Alberta Health Services urges public to plan for their advanced care

ALBERTA | The Medicine Hat News – 26 March 2014 – A Green Sleeve no longer means a part of clothing but rather a document about the medical treatment you would like if you are no longer able to express that for yourself. In a province-wide initiative, Alberta Health Services [AHS] is asking everyone to take five steps towards advance care planning ... [to] ...“think about your values and wishes, learn about your health, choose someone to make decisions and speak on your behalf if there comes a time that you can't communicate your wishes and values about health care ... [and, to] ... document it all in a personal directive.” Ultimately the Green Sleeve documents will be part of a patient's electronic health record. http://medicinehatnews.com/news/local-news/2014/03/26/ahs-urges-public-to-plan-for-their-advanced-care/

Of related interest:

- SASKATCHEWAN | Global TV News (Saskatoon) – 24 March 2014 – "'End-of-life" care – the conversation experts say you need to have.' Would your family know what to do you if you couldn't communicate your end-of-life wishes? It's a difficult conversation to have and one poll shows not enough people are having it. According to a new Harris-Decima poll, six out of ten Canadians believe it's extremely important to talk to someone about their end-of-life care preferences and yet only 45% have done so. http://globalnews.ca/news/1228201/end-of-life-care-the-conversation-experts-say-you-need-to-have/
Family caregivers are increasingly male

ONTARIO | Metroland Media – 25 March 2014 – It used to be assumed caregivers for aging relatives were female, but this assumption has been changing... Caregivers used to be disproportionately women, according to a Statistics Canada report from 2012 which cites Cranswick & Dosman 2008. The study offers evidence that the number of male caregivers is rising. In 2012, an estimated 54% of caregivers were women, while 46% of Canadian family caregivers were men. http://www.yorkregion.com/news-story/4429677-family-caregivers-are-increasingly-male/


Redefining palliative care

MACLEAN'S, 2014;127(11):48-49. This article considers palliative treatment in medical care. A lack of access to palliative treatment for most Canadians and reluctance of patients to discuss palliative treatment and of physicians to refer patients to it due to its association with end-of-life care are examined. Research on palliative treatment and pilot programs at hospitals indicating it can reduce medical care costs are discussed. http://www.macleans.ca/society/health/redefining-palliative-care/


Noted in Media Watch, 24 February 2014, #346 (p.10):

- CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 20 February 2014 – 'Canada needs a "dialogue about death" says Canadian Medical Association president.' Canada is facing a severe crisis surrounding end-of-life care due to the stigma surrounding it and funding concerns. Unfortunately, palliative care is currently only available to 15-30% of Canadians. http://www.cma.ca/site/earlyreleases/20feb14_Canada-needs-a-dialogue-about-death-says-CMA-president.xhtml

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | The Hamilton Spectator – 26 March 2014 – 'Conservative MP Fletcher backs bill to allow assisted suicide.' Stephen Fletcher says he plans to introduce two private member's bills that would allow assisted suicide in some cases [i.e., 'An Act to Amend the Criminal Code: Physician Assisted Death' & 'An Act to Amend the Criminal Code: Canadian Commission on Physician Assisted Death']. The Manitoba MP, who was in an accident in 1996 that left him a quadriplegic, says one of the bills would, if passed, allow doctors to help people end their lives under certain restricted circumstances. http://www.thespec.com/news-story/4431586-conservative-mp-fletcher-backs-bill-to-allow-assisted-suicide/

Noted in Media Watch, 24 February 2014, #346 (p.2):

- THE NATIONAL | Online – 21 February 2014 – 'The Conservatives' selective interest in protecting human life.' Quebec is poised to legalize "medical aid in dying. The Conservative [federal] government is not on board. It appealed the 2012 decision by the B.C. Supreme Court striking down Canada's euthanasia laws. The Supreme Court in Ottawa is set to consider it sometime this year. Justice Minister Peter MacKay said "the Criminal Code provisions prohibiting assisted suicide and euthanasia are in place to protect all persons... http://fullcomment.nationalpost.com/2014/02/21/chris-selley-the-conservatives-selective-interest-in-protecting-human-life/
U.S.A.

Caregiver fatigue: Dealing with it starts with recognizing you have it

NEW AMERICA MEDIA | Online – 24 March 2014 – Former First Lady Roslyn Carter, founder of the Rosalynn Carter Institute for Caregiving [Georgia Southwestern State University], says there are four kinds of people in the world: "Those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers." There should be a fifth: Those who don't realize they have begun the caregiver journey – and their ranks are growing daily.  
http://newamericamedia.org/2014/03/caregiver-fatigue-deal-with-it-starts-with-recognizing-you-have-it.php

Legislation to protect quality of life

Treat the entire patient, not just the cancer

SOUTH DAKOTA | The Black Hills Pioneer (Spearfish) – 24 March 2014 – There are currently two bills pending in Congress that would improve the quality of life of patients undergoing care for serious illnesses such as cancer by expanding patient access to palliative care. The Palliative Care and Hospice Education and Training Act would award grants to encourage training and continuing education for students and existing health professionals in palliative care.\(^1\) The Patient Centered Quality of Life Act would improve the experience of cancer patients and their families by better coordinating their care and addressing often debilitating treatment symptoms.\(^2\) 
http://www.bhpioneer.com/opinion/article_6bdaff24-b36b-11e3-89f7-001a4bcf887a.html

1. Palliative Care and Hospice Education and Training Act: https://www.govtrack.us/congress/bills/113/hr1339
2. Patient Centered Quality of Life Act: https://www.govtrack.us/congress/bills/113/hr1666

N.B. GovTrack.us tracks bills in the U.S. Congress.

International

Cancer care crisis – Public health system can only care for 200 of 900 new patients

JAMAICA | The Gleaner (Kingston) – 27 March 2014 – The Inadequacy of Jamaica's health sector to care for persons with one of the most dreaded critical illnesses – cancer – was exposed when a senior government technocrat admitted that the public health system can only care for 200 of the 900 new cancer patients diagnosed annually with the non-communicable disease. Conceding that this situation is "alarming," Dr. Kevin Harvey, acting chief medical officer, told members of the Public Accounts Committee that cancer is posing a serious challenge to the health sector. But Harvey indicated that apart from the 200 new cancer cases dealt with each year, the Kingston Public Hospital also provides continuing treatment to between 600 and 800 cancer patients every year. He also shared with the committee the findings of an Inter American Development Bank study which looked at chronic illnesses in the country. He said the study indicated that in order to mitigate the impact of chronic illnesses such as cancer in Jamaica, the Government would have to increase its allocation to the health ministry by $10 billion each year until 2030. 
**End of life care in the U.K.**

Thousands of elderly cancer victims could be denied drugs: New NICE rules set to downgrade treatment for terminally ill

U.K. | The Daily Mail – 27 November 2014 – Thousands of seriously ill cancer patients could be denied treatment under changes to the way drugs are funded on the National Health Service. Campaigners are warning that proposals from the National Institute for Health and Care Excellence (NICE) will end the priority given to terminally ill patients. They estimate almost 13,000 cancer patients a year who are given life-prolonging drugs might be denied them under the new plans – with the elderly particularly vulnerable. They are urging the government to tell NICE to approve more treatments, as has been done in Scotland. NICE, which decides whether new medicines are cost-effective, is changing the criteria used to determine the value to patients and society of approving drugs. Its appraisal committees will have to adopt a more "favourable approach" when considering treatments for people whose conditions involve a "high burden" of illness and where there is a wider impact on society. But the decision to remove "end of life" criteria, which gave special consideration to the seriously ill, raised widespread concern. [http://www.dailymail.co.uk/news/article-2590340/Thousands-elderly-cancer-victims-denied-drugs-New-NICE-rules-set-downgrade-treatment-terminally-ill.html](http://www.dailymail.co.uk/news/article-2590340/Thousands-elderly-cancer-victims-denied-drugs-New-NICE-rules-set-downgrade-treatment-terminally-ill.html)

**Commentary: Time for National Health Service culture change on death**

U.K. (Scotland) | The Scotsman (Edinburgh) – 27 March 2014 – We owe it to each other ... to ensure when death is anticipated and inevitable, a "good death" should be compassionately provided for. By a "good death" I am referring to an experience of the end of life – over hours, days, weeks or even months – that is symptomatically and psychologically peacable, in surroundings that are secure and stress free. This should be core business at the heart of the NHS [National Health Service], if only because very few of us will encounter death without first encountering the NHS. [http://www.scotsman.com/news/comment-time-for-nhs-culture-change-on-death-1-3355117](http://www.scotsman.com/news/comment-time-for-nhs-culture-change-on-death-1-3355117)

**Of related interest:**

- **U.K. | The Belfast Telegraph** – 28 March 2014 – "Concern over palliative care deaths." The way hospitals record deaths could be covering up poor treatment and costing lives, according to a new report. Figures show a dramatic rise in the number of people recorded as needing "palliative care" at the end of their lives, with some hospitals saying more than 35% of their patients die this way. Hospitals could actually be hiding the fact patients were admitted for treatment which then failed. [http://www.belfasttelegraph.co.uk/news/local-national/uk/concern-over-palliative-care-deaths-30134063.html](http://www.belfasttelegraph.co.uk/news/local-national/uk/concern-over-palliative-care-deaths-30134063.html)


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**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.ipcr.net/barry-r-ashpole.php](http://www.ipcr.net/barry-r-ashpole.php)
U.K. | Leadership Alliance for the Care of Dying People\textsuperscript{1,2} – 20 March 2014 – ‘Care for people in the last days and hours of life.’ The Alliance’s latest joint statement identifies five priorities: 1) The possibility a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly; 2) Sensitive communication takes place between staff and the person who is dying, and those identified as important to them; 3) The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent the dying person wants; 4) The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible; and, 5) An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion. There is no hierarchy within the priority areas: they are all equally important to achieving good care in the last days and hours of life.  

1. ‘Experts to examine end-of-life care after axing of Liverpool Care Pathway,’ The Guardian, 29 August 2013. [Noted in Media Watch, 2 September 2013, #321 (p.4)]  

2. Independent Report: Review of Liverpool Care Pathway for dying patients, Department of Health [England], July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)]  

End-of-life care in Australia

New options for palliative care

AUSTRALIA (New South Wales) | The Braidwood Times – 25 March 2014 – The Southern NSW [New South Wales] Medicare Local and the Southern NSW Local Health District have joined forces with NSW Ambulance to promote a protocol that allows paramedics to treat palliative patients in their own home on the instructions of their GP rather than transfer them to hospital. NSW Ambulance attends more palliative care patients per year than any single Local Health District in the State. The care protocol was introduced by NSW Ambulance to support paramedic decision making in meeting the needs of individual patients with specific medical conditions.  

Specialist Publications

‘Elements of effective palliative care models: A rapid review’ (p.6), in BMC Health Services Research.

Noted in Media Watch, 22 July 2013, #315 (p.10):

- JOURNAL OF PARAMEDIC PRACTICE, 2013;5(7):394-399. ‘End-of-life care in the community: The role of ambulance clinicians.’ This article presents the issues that impact on the delivery of care to patients at the end of life... http://www.paramedicpractice.com/cgi-bin/go.pl/library/article.cgi?uid=99703;article=pp_5_7_394_399

Updated 31 March 2014

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.11.
End-of-life care in Ireland

Preparing for end of life

IRELAND | *The Irish Times* (Dublin) – 24 March 2014 – The likelihood that advance healthcare directives (AHDs) will soon be part of legislation should be welcomed by medical and legal professionals as well as all who believe in personal autonomy. For too long, despite treaties and conventions urging such mechanisms, Ireland has been slow to legislate. The signal from the Supreme Court has also been clear. A person with capacity should have the right to control his or her treatment and care, including the right to refuse treatment that would facilitate a natural death.


1. 'Draft legislation for Bill allowing terminally ill to make "living wills,"' *The Irish Times*, 5 February 2014. [Noted in Media Watch, 10 February 2014, #344 (p.3)]

2. 'Marie Fleming loses Supreme Court right-to-die case,' *The Independent* (Dublin), 29 April 2013. [Noted in Media Watch, 6 May 2013, #304 (p.6)]

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

End-of-life care in Australia

**Elements of effective palliative care models: A rapid review**

*BMC HEALTH SERVICES RESEARCH* | Online – 26 March 2014 – Of 1,959 peer-reviewed articles, 23 reported systematic reviews, 9 additional randomized control studies, and 34 non-randomised comparative studies. Models of palliative care should integrate specialist expertise with primary and community care services and enable transitions across settings, including residential aged care. The increasing complexity of care needs, services, interventions and contextual drivers warrants future research aimed at elucidating the interactions between different components and the roles played by patient, provider and health system factors. The findings of this review are limited by its rapid methodology and focus on model elements relevant to Australia’s health system.

http://www.biomedcentral.com/content/pdf/1472-6963-14-136.pdf

**Principle of double effect**

**Decisions that hasten death: Double effect and the experiences of physicians in Australia**

*BMC MEDICAL ETHICS* | Online – 25 March 2014 – The principle of double effect, as a simplistic and generalised guideline, was identified as a convenient mechanism to protect physicians who inadvertently or intentionally hastened death. But its narrow focus on the physician's intent illuminated how easily it may be manipulated, thus impairing transparency and a physician's capacity for honesty.


Noted in Media Watch, 18 April 2011, #197 (p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 8 April 2011 – 'Double effect: A useful rule that alone cannot justify hastening death.' The rule of double effect is regularly invoked in ethical discussions about palliative sedation, terminal extubation and other clinical acts that may be viewed as hastening death for imminently dying patients. The literature tends to employ this principle in a fashion suggesting that it offers the final word on the moral acceptability of such medical procedures.
  http://jme.bmj.com/content/early/2011/04/08/jme.2010.041160.abstract
End-of-life care in the U.S.

The end of life

BRITISH MEDICAL JOURNAL | Online – 26 March 2014 – Increasingly, U.S. physicians face legal risks for doing too much or too little to help patients with end of life issues. On one hand, doctors are under more pressure to hold discussions with people who are diagnosed with terminal illnesses – exploring whether they would want to stop treatment if it became ineffective. In that case, the patient would shift to palliative care, which involves pain medications and other therapies to enhance quality of life. On the other hand, physicians may have terminally ill patients who are untreated and want to die, but assisting in their suicide is illegal in most U.S. states. In a few cases, physicians have been criminally convicted and sent to prison for helping a patient die. Even talking about end of life issues can be distressing for physicians, because their overriding concern is to heal patients, said Timothy E. Quill, a palliative care specialist in Rochester, New York. "When you've been fighting for a patient for a long time, it can be really hard to give up on treatment," said Quill, who directs the Center for Ethics, Humanities & Palliative Care at the University of Rochester School of Medicine. Quill said there are negative consequences, however, if physicians avoid talking about end of life issues with patients – as is often the case. Patients may never have the chance to choose options that could ease their deaths. And if they can't talk about their desire for suicide, they are cut off from exploring other options, such as taking antidepressants or stronger pain medications. http://www.bmj.com/content/348/bmj.g2261

Inappropriate prescribing in patients accessing specialist palliative day care services

INTERNATIONAL JOURNAL OF CLINICAL PHARMACY | Online – 22 March 2014 – A total number of 132 patients were assessed during the study period who were prescribed 1,532 medications; 238 (16%) were considered inappropriate in the context of limited life expectancy. The most common class of medications considered inappropriate were the statins, observed in 35 (27%) patients. A total of 267 potential drug-drug interactions were identified; 112 were clinically significant and 155 were not considered clinically significant. Discontinuation of inappropriate medication would reduce the total number of medications taken to 1,294 and prevent 31 clinically significant potential drug-drug interactions. Patients accessing specialist palliative day care services take many inappropriate medications. These medications not only increase the pharmacotherapeutic burden for the patient but they also contribute to potential drug-drug interactions. http://link.springer.com/article/10.1007/s11096-014-9932-y

Integrated end of life care: The role of social services

INTERNATIONAL JOURNAL OF INTEGRATED CARE | Online – 20 March 2014 – 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. If these social resources and benefits are not offered, it will mean greater costs for the health system and a dysfunctional use of the competences of health care professionals for tackling social needs that are better addressed by other types of professionals. The integration of social support in the provision of palliative care seems to be an efficient way to respond to the complex mix of needs of people in the end stage of their lives, allowing them to die according to their preferences and at the same time contributing to the sustainability of welfare systems. http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AU%3A10-1-114777/2376

Extract from International Journal of Integrated Care article

End-of-life care for multi-morbid patients is particularly complex and in most health and care systems fragmented and uncoordinated.

Cont.
Noted in Media Watch, 24 March 2014, #350 (p.8):

- **BMJ SUPPORTIVE & PALLIATIVE CARE, 2014;4(18). 'Benefits of health and social care integration.'** Scotland’s health boards and local authorities are moving towards integrated funding and service provision. [http://spcare.bmj.com/content/4/1/118.1.short](http://spcare.bmj.com/content/4/1/118.1.short)

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


"Don't get weak in your compassion": Bereaved next of kin's suggestions for improving end-of-life care in Veterans Affairs medical centers

**JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 21 March 2014 –** Next of kin provided examples that resonated with their conceptions of quality EOL [end-of-life] care. They also described distressing situations and perceptions of deficits in care. Major themes derived were compassionate care, good communication, support for family visits and privacy, and the need for death preparation and post-death guidance. The fifth theme, unique to this study, was the salience of the relationship between the veterans and their families and the [Department of] Veterans Affairs and the expectations this engendered in terms of dignity and honor. Interventions that support staff's ability to convey compassion, communicate information to families and other staff, listen to patients and families, prepare families for the individual's death, and provide consistent, coordinated information regarding after-death activities may optimize EOL hospital care for veterans. [http://onlinelibrary.wiley.com/doi/10.1111/jgs.12764/abstract](http://onlinelibrary.wiley.com/doi/10.1111/jgs.12764/abstract)

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**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.
A comparison of the willingness of resident and attending physicians to comply with the requests of patients at the end of life

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 20 March 2014 – While a majority of both attendings and residents [i.e., survey respondents] were willing to comply with each of the requests to withhold intubation (100% and 94%, respectively), to extubate (92% and 77%), and to give increasingly higher doses of narcotics (94% and 71%), a significantly larger proportion of attendings vs. residents was willing to comply with each of these requests. Small proportions of attendings and residents were willing to prescribe a lethal amount of sleeping pills (3% and 5%, respectively) and to give a lethal injection in its current illegal state (1% and 4%). A larger proportion of residents (32%) compared to attendings (19%) was willing to give a lethal injection if legal. Adjusting for socio-demographic factors, attending status was independently associated with willingness to extubate and to give a lethal injection if legal. The proportion of physicians willing to extubate increased across years since graduation, with the greatest differences occurring across the residency years (69% to 86%). http://link.springer.com/article/10.1007/s11606-014-2830-0

In the shadow of death: Existential and spiritual concerns among persons receiving palliative care

JOURNAL OF PASTORAL CARE & COUNSELING, 2014;68(1). This study explores existential and spiritual concerns from the perspective of people receiving palliative care. It examines their meaning, their influence on people's lives, and investigates the connections between them. Findings reveal existential and spiritual aspects as interconnected and an integral part of the participants' everyday existence. http://journals.sfu.ca/jpcp/index.php/jpcp/article/view/691

Representative sample of articles on spirituality and end-of-life care noted in recent issues of Media Watch:

- **ARCHIVE FOR THE PSYCHOLOGY OF RELIGION,** 2012;34(1):63-81. 'Six understandings of the word 'spirituality' in a secular country.' Spirituality is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)] http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005

  N.B. This issue of the Archive for the Psychology of Religion focuses on spirituality. Contents page: http://booksandjournals.brillonline.com/content/15736121.

- **JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE,** 2013;9(2-3):111. 'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.' This issue of the journal gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care. [Noted in Media Watch, 24 June 2013, #311 (p.12)] Contents page: http://www.tandfonline.com/toc/wswe20/current

- **ONCOLOGY NURSING FORUM,** 2014;41(1):33-39. 'Spirituality and uncertainty at the end of life.' Health professionals must recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the need to frequently assess for spiritual uncertainty. Recommendations are provided in addressing spiritual uncertainty with patients. [Noted in Media Watch, 6 January 2014, #339 (p.13)] http://ons.metapress.com/content/qu254t23r3126830/

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch
Motivations, aims and communication around advance directives. A mixed-methods study into the perspective of their owners and the influence of a current illness

PATIENT EDUCATION & COUNSELING | Online – 19 March 2014 – About half of the authors' population [i.e., study participants] had no direct motivation to draft their AD [advance directives]. Most mentioned motivation for the other half was an illness of a family member or friend. Many different and specific aims for drafting an AD were mentioned. An often mentioned more general aim in people with different ADs was to prevent unnecessary lengthening of life or treatment. Most respondents communicated about having an AD with close-ones and with their GP. In the interviews people gave vivid examples of experiences of what they hoped to prevent at the end of life. Some mentioned difficulties foreseeing the future and gave examples of response shift. http://www.sciencedirect.com/science/article/pii/S0738399114000950

The end-of-life experience of patients with rare cancers and their caregivers

RARE TUMORS | Online – 24 March 2014 – Patients were interviewed about EOL [end-of-life] preferences, planning, medical care, and followed until death. Interviews with caregivers at baseline assessed caregiver mental and physical health; and post-mortem, assessed EOL patient care. PRC [patients with common cancers] were four times more likely than PCC to be receiving both radiation and chemotherapy at study entry. PRC's caregivers were more likely to report declining health and marginally more likely to report using mental health services to cope than PCC's caregivers. PRC were as likely to acknowledge their illness was terminal, have EOL discussions, and participate in advance care planning as PCC. Future research should investigate terminal care for PRC and how providing care affects caregivers' physical and mental health. http://www.pagepress.org/journals/index.php/rt/article/view/5281

Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association/American Stroke Association

STROKE | Online – 27 March 2014 – The palliative care needs of patients with serious or life-threatening stroke and their families are enormous: complex decision making, aligning treatment with goals, and symptom control. Primary palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of illness. To optimally deliver primary palliative care, stroke systems of care and provider teams should 1) promote and practice patient- and family-centered care; 2) effectively estimate prognosis; 3) develop appropriate goals of care; 4) be familiar with the evidence for common stroke decisions with end-of-life implications; 5) assess and effectively manage emerging stroke symptoms; 6) possess experience with palliative treatments at the end of life; 7) assist with care coordination, including referral to a palliative care specialist or hospice if necessary; 8) provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated; and, 9) actively participate in continuous quality improvement and research. https://stroke.ahajournals.org/content/early/2014/03/27/STR.0000000000000015.abstract?sid=47c8fc43-e9b4-4707-a8c5-9aac14957e6a

Noted in Media Watch, 12 November 2012, #279:

- BMC PALLIATIVE CARE | Online – 9 November 2012 – 'Integrating palliative care within acute stroke services: Developing a programme theory of patient and family needs, preferences and staff perspectives.' This paper presents an explanatory framework for the integration of palliative and acute stroke care. http://www.biomedcentral.com/content/pdf/1472-684X-11-22.pdf
Inappropriate referrals at the end of life – the existing Indian scenario

SUPPORTIVE CARE IN CANCER | Online – Accessed 25 March 2014 – The Economist Intelligence Unit has ranked India’s end-of-life care last out of 40 countries. The lack of orientation towards palliative care, poor communication skills, a disease-focused, curative approach and the unending battle against death – all lead to unrealistic hope in patients and their families. Inappropriate referrals at the end of life are common and result in a lot of avoidable suffering for both the patients and their families. Propagation of clear guidelines to limit inappropriate therapeutic interventions and referrals in patients with limited prognosis is the need of the hour. Awareness, sensitization, education and training in palliative care are urgently required to change attitudes. http://link.springer.com/article/10.1007/s00520-014-2214-3


Cont. next page

Media Watch Online

International


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=b6237588904ba11300ff8522fd77f0c
HUMAN RIGHTS WATCH | World Report 2014 – 23 January 2014 – ‘Palliative care: International perspective.’ After a series of positive steps in 2012 to address the suffering of hundreds of thousands of persons with incurable diseases from pain and other symptoms, progress on palliative care in India slowed considerably in 2013. The government has so far not allocated a budget to implement India’s progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act that would dramatically improve the availability of strong pain medications. More than 7 million people in India require palliative care every year (p.338 of World Report 2014).

1. The Rajya Sabha, the upper house of parliament, has approved amendments to the Narcotic Drugs & Psychotropic Substances Act (the Drug Act) that the lower house had approved a day earlier. See ‘India: Major breakthrough for pain patients,’ Human Rights Watch report, 21 February 2014, noted in Media Watch, 24 February 2014, #346 (p.5).

INDIAN JOURNAL OF PALLIATIVE CARE, 2012;18(3):149-154. ‘Palliative care in India: Current progress and future needs.’ Despite its limited coverage, palliative care has been present in India for about twenty years.

INDIAN JOURNAL OF PSYCHIATRY, 2013;55(6):293-298. ‘End-of-life care: Indian perspective.’ This article studies the core issues of developing palliative care ... keeping in mind the ethical, spiritual and legal issues.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 March 2014 – ‘Bridging the gap between continuous sedation until death and physician-assisted death: A focus group study in nursing homes in Flanders, Belgium.’ For some [study participants], the difference is clear whereas others consider CSD [continuous sedation until death] a form of euthanasia. Another group situated CSD between pain relief and ending life.

ANNALES PHARMACEUTIQUES FRANÇAISES, 2014;72(2);82-89. ‘Euthanasia and/or medically assisted suicide: Reflection on the new responsibility of the hospital pharmacist.’ In France, Leonetti law currently sets the legal framework for the management of end of life. To address Society's demand on these issues, French President Francois Hollande appointed two ethics committees ... both of were mainly against euthanasia and assisted suicide. Though forgotten in this debate, hospital pharmacist needs to be associated in the thinking, as the main "drug-keeper.”

N.B. French language article.

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | World Report 2014 – 23 January 2014 – ‘Palliative care: International perspective.’ After a series of positive steps in 2012 to address the suffering of hundreds of thousands of persons with incurable diseases from pain and other symptoms, progress on palliative care in India slowed considerably in 2013. The government has so far not allocated a budget to implement India’s progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act that would dramatically improve the availability of strong pain medications. More than 7 million people in India require palliative care every year (p.338 of World Report 2014).

http://www.hrw.org/sites/default/files/wr2014_web_0.pdf

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Noted in Media Watch, 14 January 2013, #288 (p.10):

- INDIAN JOURNAL OF PALLIATIVE CARE, 2012;18(3):149-154. ‘Palliative care in India: Current progress and future needs.’ Despite its limited coverage, palliative care has been present in India for about twenty years.

http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2012;volume=18;issue=3;spage=149;epage=154;aulast=Khosla&type=0

- INDIAN JOURNAL OF PSYCHIATRY, 2013;55(6):293-298. ‘End-of-life care: Indian perspective.’ This article studies the core issues of developing palliative care ... keeping in mind the ethical, spiritual and legal issues.

http://www.indianjpsychiatry.org/article.asp?issn=0019-5545;year=2013;volume=55;issue=6;spage=293;epage=298;aulast=Sharma

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http://ajh.sagepub.com/content/early/2014/03/25/1049909114527152.abstract

- ANNALES PHARMACEUTIQUES FRANÇAISES, 2014;72(2);82-89. ‘Euthanasia and/or medically assisted suicide: Reflection on the new responsibility of the hospital pharmacist.’ In France, Leonetti law currently sets the legal framework for the management of end of life. To address Society's demand on these issues, French President Francois Hollande appointed two ethics committees ... both of were mainly against euthanasia and assisted suicide. Though forgotten in this debate, hospital pharmacist needs to be associated in the thinking, as the main "drug-keeper.”


N.B. French language article.

Noted in Media Watch, 24 December 2012, #285 (p.4):

- FRANCE | Radio France Internationale – 18 December 2012 – ‘No to euthanasia in France, says report.’ A report commissioned by president François Hollande ... will recommend that euthanasia remain illegal in France, while leaving the door open to assisted suicide. Under current legislation, enshrined in the 2005 so-called Leonetti Law, it is illegal to give patients medication which will kill them, but legal to administer pain relief, which might have the side effect of shortening life.

http://www.english.rfi.fr/europe/20121218-no-euthanasia-france-says-new-report

Cont.
Knowing patients' wishes regarding euthanasia appears to influence physicians, but not nurses. This is the first study to test whether knowledge of patient's wishes and profession have an impact on health professionals' intention and beliefs regarding euthanasia. http://www.omicsgroup.org/journals/effect-of-knowing-patients-wishes-and-health-profession-on-euthanasia-2165-7386.1000169.pdf

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net