Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Amyotrophic lateral sclerosis: Scroll down to <u>Specialist Publications</u> and 'Live and let die: Existential decision processes in a fatal disease' (p.13), in *Journal of Neurology*.

Canada

Compassionate care leave coming to Alberta

ALBERTA | *Benefits Canada* – 14 January 2014 – Starting in February, Alberta employers will be required to provide compassionate care leave to their workers. Amendments to the province's Employment Standards Code will provide eligible employees with up to eight weeks of unpaid leave to care for or support a seriously ill family member for whom the employee is the primary caregiver. The amendments provide job security for employees who take time off work to care for a dying family member. <u>http://www.benefitscanada.com/benefits/other/compassionate-care-leave-coming-to-alberta-48478</u>

Noted in Media Watch, 20 May 2013, #306 (p.1):

 ALBERTA | Global TV News (Edmonton) – 14 May 2013 – 'Alberta caregivers applaud new bill.' The Compassionate Care Leave bill ... will provide job protected leave to family caregivers who take time off work to look after a dying family member. Prior to the passing of the bill, Alberta was the only jurisdiction in Canada without Compassionate Care Leave in its employment standards code. http://globalnews.ca/news/561161/alberta-caregivers-applaud-new-bill/

Breaking bad news is never easy, but for doctors, there are better ways to do it

THE NATIONAL POST | Online – 14 January 2014 – A cancer diagnosis is terrible for the patient to receive. It's also difficult to impart. The delivery of bad news is one of the trickiest aspects of a doctor's job. A 2000 study co-authored by doctors from Toronto's Sunnybrook Hospital revealed just how frequently one slice of the medical profession has to do it: about 60% of the respondents, all oncologists, broke bad news between five and 20 times per month.¹ And, 14% of respondents said they did it more than 20 times per month. Because it's something doctors have to do a lot, the medical profession has devoted a lot of energy to providing us with guidance on best practices. Another academic article ... by doctors from the Memorial Sloan-Kettering Cancer Center ... speculates that a link, not yet clinically proven, may exist between doctor communication skills and better results for their patients.² http://life.nationalpost.com/2014/01/14/dr-aw-breaking-bad-news-is-never-easy-but-for-doctors-there-are-better-ways-to-do-it/

- 'SPIKES A six-step protocol for delivering bad news: Application to the patient with cancer,' *The Oncologist*, 2000;5(4):302-311. http://theoncologist.alphamedpress.org/content/5/4/302.full.pdf+html
- 2. 'Communication skills training for oncology professionals,' *Journal of Clinical Oncology*, 2012:30(11):1242-1247. <u>http://jco.ascopubs.org/content/30/11/1242.abstract</u>

Noted In Media Watch, 23 August 2010, #163 (p.7):

INDIAN JOURNAL OF PALLIATIVE CARE, 2010;16(2):61-65. 'BREAKS protocol for breaking bad news.' SPIKES is widely used for breaking bad news. In this paper, the authors put forward another six-step protocol. The BREAKS protocol as a systematic and easy communication strategy for breaking bad news. <u>http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2010;volume=16;issue=2;spage=61;epage=65;aulast=Narayanan</u>

N.B. SPIKES = Setting, Perception, Invitation, Knowledge, Empathy, Summary; BREAKS = Background, Rapport, Explore, Announce, Kindling, Summarize.

Community and home care

Charities fill home-care gap

ONTARIO | *The Toronto Star* – 14 January 2014 – There are dozens of agencies and hundreds of services to help Ontarians with dementia and chronic illness live at home. But most people don't know where to look, whom to call, what to ask for and how much it will cost. The moment frail, elderly patients are discharged from the hospital, they fall into a void. They still need medical assistance, personal care, help with basic household tasks, someone to buy groceries and fill drug prescriptions and drive them to doctor's appointments. But they can't line up all the services they need. So their desperate spouses and time-starved children are left scrambling. There is a better way, says Sarah Saso ... of Green Shield Canada Foundation. Her organization is spending \$3 million to develop it. "We want to get out in front of the silver tsunami before it's too late." That is what Ontario's government should be doing. But seniors and their families can't wait for the slow-moving, bureaucratic Ministry of Health & Long-term Care to act. For seven years, the Liberals have promised an "aging at home" strategy . Rather than wait, non-profit agencies, philanthropic foundations and far-sighted medical practitioners are stepping into the breach. http://www.thestar.com/opinion/commentary/2014/01/14/charities fill homecare gap goar.html

N.B. 'Health Comes Home: A Conversation about the Future of Care,' Ontario Association of Community Care Access Centres, 14 January 2014. <u>http://oaccac.com/News/Pages/Health-comeshome-part-4.aspx</u>

Noted in Media Watch, 8 April 2013, #300 (p.2):

- CTV NEWS | Online 4 April 2013 'Provinces need to follow through on home care funding commitments: Report.' Canada's provinces and territories talk a good game when it comes to funding in-home health care, but a new report is urging all orders of government to put their money where their mouths are.¹ <u>http://www.ctvnews.ca/canada/provinces-need-to-follow-through-on-home-care-funding-commitments-report-1.1223641</u>
 - 1. 'Portraits of Home Care,' Canadian Home Care Association, April 2013. http://www.cdnhomecare.ca/media.php?mid=3394

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.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | The Montreal Gazette 17 January 2014 'Quebec legislation on medically assisted dying moves another step forward.' Quebec took a major step toward adopting its law regarding medically assisted death when Bill 52 cleared clause-by-clause study by a National Assembly committee. Véronique Hivon, who as junior minister for health and youth protection sponsored the bill, called the bill "a significant advance" and told reporters she wants it adopted as soon as possible after the assembly resumes sitting 11 February. The bill also calls for improvements in palliative care, offering the option of medical assistance to die only in exceptional circumstances, and only for patients who have requested it beforehand. http://www.montrealgazette.com/news/Quebec+legislation+medically+assisted+dying+moves+ another+step+forward/9396857/story.html
- CBC NEWS | Online 16 January 2014 'Assisted suicide case appeal to be heard by Supreme Court.' The Supreme Court of Canada said it will hear an appeal by the B.C. Civil Liberties Association a case that could grant terminally ill Canadians the right to assisted suicide. The case seeks to allow seriously and incurably ill but mentally competent adults the right to receive medical assistance to hasten death under specific safeguards. The Association had asked the top court to hear the appeal, arguing criminal laws that deny seriously ill Canadians the right to choose an assisted death are unconstitutional, and the issue is of profound national importance. In 2012, the B.C. Supreme Court ruled the Criminal Code of Canada provisions against assisted dying violate the rights of the gravely ill, and gave Parliament one year to rewrite the laws. But the federal government appealed and the B.C. Court of Appeal overturned the lower court's ruling in late 2013 and upheld the ban, stating it was bound by the Supreme Court of Canada's 20-year-old Rodriguez decision. http://www.cbc.ca/news/canada/british-columbia/assisted-suicide-case-appeal-to-be-heard-by-supreme-court-1.2498892

Noted in Media Watch, 14 October 2013, #327 (p.2):

- BRITISH COLUMBIA | CBC News (Vancouver) 10 October 2013 'Doctor-assisted suicide ban upheld in B.C.' The B.C. Court of Appeal, in a split decision, has affirmed the law against assisted suicide, in a controversial and historic right-to-die case. Last year, ALS patient Gloria Taylor of Kelowna won a landmark ruling when a B.C. Supreme Court judge struck down Canada's law that made doctor-assisted suicide illegal. Regardless of [this lat-est] ruling, many observers expect the case will end up at the Supreme Court of Canada. http://www.cbc.ca/news/canada/british-columbia/doctor-assisted-suicide-ban-upheld-in-b-c-1.1958888
- QUEBEC | The Montreal Gazette 16 January 2014 'Liberals to debate hot-button issue of doctor-assisted suicide.' The Supreme Court won't be the only place where arguments for and against euthanasia will be heard. Federal Liberals are set to wade into the heated debate next month when they gather ... to discuss what policies they would like the party to champion during the next federal election. The Young Liberals ... are the driving force behind the move after they agreed to sponsor a resolution calling for the legalization of doctor-assisted suicide. http://www.montrealgazette.com/health/Liberals+debate+button+issue+doctor+assisted+suicid e/9396712/story.html

N.B. In October 1996, the Liberal Party of Canada passed a resolution "endorsing legalizing euthanasia." No further action, however, was taken on the issue. 'Euthanasia & Assisted Suicide in Canada,' Library of Parliament Research Paper, 15 February 2013. [Noted in Media Watch, 22 April 2013, #302 (p.1)] <u>http://www.parl.gc.ca/Content/LOP/ResearchPublications/2010-68-e.htm</u>

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

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

What happens when hospice patients recover?

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 13 January 2014 – The case of a female patient who was treated and later discharged from Bethany Hospice Services of Western Pennsylvania after her condition improved, is wending its way through the state legal system, after the state Department of Welfare refused to pay for her care through its Medicaid program. The woman, who was 79 when she was admitted to Bethany in 2006, is described in court documents as being mentally challenged; she was also suffering from dementia, losing weight, and bedridden when her family admitted her to Bethany in June 2006. However, the patient was discharged from Bethany in June 2008, after it determined her prognosis had improved to the point she no longer met the criteria to remain in hospice care. Pennsylvania's criteria for hospice care under its Medicaid program require that a patient be certified as terminally ill by a doctor... While the case must be re-certified every sixty days, there is no state limit on how long a patient may remain in hospice in order to qualify for Medicaid reimbursement. <u>http://www.postgazette.com/business/legal/2014/01/13/What-happens-when-hospice-patientsrecover/stories/201401080135</u>

Hospice care: Limited end-of-life care fails to take into account such care may prolong life

NEW HAMPSHIRE | The Union Leader (Manchester) - 11 January 2014 - With health care reform ramping up, some hospice programs have come under government scrutiny for taking some patients too early and keeping them too long. But experts here say the real problem, in New Hampshire and elsewhere, is that most terminally ill patients and their families are coming into hospice too late. "Hospice was designed to give end-of-life care, but it's turning out to be brink-of-death care," said Dr. Ira Byock, a palliative care expert and author who is a professor of medicine at the Geisel School of Medicine at Dartmouth. Janice McDermott is executive director of New Hampshire Hospice & Palliative Care Organization (NHHPCO). She said the average length of stay in New Hampshire hospice programs in 2012 was 56 days. But nearly half - 47% - of patients were in hospice fewer than 30 days, and 28% received care for less than a week. New Hampshire

has 23 hospice programs licensed by the state; 70% are non-profit and the rest are for-profit agencies, according to NHHPCO. http://www.unionleader.com/article/2014011 2/NEWS12/140119839

Extract from New Hampshire Union Leader article

Byock ... sees irony in the scrutiny of hospices where patients have outlived the six-month period that federal law defines for such care. "While fraud and abuse does exist, it's also true that the hospice program's good care may improve somebody's condition and be the cause of them living longer," he said. "And we have to be sophisticated enough to applaud that while also ferreting out fraud and abuse. What other part of the health care system is penalized and has to worry about lawsuits if their patients live too long?" he asked. "It's just horrendous."

Of related interest:

NEW HAMPSHIRE | The Union Leader (Manchester) – 11 January 2014 – 'Hospice provider agrees to pay \$150m in settlement.' A for-profit hospice and home health care provider with eight locations in New Hampshire has agreed to pay \$150 million to settle an investigation by the U.S. Department of Justice into its billing practices. Amedisys Home Health & Hospice, which is based in Baton Rouge, Louisiana, admitted no wrongdoing, according to a company statement. <u>http://www.unionleader.com/article/20140112/NEWS12/140119828</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW MEXICO | The Albuquerque Journal – 13 January 2014 – 'Judge: Docs can prescribe meds for aid in dying.' State law provides a fundamental right to a terminally ill, competent patient to choose a physician's aid in getting prescription medications that will allow a peaceful death, a state judge ruled in a seminal case. Second Judicial District Judge Nan Nash said Drs. Katherine Morris and Aroop Mangalik, oncologists at the University of New Mexico Hospital, could not be prosecuted under the state's Assisted Suicide Statute, which is defined as the act of "deliberately aiding another in the taking of his own life." The practice recognizes the patient is dying from his or her underlying disease and allows the patient to have medication ... that may be taken at a time of the patient's choosing to achieve a peaceful death. Patients who most often choose the option are those dying of cancer. Nash found that the right exists under the New Mexico Constitution, which prohibits the state from depriving a person of life, liberty or property without due process. http://www.abgjournal.com/335913/abgnewsseeker/judge-doctors-can-prescribe-meds-to-aid-dying.html

International

End-of-life care in Australia

Doctors unclear on advance care planning laws

AUSTRALIA (New South Wales) | *Australian Ageing Agenda* – 17 January 2014 – Many doctors are confused about the legality of advance care directives and the authority of substitute decision-makers, leaving them open to possible legal action, new research has found.¹ According to the study led by Professor Colleen Cartwright from Southern Cross University only half of surveyed doctors in New South Wales [NSW] correctly understood that an enduring power of attorney does not allow the person appointed to make healthcare decisions. Doctors were also unclear about the order of authority if no enduring guardian had been appointed, which in NSW is not the next-of-kin. Cartwright said a lack of knowledge in this area may lead medical practitioners to accept the decision of a person who does not have legal authority to make those decisions for the patient, with potentially significant legal consequences. While the majority of doctors (77% of specialists and 76% of GPs) in the study said they would respect the patient's autonomy and follow their wishes in an advance care directive, older doctors were least likely to agree with this action. http://www.australianageingagenda.com.au/2014/01/17/doctors-unclear-advance-care-planning-laws/

 'Medical practitioners' knowledge and self-reported practices of substitute decision-making and implementation of advance care plans,' *Internal Medicine Journal*, 24 December 2013. <u>http://onlinelibrary.wiley.com/doi/10.1111/imj.12354/citedby</u>

Cont. next page



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 Of related interest:

- AUSTRALIA (Queensland) | *The Courier Mail* (Brisbane) 13 January 2014 'Let's heed Australian Medical Association president Steve Hambleton's call to have a debate about death.' Modern medical science makes it possible for health professionals to prolong the lives of the terminally ill. But is that always the best course of action? It is a controversial question but one that the Australian Medical Association [AMA] believes needs discussing. Association president Steve Hambleton is calling for "a mature debate" about the always sensitive issue of how we as a society deal with the dying,¹ a call endorsed by both State Health Minister Lawrence Springborg and his federal counterpart Peter Dutton. They insist it is not about the money but rather what's best for patients, which is as it should be. But the reality is that some current practices including the use of powerful and costly drugs, which in some cases are prolonging life by little more than weeks, translate to a growing burden on the public purse. But even without considering the economics of end-of-life care, the debate that the Association is trying to spark, is sure to be contentious. http://www.couriermail.com.au/news/opinion/editorial-lets-heed-ama-president-steve-hambletons-call-to-have-a-debate-about-death/story-fnihsr9v-1226800174749
 - 'Australian Medical Association president Steve Hambleton calls for a debate on treatment for terminally ill patients,' *The Courier Mail*, 13 January 2014. The Association calls for a "mature debate" about death by revealing that some patients are prescribed costly drugs that only prolong life by a few weeks, but leave patients with serious side-effects. It comes as a leading health economist says Australians have an unrealistic view about dying, and want a pill for everything. <u>http://www.couriermail.com.au/news/queensland/ama-presidentsteve-hambleton-calls-for-a-debate-on-treatment-for-terminally-ill-patients/story-fnihsrf2-1226800225117
 </u>

Dying at home in the U.K.

The government wants you to have a comfortable (and cheap) death

U.K. | The Economist – 17 January 2014 – Surveys show that over two-thirds of Britons would like to die at home. Like Dr. [Kate] Granger [a 32-year-old doctor suffering from an incurable form of sarcomal, they want to be with family and free of pain. Yet hospital remains the most common place of death. For some this is unavoidable – not every disease has as clear a turning point as cancer - but for others a lack of planning is to blame. The government, motivated by both compassion and thrift, wants to help. In death, at least, public wishes align neatly with the state's desire to save money. The National Health Service has calculated that if roughly one more patient per general practitioner died outside hospital each year, it would save £180m (\$295m). In 2008 it introduced a broad end-of-life care strategy, which sought to increase awareness of how people die while improving care. Since then the proportion of people dying at home or in care homes (the split is about half-and-half between them) has increased, from 38% to 44%. To steer patients away from hospitals, GPs have been encouraged to find their 1% - those patients likely to die in the next year – and start talking about end-of-life care. This can be difficult for doctors. "As a profession we view death as failure," says Dr. Granger. Yet when there is no cure to be had, planning for death can be therapeutic for patients. http://www.economist.com/news/britain/21594321government-wants-you-have-comfortable-and-cheap-death-home-help

Of related interest:

U.K. | The Guardian – 15 January 2014 – 'Dying patients should be exempt from social care charges.' The care bill committee is debating who should be eligible for social care. MPs will also consider whether to add a clause that would enable exemption from social care charges for those at the end of their lives. The amendment would also establish the need for better forward planning about where we would like to die. Most of us would prefer to be at home surrounded by the people we love, yet fewer than 1-in-3 are currently able to do so. http://www.theguardian.com/commentisfree/2014/jan/15/dying-patients-free-social-care-end-of-life

U.K. (England) | *The West Morning News* (Plymouth) – 15 January 2014 – 'Risk patient wishes for no treatment ignored at west hospital.' A west country hospital has been ordered to make improvements after inspectors found that there was a risk that patients' wishes not to be resuscitated may not be followed. The Care Quality Commission ... which mounts independent inspections of health trusts ... issued a largely clean bill of health saying patients were well cared for in an adequately staffed environment at the Barnstaple-based hospital. http://www.westernmorningnews.co.uk/Risk-patient-wishes-treatment-ignored-West/story-20445401-detail/story.html

N.B. Care Quality Commission website: http://www.cqc.org.uk/

- U.K. (England) | Leadership Alliance for the Care of Dying People 14 January 2014 'Extracts of a joint statement by the Leadership Alliance for the Care of Dying People.' This is an update on work being carried out ... following the report of the independent panel on the Liverpool Care Pathway (LCP).¹ The panel concluded that many of the issues around the LCP were that it had come to be regarded and used as a generic protocol and sometimes as a tick box exercise which is the wrong approach. The alliance is currently engaging on the draft outcomes and guiding principles. The end-date for phasing out the Pathway is 14 July 2014. http://www.england.nhs.uk/wp-content/uploads/2014/01/lacdp-interim-statement.pdf
 - Independent Report: Review of Liverpool Care Pathway for dying patients [in England), Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <u>https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients</u>
- U.K. | Homecare 13 January 2014 'Islington and Southwark councils become first to ban zero hour contracts for home care.' Two local authorities in London have become the first to formally sign up to the Unison Ethical Care Charter, which sets out minimum standards for home care services designed to protect the dignity and quality of life for people who need home care...¹ <u>http://www.homecare.co.uk/news/article.cfm/id/1562085/islington-southwarkcouncils-first-to-ban-zero-hour-contracts-home-care</u>
 - 1. 'Ethical Care Charter,' Unison (Public Service Union), June 2013. <u>http://www.unison.org.uk/upload/sharepoint/Research%20Material/Final%20Ethical%20Car</u> <u>e%20Charter%20PDF.pdf</u>

Let's try a new way of caring for people

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 16 January 2014 – Predictions of the challenges facing health and social care in Scotland present a gloomy picture. Scotland has one of the lowest life expectancies in Western Europe. Men living in the most deprived areas of the country can expect to live 11 years less than those in the least deprived. By 2035, the number of people aged 75 and over is projected to increase by 82%. The number of people with long-term conditions is expected to double by 2030, as is the number of people with dementia. Meanwhile, the Centre for Public Policy for Regions at Glasgow University reports that the public spending cuts still to come will be the harshest yet. But are we asking the right questions about the future? Suppose that, instead of asking when the tide of disease will overwhelm us, we asked what is most likely to keep us well? Or, rather than wondering how to further stretch an overburdened public sector, we asked what we could do differently, what we could stop doing at all and what contribution we could all make to creating a different future? <u>http://www.scotsman.com/news/let-s-try-a-new-way-of-caring-for-people-1-3269998</u>

Online guide seeks to educate healthcare professionals on important ethical challenges

SINGAPORE | *Today* – 15 January 2014 – A 74-year-old woman refuses to undergo surgery to fix a broken hip while her children, a daughter and a son, who lives overseas, argue over the type of treatment and care their mother should receive. Meanwhile, the old woman's condition is getting worse. Caught in the middle is the healthcare team who must address the children's concerns and resolve the conflict in the most ethical way. The case illustrates one of the many ethical challenges doctors face, and an online guide intends to highlight such cases to help healthcare professionals better understand key ethical situations. 'Making Difficult Decisions With Patients and Families: A Singapore Casebook,'¹ is a collaboration between the Centre for Biomedical Ethics at the National University of Singapore Yong Loo Lin School of Medicine, Hastings Center in New York, and Ethox Centre at the University of Oxford ... [and] ... funded by the Lien Foundation. <u>http://www.todayonline.com/singapore/e-casebook-medical-ethics-be-launched</u>

 'Making Difficult Decisions With Patients and Families: A Singapore Casebook.' <u>http://www.bioethicscasebook.sg/</u>' Sample of content: 'Advance Decision Making in Singapore.' <u>http://www.bioethicscasebook.sg/backgrounder/advance-directives/</u>

India has a problem with morphine

INDIA | The Globe & Mail (Canada) - 14 January 2014 - Once again, Indian MPs have failed to help millions who need relief from pain. In the winter session of parliament ... they were expected to pass an amendment to an existing law that would allow people with cancer. AIDS or other serious diseases to receive morphine when they need it. The current law, aimed at curbing drug abuse, makes it so difficult for hospitals to obtain morphine that cancer patients die in agony while their doctors and families look on helplessly. MPs were so busy bickering about other issues they did not even have time to discuss the amendment. They should try touring rural India to see what happens when morphine is not available. Most government hospitals, assuming they have such luxuries as oncologists, have no supplies of morphine. When patients are diagnosed with cancer and have no money to go to a private hospital (which can sometimes procure it), they walk out of the hospital gates to return to their villages or slums to die. The reason is that the Narcotic Drugs & Substance Abuse Act of 1985, passed to prevent drug trafficking, lumps morphine in with other drugs as a narcotic (which ... it is) and imposes draconian restrictions on its manufacture and availability, even for medical use. Owing to the law, drug companies don't make it. Hospitals don't stock it. So naturally, if it's not available, doctors don't prescribe it. To get

their hands on morphine, hospitals have to apply for a special licence that can take five or six years. Once they receive it, they have to apply for several other licences to store it. <u>http://www.theglobeandmail.com/globe-</u> <u>debate/indias-morphine-</u> <u>problem/article16314750/</u>

Israeli oncologist: Palliative care neglected in developing world

ISRAEL | The Jerusalem Post – 11 January 2014 - The first-ever global survey by the European Society for Medical Oncology [ESMO] has found a "pandemic of untreated cancer pain" caused by too strict regulation of pain medication [that] has become a "scandal of global proportions." Called "groundbreaking" ... the international collaborative survey ... shows more than half of the world's population - four billion people - live in developing countries where regulations aimed at stemming drug misuse leave cancer patients without access to opioid medicines for managing cancer pain. "The Global Opioid Policy Initiative study [see next page] shows in the developing world it is catastrophically difficult to provide basic medication to relieve strong cancer pain," says Prof. Nathan Cherny, oncologist and head of palliative medicine at Jerusalem's Shaare Zedek Medical Center, chairman of the ESMO Palliative Care Working Group. http://www.jpost.com/Health-and-Science/Israeli-oncologist-Palliative-careneglected-in-developing-world-337863

Noted in Media Watch, 2 December 2013, #334 (p.6, p.9):

- INDIA | The Telegraph (Calcutta) 26 November 2013 'Cry for law to help ease cancer pain.' Nagesh Simha, a palliative care physician in Bangalore ... is among doctors waiting for the government to revise narcotics rules to make morphine available to end-stage cancer patients, amid concerns that hundreds of thousands of such patients across India receive inadequate pain medication. The Indian Association for Palliative Care issued a fresh call to the government to speed up passage of the bill amending the Narcotic Drugs & Psychotropic Substances Act, easing for hospitals the process of procuring morphine for terminally ill patients. http://www.telegraphindia.com/1131126/jsp/nation/story_17613001.jsp#.UpTRjdJwrhc
- ANNALS OF ONCOLOGY, 2013;24(suppl11):xi7-xi13. 'The Global Opioid Policy Initiative (GOPI) project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology.' Data provided highlight, on a country-by-country basis, issues in formulary inadequacy, problems with cost to consumer and actual availability of medication, and the extent of regulatory barriers that may be impeding accessibility of opioids to patients in need. http://annonc.oxfordjournals.org/content/24/suppl_11/xi7.full.pdf+html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | The Guardian 16 January 2014 'Hayley Cropper's Coronation Street suicide shows how soaps can influence the national debate.' A few years ago, Kevin Spacey made a plea - echoing intermittent comments from senior TV screenwriters - for the return of 'Play for Today' [PFT], the series of socially and politically committed single dramas that ran on BBC1 between 1970 and 1984. The American actor met the familiar counter-argument from industry executives and commentators that the issue-raising role of the PFT remit had passed to soap operas. And, while continuing fiction is never as politically engaged as those Tuesdaynight plays, evidence that it has taken over the single drama's task of debating contentious social issues is provided by the extraordinary media and public reaction to the current 'Coronation Street' storyline, in which the character Hayley Cropper, played by Julie Hesmondhalgh, has decided to take her own life rather than endure the final stages of incurable cancer. This storyline ... continues a long tradition of what are known in TV as "helpline episodes," from the requirement of TV regulators that plots that might reflect traumatic events in a viewer's life - or encourage them to behave in the same way as the character - should be followed by a telephone number for anyone "who has been affected by any issues in this programme." http://www.theguardian.com/tv-and-radio/tvandradioblog/2014/jan/16/hayley-croppercoronation-street-suicide-euthanasia
- BELGIUM | *EuroNews* 15 January 2014 'Child Euthanasia Bill passes latest hurdle.' A Judiciary Committee has rejected calls for extra hearings before sending Belgium's Child Euthanasia Bill for a final parliamentary vote. The decision clears the way for it to be passed to the lower house for consideration and a vote sometime before May. Last week the Senate voted by 50 to 17 that euthanasia should be legal for children suffering from a terminal illness that is causing severe physical pain. Unlike The Netherlands which allows euthanasia for children over 12, Belgium is set to become the first nation in the world to lift all age restrictions. http://www.euronews.com/2014/01/15/belgium-child-euthanasia-bill-passes-latest-hurdle/
- IRELAND | The Independent (Dublin) 14 January 2014 'Irish resident had assisted suicide last year.' The Swiss-based assisted suicide organisation Dignitas has said it helped one Irish resident to die last year. In total, the controversial organisation said 202 people had an "accompanied suicide" last year this is the highest number since it was set up more than 15 years ago. A total of eight Irish residents are now believed to have travelled to Switzerland to take their own lives in that time period. While euthanasia or assisted suicide is legal in four European countries Belgium, Luxembourg, The Netherlands and Switzerland it is only in the latter that non-residents with a terminal illness are allowed to have an assisted suicide. In total, Dignitas has assisted in the suicides of almost 1,700 people from 42 countries since 1998, with almost half of the people from Germany. http://www.independent.ie/irish-news/irish-resident-had-assisted-suicide-last-year-29915028.html

Noted in Media Watch, 25 November 2013, #333 (p.7):

 IRELAND | The Irish Times (Dublin) – 22 November 2013 – 'Cabinet may set up expert group on assisted suicide, Gilmore says.' Tánaiste [deputy prime Minister] Eamon Gilmore said he will discuss with Cabinet colleagues commissioning an expert report on assisted suicide. Mr. Gilmore was responding in the Dáil [lower house of the Irish parliament] to Independent TD [Teachta Dála], a member of the lower house] Stephen Donnelly, who suggested the expert report. <u>http://www.irishtimes.com/news/politics/oireachtas/cabinetmay-set-up-expert-group-on-assisted-suicide-gilmore-says-1.1602665</u>

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

Communication about advance directives and end-of-life care options among internal medicine residents

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online - 10 January 2014 - 83 (50%) of residents [at a large academic medical center] completed the 2013 [online] survey. About half (52%) felt strongly that they were able to have open, honest discussions with patients and families, while 71% felt conflicted about whether CPR was in the patient's best interest. About half (53%) felt strongly that it was okay for them to tell a patient/family member whether or not CPR was a good idea for them. Modest improvements were made over time [i.e., since a 2006 survey] in trainees' exposure to EOL [end-of-life] discussions; however, many residents remain uncomfortable and conflicted with having EOL care discussions with their patients. More effective training approaches in communication are needed to train the next generation of internists. http://aih.sagepub.com/content/early/2014/0 1/10/1049909113517163.abstract

Gently into the good night: Toward a compassionate response to end-stage illness

TEMPLE POLITICAL & CIVIL RIGHTS LAW RE-VIEW. 2013:22(2):475-492. End-of-life decision making by health care providers must respect individual patient values. Indeed, these values must always be viewed as the baseline for developing and pursuing patient-centered palliative care for those with terminal illness. Co-ordinate with this fundamental bioethics principle is that of beneficence or ... respect for conduct which benefits the dying patient by alleviating end-stage suffering - be it physical or existential. Compassion, charity, agape and/or just common sense, should be a part of setting normative standards and of legislative and judicial responses to the task of managing death. Aided by the principles of medical futility, palliative care protocols, greater acceptance of a patient's right to refuse treatment, and a spirit of basic humaneness, an ethic of adjusted care that seeks to secure dignity during the dying process without unreasonable interference by the state should be validated. http://papers.ssrn.com/sol3/papers.cfm?abstract id=2377281

Terminally ill African American elders' access to and use of hospice care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 9 January 2014 – The underuse of hospice care by terminally ill African American elders suggests they are suffering when hospice care could offer quality end of life care. Guided by the Behavioral Model for Vulnerable Populations, this study sought understanding of structural barriers faced when seeking access to hospice care and reasons for using it when access is possible. Data was collected through interviews with 28 African American hospice patients. Themes from directed content analysis provide insights into strategies used to overcome access barriers posed by income, health insurance and administrative procedure, as well as the role religion, family, information and health beliefs played in using it. Distributing educational materials and addressing spiritual/religious concerns in choosing hospice care are key in promoting African Americans' use of hospice care. http://ajh.sagepub.com/content/early/2014/01/09/1049909113518092.abstract

Noted in Media Watch, 7 October 2013, #326 (pp.6-7):

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 4 October 2013 'Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development.' African Americans are less likely to complete advance directives and enroll in hospice. Barriers included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. <u>http://ajh.sagepub.com/content/early/2013/10/03/1049909113507127.abstract</u>
- N.B. Noted in this issue of Media Watch are additional articles on African Americans' attitudes towards hospice.

Tying the knot: Helping patients who want to get married in hospital

BRITISH JOURNAL OF HOSPITAL MEDICINE, 2014;75(1):35-38. When faced with a serious or terminal illness people may want, for practical or emotional reasons, to get married to their partner. This article gives guidance to health-care professionals about their role in helping to organize weddings and civil partnerships for patients who are terminally ill and too unwell to leave hospital. http://www.bjhm.co.uk/cgi-bin/go.pl/library/abstract.html?uid=102579

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

 JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 June 2012 – 'Till death do us part: Getting married at the end of life.' The authors report the case of a patient with advanced cancer who got married in the acute palliative care unit weeks before her death. The wedding gave her the opportunity to acquire further meaning in life, deepen her connection with her loved ones, and enhance her sense of dignity, self-worth, and pride. http://www.jpsmjournal.com/article/S0885-3924(12)00148-0/abstract

Indefinite loss: The experiences of carers of a spouse with cancer

EUROPEAN JOURNAL OF CANCER CARE | Online – 14 January 2014 – This article explores cancer carers' experiences of loss ... [and] ... findings suggest that in addition to conventional and anticipatory grief, many carers experience indefinite loss. Indefinite loss characterised the experiences of spouses [i.e., study participants] caregiving outside of the terminal stage. They experienced the current loss of a taken-for-granted certain future, but the future loss of their spouse remained uncertain. They described a heightened awareness of mortality, and an inability to plan for the future. Losses that are uncertain and potential are largely neglected within the literature. http://onlinelibrary.wiley.com/doi/10.1111/ecc.12175/abstract;jsessionid=98888AE7DAD31AE183

Advantages and challenges: The experience of geriatrics health care providers as family caregivers

GERONTOLOGIST | Online – 31 December 2013 – Little is known about family caregivers who are also geriatrics health care professionals. This study examines the dual roles of such professionals, the impact of their geriatrics expertise on the care of family members, and the influence of those caregiver experiences on their clinical practice. The authors found three major themes: a) dual role advantages and disadvantages; b) emotional impact of dual roles; and, c) professional impact of family caregiving. Geriatrics expertise provided both advantages and disadvantages in caring for their older family members. Although their expertise introduced a significant emotional intensity to their personal caregiving experiences, those experiences positively influenced their professional insight, empathy, and advocacy for the caregivers of their own patients. http://gerontologist.oxfordjournals.org/content/early/2013/12/30/geront.gnt168.abstract?sid=dcfde 192-26d0-4b47-8522-af6243b1c164

The need of pediatric palliative care education among pediatric postgraduates in South India

INDIAN JOURNAL OF PEDIATRICS | Online – 11 January 2014 – Eighty-eight percent of the postgraduates [i.e., study participants] had never received any training in any aspect of palliative care. 77.3% felt uncomfortable in initiating a discussion about palliative care with the family members. 60.7% were not comfortable with the care of the dying patient. 87.3% strongly supported that a formal training in palliative care would improve their competence in this field. There is a huge *lacunae* in the delivery of palliative care services and hence an urgent need to inculcate targeted curriculum to provide focused skills and training for the pediatric postgraduates. http://link.springer.com/article/10.1007/s12098-013-1295-1

Of related interest:

- INTERNATIONAL JOURNAL OF PRACTICE-BASED LEARNING IN HEALTH & SOCIAL CARE | Online 13 January 2014 'Passing away: An exploratory study into physiotherapy students' experiences of patient death whilst on clinical placement.' If placement is to be an effective learning environment ... then established healthcare professionals and educators need to be positive role models. Without this the values and skills that are necessary for providing quality end-of-life care may struggle to develop, as well as the culture of openness and transparency that is essential so that students no longer feel they have to hide their emotional distress. http://journals.heacademy.ac.uk/doi/abs/10.11120/pblh.2014.00026
- JOURNAL OF PALLIATIVE MEDICINE | Online 8 January 2014 'Assessment of an interprofessional online curriculum for palliative care communication training.' Curricular changes ... are needed to accommodate a variety of learners, especially in lieu of the projected national [U.S.] shortage of hospice and palliative medicine physicians and nurses. This study assessed the utility of a palliative care communication curriculum offered through an online platform and also examined health care professionals' clinical communication experiences related to palliative care topics. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0270
- NURSE EDUCATION TODAY | Online 9 January 2014 'A qualitative exploratory study of nursing students' assessment of the contribution of palliative care learning.' Four themes were identified. Firstly, the PC [palliative care] course provided a comprehensive view of the nursing discipline. Secondly, the course helped the students to know how to interact with, communicate with and better understand patients. Thirdly, the contribution of the course to the students' personal growth prompted them to reflect personally on death, thus promoting self-awareness. http://www.sciencedirect.com/science/article/pii/S0260691714000033

Regional medical professionals' confidence in providing palliative care, associated difficulties and availability of specialized palliative care services in Japan

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 11 January 2014 – Confidence in providing palliative care was low and difficulties frequent for all types of medical professionals assessed. Only 8-24%, depending on category, agreed to "having adequate knowledge and skills regarding cancer pain management." 55-80% of medical professionals acknowledged difficulty with "alleviation of cancer pain." Analysis revealed confidence was positively correlated with the amount of relevant experience and, for medical doctors, with "prescriptions of opioids (per year)." http://jico.oxfordjournals.org/content/early/2014/01/08/jjco.hyt204.abstract

Noted in Media Watch, 26 November 2012, #281 (p.9):

JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 19 November 2012 – 'Past, present, and future of palliative care in Japan.' Palliative care is steadily growing with a trend away from palliative care units toward palliative care teams and care in the home. Whereas it was once seen as the limited treatment of terminal care, palliative care is increasingly becoming integrated into mainstream treatment. Basic education programs for physicians not specializing in palliative care and other medical practitioners are bringing about the spread of basic palliative care in Japan, thus putting in place broad foundations for the practice of palliative care. http://jico.http:/

Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives

JOURNAL OF MEDICAL ETHICS | Online – 14 January 2014 – In W v M, family members made an application to the [U.K.] Court of Protection for withdrawal of artificial nutrition and hydration from a minimally conscious patient. Subsequent scholarly discussion has centred around the ethical adequacy of the judge's decision not to authorise withdrawal. This article brings a different perspective by drawing on interviews with 51 individuals with a relative who is (or was) in a vegetative or minimally conscious state (MCS). Most professional medical ethicists have treated the issue as one of life versus death; by contrast, families – including those who believed that their relative would not have wanted to be kept alive – focused on the manner of the proposed death and were often horrified at the idea of causing death by "starvation and dehydration." The practical consequence of this can be that people in permanent vegetative state (PVS) and MCS are being administered life-prolonging treatments long after their families have come to believe that the patient would rather be dead. The authors suggest that medical ethicists concerned about the rights of people in PVS/MCS need to take this empirical data into account in seeking to apply ethical theories to medico-legal realities. <u>http://jme.bmj.com/content/early/2014/01/03/medethics-</u> 2013-101799.abstract

Noted in Media Watch, 3 October 2011, #221 (p.6):

U.K. | Daily Telegraph - 28 September 2011 - 'Judge rejects family's right to die case.' In the first case of its kind in this country, Mr. Justice Baker said that preservation of life was a fundamental principal of law. The woman's mother and sister had urged him to allow her to die, describing her "pointless existence" and saying she would not have wanted to live in such a state. But the judge found that the woman, identified only as "M," did have "some positive experiences" and crucially there was a "reasonable prospect" that those experiences could be extended. In a landmark 43,000 word judgment, he acknowledged that prior to her illness, "M" had told her family that she would not want to be kept alive in such circumstances, but said that such statements were "informal" and therefore not legally binding. The judge added: "The factor which does carry substantial weight, in my judgment, is the preservation of life. Although not an absolute rule, the law regards the preservation of life as a fundamental principle." Ruling that it would not be in the M's best interests to withdraw artificial nutrition and hydration, he expressed sympathy for M's family, who have endured "years of anguish" and had demonstrated a deep devotion to M. But he said that they should now work together with M's doctors and carers on a revised care plan. http://www.telegraph.co.uk/health/healthnews/8794013/Judgerejects-familys-right-to-die-case.html

Amyotrophic lateral sclerosis

Live and let die: Existential decision processes in a fatal disease

JOURNAL OF NEUROLOGY | Online – 16 January 2014 – More than half of patients [i.e., study participants] had a positive attitude towards life-sustaining treatments and they had a low desire for hastened death. Of those with undecided or negative attitude, 10 % changed attitudes towards life-sustaining treatments in the course of 1 year. Patients' desire to hasten death was low and decreased significantly within 1 year despite physical function decline. Those with a high desire for hastened death decided against invasive therapeutic treatments. QoL [quality of life], depression and social support were not predictors for vital decisions and remained stable. Feeling of being a burden was a predictor for decisions against life-supporting treatments. Throughout physical function loss, decisions to prolong life are flexibly adapted while desire to shorten life declines. http://link.springer.com/article/10.1007/s00415-013-7229-z

Noted in Media Watch, 18 February 2013, #293 (p.11):

JOURNAL OF CLINICAL NURSING | Online – 7 February 2013 – 'Finding meaning despite anxiety over life and death in amyotrophic lateral sclerosis patients.' Two themes emerged [in this study] to illuminate the complex life situation of the interviewees: experiences of anxiety over life and death and finding meaning despite the illness. It became clear that the uncertain journey towards death was more frightened than death itself. Despite the incurable disease, which brought feelings of life and death anxiety, physical loss, unfairness, guilt, shame and existential loneliness, they also found meaning in life, which strengthened their will to live. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12071/abstract

N.B. Additional articles on people living with amyotrophic lateral sclerosis, in the context of end-of-life care, are noted in this issue of Media Watch.

End-of-life dreams and visions: A longitudinal study of hospice patients' experiences

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 January 2014 – End-of-life dreams and visions are commonly experienced phenomena during the dying process, characterized by a consistent sense of realism and marked emotional significance. These dreams/visions may be a profound source of potential meaning and comfort for the dying, and therefore warrant clinical attention and further research. <u>http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0371</u>

Continuous palliative sedation: Not only a response to physical suffering

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 January 2014 – Together with physical symptoms, psychological and existential suffering may combine to produce a refractory state for which other treatment options than CPS [continuous palliative sedation] were not available or considered inappropriate. A limited life expectancy was by many considered crucial (e.g., to avoid hastening death) and by some less important (e.g., because the patient's suffering was considered to be key). Issues influencing the decision to use CPS related to patient preferences (e.g., dignity, not wanting to experience further suffering) or family issues (impact of suffering on family, family requesting CPS). http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0121

The argument for palliative care in prostate cancer

TRANSLATIONAL ANDROLOGY & UROLOGY, 2013;2(4):278-280. Referrals to palliative care typically occur late in the disease process because of its inappropriate association with end-of-life care and failure to recognize that symptom management can be utilized throughout the course of a disease. Dalal *et al* found that one barrier to care was the name "palliative care" itself.¹ After changing their group's name from "palliative care" to "supportive care" they received an increase in consultations and shorter duration from the time of diagnosis to consultation. Similar to the change in terminology from "watchful waiting" to "active surveillance" indicating use in different patient populations and treatment interventions, perhaps palliative care would benefit from a name change to broaden its recognition and allow patients with non-life-threatening disease to benefit from its incorporation into routine care. http://www.amepc.org/tau/article/view/2970/4034

 'Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center, *The Oncologist*, 2011;16(1):105-111. <u>http://theoncologist.alphamedpress.org/content/16/1/105.abstract?sid=683fd49a-fe86-4795-8a4a-c4c74336bc25</u>

Representative sample of articles on definitions and terminology to describe end-of-life care noted in past issues of Media Watch:

- PLOS ONE | Online 3 July 2013 'Diversity in defining end-of-life care: An obstacle or the way forward?' Responses to a survey were received from 167 individuals, mainly from academics (39%) and clinical practitioners working in an academic context (23%) from 19 countries in Europe and beyond: 29% said explicitly there was no agreed definition of end-of-life care in practice; 14% offered a standard definition. [Noted in Media Watch, 15 July 2013, #314 (p.13)] http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0068002
- THE ONCOLOGY REPORT | Online 10 April 2013 'Is the moniker "palliative care" too loaded?' A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html
- PALLIATIVE & SUPPORTIVE CARE | Online 11 January 2013 'Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.' Although most [study participants] claimed that early referrals to the service are preferable, on-cologists identified several challenges, related to the timing and communication with patients regarding the referral... [Noted in Media Watch, 14 January 2013, #288 (p.7)] http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextTy perception

Cont. next page

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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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.

 SUPPORTIVE CARE IN CANCER | Online – 31 August 2012 – 'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.' Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <u>http://link.springer.com/article/10.1007/s00520-012-1564-y</u>

Media Watch Online
International
INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2014/1/media-watch/</u>
INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <u>http://www.ipcrc.net/archive-global-palliative-care-news.php</u>
PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch
PALLIMED (Hospice & Palliative Medicine Blog): <u>http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</u> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]
Asia
ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <u>HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/</u>
SINGAPORE Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/updates/international-palliative-care-resource-</u> center-media-watch/
Australia
WESTERN AUSTRALIA Palliative Care WA Inc: <u>http://palliativecarewa.asn.au/site/helpful-resources/</u> [Scroll down to 'International Websites' and <u>www.ipcrc.net/archive-global-palliative-care-news.php</u> to access the weekly report]
Canada
ONTARIO Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1
ONTARIO Central West Palliative Care Network: <u>http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1</u>
ONTARIO Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx [Click on 'Current Issue' under 'Media Watch']
ONTARIO HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html
ONTARIO Mississauga Halton Palliative Care Network: <u>http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1</u>
ONTARIO Palliative Care Consultation Program (Oakville): <u>http://www.acclaimhealth.ca/menu-services/palliative-care-</u> <u>consultation/resources/</u> [Scroll down to 'Additional Resources']
ONTARIO Toronto Central Hospice Palliative Care Network: <u>http://www.tcpcn.ca/news-events</u> [Scroll down to 'Media Watch']
Europe
EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://www.eapcnet.eu/Themes/Organization/Links.aspx</u> [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-of-life-news-n-470.htm ?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Assisted (or facilitated) death

Representative sample of recent articles, etc:

PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE | Online – 15 January 2014 – 'Should assisted dying be legalised?' When an individual facing intractable pain is given an estimate of a few months to live, does hastening death become a viable and legitimate alternative for willing patients? Has the time come for physicians to do away with the traditional notion of healthcare as maintaining or improving physical and mental health, and instead accept their own limitations by facilitating death when requested? The Universities of Oxford and Cambridge held the 2013 Varsity Medical Debate on the motion "This House Would Legalise Assisted Dying". This article summarises the key arguments developed over the course of the debate. The authors will explore how assisted dying can affect both the patient and doctor; the nature of consent and limits of autonomy; the effects on society; the viability of a proposed model; and, perhaps most importantly, the potential need for the practice within our current medico-legal framework. http://www.peh-med.com/content/9/1/3/abstract

Worth Repeating

A voice unheard: Grandparents' grief over children who died of cancer

MORTALITY, 2007;12(1):66-78. Traditionally, bereavement care for families of children who have died is provided for parents and siblings. A literature review revealed that grandparents' bereavement has barely been studied or reported. The aim of this study is to examine the special characteristics, needs and grief coping strategies of this population. The group discussions raised a variety of themes, some common to other grief groups and some unique to grandparents. The themes unique to grandparents dealt with issues such as the legitimacy of their grief, their pained relationship with their children, and the specific meaning of this loss at old age. Based on the authors' findings, a model of three concentric circles is suggested: 1) the personal level deals with effects on grief of advanced age, closeness to one's own death, and other losses in life; 2) the family circle focuses on the dynamics of the three-generation-family and the role of the grandparents; and, 3) the culture circle relates to the questions of the "place" of grandparents' bereavement: where, how, when, and with whom do grandparents experience and express their grief. http://www.tandfonline.com/doi/abs/10.1080/13576270601088475

Noted in Media Watch, 25 April 2011, #198 (p.4):

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2011;17(4):170-176. 'Forgotten grievers: An exploration of the grief experiences of bereaved grandparents.' The small body of literature generally claims that grandparents experience "double pain," meaning that they concurrently experience feelings of loss for their grandchild and pain associated with their own child's grief. However, this study found that grandparents experience "cumulative pain." http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=83356;article=IJPN 17 4 170 176

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