# ***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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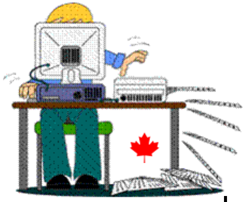


**Compiled & Annotated by Barry R. Ashpole**

**The illness experience: Scroll down to Specialist Publications and 'Reframing the goals of care conversation: "We're in a different place" (p.13), in *Journal of Palliative Medicine.***

## Canada

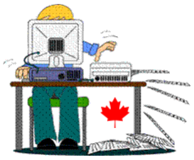
### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online Commentary – 16 June 2014 – **'Euthanasia hurts families.'** Bill 52, which ushers in doctor-assisted suicide in Quebec, has been discussed a lot by now. However, no one has addressed how arguments over life and death for loved ones can have lasting effects on family relationships and radically alter family dynamics. Protecting life was once a bright line in the medical profession. That it is no longer will cause confusion that only compounds grief at a difficult time. Familial relationships of those left living may never recover. http://fullcomment.nationalpost.com/2014/06/16/derek-miedema-euthanasia-hurts-families/

  From the archives:

  - *BRITISH MEDICAL JOURNAL*, 2003;327(7408):189. **'Effects of euthanasia on the bereaved family and friends: A cross sectional study.'** Possible explanations for *less* grief symptoms among the bereaved family and friends of cancer patients [i.e., study participants] who died by euthanasia are: a) the opportunity to say goodbye while these patients were generally still fully aware; b) the bereaved family and friends of these were probably more prepared for the way and day of the imminent death; and, c) when a terminally ill patient requests euthanasia, family members and the patient are often able to talk openly about death. http://www.bmj.com/content/327/7408/189



**Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

## U.S.A.

### How dying became a multibillion-dollar industry

*THE HUFFINGTON POST* | Online – 19 June 2014 – The U.S. hospice industry has quadrupled in size since 2000. Nearly half of all Medicare patients who die now do so as a hospice patient – twice as many as in 2000, government data shows. Since 2006, the U.S. government has accused nearly every major for-profit hospice company of billing fraud. Hospices bill by the day, and stays at for-profits are substantially longer than at non-profits (105 days versus 69 days). In 2009, for-profit hospices charged Medicare 29% more per patient than non-profits, according to the inspector general for the health service. The average hospice stay has increased dramatically since 2000, regardless of diagnosis, a HuffPost analysis of Medicare data found. This has led to a surge in expenditures: $15 billion in federal dollars in 2013. Despite widespread allegations of fraud and abuse, regulators have consistently rated hospice as a lower priority for inspection than traditional health facilities like hospitals. The average U.S. hospice has not undergone a full inspection in more than 4.5 years... HuffPost found 866 hospices that haven't been inspected in more than 6 years. Nursing home inspections, by contrast, are required by federal law at least every 15 months. Over a recent three-year span, 55% [of] all U.S. hospices were cited for a violation, many care-related, HuffPost found; 20 providers that were cited for more than 70 violations each during that time... http://projects.huffingtonpost.com/hospice-inc

### Specialist Publications

**'Patients surviving six months in hospice care: Who are they?'** (p.12), in *Journal of Palliative Medicine.*

Noted in Media Watch, 10 March 2014, #348 (p.5):

- *THE NEW YORK TIMES* | Online – 3 March 2014 – **'Differences in care at for-profit hospices.'** People who pay attention to hospice care, so often a godsend for the dying and their families, have noticed and wondered about two trends in recent years: 1) What began as a grass-roots movement to improve end-of-life care is becoming a business; and, 2) We've also seen hospice patients are increasingly likely to be disenrolled before they die. Patients are getting bounced as corporate bottom lines come to matter more. A study has found for-profit hospices have significantly higher disenrollment rates than non-profits, among other disparities. http://newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/?_php=true&_type=blogs&_r=0

    1. 'National hospice survey results: For-profit status, community engagement, and service,' *JAMA Internal Medicine*, 24 February 2014. [Noted in Media Watch, 3 March 2014, #347 (p.9)] https://archinte.jamanetwork.com/article.aspx?articleid=1832198

**N.B.** Articles on for-profit and non-profit hospice are noted in the issues of Media Watch 3 March 2014, #347 (p.4, pp.9-10), and 13 January 2014, #340 (pp.3-4).

Of related interest:

- *THE NEW YORK TIMES* | Online – 17 June 2014 – **'How to choose a hospice.'** The American Hospice Foundation ... will close its doors at the end of this month. The foundation has lost too much funding to continue, its founding president and chief executive Naomi Naierman said. As a parting gift, however, Ms. Naierman ... has passed along some consumer advice. Even as Americans make greater use of hospice care, families often don't grasp that in most places they have a choice of programs. http://newoldage.blogs.nytimes.com/2014/06/17/how-to-choose-a-hospice/?_php=true&_type=blogs&_r=0

**American Association of Retired Persons scorecard**

### How your state rates in terms of long-term care

NATIONAL PUBLIC RADIO | Online – 19 June 2014 – A study from the American Association of Retired Persons says that care could vary dramatically in cost and quality depending on where they live.[1] The study was motivated by a simple fact: The number of available family caregivers is declining. In 2010, there were potentially seven for each person 80 years old or older. By the time baby boomers reach that age, there will be only four potential caregivers for each of them. http://www.npr.org/blogs/health/2014/06/19/323356217/how-your-state-rates-in-terms-of-long-term-care

1. 'Raising Expectations, 2014: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers,' American Association of Retired Persons.' http://www.longtermscorecard.org/2014-scorecard#.U6L2TZRdX8l

Of related interest:

- MICHIGAN | *The Detroit Free Press* – 19 June 2014 – **'Nursing home care now costs more than twice seniors' average income.'** The annual cost of nursing home care may have grown even less affordable to Michigan's seniors and people with disabilities, costing families about $93,075 – more than 2½ times older adults' average income of $35,504, according to a report.[1] http://www.freep.com/article/20140619/NEWS06/306190034/nursing-homes-long-term-care-Michigan

    1. 'Raising expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers,' Commonwealth Fund, the Scan Foundation and the American Association of Retired Persons, June 2014. http://www.freep.com/assets/freep/pdf/C4221884619.PDF

### When patients are counting on miracles

*THE ATLANTIC* | Online – 18 June 2014 – An estimated 60% of people think divine intervention can save patients who are in a vegetative state. A new study looks at what happens when doctors and divinity seem to be competing as caregivers. But doctors aren't so into the miracle thing. In the same study, only 20% of a large sample of trauma-care workers said they believed in medical miracles. Many people believe faith complements medicine; seeing God in physician's work can be a source of comfort. But things can get awkward for doctors who don't believe in God... "All too often, clinicians unintentionally place themselves in direct competition with ... God," the authors [of the study], led by Johns Hopkins chaplain Rhonda Cooper, write. "The [medical] provider may be thinking, 'Well, you can believe all you want, but that miracle is not going to happen.'" That seems like a rather sarcastic thing to think to yourself in a room with a dying patient and her family, but the authors are medical professionals – they must know a God-related eye roll when they see one. http://www.theatlantic.com/health/archive/2014/06/living-on-a-prayerand-a-ventilator/372972/

1. 'AMEN in challenging conversations: Bridging the gaps between faith, hope, and medicine,' *Journal of Oncology Practice*, 6 May 2014. All health care practitioners face patients and families in desperate situations who say, "We are hoping for a miracle." Few providers have any formal training in responding to this common, difficult, and challenging situation. http://jop.ascopubs.org/content/early/2014/05/06/JOP.2014.001375.abstract

**Specialist Publications**

**'A European survey on attitudes towards pain and end-of-life issues in locked-in syndrome'** (p.10), in *Brain Injury.*

Cont.

Noted in Media Watch, 7 October 2013, #326 (p.2):

- CALIFORNIA | *The Merced Sun-Star* – 3 October 2013 – **'Health care: How long should we wait for a miracle?'** In medicine our job is not to squelch another person's hope for a miracle. And while I do not think I have actually seen a miracle, I know others have – or they believe they have. There is no question very, very rare things do happen on occasion. That includes spontaneous remissions from cancer and recovery from illnesses everyone thought was impossible. Are these miracles? I am not sure, but 76% of Americans believe in miracles and herein lies the problem. http://www.mercedsunstar.com/2013/10/03/3255640/health-care-how-long-should-we.html

## Stopping fluids at the end of life: A dilemma not just for Kasem's family

REUTERS | Online – 17 June 2014 – In the family disputes that surrounded American radio icon Casey Kasem's last weeks of life, his daughter's decision to carry out Kasem's wish – to suspend artificial feedings and fluids – was among the most contested. Kasem's advance directive called for no life-sustaining treatment if it "would result in a mere biological existence." But his wife opposed a court order allowing an end to artificial measures; her attorney called it a "functional equivalent of a death sentence." The Kasem family infighting is unfortunately not unique. It mirrors the struggles of countless other families, whether their loved ones have dementias like Kasem's, or advanced cancers and other terminal conditions. The choice of when to stop artificial feeding and fluids is one of the hardest families face when caring for a patient nearing death. The decision is entwined with fears of abandonment, violations of cultural norms and moral concerns. http://www.reuters.com/article/2014/06/17/us-dying-fluids-decisions-idUSKBN0ES2F820140617

Of related interest:

- *THE NEW YORK TIMES* | Online – 19 June 2014 – **'Who can speak for the patient?'** Our patient was never going to wake up. He had an unrecoverable brain injury. The prognosis had become clear over time. As the patient's attending physician in the intensive care unit, I arranged a meeting with his sister, the only visitor we'd seen for days, and explained. She was resolute. "He'll wake up," she said. "He's a fighter. Do everything you can to keep him alive." The next day I told the social worker what the patient's sister had said. "What about the wife?" the social worker asked. That was the first I'd heard of a wife. A spouse is the official next of kin. No decision should ever be made without the spouse. But I hadn't known she existed. I discovered that she visited the patient after her work shift, usually at 8 p.m. By that hour, our team was gone. The doctors on night duty were on for emergencies, not conversation. And so she was invisible to us. http://well.blogs.nytimes.com/2014/06/19/who-can-speak-for-the-patient/?_php=true&_type=blogs&ref=health&_r=0

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | Gallup – 18 June 2014 – **'Seven in 10 Americans back euthanasia.'** Most Americans continue to support euthanasia when asked whether they believe physicians should be able to legally "end [a] patient's life by some painless means." Strong majorities have supported this for more than 20 years. Support for euthanasia is related to Americans' underlying religiosity. The more frequently an American attends religious services, the less likely he or she is to support euthanasia. Less than half (48%) of those who frequent their places of worship weekly are likely to support the idea of a doctor "ending a patient's life by some painless means," compared with three in four Americans who attend services nearly weekly (74%) and 82% of those who go less often. Americans are less likely to support euthanasia when the question emphasizes that the doctor would "assist the patient to commit suicide" than when the question does not mention the word suicide. In the most recent poll, 58% of Americans favor doctor-assisted suicide when the question is asked in this way. http://www.gallup.com/poll/171704/seven-americans-back-euthanasia.aspx

## International

### End-of-life care in Ireland

### Nursing homes should give training in "Irish cultural awareness," says report

IRELAND | *The Irish Times* (Dublin) – 19 June 2014 – Nursing homes should provide training in "Irish cultural awareness" for all staff regardless of their country of origin, according to a new report on end-of-life care.[1] Healthcare professionals working with older people should actively remove "negative language" from their lexicon, the report from Dublin City University's school of nursing says. Staff also need to demystify the "taken-for-granted language" of everyday life in a nursing home, in particular the language used to discuss end-of-life care issues, authors Dr. Mel Duffy and Dr. Eileen Courtney say, pointing to a disconnect between medical language and lay understanding. Healthcare professionals need to be sensitive to the range of feelings associated with "surrendering" a loved one to nursing home care and the emotional turmoil many families experience during this transition. Nursing homes need to take account of family dynamics so that carers are not marginalised in decision-making after a person is admitted, the report says. http://www.irishtimes.com/news/health/nursing-homes-should-give-training-in-irish-cultural-awareness-says-report-1.1837094

1. 'The Journey Through Death and Dying: Families' Experiences of the End-of-Life Care in Private Nursing Homes,' School of Nursing & Human Sciences, Dublin City University, June 2014. http://doras.dcu.ie/20001/

### End-of-life care in Singapore

### Insufficient training, manpower to care for terminally-ill, survey finds

SINGAPORE | Channel NewsAsia – 18 June 2014 – While almost all doctors and nurses consider hospice palliative care important for those with life-threatening illnesses, a number of them feel that medical professionals do not know enough about this approach to care-giving, a survey commissioned by the Lien Foundation revealed. The survey ... showed that 95% of doctors and 94% of nurses surveyed considered hospice palliative care important for the terminally-ill, while 98% of doctors and 95% of nurses want such care to be made readily available. http://www.channelnewsasia.com/news/singapore/insufficient-training/1173884.html

**Extract from Channel NewsAsia report**

According to the survey, 62% of doctors and 38% of nurses said basic medical or nursing education was not enough to prepare them to support patients with life-threatening illnesses.

**N.B.** Of related interest is the 'Report of a National Education Needs Assessment of Healthcare Professionals for Palliative Care in Singapore,' The Lien Foundation and Duke-National University of Singapore, April 2014 [Noted in Media Watch, 7 April 2014, #352 (p.8)] http://lcpc.duke-nus.edu.sg/sites/default/files/lcpc/Files/An%20ENA%20Report%20for%20Palliative%20Care%2030%20March%2014.pdf

**Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

**Royal College of General Practitioners report**

### Doctors told to dispense with confusing medical jargon

U.K. | *The Guardian* – 18 June 2014 – A report by the Royal College of GPs urges the U.K.'s 250,000 medics to avoid the use of words such as "chronic," "palliative" and "hospice," and warns that describing a diagnosis of cancer as "positive" can be misinterpreted as good news.[1] Doctors may fail to realise that they have failed to make themselves understood to the patient and should check they have done so by asking the patient to repeat the information back to them if they are unsure, it recommends. Equally, some patients are too embarrassed to ask doctors questions they want answered because they do not want to reveal their lack of understanding of what they have been told or their poor reading skills. It cites the word "chronic" as an example of where "doctors can unintentionally use words that are unfamiliar to their patients, without realising that the meaning is not clear. Some concepts familiar and obvious to doctors may be alien to patients." While doctors use "chronic" to mean persistent or long-term, the word is widely understood to mean "severe," giving rise to a potential confusion. http://www.theguardian.com/society/2014/jun/18/doctors-dispense-with-medical-jargon-patients

**Extract for *The Guardian* article**

National Voices [an umbrella group representing scores of charities] had come across examples of patients at the end of their lives who were offered "palliative" care or a place in a "hospice," but did not understand what either involved.

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1. 'Health Literacy: Report from an RCGP-led health literacy workshop,' Royal College of General Practitioners, June 2014. http://www.rcgp.org.uk/news/2014/june/~/media/Files/Policy/RCGP-Health-Literacy-2014.ashx

**Court of Appeal in England ruling**

### Legal duty over resuscitation orders

U.K. (England) | BBC News – 17 June 2014 – Doctors now have a legal duty to consult with and inform patients if they want to place a do not resuscitate (DNR) order on medical notes, the Court of Appeal in England ruled. The issue was raised by a landmark judgement that found doctors at Addenbrooke's Hospital, in Cambridge, had acted unlawfully. Janet Tracey, who had terminal lung cancer, died there three years ago. Her family say she and they were not consulted when a DNR notice was placed. Guidelines for doctors already recommend that patients and families are involved in such decisions, but the court ruling now makes it a legal requirement. In the judgement, the Master of the Rolls, Lord Dyson, said the hospital trust violated Mrs. Tracey's right to respect for her private life under Article 8 of the European Convention of Human Rights. He said: "A do not attempt cardiac pulmonary resuscitation decision is one which will potentially deprive the patient of life-saving treatment, there should be a presumption in favour of patient involvement. There need to be convincing reasons not to involve the patient." He went on to warn that "doctors should be wary of being too ready to exclude patients from the process on the grounds that their involvement is likely to distress them." http://www.bbc.com/news/health-27886265

**N.B.** Court of Appeal in England ruling in *Tracey v Cambridgeshire National Health Service Foundation Hospital Trust*: http://www.judiciary.gov.uk/wp-content/uploads/2014/06/tracey-approved.pdf

Noted in Media Watch, 27 January 2014, #342 (p.3):

- U.K. (England) | *The Guardian* – 24 January 2014 – **'Way cleared for family's challenge over "do not resuscitate" orders.'** Appeal court judges have cleared the way for a family to continue their legal challenge over the way decisions are made not to attempt resuscitation of critically ill patients in England. http://www.theguardian.com/law/2014/jan/24/appeal-court-tracey-family-do-not-resuscitate-orders

**End-of-life care in Scotland**

### Councils charging terminally ill for personal care, says charity

U.K. (Scotland) | LocalGov – 16 June 2014 – Local authorities are wrongly charging terminally ill people for personal care, according to a report from MND [Motor Neurone Disease] Scotland.[1] The charity is warning that many people under 65 years with motor neurone disease are being charged by their local council for personal care, despite COSLA [Convention of Scottish Local Authorities] guidance stating those with a terminal illness should not have to pay. The report finds those under 65 years old face a "postcode lottery" when it comes to personal care charging as it is up to each local authority if someone should make a financial contribution. It revealed that some local authorities waive charges if a person has a letter or DS1500 [medical] form from their doctor, while some only allow for "discretion" in charging. MND Scotland is calling for all local authorities to make all terminally ill people exempt from personal care charging. It also wants COSLA to amend its guidance so a doctor's letter or DS1500 will be accepted as evidence that a person is terminally ill. http://www.localgov.co.uk/Councils-charging-terminally-ill-for-personal-care-says-charity/36522

1. 'Scottish local authorities' personal care charging for under 65s who are terminally ill,' MND Scotland, June 2014. http://www.mndscotland.org.uk/personal-care-charges/

## 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.

## 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

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FRANCE | BBC News (U.K.) – 20 June 2014 – **'French passive euthanasia: Court says end life support.'** A man who has been in a vegetative state for six years should have his treatment ended, the public rapporteur of France's top court has recommended. Vincent Lambert, 39, was left a tetraplegic after a motorcycle accident six years ago. His family is split over whether he should be kept alive. Now the Council of State's public rapporteur has said he has no hope of recovery and no way of communicating. The case is seen as unprecedented in France, where euthanasia is illegal, although doctors can withdraw care under a 2005 law that says life should not be prolonged "artificially" through "unnecessary or disproportionate treatment." http://www.bbc.com/news/world-europe-27938915

- U.K. | *The Times* – 16 June 2014 – **'GPs back the right to die for terminally ill.'** A small majority of GPs would like the option of an assisted suicide if they were terminally ill, according to a survey. The poll of 1,005 doctors found 40% in favour, 32% against, and a quarter undecided, in research carried out by MedeConnect Healthcare Insight... However, two thirds said the British Medical Association and royal colleges, currently opposed to change, should take a neutral stance. http://www.thetimes.co.uk/tto/health/news/article4120159.ece

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

### Understanding the views of those who care for patients with cancer on advance care planning and end-of-life care

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 16 June 2014 – If diagnosed with a serious incurable illness with limited life expectancy, 97% [of survey respondents] would want to discuss their prognosis, 74% would refuse cardiopulmonary resuscitation, and 72% favored supportive/comfort care to more aggressive life-prolonging treatments. However, prognosis was thought to be discussed with only 52% of such patients, and just 5% thought doctors were either very or extremely successful at explaining advanced life-sustaining treatments to patients. Greater than 90% believed these discussions should best occur when a patient is thought to have one or more years to live and 80% thought they are best initiated in the outpatient setting. http://ajh.sagepub.com/content/early/2014/06/16/1049909114540035.abstract

Of related interest:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 17 June 2014 – **'Lesbian, gay, bisexual and transgender people's knowledge of and preparedness to discuss end-of-life care planning options.'** The focus of this paper is the preparedness [of survey respondents] to discuss with healthcare providers any end-of-life care plans. The results highlight that while the majority of respondents were aware of three of the four key end-of-life care planning options available in New South Wales [Australia] – enduring powers of attorney, enduring guardians and person responsible (only a minority had heard of advance healthcare directives) – a much smaller number of people had actually taken up these options. Only a minority of respondents were able to identify correctly who had the legal right to make treatment decisions for a person who is unconscious following a car accident. A small proportion of people had discussed end-of-life care options with general practitioners or another main healthcare provider, and only in very few cases were these issues raised by the practitioners themselves. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12113/abstract

  Noted in Media Watch, 25 February 2013, #294 (p.10):

  - *JOURNAL OF SOCIAL SERVICE RESEARCH*, 2013;39(2):233-252. **'Factors affecting the LGBT population when choosing a surrogate decision maker.'** This review examines 14 articles to identify factors influencing individual surrogate choice and existing gaps in the literature. http://www.tandfonline.com/doi/abs/10.1080/01488376.2012.754205

Cont.

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 16 June 2014 – **'Association of experience with illness and end-of-life care with advance care planning in older adults.'** [Among study participants] having one or more experiences with others was associated with greater readiness to complete a living will and healthcare proxy, discuss life-sustaining treatment with loved ones, and also discuss quantity versus quality of life with loved ones and with physicians. http://onlinelibrary.wiley.com/doi/10.1111/jgs.12894/abstract

- *JOURNAL OF CLINICAL ETHICS*, 2014;25(2):120-130. **'Uncharted terrain: Preference construction at the end of life.'** Respect for patients' self-determination has long been considered central to efforts to improve end-of-life care, yet efforts to promote advance directives or engage patients in end-of-life discussions are often unsuccessful. The author contends that this is because the shared decision-making approach typically used in healthcare assumes patients' capacity to make rational choices, which is not always possible in end-of-life decisions. http://www.clinicalethics.com/single_article/9RX5IFQKQXA.html

### Social capital in a lower socioeconomic palliative care population: A qualitative investigation of individual, community and civic networks and relations

*BMC PALLIATIVE CARE* | Online – 16 June 2014 – Participants identified that individual and community networks and relations of support were mainly inadequate to meet care needs. Specifically, data revealed: 1) individual (informal caregivers) networks and relations were small and fragile due to the nature of conflict and crisis; 2) community trust and engagement was limited and shifted by illness and caregiving; and, 3) formal care services were inconsistent and provided limited practical support. Some transitions in community relations for support were noted. Levels of civic and government engagement and support were overall positive and enabled access to welfare resources. http://www.biomedcentral.com/content/pdf/1472-684X-13-30.pdf

Noted in Media Watch, 25 November 2013, #333 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 November 2013 – **'Identifying changes in the support networks of end-of-life carers using social network analysis.'** This paper analyses the caring networks of people with a terminal illness who are being cared for at home and identifies changes in these caring networks that occurred over the period of caring. http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2012-000257.full

### Home telehealth and paediatric palliative care:
### Clinician perceptions of what is stopping us?

*BMC PALLIATIVE CARE* | Online – 16 June 2014 – Home telehealth has the potential to provide a solution to inequity of access to care, facilitate peer support, and maintain continuity of care with families. However, significant limitations and challenges may impede its use. The virtual space creates additional challenges for communication, which clinicians and families may not intuitively understand. For home telehealth to be integrated into routine care, greater understanding of the nature of communication in the virtual space is required. Four themes are reported [in this study]: managing relationships; expectations of clinicians; co-ordination, and the telehealth compromise. Core concepts that emerged from the data were the perceived ability to control clinical encounters in a virtual environment and the need to trust technology. These concepts help explain the telehealth compromise and low utilisation of the home telehealth program. http://www.biomedcentral.com/content/pdf/1472-684X-13-29.pdf

Noted in Media Watch, 4 February 2013, #291 (p.5):

- *BMC PALLIATIVE CARE* | Online – 1 February 2013 – **'The case for home based telehealth in pediatric palliative care: A systematic review.'** There were thirty-three studies that met the inclusion criteria of which only six were pediatric focussed. While studies generally identified benefits of using home telehealth in palliative care, the utilisation of home telehealth programs was limited by numerous challenges. http://www.biomedcentral.com/content/pdf/1472-684X-12-4.pdf

### A European survey on attitudes towards pain and end-of-life issues in locked-in syndrome

*BRAIN INJURY* | Online – 9 June 2014 – This study reports third-person attitudes towards several salient issues on locked-in syndrome. From the 3,332 respondents [to a close-ended survey] – 33% physicians, 18% other clinicians, 49% other professions; 47% religious – 90% agreed that patients with locked-in syndrome can feel pain. The majority (75%) disagreed with treatment withdrawal, but 56% did not wish to be kept alive if they imagined themselves in this condition. Religious and southern Europeans opposed to treatment withdrawal more often than non-religious and participants from the North. When the locked-in syndrome was compared to disorders of consciousness, more respondents endorsed that being in a chronic locked-in syndrome was worse than being in a vegetative state or minimally conscious state for patients (59%) than they thought for families. http://informahealthcare.com/doi/abs/10.3109/02699052.2014.920526

**End-of-life care in Canada**

### Final days at home

*CANADIAN FAMILY PHYSICIAN*, 2014; 60(6):543-545. Most dying people wish to be cared for and die at home. Ensuring that all involved experience a home death as a "good death" requires considerable planning. In the final days at home, care goals are focused on comfort, and the health care team, all family, and paid and unpaid caregivers need to be aware of the patient's anticipated course and of what to do if they need help before or following the death. The final days of life tend to culminate in a common cluster of symptoms, regardless of the underlying disease or site of care. Symptoms include pain, dyspnea, delirium, dysphagia, weakening of voice, loss of appetite, incontinence, dry mouth, and noisy upper airway secretions. As loss of the ability to take medication orally is almost universal, care must be taken with prescribing in the final days. All unnecessary medications should be discontinued. To avoid any need for emergency personnel or police after the death, there must be a copy of the letter of anticipated death at the funeral home and medical examiner's office. Family members need to be prepared and advised to call the care team, and not 911, if they need help. http://www.cfp.ca/content/60/6/543.short

### "A true human interaction": Comparison of family caregiver and hospice nurse perspectives on needs of family hospice caregivers

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(5):282-290. [In this study] caregivers described information, explanation, trust, and respect as their greatest needs. Nurses also described information as the most critical need of caregivers, followed by instruction, honesty, and reassurance. Although these concepts shared similarities, caregivers and nurses related them differently to caregiver support. Both groups focused on relationship building, suggesting two themes that highlighted both contrasts and mutual understanding of the importance of effective relationships: "breaking it down to build it up" and "doing to, doing for, or doing with." http://journals.lww.com/jhpn/Abstract/2014/07000/_A_True_Human_Interaction___Comparison_of_Family.8.aspx

**N.B.** French language version: http://www.cfp.ca/content/60/6/e304.full

**Palliative care in advanced dementia**

*CLINICS IN GERIATRIC MEDICINE* | Online – 16 June 2014 – Because neurodegenerative dementias are progressive and ultimately fatal, a palliative approach focusing on comfort, quality of life, and family support can have benefits for patients, families, and the health system. Elements of a palliative approach include discussion of prognosis and goals of care, completion of advance directives, and a thoughtful approach to common complications of advanced dementia. Physicians caring for patients with dementia should formulate a plan for end-of-life care in partnership with patients, families, and caregivers, and be prepared to manage common symptoms at the end of life in dementia, including pain and delirium. http://www.geriatric.theclinics.com/article/S0749-0690(14)00039-1/abstract

Of related interest:

- *SOCIOLOGY OF HEALTH & ILLNESS* | Online – 17 June 2014 – **'"The living death of Alzheimer's" versus "Take a walk to keep dementia at bay": Representations of dementia in print media and carer discourse.'** A "panic-blame" framework was evident in much of the print media coverage [the author studied]. Dementia was represented in catastrophic terms as a "tsunami" and "worse than death," juxtaposed with coverage of individualistic behavioural change and lifestyle recommendations to "stave off" the condition. Contrary to this media discourse, in carers' talk there was scant use of hyperbolic metaphor or reference to individual responsibility for dementia, and any corresponding blame and accountability. http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12122/abstract

Representative sample of articles on end-of-life care for people living with dementia noted in past issues of Media Watch:

- *AUSTRALIAN AGEING AGENDA* | Online – 12 February 2014 – **'Knowledge lacking on end-of-life rights.'** The end-of-life wishes of people with dementia are not being met and this is partly due to a lack of knowledge among care professionals about a person's right to refuse treatments, according to a report by Alzheimer's Australia and Palliative Care Australia. The survey found that one in five family carers (20%) and almost one in three culturally and linguistically diverse family carers (30%) were dissatisfied or very dissatisfied with the wishes of the person with dementia being followed. [Noted in Media Watch, 17 February 2014, #345 (p.6)] http://www.australianageingagenda.com.au/2014/02/12/knowledge-lacking-end-life-rights/

- *DEMENTIA*, 2014;13(1):96-110. **'Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers.'** What emerges ... is a range of perspectives that provide contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia and insights drawn from hearing directly from carers may be powerful learning tools. [Noted in Media Watch, 30 December 2013, #338 (p.8)] http://dem.sagepub.com/content/13/1/96.abstract

- *PALLIATIVE MEDICINE*, 2014;28(3):195-196. **'Building the evidence base for palliative care and dementia.'** There is growing recognition among clinicians, researchers, and policy makers of the need for high-quality palliative care for patients with dementia. This recognition is increasing as evidence mounts that dementia is a terminal disease and that patients have many unmet needs for palliative care. Three articles from this edition of *Palliative Medicine* add to our knowledge base and provide guidance for clinicians seeking to improve palliative care quality for patients with dementia. [Noted in Media Watch, 10 February 2014, #344 (p.9)] Journal contents page: http://pmj.sagepub.com/content/28/3.toc

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia and a framework to provide guidance for clinical practice, policy and research. Sixty-four experts from twenty-three countries evaluated a set of eleven domains and fifty-seven recommendations. [Noted in Media Watch, 8 July 2013, #313 (p.10)] http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract

### Interventions for health care professionals, organizations and patients to enhance quality of life for people diagnosed with non-curative palliative esophago-gastric cancer: A systematic review protocol of the quantitative evidence

*JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2014;12(5):66-79. Overall there remains a lack of empirical evidence into the most effective service model(s) supporting palliative care for patients diagnosed with palliative esophago-gastric cancer and anecdotal evidence identifies inconsistent provision of palliative care support between services within and across primary and secondary care boundaries. For example, while a significant proportion of patients will receive palliative stent insertion, local experience suggests a need for greater clarity and coordination between services regarding follow-up and on-going support of the patient and family/carers in order to reflect the ambitions of best practice in cancer care. http://joannabriggslibrary.org/index.php/jbisrir/article/view/1165/1969

### Exploring children/adolescents' final conversations with dying family members

*JOURNAL OF FAMILY COMMUNICATION*, 2014;14(3):208-229. Sixty-one children/adolescents, aged 5-18, participated in semi-structured interviews regarding their final conversations with a dying family member. Four overarching themes emerged: 1) everyday communication; 2) messages of love; 3) messages of individual identity; and, 4) messages related to religion/spirituality. Discussion of results, including limitations and directions for further research, is outlined. http://www.tandfonline.com/doi/abs/10.1080/15267431.2014.908198#.U6BHbJRdX8k

Noted in Media Watch, 15 April 2013, #301 (p.12):

- *END OF LIFE JOURNAL*, 2013;3(2). **'Encouraging/supporting dying parents to talk to their children.'** This article provides an overview of the main factors for ... health professionals to consider when supporting dying parents to communicate with their children. http://endoflifejournal.stchristophers.org.uk/clinical-skills/encouraging-supporting-dying-parents-to-talk-to-their-children

Noted in Media Watch, 17 September 2012, #271 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 September 2012 – **'How do we talk to the children? Child life consultation to support the children of seriously ill adult inpatients.'** Adult interdisciplinary palliative medicine teams often feel unprepared to facilitate the open communication with these children that has been shown to reduce anxiety, depression, and other behavioral problems. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0019

### Patients surviving six months in hospice care: Who are they?

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 June 2014 – On 1 January 2011, the Centers for Medicare & Medicaid Services (CMS) began requiring U.S. hospices to conduct a "face-to-face" (F2F) assessment of eligibility for continued hospice care with patients entering their third certification period (180 days after initial enrollment). Understanding which patient populations require F2F assessment is important for evaluating the impact of the CMS regulation and gauging the appropriateness of the 6-month prognosis criteria for different patient groups. Unlike hospice patients with cancer, patients with a primary diagnosis of dementia or debility are more likely to remain in hospice care beyond 6 months and require F2F recertification. Still, these patients need the services provided by hospice care and may be limited by the 6-month recertification criteria. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0512

### Reframing the goals of care conversation: "We're in a different place"

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 June 2014 – Three preferred communication practices were identified from [study] participants' comments. The first practice involves a necessary disruption of the patient's expectations about "trying another chemo" ("We're in a different place"). The second practice is offering actionable responses to the disruption ("Here's what we can do now"). The third practice is to find a new place that acknowledges death is closer yet still allows for "living forward" ("Use your inner wisdom"). This study of patient and family feedback indicates that patients and families perceive a conversation about goals of care to require disruption of an existing routine, followed by a process of searching and then reconfiguration, rather than a logical decision process. These findings suggest that assessing quality from patient perspectives must take into account a period of disruption and chaos. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0651

Of related interest:

- *JOURNAL OF CLINICAL ETHICS*, 2014;25(2):83-95. **'How to help patients and families make better end-of-life decisions.'** Patients and family members experience extreme stress at the end of life, a high-stakes situation in which few of us have extensive experience. This stress can make us less able to process new information, cripple decision making, and even lead to long-term harm. The author provides a number of practical approaches that clinical ethics consultants can use to help patients and family members in these situations, so that their decisions may reflect more what they really want and so that, after this stress has diminished, they may then do better. http://www.clinicalethics.com/single_article/BM0GKFKOCLA.html

- *PALLIATIVE MEDICINE* | Online – 18 June 2014 – **'How do general end-of-life treatment goals and values relate to specific treatment preferences? A population-based study.'** For a sizable minority of [study] participants, specific treatment preferences did not agree with their general end-of-life goals. The more frequent desire to forgo treatments in case of dementia than cancer suggests that physical deterioration is more acceptable than cognitive decline. Findings underline the importance of discussing general care goals, different end-of-life scenarios and the risks and burdens of treatments to frame discussions of more specific treatment preferences. http://pmj.sagepub.com/content/early/2014/06/17/0269216314540017.abstract

### The effect of using high facilitation when implementing the Gold Standards Framework in Care Homes programme: A cluster randomised controlled trial

*PALLIATIVE MEDICINE* | Online – 18 June 2014 – The provision of quality end-of-life care is increasingly on the national agenda in many countries. In the U.K., the Gold Standards Framework for Care Homes programme has been promoted as a national framework for improving end-of-life care. While its implementation is recommended, there are no national guidelines for facilitators to follow to undertake this role. There is a danger that without national guidelines, facilitation of the Gold Standards Framework for Care Homes programme will vary and consequently so will its implementation. http://pmj.sagepub.com/content/early/2014/06/17/0269216314539785.abstract

### "I beg your pardon?" – Nurses' experiences in facilitating doctors' learning process: An interview study

*PATIENT EDUCATION & COUNSELING* | Online – 19 June 2014 – Working alongside specialized palliative care nurses brings about learning opportunities for general practitioners. The views of these nurses towards their role as facilitator of learning is unknown. The aim of this study is to clarify the views and preferences of these nurses towards their role as facilitator of physicians' learning. First, all interviewees shared the conviction that patient care is their core business. Secondly, two core themes were defined: nurses' preferences towards sharing knowledge and their balancing between patient care and team care. Combining these themes yielded a typology of nurses' behavioral style: the clinical expert-style, the buddy-style, the coach-style and the mediator-style. http://www.pec-journal.com/article/S0738-3991(14)00236-5/abstract

## Media Watch Online

**International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/

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]

**Asia**

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

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

**Australia**

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

**Canada**

ONTARIO | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/ [Scroll down to 'Additional Resources']

**Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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