts which expressed concerns about diagnosing dying, excluding reversible causes, withdrawing medications, and symptom control. [Noted in Media Watch, 13 February 2012, #240 (p.13)] <a href="http://www.ncpc.org.uk/news/83">http://www.ncpc.org.uk/news/83</a>

# Pediatric oncology providers perceptions of barriers and facilitators to early integration of pediatric palliative care

PEDIATRIC BLOOD & CANCER | Online – 9 July 2013 – Pediatric oncology providers were recruited to participate in four focus groups. A proposal for early integration of a pediatric palliative care team (PPCT) was presented and followed by a facilitated discussion. Barriers to the proposed care model of early integration of a PPCT included provider role, conflicting philosophy, patient readiness, and emotional influence and were more prevalent in the physician participants compared to nurse practitioner, nursing, and social work participants. Facilitators included patient eligibility, improved patient care, education, and evidence-based medicine. Though all participants were invested in providing optimal patient care, physician participants believed the current standard of care model is meeting the needs of patients and family, while the nurse practitioner, nursing, and social work participants working on the same healthcare team believed the proposed care model would improve the overall care of children diagnosed with cancer. Differing perceptions among healthcare providers regarding the care of children with cancer suggest that team functioning could be improved. Avenues for pilot testing early integration of PC could provide useful information for a next study. <u>http://onlinelibrary.wiley.com/doi/10.1002/pbc.24673/abstract</u>

Articles on pediatric palliative care noted in past issues of Media Watch:

- JOURNAL OF CHILD HEALTH | Online 22 April 2013 'Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the U.K.' The association of palliative care with end of life may be a modifiable factor relevant to late and non-referral, and deserving of further investigation and attention... [Noted in Media Watch, 29 April 2013, #303 (p.11)] http://chc.sagepub.com/content/early/2013/02/28/1367493512468363.abstract
- CHILD: CARE, HEALTH & DEVELOPMENT | Online 28 November 2012 'Was there a plan? End-of-life care for children with life-limiting conditions: A review of multi-service healthcare records.' This review compares documented end-of-life planning with published children's palliative care standards, across a range of children's healthcare services and to assess the impact on practice of written guidelines... [Noted in Media Watch, 10 December 2012, #283 (p.9)] http://onlinelibrary.wiley.com/doi/10.1111/cch.12020/abstract
- PROGRESS IN PALLIATIVE CARE | Online 15 October 2012 'The child's voice in pediatric palliative and end-of-life care.' Children and adolescents who are receiving treatment for a life-threatening illness are not routinely asked how they experience the treatment intended to save or prolong their lives. [Noted in Media Watch, 22 October 2012, #276 (p.9)] http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035
- CURRENT PEDIATRIC REVIEWS, 2012;8(2):152-165. 'Living life to the fullest: Early integration of palliative care into the lives of children with chronic complex conditions.' This paper dispels common misconceptions about pediatric palliative care and outlines the benefits realized by children living with chronic complex conditions, and their families, when palliative care is introduced early in the course... [Noted in Media Watch, 4 June 2012, #256 (p.8)] <a href="http://www.ingentaconnect.com/content/ben/cpr/2012/0000008/0000002/art00007">http://www.ingentaconnect.com/content/ben/cpr/2012/0000008/0000002/art00007</a>

### Diversity in defining end-of-life care: An obstacle or the way forward?

*PLOS ONE* | Online – 3 July 2013 – The terms used to describe care at the end of life (EoL), and its definitions, have evolved over time and reflect the changes in meaning the concept has undergone as the field develops. Responses [to a survey] were received from 167 individuals, mainly from academics (39%) and clinical practitioners working in an academic context (23%) from 19 countries in Europe and beyond: 29% said explicitly that there was no agreed definition of EoL care in practice and only 14% offered a standard definition (WHO, or local institution). 2% said that the concept of EoL care was not used in their country, and 5% said that there was opposition to the concept for religious or cultural reasons. Two approaches were identified to arrive at an understanding of EoL care: exclusively by drawing boundaries through setting time frames, and inclusively by approaching its scope in an integrative way. This led to reflections about terminology and whether defining EoL care is desirable. The global expansion of EoL care contributes to the variety of interpretations of what it means. This complicates the endeavour of defining the field. http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0068002

Articles on defining end-of-life care noted in past issues of Media Watch:

- THE ONCOLOGY REPORT | Online 10 April 2013 'Is the moniker "palliative care" too loaded?' A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] <a href="http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html">http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html</a>
- PALLIATIVE & SUPPORTIVE CARE | Online 11 January 2013 'Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.' Although most [study participants] claimed that early referrals to the service are preferable, on-cologists identified several challenges, related to the timing and communication with patients regarding the referral... [Noted in Media Watch, 14 January 2013, #288 (p.7)] <a href="http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextTy">http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextTy</a>
- SUPPORTIVE CARE IN CANCER | Online 31 August 2012 'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.' Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <u>http://link.springer.com/article/10.1007/s00520-012-1564-y</u>

### Holistic models for end-of-life care: Establishing the place of culture

*PROGRESS IN PALLIATIVE CARE* | Online – 10 July 2013 – Holistic models of patient care are essential to the practise of patient-centred care. However, these models have up to now largely neglected the role of culture and the search for meaning in the illness experience, despite evidence of disparities in the access of palliative care services by people from ethnic minority groups. A phenomenological approach to illness highlights three principles: that illness is cultural, that the search for meaning related to the finitude of human life is fundamental to the illness experience, and that illness narratives are culturally conditioned manifestations of the search for meaning in illness. A holistic model for palliative care is presented on the basis of these principles. <a href="http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X13Y.0000000063">http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X13Y.0000000063</a>

### The impact of awareness of terminal illness on quality of death and care decision making: A prospective nationwide survey of bereaved family members of advanced cancer patients

PSYCHO-ONCOLOGY | Online - 10 July 2013 - The authors assess whether awareness of a terminal illness can affect care decision making processes and the achievement of a good death in advanced cancer patients receiving palliative care services. Among the 345 patients included in the final analysis, the majority (68.4%) of the patients were aware of the terminal illness. [This awareness] tended to reduce discordances in care decision making, and increased the patients' own decision making when there were discordances between patients and their families. The Good Death Inventory score was significantly higher among patients who were aware of their terminal illnesses compared with those who were not and especially in the domains of "control over the future," "maintaining hope and pleasure," and "unawareness of death." Awareness ... had beneficial effect on the harmonious decision making, patient autonomy, and patient's quality of death. http://onlinelibrary.wiley.com/doi/10.1002/po n.3346/abstract

Media coverage of medical decision making at the end of life: A Belgian case study

DEATH STUDIES | Online - 12 July 2013 - The authors examine a selection of press articles and the differences among media genres in covering the issue [of end-of-life decision-making]. In general terms, they found an over-reporting of euthanasia; a focus on dying processes resulting from cancer and Alzheimer's disease: and. an attention to political discussions and political voices, which outnumber patient voices. In genre-specific terms, unlike mainstream media, niche media reported less mediagenic aspects of the end of life. Finally, although popular mainstream media focus on personal aspects of the end-of-life, elite mainstream media privilege political aspects. http://www.tandfonline.com/doi/abs/10.1080/0748 1187.2012.738766

# Cont. next page

### 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.

Noted in Media Watch, 29 April 2013, #303 (p.4):

- CALIFORNIA | The Los Angeles Times 25 April 2013 'Physicians debate whether patients need to know they're dying.' How, when and why does one inform a patient that he or she is dying? The latest evidence of that ongoing discussion was published in the British Medical Journal.<sup>1,2</sup> <u>http://www.latimes.com/health/boostershots/la-heb-physicians-terminal-patients-20130424,0,1331439.story</u>
  - 'Do patients need to know they are terminally ill? No.' Patients do not need to be told that they are terminally ill. However, this does not mean we should pretend we can cure them of incurable illnesses or that we should withhold prognostic information from those who want it. <u>http://www.bmj.com/content/346/bmj.f2560</u>
  - 2. 'Do patients need to know they are terminally ill? Yes.' Patients have the right to make informed decisions about their healthcare. Informed consent, and the process of balancing risks and benefits of treatment, is a fundamental ethical principle. This principle is no less relevant for a patient with terminal illness... <u>http://www.bmj.com/content/346/bmj.f2589</u>

### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- BMC MEDICAL ETHICS | Online 4 July 2013 'Factors associated with the rejection of active euthanasia: A survey among the general public in Austria.' The abstract question was about active voluntary euthanasia [AVE] and [was] answered negatively by 28.8% [of the participants in this study], while 71.2% opted in favour of AVE or were undecided. Regression analyses showed rejection of AVE was positively correlated with number of adults and children in the household, experience with care of seriously ill persons, a conservative worldview, and level of education. Mean or high family income was associated with lower levels of rejection. No independent correlations were found for variables such as sex, age, political orientation, self-rated health, and experiences with care of terminally ill patients. Correlation for the situational problem formulation was weaker and included fewer predictors than for the abstract question. <a href="http://www.biomedcentral.com/content/pdf/1472-6939-14-26.pdf">http://www.biomedcentral.com/content/pdf/1472-6939-14-26.pdf</a>
- INDIAN JOURNAL OF PSYCHOLOGICAL MEDICINE, 2013;35(1):101-105. 'Physicianassisted suicide and euthanasia in Indian context: Sooner or later the need to ponder!' The legal status of PAS [physician assisted suicide] and euthanasia in India lies in the Indian Penal Code... According to Penal Code 1860, active euthanasia is an offence under Section 302 (punishment for murder) or at least under Section 304 (punishment for culpable homicide not amounting to murder). The difference between euthanasia and physician assisted death lies in who administers the lethal dose; in euthanasia, this is done by a doctor or by a third person, whereas in physician-assisted death, this is done by the patient himself. Various religions and their aspects on suicide, PAS, and euthanasia are discussed. People argue that hospitals do not pay attention to patients' wishes, especially when they are suffering from terminally ill, crippling, and non-responding medical conditions. http://www.ijpm.info/article.asp?issn=0253-7176;year=2013;volume=35;issue=1;spage=101;epage=105;aulast=Khan;type=0
- INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY | Online 5 July 2013 'The clinician's dilemma: Two dimensions of ethical care.' There is a continuing intense medicoethico-legal debate around legalized euthanasia and physician assisted suicide such that ethically informed clinicians often agree with the arguments but feel hesitant about the conclusion, especially when it may bring about a change in law. The authors argue this confusion results from the convergence of two continua that underpin the conduct of a clinician... The two continua concern the duty of care and the importance of patient autonomy and they do not quite map into traditional divides in debates about sanctity of life, paternalism, and autonomy. As ethical dimensions, they come into sharp focus in the psychological complexities of end-of-life care and form two key factors in most ethical and legal or disciplinary deliberations about a clinician's actions. <u>http://www.sciencedirect.com/science/article/pii/S016025271300071X</u>

- INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY | Online 2 July 2013 'Physician-assisted suicide in psychiatry and loss of hope.' In The Netherlands, euthanasia and physician-assisted suicide (PAS) are considered acceptable medical practices in specific circumstances. The majority of cases of euthanasia and PAS involve patients suffering from cancer. However, in 1994 the Dutch Supreme Court in the so-called Chabot-case ruled that "the seriousness of the suffering of the patient does not depend on the cause of the suffering," thereby rejecting a distinction between physical (or somatic) and mental suffering. This opened the way for further debate about the acceptability of PAS in cases of serious and refractory mental illness. An important objection against offering PAS to mentally ill patients is that this might reinforce loss of hope, and demoralization. Based on an analysis of a reported case, this argument is evaluated. http://www.sciencedirect.com/science/article/pii/S0160252713000745
- INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY | Online 2 July 2013 'The problem of the possible rationality of suicide and the ethics of physician-assisted suicide.' Opponents of the legalization of physician assisted suicide (PAS) often claim that physicians must not give a helping hand to suicidal patients because: 1) it is morally forbidden to help somebody to carry out an action which is inherently irrational and which will probably cause him severe harm; and, 2) the act of self-killing is necessarily irrational and self-harming. This article focuses on the second premise of this paternalistic argument against the moral permissibility of PAS and its legalization. First, it is shown that this premise can be understood in two ways, depending on whether the predicate "irrational" is taken to refer to a human being's lack of the capacity to decide and act rationally or irrationally, or to the property of the decision to end one's life. <a href="http://www.sciencedirect.com/science/article/pii/S0160252713000630">http://www.sciencedirect.com/science/article/pii/S0160252713000630</a>
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 8 July 2013 'Dignity, death, and dilemmas: A study of Washington hospices and physician-assisted death.' The legalization of physician-assisted death in states such as Washington and Oregon has presented defining ethical issues for hospice programs because up to 90% of terminally ill patients who use the state-regulated procedure to end their lives are enrolled in hospice care. The authors recently partnered with the Washington State Hospice & Palliative Care Organization to examine the policies developed by individual hospice programs on program and staff participation in the Washington Death with Dignity Act. This article sets a national and local context for the discussion of hospice involvement in physician-assisted death, summarizes the content of hospice policies in Washington State, and presents an analysis of these findings. <a href="http://www.jpsmjournal.com/article/S0885-3924(13)00270-4/abstract">http://www.jpsmjournal.com/article/S0885-3924(13)00270-4/abstract</a>

Noted in Media Watch, 24 June 2013, #311 (p.4):

- WASHINGTON STATE | The Associated Press 20 June 2013 'Washington assisted suicide report shows 17% jump in people requesting lethal prescriptions.' Washington State's annual assisted suicide report shows a 17% jump in the number of people requesting lethal prescriptions in 2012 compared to the previous year.<sup>1</sup> <u>http://www.oregonlive.com/pacific-northwestnews/index.ssf/2013/06/washington assisted suicide re.html</u>
  - 1. Death with Dignity Act, Washington State Department of Health, website: http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityA ct.aspx
- PATIENT EDUCATION & COUNSELING | Online 2 July 2013 'What happens after a request for euthanasia is refused? Qualitative interviews with patients, relatives and physicians.' Interviews [were conducted] with nine patients whose EAS [euthanasia or physician-assisted suicide] request was refused and seven physicians of these patients, and with three relatives of patients who had died after a request was refused and four physicians of these patients. Interviews were conducted at least 6 months after the refusal. A wish to die remained in all patients after refusal, although it sometimes diminished. In most cases patient and physician stopped discussing this wish, and none of the physicians had discussed plans for the future with the patient or evaluated the patient's situation after their refusal. <a href="http://www.sciencedirect.com/science/article/pii/S0738399113002322">http://www.sciencedirect.com/science/article/pii/S0738399113002322</a>

### Media Watch Online

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <u>HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/</u>

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

#### Australia

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

#### Canada

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

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <u>http://www.tcpcn.ca/?s=ashpole</u>

#### 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: <u>http://www.omega.uk.net/media-watch-hospice-palliative-care-and-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</u>

### International

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

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

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

Barry R. Ashpole Beamsville, Ontario CANADA 'phone: 905.563.0044 e-mail: <u>barryashpole@bell.net</u>