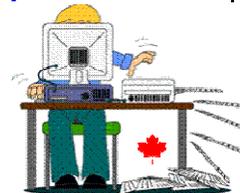


Media Watch...

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.

12 May 2014 Edition | Issue #357



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience" Scroll down to [Specialist Publications](#) and 'Patients' sense of security during palliative care – What are the influencing factors?' (p.11), in *Journal of Pain & Symptom Management*.

Canada

Strategy to improve palliative care for Nova Scotians

NOVA SCOTIA | *The Truro Daily News* – 6 May 2014 – The provincial government is releasing a new strategy to help provide Nova Scotians with more choices about how they are cared for as they approach the end of their lives.¹ The strategy includes establishing an advisory committee to guide implementation. It also includes hiring a provincial palliative care co-ordinator and additional palliative care team members in South Shore, Annapolis Valley and Capital district health authorities... The strategy recognizes that palliative care and planning need to start when a patient is diagnosed with a life-limiting illness, and adjusted as the patient moves through stages of the illness. Funding is going to the Nova Scotia Hospice Pallia-

tive Care Association to begin educating Nova Scotians and care providers on advance planning. The strategy gives direction for collaboration among health professionals and community support organizations. <http://www.trurodaily.com/News/Local/2014-05-06/article-3714451/Strategy-to-improve-palliative-care-for-Nova-Scotians/1>

Specialist Publications

'Canadian Medical Association call for palliative care strategy gets federal backing' (p.9), in *Canadian Medical Association Journal*.

1. 'Integrated Palliative Care: Planning for Action in Nova Scotia,' Nova Scotia Canada, 2014.' <http://novascotia.ca/dhw/palliativecare/documents/Integrated-Palliative-Care-Strategy.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.16.

U.S.A.

Judge: Indiana must continue to recognize out-of-state marriage of terminally ill woman and her wife

INDIANA | Buzz Feed – 8 May 2014 – The Indiana attorney general's office will appeal a federal court ruling that forces the state to continue recognizing the out-of-state marriage of a lesbian couple because one of the women was diagnosed with a terminal illness. U.S. District Court Judge Richard Young issued a preliminary injunction extending a 30-day emergency injunction he made last month that forces the state to recognize the marriage of Amy Sandler and Niki Quasney ... who were married in Massachusetts... Sandler and Quasney are one of five same-sex couples challenging the state's statutory ban on marriages for same-sex couples in federal court. The ruling also orders the Indiana State Department of Health

to list Sandler as Quasney's spouse on her death certificate should she die in Indiana. <http://www.buzzfeed.com/tonymerevick/judge-indiana-must-continue-to-recognize-out-of-state-marriage>

Extract from Buzz Feed article

Lambda Legal attorneys in the case argued the couple want to be recognized as married and receive the associated protections from their home state, such as survivor benefits, while Quasney is still alive, and ensure Sandler's ability to be at her side in the hospital.

Noted in Media Watch, 30 September 2013, #325 (p.3):

- OHIO | 10TV News (Columbus) – 25 September 2013 – **'Gay marriage lawsuit expansion could impact local families.'** The judge handling a case involving end-of-life issues for gay spouses expanded the suit to apply to any lesbian, gay, bisexual and transgender couples in similar situations. Judge Timothy Black of Ohio's Southern District has ruled in favor of both couples [both dealing with the death or imminent death of a spouse], granting them the right to be listed as married on their death certificates and eventually be buried next to each other. <http://www.10tv.com/content/stories/2013/09/25/reynoldsburg-gay-marriage-lawsuit-impact.html>

Bill to improve Medicaid care for seriously ill children

WASHINGTON DC | eNews Park Forest (Illinois) – 8 May 2014 – Congressman Jim Moran (Democratic – Northern Virginia), with Congresswoman Renee Ellmers (Republican – North Carolina) re-introduced legislation ... to improve health care for seriously ill children, by allowing states to bypass the years-long waiver process of including the Children's Program of All-inclusive, Coordinated Care (ChiPACC) as a state option under Medicaid. ChiPACC creates a comprehensive care plan, combining hospice services, counseling and respite with presently-available Medicaid curative care and supportive services. Currently there are only five states in the U.S. providing ChiPACC services as part of state Medicaid programs. The treatment to Medicaid-eligible children suffering from serious illnesses in the remaining 45 states results in an inconsistent and emergency system. Shifting to ChiPACC services and therefore eliminating the emergency room as the primary care facility for this population will reduce the cost of Medicaid services. The five states currently offering ChiPACC services are Florida, Colorado, California, New York and North Dakota. Other states are in various stages of seeking waivers, but are waiting on federal legislation allowing them to elect the state plan option. <http://www.enewspf.com/latest-news/health-care-reform/52750-representatives-moran-ellmers-introduce-bill-to-improve-medicaid-care-for-seriously-ill-children.html>

Cont.

Noted in Media Watch, 21 January 2013, #289 (p.10):

- NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 16 January 2013 – **'Pediatric concurrent care report emphasizes need for collaboration.'** The 'Pediatric Concurrent Care Briefing' shares examples from states that have implemented options to provide pediatric palliative and hospice care services and outlines implementation strategies... http://www.nhpco.org/files/public/ChiPPS/Continuum_Briefing.pdf

Of related interest:

- CALIFORNIA HEALTHLINE | Online – 8 May 2014 – **'Committee OKs bill to expand kids' palliative care pilot program to adults.'** The Senate Committee on Health unanimously approved a measure to expand a children's palliative care pilot program to the adult population of California. "This bill would direct the Department of Health Care Services to seek a waiver to evaluate a palliative care benefit in the Medi-Cal program," said Senator Ed Hernandez... <http://www.californiahealthline.org/capitol-desk/2014/5/committee-oks-bill-to-expand-kids-palliative-care-pilot-program-to-adults>

Population trends

Graying of America is speeding, report says

THE NEW YORK TIMES | Online – 6 May 2014 – The number of Americans 65 and older is expected to nearly double by the middle of the century when they will make up more than a fifth of the nation's population, according to a Census Bureau report.¹ By 2050, 83.7 million Americans will be 65 or older, compared with 43.1 million in 2012. Fewer than 10% were older than 65 in 1970. While demographers have long projected a significantly older country later this century, declines in fertility and mortality rates are hastening the shift, leading to what are expected to be profound changes for issues ranging from social security and health care to education. <http://www.nytimes.com/2014/05/07/us/graying-of-america-is-speeding-report-says.html?ref=health>

1. 'An Aging Nation: The Older Population in the United States,' U.S. Census Bureau, May 2014. http://www.census.gov/prod/2014pubs/p25-1140.pdf?eml=gd&utm_medium=email&utm_source=govdelivery

Lawmakers propose incentives for end-of-life planning

REUTERS | Online – 6 May 2014 – If you are one of the estimated 70% of Americans who have not documented your end-of-life healthcare preferences, Republican Senator Tom Coburn of Oklahoma hopes a cash incentive will prompt you to do the paperwork. Under his newly introduced Medicare Choices Empowerment & Protection Act, seniors could pocket up to \$75 for completing advance directives. <http://news.yahoo.com/lawmakers-propose-incentives-end-life-planning-180342065.html>

Of related interest:

- CONNECTICUT | *The Connecticut Mirror* (Hartford) – 6 May 2014 – **'End-of-life care proposal wins final passage.'** The House of Representatives has given final passage to a proposal aimed at creating a formal process for people with terminal illnesses to discuss their end-of-life care options with a health care provider and document their choices in a medical order. <http://ctmirror.org/end-of-life-care-proposal-wins-final-passage/>

Quotable Quotes

The medium is the message. Marshall McLuhan (1911-1980).

An intimate look at aging prisoners in California

CALIFORNIA | *The Wall Street Journal* – 5 May 2014 – The California Department of Corrections is taking steps to alleviate the aches and pains of prison life for the elderly, who make up the fastest-growing segment of the incarcerated population in the U.S. With an incarcerated population of 2.3 million, the U.S. detains about a quarter of the world's prisoners, while making up 5% of the global population. The percentage of prisoners 55 or older in the U.S. increased by more than 500% between 1990 and 2009, according to a 2012 Human Rights Watch Report.¹ <http://blogs.wsj.com/photojournal/2014/05/05/photos-an-intimate-look-at-aging-prisoners-in-california/>

1. 'The Aging Prison Population in the U.S.,' Human Rights Watch, January 2012. [Noted in Media Watch, 30 January 2012, #238 (p.1)] <http://www.hrw.org/reports/2012/01/27/old-behind-bars>

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of these articles and reports is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

International

So much of our lives are online, but what happens when we die?

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 7 May 2014 – So much of our lives are now played out online, but what happens after we die? We leave a digital legacy. A technological interface to provide comfort to our friends and relatives, in the form our pictures, music, emails and thoughts via Twitter, Apple, Gmail, Microsoft and Facebook. But unlike the assets of our estate, dealt with by an executor of a will, our online activities have no actual value and therefore do not form part of a traditional will. We interact online having agreed to the terms and conditions of individual applications and websites. Therefore, any arrangements we choose to make for our digital legacy become a more complicated affair. <http://www.irishexaminer.com/technology/so-much-of-our-lives-are-online-but-what-happens-when-we-die-267669.html>

Noted in Media Watch, 17 February 2014, #345 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(1):13-18. '**Palliative social media.**' The uses of social media have become ubiquitous in contemporary society at an astonishingly fast-paced rate. The Internet and in particular platforms such as Facebook, Twitter and YouTube are now part of most people's vocabulary and are starting to replace many face-to-face interactions. <http://spcare.bmj.com/content/4/1/13.abstract>

"Do not resuscitate" orders are failing patients, judges told

U.K. | *The Daily Telegraph* – 7 May 2014 – Seriously ill patients are being denied a say in whether they live or die because of a lack of clear rules on whether doctors must consult them before deciding whether to attempt to resuscitate them, three senior judges have heard. The Government's human rights watchdog has joined the family of a woman who had a do not resuscitate order placed on her medical notes without her knowledge in a Court of Appeal challenge in an attempt to clarify the law. Lawyers for David Tracey, whose late wife Janet was placed under such an order at Addenbrooke's Hospital in Cambridge in 2011, argue that the decision was unlawful because she was not consulted. The Equality & Human Rights Commission, which is intervening in the case on behalf Mr. Tracey, argues that patients are being denied their human rights. <http://www.telegraph.co.uk/news/10812263/Do-not-resuscitate-orders-are-failing-patients-judges-told.html>

Cont.

Noted in Media Watch, 3 February 2014, #343 (p.6):

- U.K. (England) | *The Hertfordshire Mercury* (Hertford) – 27 January 2014 – '**Court of Appeal to hear case of terminally ill Ware woman Janet Tracey.**' Three senior judges overturned an earlier ruling and agreed legal action into DNR orders at Cambridge University Hospitals, where Tracey was treated, and across the National Health Service, should continue. <http://www.hertfordshiremercury.co.uk/News/Court-of-Appeal-to-hear-case-of-terminally-ill-Ware-woman-Janet-Tracey-20140127105459.htm>

Cancer in the U.K. 2014

U.K. | Macmillan Cancer Support – 7 May 2014 – This report examines the state of cancer in the U.K. in terms of the nine issues that people affected by cancer have told Macmillan matter most to them. They include not only clinical outcomes, but also the impact of cancer on the whole of a person's life. Looking at these issues, we find that too many people are diagnosed late, shown a lack of compassion during their care, or feel abandoned after treatment to cope with the long-term consequences of cancer alone.

where you live in the U.K. and on your age. <http://www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/CancerintheUK2014.pdf>

Extract from *Cancer in the U.K. 2014*

Many people with cancer require palliative care before their condition is officially considered terminal, yet access is patchy.

Guide on the decision-making process regarding medical treatment in end-of-life situations

COUNCIL OF EUROPE | Online – 7 May 2014 – Paying particular attention to the decision making process regarding medical treatment at the end of life is a form of quality procedure, the main aim of which is to guarantee respect for patients who may be particularly vulnerable in an end-of-life situation. It is essential to promote any measure that makes it possible to adhere as closely as possible to the patient's wishes, which can be expressed either by the patient him or herself or by means of advance directives. Collective discussion relates to the complex clinical situations in which patients find themselves at the end of life. In such situations, in which many ethical issues are

raised, there is a need to discuss and compare arguments to enhance the response and formulate a decision geared to the situation and shows due respect for the patient. http://www.coe.int/t/dg3/healthbioethic/conferences_and_symposia/FDV%20Guide%20Web%20e.pdf

Specialist Publications

'World Innovation Summit for Health forum: A five-step plan of action for improving end-of-life care' (p.9) in *European Journal of Palliative Care*.

N.B. The 34-page publication does not address euthanasia or assisted suicide, but it summarises the principles that could be applied to decisions on medical treatment when "a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future." [Source: *British Medical Journal*, 8 May 2014.] <http://www.bmj.com/content/348/bmj.g3167>

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>

Elder care in the U.K.

Care home fraud soars among middle classes

U.K. | *The Times* – 5 May 2014 – Fraud in the care system has almost doubled in a year as middle-class families try to hide their assets from the taxman, a watchdog has claimed. The Audit Commission recorded an 82% rise in the amount lost to councils last year as families avoided nursing-home fees, pocketed money destined for home-care services for elderly relatives, or failed to report the death of a loved-one to keep receiving payments of up to £60,000 a year. <http://www.thetimes.co.uk/tto/news/uk/crime/article4081097.ece>

End-of-life care in Singapore

More needs to be done for paediatric palliative care: Experts

SINGAPORE | Channel Asia News – 4 May 2014 – Imagine your child having to die before you. This situation, unfortunately, faces a few dozen families in Singapore a year, as their children suffer from life-limiting illnesses. Experts in the field of paediatric palliative care said they want more to be done for the service, through funding, facilities and training. They said a lack of awareness has also held some parents back from opting for the service. Two examples of children hospices overseas are Bear Cottage in Syd-

ney (Australia) and Helen House in the U.K. <http://www.channelnewsasia.com/news/singapore/more-needs-to-be-done-for/1094758.html>

Specialist Publications

'A charter for the rights of the dying child' (p.12), in *The Lancet*.

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

Palliative sedation: An analysis of international guidelines and position statements

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 May 2014 – Guidelines were published by American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). Variances throughout guidelines include definitions of the practice, indications for its use, continuation of life-prolonging therapies, medications used, and timing/prognosis. The development and implementation of institutional-based guidelines with clear stance on the discussed variances is necessary for consistency in practice. <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

Noted in Media Watch, 9 July 2012, #261 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2012 – **'Framework for Continuous Palliative Sedation Therapy (CPST) in Canada.'** Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy (CPST). Although a number of institutional and regional guidelines exist, Canadian practice varies. Given the lack of international and national consensus, the Canadian Society for Palliative Care Physicians (CSPCP) formed a special task force to develop a consensus-based framework for CPST. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0498>

N.B. Recent articles on palliative or terminal sedation are noted in Media Watch, 10 February 2014, #344 (pp.10-11).

Diagnosing dying: An integrative literature review

BMJ PALLIATIVE & SUPPORTIVE CARE | Online – 29 April 2014 – Analysis reveals an overarching theme of uncertainty in diagnosing dying and two sub-themes: 1) "characteristics of dying" involve dying trajectories that incorporate physical, social, spiritual and psychological decline towards death; and, 2) "treatment orientation" where decision making related to diagnosing dying may remain focused towards biomedical interventions rather than systematic planning for end-of-life care. The findings of this review support the explicit recognition of "uncertainty in diagnosing dying" and the need to work with and within this concept. Clinical decision making needs to allow for recovery where that potential exists, but equally there is the need to avoid futile interventions. <http://spcare.bmj.com/content/early/2014/04/29/bmjspcare-2013-000621.short>

Noted in Media Watch, 21 October 2013, #328 (p.11):

- *JAMA INTERNAL MEDICINE* | Online – 14 October 2013 – '**How long do I have?**' Aside from the difficulty of prognosis, there also seems to be a reluctance by many physicians to wade into the murkiness of prognostication, even though patients and families desperately want to know. <http://archinte.jamanetwork.com/article.aspx?articleid=1748833>

Noted in Media Watch, 1 July 2013, #312 (p.11):

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;26(368):2448-2450. '**Uncertainty – the other side of prognosis.**' Prognoses will always have inherent uncertainty, which is often difficult for patients, their families, and even physicians to deal with. But there are ways clinicians can communicate more effectively to help patients and families manage uncertainty. <http://www.nejm.org/doi/full/10.1056/NEJMp1303295>

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.

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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.

Structuring a palliative care service in Brazil: Experience report

BRAZILIAN JOURNAL OF ANESTHESIOLOGY | Online – 29 April 2014 – One of the biggest obstacles ... for the viability of palliative care (PC) programs in developing countries is the lack of government commitment to the PC philosophy. In these countries, and Brazil is included, many of the difficulties in implementing PC services derive from the absence of governmental strategies and consistent national policy for pain relief... The role of governments is so important that it determines the way PC is developed in a particular country. Globally, two scenarios ... are described: the bottom-up and top-down approaches. The bottom-up model is characterized by an energetic group of activists that identify a local need and initiate activities to improve the scenario [e.g., in Zimbabwe, Myanmar]. The top down model occurs when the Ministry of Health is involved in the early stages, encouraging, legislating, creating a national policy and, finally, incorporating the PC to the national health system of the country [e.g., Philippines, Mongolia, and Kazakhstan]. The implementation of a consistent and organized PC network is a challenging task. Despite all the government initiatives, PC implementation in the Brazilian health system is slow and disarticulated. <http://www.sciencedirect.com/science/article/pii/S0104001413001450>

Noted in Media Watch, 12 July 2010, #157 (p.3):

- ACADEMIA NACIONAL DE CUIDADOS PALIATIVOS | Online – 10 July 2010 – **'Brazil is facing a crucial moment in its palliative care system.'** Conselho Federal de Medicina [Brazilian Federal Medicine Council] has established, for the first time in history, palliative care as a fundamental right for the patient and an obligation for the physicians. Associação Médica Brasileira [Brazilian Medical Association] is regulating the activity of palliative medicine and soon it will be allowed for medical colleges and major hospitals to develop internship and post-graduation programs in palliative care. <http://www.paliativo.org.br/noticias/2010/07/english-information-about-the-iv-congresso-internacional-de-cuidados-paliativos/>



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>

Palliative care in Latin America

Atlas de Cuidados Paliativos de Latinoamérica, Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch, 7 January 2013, #287, (p.8)]

Spanish language edition:

<http://cuidadospaliativos.org/uploads/2012/10/atlas/Atlas%20de%20Cuidados%20Paliativos%20en%20Latinoamerica.pdf>;

Portuguese language edition:

<http://cuidadospaliativos.org/uploads/2014/1/Atlas%20portugues.pdf>;

English language edition:

<http://cuidadospaliativos.org/uploads/2013/12/Atlas%20of%20Palliative%20Care%20in%20Latin%20America.pdf>

Atlas de Cuidados Paliativos de Latinoamérica: Edición Cartográfica 2013, Asociación Latinoamericana de Cuidados Paliativos, 2013. [Noted in Media Watch, 2 December 2013, #334 (p.5)]

Spanish language edition:

<http://cuidadospaliativos.org/uploads/2014/3/Atlas%20latinoamerica%20-%20edicion%20cartografica.pdf>

Canadian Medical Association call for palliative care strategy gets federal backing

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 2 May 2014 – The Canadian Medical Association (CMA) and a Parliamentary All-Party Committee have joined forces to advocate for the development of a national strategy on palliative care. CMA President-elect Dr. Chris Simpson noted that as few as 16% of Canadians will have access to any palliative care services this year. "How comfortable and peaceful a death we have should not depend on our postal code," he said. "The Canadian Medical Association calls on governments, federal and provincial, and Canadians everywhere to join these farsighted parliamentarians in thinking with compassion and practicality." The committee on palliative and compassionate care is an *ad-hoc* caucus of MPs from all parties founded four years ago and dedicated to promoting awareness of, and fostering research and constructive dialogue on palliative and compassionate care in Canada. It has the support of 55 Members of Parliament and two years ago issued a comprehensive report 'Not to be Forgotten: Care of Vulnerable Canadians' which dealt with end-of-life care, elderly abuse and suicide prevention.¹ <http://www.cma.ca/cmacallforpalliativecarestrategygetsfederalbacking>

1. 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

N.B. On 14 May Timmins-James Bay New Democratic Party Member of Parliament Charlie Angus will ask parliament to approve his private member's motion M-456 to establish a Pan-Canadian Palliative & End-of-life Care Strategy. [Source: *North Shore News*, North Vancouver, British Columbia, 7 May 2014] <http://www.nsnews.com/james-a-long-road-for-palliative-care-strategy-1.1024636>

World Innovation Summit for Health forum: A five-step plan of action for improving end-of-life care

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(3):136-137. At the World Innovation Summit for Health in Qatar in December 2013, experts discussed global health problems, including how to improve end-of-life care worldwide. The report of the forum on end-of-life care, outlines five steps as a possible plan of action to make effective end-of-life care available to all who need it.¹ The authors of the report aim to change practices and attitudes around the world in an effort to make palliative care more readily available for those who need it. By identifying the necessary steps, learning from good practice and taking action, it is hoped that vital improvements can be made.

1. *Dying healed: Transforming end-of-life care through innovation*, World Innovation Summit for Health, 2013. <http://www.wish-qatar.org/app/media/386>

A new European Association of Palliative Care Task Force will investigate hospice volunteering in Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(3):148-149. The situation of volunteers involved in hospice and palliative care varies greatly between European countries. Volunteers often play an important part in the care of patients and families, but also in a variety of other tasks, including fundraising and administration. Many hospices depend on volunteers to be able to deliver the services they provide. The European Association for Palliative Care Task Force on Volunteering in Hospice & Palliative Care was launched in November 2013 to explore the current state of volunteering in Europe and identify ways of improving volunteers' involvement.

N.B. Access to the journal requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=509

Cont.

Noted in Media Watch, 5 May 2014, #356 (p.11):

- *PAIN PRACTICE* | Online – 28 April 2014 – **'Volunteers in palliative care – a comparison of seven European countries: A descriptive study.'** As part of the European Union co-funded Europall project, four aspects of volunteering in palliative care were studied for 7 European countries (Belgium, England, France, Germany, the Netherlands, Poland, and Spain). These included: 1) involvement of volunteers in palliative care; 2) organization of palliative care volunteering; 3) legal regulations concerning volunteering; and, 4) education and training of palliative care volunteering. <http://onlinelibrary.wiley.com/doi/10.1111/papr.12209/abstract>

Strategies for the economic evaluation of end-of-life care

EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH | Online – 2 May 2014 – Economic evaluation of end of life care is increasingly expected from both research funders and those making decisions about the use of health and social care resources. There are, however, difficulties in applying the currently established evaluative methods to end of life. These are partly associated with the sensitivity of the topic and the feasibility of data collection but also, more fundamentally, a lack of agreement about the terms in which such care should be evaluated. This paper examines different theoretical perspectives from which economic evaluation of end of life care could be conducted, and argues for the application of a capability approach focusing on the opportunity for a good death. It then examines challenges with taking forward such an approach, including defining, measuring and valuing appropriate outcomes. Such an approach is viable, and explores how it might be taken forward to assist with resource allocation decisions. <http://informahealthcare.com/doi/abs/10.1586/14737167.2014.914436>

Noted in Media Watch, 27 July 2009, #107 (p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2009;38(1):4-10. **'Optimal approaches to the health economics of palliative care: Report of an international think tank.'** The full breakdown of the costs of palliative care is yet to be unveiled, and this has left huge unresolved questions for funding, costing, evaluating, and modeling palliative care. This article reports the discussions that took place and the views of this international group of experts on the best research approaches to capture, analyze, and interpret data on both costs and outcomes for families and patients toward the end of life. [http://www.jpsmjournal.com/article/S0885-3924\(09\)00501-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(09)00501-6/abstract)

N.B. This issue of the *Journal of Pain & Symptom Management* focuses on the economics of palliative care and features several articles offering North American and international perspectives on the topic. Journal contents page: [http://www.jpsmjournal.com/issues?issue_key=S0885-3924\(09\)X0007-2](http://www.jpsmjournal.com/issues?issue_key=S0885-3924(09)X0007-2)

Are we ready to "think ahead"? Acceptability study using an innovative end of life planning tool

IRISH MEDICAL JOURNAL, 2014;107(5). Results indicate high levels of acceptability and positive experience for most participants [of the end-of-life planning tool 'Think Ahead']. A majority (63%) indicated "no difficulty" in completing 'Think Ahead;' 74% reported they did not find completing the folder to cause upset; 87% indicated they felt the folder should be more widely available, and 68% indicated they felt 'Think Ahead' would be of general interest. The study was effective in encouraging discussion on end of life issues with family(83%) with 49% indicating they had done so in detail, and 34% indicating having "done so somewhat," having read 'Think Ahead;' 27% indicated aspects of it were upsetting. Results will be used to inform further development of the tool. <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=12613>

"This is our last stop": Negotiating end-of-life transitions in assisted living

JOURNAL OF AGING STUDIES, 2014;30:1-13. [The authors] present a preliminary model for how EOL [end-of-life] care transitions are negotiated in AL [assisted living] that depicts the range of multi-level intersecting factors that shape EOL processes and events in AL. Facilities developed what the authors refer to as an *EOL presence*, which varied across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EOL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EOL processes and events, including how deaths were communicated and formally acknowledged and the impact of death and dying on the residents and staff. The authors' findings indicate that in the majority of cases, EOL care must be supported by collaborative arrangements of care partners and that hospice care is a critical component. <http://www.sciencedirect.com/science/article/pii/S0890406514000103>

Patients' sense of security during palliative care – What are the influencing factors?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 6 May 2014 – Respondents' ratings of their sense of security ranged from 1 (never) to 6 (always)... Patients with lower feelings of security experienced higher stress; more worry about personal finances; lower feelings of self-efficacy; a lower sense of security with the palliative care provided (lower ratings on subscales of care interaction); mastery; prevailed own identity; higher symptom intensity (especially depression, anxiety, and lack of well-being); lower health-related quality of life; lower attachment anxiety and avoidance; less support from family, relatives, and friends; lower comfort for those closest to them... [http://www.jpmsjournal.com/article/S0885-3924\(14\)00070-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00070-0/abstract)

Noted in Media Watch, 24 February 2014, #346 (p.15):

- *PSYCHO-ONCOLOGY* | Online – 14 February 2014 – **'The instrument 'Sense of Security in Care – Patients' Evaluation': Its development and presentation.'** The SEC-P ['Sense of Security in Care – Patients'] provides a three-component assessment of palliative home care settings using valid and reliable scales. These were associated with other concepts in ways that were expected. The SEC-P is a manageable means of assessment that can be used to improve quality of care and in research focusing on patients' sense of security in care. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3502/abstract;jsessionid=346A360A992574D035DB027397E5CEDA.f01t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 9 May 2011, #200 (p.9):

- *PSYCHO-ONCOLOGY* | Online – 6 May 2011 – **'What is a "secure base" when death is approaching? A study applying attachment theory to adult patients' and family members' experiences of palliative home care.'** Informants [i.e., study participants] expressed the relevance of sensing security during palliative home care because death and dying were threats that contributed to vulnerability. Palliative home care could foster a feeling of security and provide a secure base. <http://onlinelibrary.wiley.com/doi/10.1002/pon.1982/abstract>



World hospice &
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11 October 2014

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A charter for the rights of the dying child

THE LANCET, 2014;383(9928):1547-1548. The death of a child is a devastating and tragic event for all those involved: the family members distraught by grief and the health-care providers who are called on to address the child's complex care needs, where professionalism, ethics, deontology, and practice must reckon with personal emotions, experiences, and fears. But, it is the children who pay the highest price, suffering, and coping directly with the burden of incurable illness and death, the trauma of separation, the loss of their future and often, in solitude, the consequences of their illness, fears, and emotions. Sometimes, the people closest to them refuse to accept the negative progression of the disease and, consequently, do not recognise terminal illness and death as real and imminent issues to be addressed. As a result, these children are subjected to unrealistic decisions and treatment choices. More frequently, although fully aware of the reality of the situation, those caring for the child try to protect the child from a truth that they consider too difficult and painful to cope with by avoiding it in conversation, justifying it as the price to pay for an imaginary better future or, despite the obvious state of affairs, blatantly denying it. In both cases, even if the protagonist is the child, he or she becomes the object of treatment, care, and love, and is deprived of his or her role as a person able to speak out, decide, express, and discuss personal feelings, wishes, hopes, and deepest fears. It is certainly not an easy problem to address, since the factors conditioning and influencing behaviour and choices are complex and deep rooted. However, the difficulties encountered in addressing this problem cannot hinder the undertaking nor generate doubts and misgivings regarding the rights of these children and the duties of those accompanying and caring for them during the final phase of their life. In September 2012, a group of professionals working with children affected by incurable illness in Italy launched a project ...

to formulate a charter of rights for children approaching the end of their lives. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(14\)60746-7/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)60746-7/fulltext)

The rights of the dying child – the Trieste Charter proposal

To be considered a person until death irrespective of age, location, illness, and care setting

To receive effective treatment for pain, and physical and psychological symptoms causing suffering through qualified, comprehensive, and continuous care

To be listened to and properly informed about his or her illness with consideration for his or her wishes, age, and ability to understand

To participate, on the basis of his or her abilities, values and wishes, in care choices about his or her life, illness, and death

To express and, whenever possible, have his or her feelings, wishes, and expectations taken into account

To have his or her cultural, spiritual, and religious beliefs respected and receive spiritual care and support in accordance with his or her wishes and choices

To have a social and relational life suitable to his or her age, illness, and expectations

To be surrounded by family members and loved ones who are adequately supported and protected from the burden of the child's illness

To be cared for in a setting appropriate for his or her age, needs, and wishes and that allows the proximity of the family

To have access to child-specific palliative-care programmes that avoid futile or excessively burdensome practices and therapeutic abandonment

Cont.

Of related interest:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(3):127-129. **'The influence of childhood trauma upon dying.'** Difficulties stemming from childhood and causing the patient distress may be evoked again in the dying phase of an illness. The trauma of an event in childhood may be remembered or may be buried within the unconscious and carried somatically. A psychoanalytical perspective that is curious about the patient's early life may enable palliative care practitioners to help them find greater peace and understanding in their final days.

N.B. Access to the journal requires a subscription. Contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=509

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2014;15(4):suppl.9. **'The setting and quality of communication at end of life in the pediatric intensive care unit.'** [In this study] substantially more ... end-of-life communication occurred at bedside than during family conferences or rounds. With the exception of non-private locations, setting was not associated with the quality of communication as perceived by practitioners. These findings have educational implications in that practitioners need to be prepared to hold end-of-life conversations not only as a team, but also independently across settings, particularly naturally occurring bedside conversations. http://journals.lww.com/pccmjournals/Fulltext/2014/05001/Abstract_23_the_Setting_and_Quality_of_23.aspx

American Academy of Pediatrics: Policy statement

- *PEDIATRICS*, 2014;133(5):e1471-e1478. **'Child life services.'** Child life programs are an important component of pediatric hospital-based care to address the psychosocial concerns that accompany hospitalization and other health care experiences. Child life specialists focus on the optimal development and well-being of infants, children, adolescents, and young adults while promoting coping skills and minimizing the adverse effects of hospitalization, health care, and/or other potentially stressful experiences. Using therapeutic play, expressive modalities, and psychological preparation as primary tools, in collaboration with the entire health care team and family, child life interventions facilitate coping and adjustment at times and under circumstances that might otherwise prove overwhelming for the child. Play and developmentally appropriate communication are used to: 1) promote optimal development; 2) educate children and families about health conditions; 3) prepare children and families for medical events or procedures; 4) plan and rehearse useful coping and pain management strategies; 5) help children work through feelings about past or impending experiences; and 6) establish therapeutic relationships with patients, siblings, and parents to support family involvement in each child's care. <http://pediatrics.aappublications.org/content/133/5/e1471.short>

Importance of psychological research in palliative care: Barriers in its development

PALLIATIVE MEDICINE & HOSPICE CARE OPEN, 2014;1(1):1-3. The analysis of the psychosocial aspects in patients with advanced illness or at the end of life has a number of characteristics that are difficult to study. The barriers to psychological research [identified in this study] are related to the following aspects: 1) psychological issues are subjective, variables or constructs are complex and difficult to operationalize; 2) psychological variables are difficult to measure; 3) the patients are fragile, their condition (both their physical and psychological state) is mediated by the progress of the disease and the presence of impending death; 4) health professionals have limited time to conduct assessments or research; and, 5) there is a lack of validated clinical tools. <http://openventio.org/PalliativeMedicineandHospiceCareOpenJournal/ImportanceofPsychologicalResearchinPalliativeCareBarriersinitsDevelopment-PMHCOJ-1-101.pdf>

Noted in Media Watch, 12 August 2013, #315 (p.10):

- *PALLIATIVE MEDICINE* | Online – 9 August 2013 – **'Research on psychological and social factors in palliative care.'** Psychosocial research in palliative care has grown in rigor and volume ... and a variety of novel interventions have been developed and evaluated. However, the findings from this research have only begun to have an impact on clinical practice in palliative care. <http://pmj.sagepub.com/content/early/2013/08/07/0269216313499961.abstract>

The real-world problem of care coordination: A longitudinal qualitative study with patients living with advanced progressive illness and their unpaid caregivers

PLOS ONE | Online – 2 May 2014 – Within the context of serious illness, care coordination is a shared responsibility and it is a complex intervention facilitated, in part, through the deliberate efforts of patients, unpaid caregivers and staff that work in partnership across services and settings. The authors' model addresses the paucity of care coordination models, it provides conceptual coordination fidelity, it provides an alternative to the current overreliance on process and satisfaction measures as proxy measures for coordination, and helps address the challenge of not oversimplifying a real-world problem, such as care coordination. Avoiding oversimplifying the real-world problem of care coordination in a complex health and social care system that caters for patients with complex needs is important to advance the development, evaluation and implementation of coordination interventions for patients and their unpaid caregivers in the future. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0095523>

Of related interest:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 6 May 2014 – '**Caregiver experience during advanced chronic illness and last year of life.**' During chronic illness and at the end of life, high caregiver esteem was almost universal (95%); more than 25% of the sample reported health, family, and financial burden. Schedule burden was the most prevalent form of burden; end-of-life caregivers (58%) experienced it more frequently than chronic-illness caregivers (32%). <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12841/abstract>

Noted in Media Watch, 31 March 2014, #351 (p.7):

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 20 March 2014 – '**Integrated end of life care: The role of social services.**' If palliative care must be holistic, then it should include the social nature of the aid. Many of the effective solutions that are often required to adequately take care of each case are not health services but rather social ones. <http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-114777/2376>

Noted in Media Watch, 13 May 2013, #305 (p.13):

- *HEALTH SERVICE JOURNAL* | Online – 8 May 2013 – '**Redesigning end of life care in the community.**' The challenges for the health and social care system in our ageing society and the pressure associated with ongoing public spending constraints are clear for all to see. <http://www.hsj.co.uk/home/innovation-and-efficiency/redesigning-end-of-life-care-in-the-community/5057553.article?blocktitle=Resource-Centre&contentID=8630>

Place of death in patients with amyotrophic lateral sclerosis

REVISTA PORTUGUESA DE PNEUMOLOGIA | Online – Accessed 6 May 2014 – In order to analyze the characteristics of amyotrophic lateral sclerosis patients who die at home and in hospital, and to study the variability of clinical practice, a retrospective medical records analysis was performed... patients who die at home are related to a set of elements in which health resources, physician attitudes and support resources in the community play a role in the decision-making process. There is great variability between countries and between hospitals in the same country. [http://apps.elsevier.es/watermark/ctl_servlet?f=10&pident_articulo=0&pident_usuario=0&pcontactid=&pident_revista=320&ty=0&accion=L&origen=elsevierpt%20&web=www.elsevier.pt&lan=en&fichero=S0873-2159\(14\)00044-0.pdf&eop=1&early=si](http://apps.elsevier.es/watermark/ctl_servlet?f=10&pident_articulo=0&pident_usuario=0&pcontactid=&pident_revista=320&ty=0&accion=L&origen=elsevierpt%20&web=www.elsevier.pt&lan=en&fichero=S0873-2159(14)00044-0.pdf&eop=1&early=si)

Cont.

Noted in Media Watch, 17 March 2014, #349 (p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 March 2014 – **'Comparison between home and hospital as the place of death for individuals with amyotrophic lateral sclerosis in the last stages of illness.'** Providing family education and ensuring the availability of local family physicians are vital to meeting a patient's desire to die at home. <http://ajh.sagepub.com/content/early/2014/03/11/1049909114525259.abstract>

A qualitative study: Potential benefits and challenges of traditional healers in providing aspects of palliative care in rural South Africa

RURAL & REMOTE HEALTH | Online – 11 May 2014 – Healthcare workers' experiences revealed that patients they cared for valued traditional rituals connected to illness, dying, death and bereavement. Participants suggested that traditional healers should be included in palliative care training programs as they could offer appropriate psychological, cultural and spiritual care. A challenge identified by participants was the potential of traditional healers to foster a false sense of longevity in patients facing death. <http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=2378>

What constitutes a good death? A clergy perspective

RURAL THEOLOGY | Online – 30 April 2014 – This qualitative study is concerned with the views of clergy about the constituent elements of a "good death." The method employed to explore the question was a set of cards called the 'Conversations Game.' These cards, developed from research in the U.S. in 1999, contain a list of identified ingredients of a "good death." Within this study, the cards were further ordered to conceptualise the field under four headings, covering the four elements of palliative care: 1) physical care; 2) emotional (or psychological) care; 3) social care; and 4) spiritual care. Choices made from the cards formed the content of structured interviews ... with a randomly selected group of Church of England clergy... The study indicated that the clergy interviewed differed in their chosen components of a good death from the professional consensus in healthcare in some respects. Chief among these was a high priority given to spiritual care concerns. <http://essential.metapress.com/content/k556081255528061/>

Of related interest:

- *DISCOURSE STUDIES* | Online – 1 May 2014 – **"Good" and "bad" deaths: Narratives and professional identities in interviews with hospice managers.'** The interviewees' responses include a variety of remarkably consistent "narratives of successful/frustrated intervention," which exhibit distinctive formal characteristics in terms of the starting point and core of the action, the choice of personal pronouns and metaphors, and the ways in which positive and negative evaluation is expressed. In functional terms, the hospice managers' narratives play an important role in representing and constructing their professional views, challenges and identities. <http://eprints.lancs.ac.uk/69329/>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(3):115-118. **'Euthanasia and assisted suicide: View of the Polish Association for Palliative Medicine and Polish Psycho-oncology Society.'** Most doctors, nurses and medical students in Poland are against the practice of euthanasia and assisted suicide and, to a lesser extent, their decriminalisation. The Polish Association for Palliative Medicine and the Polish Psycho-oncology Society are convinced that the provision of appropriate medical, psychosocial and spiritual support to patients with cancer or other life-threatening diseases can render euthanasia and assisted suicide unnecessary.

N.B. Access to the journal requires a subscription. Contents page:
http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=509

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

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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