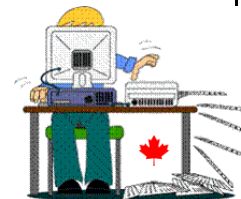


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Parenting challenges in the setting of terminal illness: A family-focused perspective' (p.9), in *Current Opinion in Supportive & Palliative Care*.

Canada

End of life care: Doctors, machines and technology can keep us alive, but why?

POSTMEDIA NEWS | Online – 22 January 2015 – "Bad deaths" happen because of an unwillingness to confront that, fundamentally, most diseases cannot be cured, [James] Downar [a critical- and palliative-care doctor at the University Health Network in Toronto] says. They happen because doctors, untrained and profoundly uneasy confronting our deepest fears and anxieties, see death as a failure, and it can sometimes be easier to continue with aggressive treatment than to tell a patient or family, "I can't turn this around." They happen because difficult conversations aren't happening until there is a crisis and families are in such emotionally hot states they cannot think, concentrate or hear properly. More than 259,000 Canadians take their last breath each year. By 2036, the number will grow to more than 450,000 as the population ages. Yet most lives do not end suddenly, meaning many people can, if they choose, plan the circumstances of their deaths...<http://www.canada.com/health/life+care+doctors+machines+technology+keep+alive/10748281/story.html>

N.B. This article is the first in a 3-part series: Part 2 – 'End of life care: A shift to living well before dying.' <http://www.canada.com/health/life+care+shift+living+well+before+dying/10751508/story.html>
Part 3 – 'End of life care: Creating an exit strategy.' <http://o.canada.com/health/end-of-life-care-creating-an-exit-strategy>

Makayla Sault case reignites debate over a minor's right to refuse treatment

ONTARIO | CBC News – 21 January 2015 – The death of Makayla Sault, the 11-year-old First Nation girl who was given the right to refuse treatment for leukemia, has reignited the debate about when governments should be able to overrule family wishes in life-threatening medical cases. Last March, Makayla was diagnosed with acute lymphoblastic leukemia and authorities said she had a 75% chance of survival if she underwent chemotherapy. Makayla, whose family is

Cont.

from the New Credit First Nation near Caledonia, Ontario, underwent 11 weeks of chemo at McMaster Children's Hospital in Hamilton, but eventually abandoned it while in remission to pursue alternative and traditional indigenous medicine. When Makayla decided against continuing chemotherapy, the hospital referred her case to the Brant Children's Aid Society. But, after an investigation, it decided in May that Makayla was not a child in need of protection, that she was part of a loving family and that it would not apprehend her to return her to treatment. Late last year, a judge rejected an application from a hospital that would have compelled child-welfare authorities to intervene in the case of another Ontario aboriginal girl whose family had also stopped her chemo in favour of traditional medicine. (The girl's name is protected by a publication ban.) These related cases highlight some of the issues at play when a government agency or medical authorities consider intervening in situations involving very sick children whose families refuse treatment. <http://www.cbc.ca/news/canada/makayla-sault-case-reignites-debate-over-a-minor-s-right-to-refuse-treatment-1.2920245>

Noted in Media Watch, 17 November 2014, #384 (p.1):

- ONTARIO | *The Globe & Mail* – 14 November 2014 – '**Ontario hospital cannot force chemo on 11-year-old native girl, court rules.**' In a decision that could affect First Nations people across Canada, a judge in Ontario has ruled that a hospital cannot force a cancer-stricken 11-year-old girl to resume chemotherapy because the Constitution protects her mother's right to treat the child with traditional aboriginal medicine instead. In his decision, Justice Edward, who ... is a member of the Six Nations band, discussed whether J.J. [as the patient is known] would qualify as a child in need of protection under The Child & Family Services Act in Ontario. <http://www.theglobeandmail.com/life/health-and-fitness/health/cancer-patient-has-right-to-use-aboriginal-healing-instead-of-chemo-judge-rules/article21587859/>

Employers want to help caregivers balance responsibilities, report finds

THE GLOBE & MAIL | Online – 20 January 2015 – Canadian employers do not realize how many of their workers balance their jobs with the responsibilities of caring for a loved one, but want to make things easier for employees in that situation. Those are the findings of a report¹ ... by a panel of executives and experts [i.e., the Employer Panel for Caregivers] that the federal government formed to ask Canadian companies what they are doing to help employees who are also looking after someone who is aging or who has a long-term illness. According to Statistics Canada, 35% of employed Canadians provide that type of informal care, in some cases spending 30 or more hours a week at it. Their absenteeism and reduced productivity is estimated to cost the Canadian economy \$1.3-billion annually. And the number of seniors requiring care is expected to double by 2031. The panel, which surveyed a wide range of organizations, from large multinationals to small owner-managed businesses, found employers were "generally surprised" caregiving was so pervasive – perhaps because their workers do not routinely bring it to their attention. <http://www.theglobeandmail.com/news/national/employers-want-to-help-caregivers-balance-responsibilities/article22530359/>

1. 'Report from the Employer Panel for Caregivers – When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers,' Government of Canada, January 2015. <http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml>

Cont. next page

[**Media Watch Online**](#)

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

Noted in Media Watch, 8 December 2014, #387 (p.1):

- *THE FINANCIAL POST* | Online – 1 December 2014 – '**Don't make employees choose between their job and providing end-of-life care to a loved one.**' Job protection for those taking time off from work to provide end-of-life care for loved ones is guaranteed by both federal and provincial governments. Many companies are implementing their own compassionate care leave policies to provide greater comfort and accommodation to employees. A recent survey found 59% of 692 organizations polled had formal compassionate care leave policies that recognize and accommodate employees' family and dependent care responsibilities for providing end-of-life care to loved ones.¹ <http://business.financialpost.com/2014/12/01/dont-make-employees-choose-between-their-job-and-providing-end-of-life-care-to-a-loved-one/>
 1. 'Compassionate Care Policy,' Research by the Human Resources Professionals Association, with the Canadian Hospice Palliative Care Association, October 2014. http://www.hrpa.ca/Documents/360/Compassionate_Care_Policy.pdf

Noted in Media Watch, 16 June 2014, #362 (p.1):

- CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – '**Balancing work and caregiving obligations: New guide walks you through it.**' The Commission has released its 'Guide to Balancing Work & Caregiving Obligations: Collaborative approaches for a supportive and well-performing workplace.' The guide offers employers and employees practical tips on what to do when an employee's family caregiving and work responsibilities come into conflict. http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

U.S.A.

Death doulas help the terminally ill, and their families, cope

THE NEW YORK TIMES | Online – 23 January 2015 – Mary Hilburn spent the last three years watching her partner of 17 years, Jo Allison Bennett, die of brain cancer. Their families weren't supportive, and many of their friends found the experience too emotionally wrenching to become very involved. So in the last few months of Ms. Bennett's life, Ms. Hilburn turned for help to Deanna Cochran, a death doula. The word doula, Greek for "woman who serves," is usually associated with those who assist in childbirth. But increasingly, doulas are helping people with leaving the world as well. Ms. Cochran, a former hospice nurse, helped Ms. Hilburn with practical arrangements, like choosing and organizing caregivers, but more important, she was there "during that in-between time, after hospice had gone, when you want to say, 'Can you come and just hold my hand or sit with me?'" Ms. Hilburn said. "That's where the doula fits in." The concept is not completely new; hospices have long had "vigil volunteers" who sit by the bedside of the dying, but it has now expanded far beyond that. Since there are no federal or state accrediting agencies for death doulas – also called end-of-life doulas, death midwives or simply companions – there are no statistics on how many exist. http://www.nytimes.com/2015/01/24/your-money/death-doulas-help-the-terminally-ill-and-their-families-cope.html?_r=0

Noted in Media Watch, 22 September 2014, #376 (p.12):

- *JOURNAL OF CHRISTIAN NURSING*, 2014;31(4):240-245. '**Palliative care doula: An innovative model.**' This article introduces a model for experienced and advanced practice palliative care nurses to support patients and families during the ... period of end-of-life care. http://journals.lww.com/journalofchristiannursing/Abstract/2014/12000/Palliative_Care_Doula_An_Innovative_Model.12.aspx

Cont.

Noted in Media Watch, 21 November 2011, #228 (p.4):

- ILLINOIS | *The Chicago Tribune* – 21 November 2011 – **'Death midwife also assists at the end of life.'** Ana Blechschmidt is a certified birth doula who works in this regard, she also specializes in the end of life, helping people pass on. That makes her a death doula, or death midwife. <http://www.chicagotribune.com/news/columnists/ct-met-trice-death-doula-1114-20111121,0,6947868.column>

Case sparks debate about teen decision making in health

U.S. NEWS & WORLD REPORT | Online – 22 January 2015 – Only months before turning 18, a Connecticut girl has been told by her state's supreme court that she must undergo chemotherapy against her wishes in a case that has drawn national headlines and raised questions about what rights minors truly have over their bodies. The teen, identified in court papers only as "Cassandra C.," was removed from her home in December after she missed medical appointments for Hodgkin's lymphoma, or cancer of the lymph system. The Leukemia and Lymphoma Society says the disease is highly curable, with an 85% chance of survival. Doctors proposed a six-month chemotherapy course. Without it, she is likely to die in two years. But Cassandra balked at the treatment and said she didn't want to go through with it. Social services became involved and, after an emergency legal appeal, the state's high court said on Jan. 8 the teen could be forced to receive the therapy. Cassandra's case stands apart from the right-to-die movement, which aims

to give terminally ill people the right to physician-assisted suicide. And she hasn't objected to the treatment on religious grounds, which are often cited when minors – or their parents on their behalf – refuse medical procedures. Cassandra has not closed the door on chemotherapy, she just wanted the chance to look into alternative options and felt she was not given time. It's a decision her mother supported, despite being reported to Connecticut's Department of Children & Families for medical neglect. <http://www.usnews.com/news/articles/2015/01/22/case-sparks-debate-about-teen-decision-making-in-health>

Specialist Publications

'Determining "best interests" in end-of-life decisions for the developmentally disabled: Minnesota state guardians and wards' (p.10), in *Disabilities Study Quarterly*.

End-of-life care in America is a scam

NEWSWEEK | Online – 21 January 2015 – Can we speak honestly about end-of-life care in America? Apparently not. In 2014, the National Academy of Sciences and its Institute of Medicine hired a 21-member panel of big shots and wrote a 507-page report¹ ... to state the incredibly obvious point that end-of-life care in America is completely broken. You know this already if you have had a parent or grandparent enter the system and stay there until death. You also already know the scam. It's all about extracting the last dime first from private wealth and then from the taxpayer through government programs, until all excuses run out and the patient is finally and mercifully allowed to die. Not only has the system gradually turned into a gigantic financial racket that plays on people's normal sense of wanting to prolong life as much as possible; it is the cause of wrecked families, massive heartache and terrible suffering spread far and wide, not to mention pillaged family estates. <http://www.newsweek.com/end-life-care-america-scam-300973>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

International

End-of-life care in England

How hospices can save hospitals

U.K. (England) | *The Telegraph* (OpEd) – 20 January 2015 – Today the health select committee begins taking evidence for a new inquiry into end-of-life care. This comes after considerable public concern about the quality of care that people receive as they die, and six months after the controversial Liverpool Care Pathway for the terminally ill was officially withdrawn from use in the NHS [National Health Service]. The truth is that many frail elderly and terminally ill people are in hospital unnecessarily after being admitted via Accident & Emergency. Often, they would be far better cared for elsewhere. But in many instances, patients head to their local casualty department simply because alternative – and, in many cases, more appropriate – care is not available. NHS community services are in short supply, health care professionals are frequently unaware that other measures, such as hospice care, could help, and planning to discharge patients from hospitals to community services is complex and difficult. This means that of the 500,000 people who die in England each year, about half do so in hospital, even

though many have no clinical need to be there and very few want to die there. The vast majority (80%) say that they would like to be cared for and die at home or in a hospice. Since the Sixties, hospices have been at the forefront of providing high-quality care for people approaching the end of life. <http://www.telegraph.co.uk/news/health/11355738/How-hospices-can-save-hospitals.html>

Specialist Publications

'Geographical and temporal understanding in place of death in England (1984-2010): Analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) primary research' (p.11), in *Health Services & Delivery Research*.

'Current challenges in palliative care provision for heart failure in the U.K.: A survey on the perspectives of palliative care professionals' (p.13), in *OpenHeart*.

Of related interest:

- U.K. (England) | *The Independent* – 21 January 2015 – '**Care for elderly in state of "calamitous decline" amid £1 billion of austerity cuts.**' Care of the elderly in England is in a state of "calamitous, quite rapid decline," a leading charity has warned, with hundreds of thousands fewer people receiving care than five years ago. More than £1 billion has been slashed from ... social care budgets since 2010, despite an increase in the elderly population, meaning thousands who would have previously received help with basic daily tasks ... no longer get support, Age UK said. <http://www.independent.co.uk/life-style/health-and-families/health-news/care-for-elderly-in-state-of-calamitous-decline-amid-1bn-of-austerity-cuts-9991321.html#>

How the care system works across the U.K.

U.K. | BBC News – 21 January 2015 – Care in later years covers everything from help in an individual's home for tasks such as washing and dressing, to round-the-clock help in a care home or nursing home. The way the system works is different, depending on which part of the U.K. a person lives in. Unlike the NHS, services are not free. Some people will get help towards their costs, but others can pay the full cost of their care. <http://www.bbc.com/news/health-30902552>

- U.K. (England) | *The Telegraph* – 20 January 2015 – **"Wide variation" in end of life care at hospitals.** Dying patients are receiving "wide variations" of care because of hospitals' failures to replace the controversial Liverpool Care Pathway, the Chief Inspector of Hospitals for the Care Quality Commission, Prof. Sir Mike Richards, has said. Sir Mike said that some hospitals had responded slowly to the withdrawal of the guidance last summer, saying that it had created a "hiatus" in management. <http://www.telegraph.co.uk/news/health/11358520/Wide-variation-in-end-of-life-care-at-hospitals.html>
- U.K. (England) | *The Guardian* – 19 January 2015 – **'NHS cannot cope with ageing population, warns top doctor.'** The NHS's future is in danger because its model of care cannot meet the relentlessly growing demand for treatment caused by the ageing population, the service's top doctor has warned. Prof. Sir Bruce Keogh, medical director of the NHS in England, said that without massive changes to the way the NHS treats patients, including far less reliance on hospitals, the service risked becoming unaffordable and could see its entirely taxpayer-funded status challenged. <http://www.theguardian.com/society/2015/jan/19/nhs-we-have-not-fit-for-future-warns-top-doctor-bruce-keogh>

Most Australians want a good death at home, but only 14% get it

AUSTRALIA | *Business Insider* (Sydney, New South Wales) – 19 January 2015 – Most Australians would prefer to die at home but only about 14% get the opportunity to do so...¹ Hal Swerissen and Stephen Duckett from the Grattan Institute ... say dying in Australia is now highly institutionalised with 54% ending their days in hospitals and 32% in residential care. However, most (60% to 70%) Australians prefer to die at home. A good death, they say, is one in which the patient had choice about who will be present, where they will die, what services they will get, and one in which their symptoms are well managed with personal, social and psychological support. Most want to have the opportunity to say goodbye and leave "when it was time to go without pointlessly prolonging life." The professors suggest a public education campaign focused on encouraging people to "discuss their preferences and choices for end-of-life care with health professionals, including general practitioners." <http://www.businessinsider.com.au/doctors-when-the-end-comes-most-australians-want-a-good-death-at-home-2015-1>

Specialist Publications

'Advance care planning in palliative care: A national survey of health professionals and service managers' (p.12), in *Australian Health Review*.

'Palliative care health professionals' experiences of caring for patients with advance care directives' (p.12), in *Australian Health Review*.

'Making it easier for people to die at home – an innovative programme in New South Wales, Australia' (p.12), in *European Journal of Palliative Care*.

'What can we do to help Australians die the way they want to?' (p.12), in *Medical Journal of Australia*.

Noted in Media Watch, 6 October 2014, #378 (p.7):

- AUSTRALIA (Victoria) | Grattan Institute (Melbourne) – September 2014 – **'Dying Well.'** Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well. <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

Cont.

Noted in Media Watch, 27 October 2014, #381 (p.4):

- AUSTRALIA (Australian Capital Territory) | *The Canberra Times* – 22 October 2014 – '**Call for rethink on end-of-life care as health costs climb.**' Frontline health workers are calling for an overhaul of end-of-life care to reduce the number of people dying in hospitals and help rein in spiralling spending. <http://www.canberratimes.com.au/act-news/call-for-rethink-on-endoflife-care-as-health-costs-climb-20141022-119ut0.html>

N.B. Additional articles on end-of-life care in Australia are noted in this issue of Media Watch (pp.4,8,12).

Of related interest:

- AUSTRALIA | Gay News Network – 20 January 2015 – '**Aged care funding to target minorities including LGBTI.**' Older LGBTI [Lesbian, Gay, Bisexual, Transgender/Transsexual and Intersexed] Australians are among those to benefit from more than \$1.5 million in grants as part of the Decision Assist Linkages project to build better links between the providers of palliative and aged care across Australia. The homeless, indigenous and culturally and linguistically diverse communities across Australia are the focus of the grants which recognise that older people living in all types of circumstances need access to good quality palliative care. <http://gaynewsnetwork.com.au/news/national/aged-care-funding-to-target-minorities-including-lgbti-16241.html>

End-of-life care in Croatia

Where the terminally ill die without palliative care

CROATIA | WEST (Welfare Society Territory) – 19 January 2015 – For the terminally ill in Croatia, there is no public healthcare. The situation is so bad that some patients are left without food or water in their homes, dying in excruciating pain. This is the dramatic reality denounced by the Croatian Association for Palliative Medicine, which is calling for a drastic sea change. The Balkan country is the only one in the European Union that does not provide palliative care and specific drugs for patients suffering from rare and terminal diseases. The chronic lack of medical resources and multi-disciplinary personnel means that besides medical support there is also a need for psychological care. In short, the national health system needs to change from the roots up. This is a warning that should be heeded, considering the progressive ageing of the population (with more than 20% over 65 years) and the increase of incurable diseases, in particular dementia. <http://www.west-info.eu/where-the-terminally-ill-die-without-palliative-care/>

Noted in Media Watch, 16 July 2012, #262 (p.11):

- *MEDICINA FLUMINENSIS*, 2012;48(2):131-141. '**Palliative care in Croatia on the threshold of entering the European Union: Medical-legal and medical-ethical review.**' Recommendations from the European Association for Palliative Care prove the flaw in the Croatian system of palliative care, with special emphasis on the need to prompt establishment of a national health policy of palliative care. The first step on this path should be the establishment of institutions for palliative care. http://hrcak.srce.hr/index.php?show=clanak&id_clanak_jezik=125308



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>

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

Variation in the place of death among nursing home residents in France

AGE & AGEING | Online – 20 January 2015 – This study demonstrates the existence of major differences across regions in France and highlights the need for targeted interventions regarding end-of-life care in nursing home facilities. The characteristics of the facilities had a significant influence on the proportion of in-hospital deaths among the nursing home decedents. At the regional level, both the rate of acute hospital beds and the rate of general practitioners were found to be strongly correlated with the probability of reporting worse-than-average outcomes... <http://ageing.oxfordjournals.org/content/early/2015/01/20/ageing.afu197.abstract>

American Thoracic Society Policy Statement

Managing conscientious objections in intensive care medicine

AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE, 2015;191(2):219-227. The policy recommendations are based on the dual goals of protecting patients' access to medical services and protecting the moral integrity of clinicians. Conceptually, accommodating conscientious objections (COs) should be considered a "shield" to protect individual clinicians' moral integrity rather than as a "sword" to impose clinicians' judgments on patients. The committee recommends: 1) COs in ICUs be managed through institutional mechanisms; 2) institutions accommodate COs, provided doing so will not impede a patient's or surrogate's timely access to medical services or information or create excessive hardships for other clinicians or the institution; 3) a clinician's CO to providing potentially inappropriate or futile medical services should not be considered sufficient justification to forgo the treatment against the objections of the patient or surrogate; and, 4) institutions promote open moral dialogue and foster a culture that respects diverse values in the critical care setting. http://www.atsjournals.org/doi/abs/10.1164/rccm.201410-1916ST#.VL5XHtLF_YR

Noted in Media Watch, 9 May 2011, #200 (p.8):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2011;305(17):1804-1805. **'Would accommodating some conscientious objections by physicians promote quality in medical care?'** Genuine conscience-based refusals are refusals in which a physician believes providing the requested service would violate his or her core moral beliefs (religious or secular), thereby causing personal moral harm. <http://jama.ama-assn.org/content/305/17/1804.extract>

A review on problems of China's hospice care and analysis of possible solutions

CHINESE MEDICAL JOURNAL, 2015;128(2):279-281. Taiwan scholar Xie Mei introduced the concept of hospice care to the mainland of China in 1982... Tianjin Medical University had set up the Institute of Hospice Care. Major state-owned hospitals have established hospice wards. There are also some hospice agencies set up through private fund raising. However, after all these years of development, the supply of the hospice care service in China is still much less than the demand, between which the gap is big. There are three main reasons for this: 1) the obstructions from traditional Chinese culture; 2) the lack of support from the government; and, 3) the scarcity of hospice care specialists. The author goes on to propose a number of possible solutions. http://www.cmj.org/temp/ChinMedJ1282279-2965609_081416.pdf

N.B. English language article.

Selected articles on end-of-life care in China noted in past issues of Media Watch:

- *ASIAN BIOETHICS REVIEW*, 2014;6(3):315-319. **'Medical futility and palliative care gain momentum in China.'** In China, around 160 to 200 million patients are diagnosed with cancer every year, and there are more than 300 million existing cancer patients with an increasing trend of 3% per year. The number of deaths among cancer patients is about 1.4 million per annum. It is important to mention that China has improved the health status of their population by using only 1% of the world's health expenditure, and life expectancy is currently 74 years, one of the best in the world... [Noted in Media Watch, 15 September 2014, #375 (p.9)] http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v006/6_3.pazooki.html
- *NURSING ETHICS* | Online – 30 May 2014 – **'Preference of Chinese general public and healthcare providers for a good death.'** The attributes perceived as important by survey respondents for a good death were maintaining hope and pleasure, good relationship with medical staff, good relationship with family, independence, environment comfort, being respected as an individual, preparation for death, physical and psychological comfort, dying in a favorite place, and not being a burden to others. [Noted in Media Watch, 9 June 2014, #361 (p.16)] <http://nej.sagepub.com/content/early/2014/05/30/0969733014524760.abstract>
- *ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT*, 2013;8(1):9-13. **'Palliative care on Mainland China.'** Factors that have slowed development of palliative care include cultural values that encourage efforts to cure (even when such treatment is likely to be futile) over the alleviation of suffering, limited public policies and funding, and poor education of healthcare professionals about end-of-life care. [Noted in Media Watch, 9 September 2013, #322 (p.6)] <http://search.informit.com.au/documentSummary;dn=489509343939048;res=IELHEA>
- *ASIAN JOURNAL OF GERONTOLOGY & GERIATRICS*, 2011;6(2):103-106. **'End-of-life care in Hong Kong.'** The Hong Kong government does not have a clear policy on developing end-of-life care services as a critical part of health care, nor on promoting dying in place, either at home or in a residential care home for the elderly... [Noted in Media Watch, 13 February 2012, #240 (p.8)] http://hkag.org/Publications/AJGG/V6N2/RA1_JKH%20Luk.pdf

Parenting challenges in the setting of terminal illness: A family-focused perspective

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 12 January 2015 – To date, the study of parental cancer has focused predominantly on the early stages of disease and its impact on children and adolescents. Less is known about how families with minor children prepare for parental loss. Evidence suggests that having dependent children influences parents' treatment decisions at the end of life, and that a central concern for children and parents is optimizing time spent together. Parents may feel an urgency to engage in accelerated parenting, and maintaining normalcy remains a consistent theme for the ill and healthy parent alike. There is a growing evidence base affirming the importance of responsive communication prior to death. Advancing knowledge about the parenting experience at the end of life is critical for ensuring effective support to the entire family, as it accommodates and prepares for the loss of a vital member. http://journals.lww.com/co-supportiveandpalliative-care/Abstract/publishahead/Parenting_challenges_in_the_setting_of_terminal.99651.aspx

Noted in Media Watch, 21 January 2013, #289 (p.7):

- *INTERNATIONAL JOURNAL OF ADOLESCENT MEDICINE & HEALTH* | Online – Accessed 15 January 2013 – **'Detached, distraught or discerning? Fathers of adolescents with chronic illness.'** Three time-periods describe the obstacles fathers tackle when parenting children with chronic disease: 1) diagnosis and short-term, characterized by distress, isolation and uncertainty; 2) the mastery period, characterized by the struggle to establish routine and by support and spirituality; and, 3) the long-term, characterized by relationship and personality change, worries and bereavement. <http://www.degruyter.com/abstract/ijamh.ahead-of-print/ijamh-2013-0018/ijamh-2013-0018.xml?rskey=HXDplo&result=1&q=fathers>

Determining "best interests" in end-of-life decisions for the developmentally disabled: Minnesota state guardians and wards

DISABILITIES STUDY QUARTERLY, 2014;34(4). The authors report the results of a study of 129 case files and 16 guardian interviews on end-of-life decision making for Minnesota state wards who are developmentally disabled and are seldom competent to assert their wishes. They review the legal cases, legislative statutes, and professional standards that guide public guardians in deciding whether to begin, continue, or withdraw or withhold life-sustaining medical treatment from their wards. In particular, the authors reveal how the guardians' recommendations to the state Public Guardianship Administrator include such ableist assumptions as "normal," "natural," and "reasonable," but they also recognize the guardians' resistance to mind/body dichotomies and their expertise in determining quality of life in the context of how their wards live those lives. <http://dsq-sds.org/article/view/4276/3797>

European Association for Palliative Care (EAPC)

Core competencies for palliative care social work in Europe: An EAPC White paper – Part 2

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(1):38-44. The aim of this White Paper has been to provide an outline of the core competencies expected of social workers in palliative and end-of-life care. The authors sought to situate these within the historical, economic, socio-cultural and international contexts of palliative and end-of-life care, and to underpin them with the value base of social work as a professional discipline. Inevitably, our competencies framework needs to fit in a wide range of national contexts and cultures, as well as a multiplicity of health and social care systems in which palliative and end-of-life care may sometimes be at an early developmental stage. This competencies framework may, therefore, need adapting to local need. But the authors would argue that, in essence, this framework embodies the core of what palliative care social workers should aspire to. The next task of the EAPC Task Force will be to develop core curricula for the education of social workers in palliative care.

Noted in Media Watch, 10 November 2014, #383 (p.12):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):300-305. **'Core competencies for palliative care social work in Europe: An European Association for Palliative Care White Paper – Part 1.'** This White Paper is the culmination of work undertaken to examine the diversity of roles, tasks and education of palliative care social workers in Europe.

Palliative care development in Serbia, five years after the national strategy

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(1):30-33. In 2009, the Serbian Ministry of Health adopted a national palliative care strategy, setting out the vision of a comprehensive and modern system of palliative care services across Serbia. From March 2011 to November 2014, a European Union-funded project was conducted to implement the strategy through the provision of technical assistance and the application of European and international standards. Major advances have been achieved in education, services, policies and legislation, as a result of which the status of palliative care in Serbia has progressed from "localised provision" to "preliminary integration." However, there is further to go in order to ensure that palliative care is fully accessible to all who need it.

N.B. Access to *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=5
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Noted in Media Watch, 21 July 2014, #367 (p.5):

- SERBIA | inSerbia – 15 July 2014 – **'This is not a ward for dying people: Palliative care unit in Cacak.'** While in Serbia palliative care has been developing for over a decade, the major progress in this field was achieved in the last three years with the financial support of the European Union through the project 'Development of Palliative Care in Serbia,' financially and strategically supported by the Ministry of Health.¹ <http://inserbia.info/today/2014/07/this-is-not-a-ward-for-dying-people-palliative-care-unit-in-cacak/>

1. 'Developing Palliative Care Services in Serbia'
<http://www.opml.co.uk/projects/developing-palliative-care-services-serbia>

Nurses' experiences of futile care at intensive care units: A phenomenological study

GLOBAL JOURNAL OF HEALTH SCIENCE, 2015;7(4):235-242. The concept and meaning of futile care depends on the existing culture, values, religion, beliefs, medical achievements and emotional status of a country. The experiences of 25 nurses were explored in 11 teaching hospitals affiliated to Social Security Organization in Ghazvin province in the northwest of Iran. They defined futile care as "useless, ineffective care giving with wastage of resources and torment of both patients and nurses having nursing and medical aspects." As nurses play a key role in managing futile care, being aware of their experiences in this regard could be the initial operational step for providing useful care as well as educational programs in ICUs. Moreover, the results of this study could help nursing managers adopt supportive approaches to reduce the amount of futile care which could in turn resolve some of the complications nurses face at these wards such as burnout, ethical conflicts, and leave. <file:///C:/Users/Barry/Downloads/41302-152428-1-PB.pdf>

Geographical and temporal understanding in place of death in England (1984-2010): Analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) primary research

HEALTH SERVICES & DELIVERY RESEARCH, 2014;2(42). (Accessed 23 January 2015) Information on where people die is essential for public health planning and end-of-life care policy. In this study the authors aimed to describe where people died over a 27-year period. They also wanted to find out what factors might be related to this. The authors analysed the death registration records of over 13 million people. Just under two-thirds had died in hospitals. The second and the third most common place of death (varied according to the cause of death. Hospices played an increasing role over time but almost exclusively for people with cancer. <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-42#abstract>

End-of-life medications draw more attention, greater scrutiny

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2015;313(3):231-233. It wasn't a popular idea at the outset. Amy Abernethy, MD, PhD, and her colleagues suggested a decade ago that patients nearing the end of life could stop at least some of their medications. But their attempts to publish material on the subject initially met with resistance. "There was great angst among reviewers about medication discontinuation of any kind," she said of a commentary they eventually published...¹ "They felt it would be equivalent to saying to a patient, 'You're not worthy to be on this medication.'" <http://jama.jamanetwork.com/article.aspx?articleid=2091302>

1. 'Managing co-morbidities in patients at the end of life,' *British Medical Journal*, 2004; 329(7471):909-912. <http://www.bmj.com/content/329/7471/909>

Comparing end-of-life practices in different policy contexts: A scoping review

JOURNAL OF HEALTH SERVICE RESEARCH & POLICY | Online – 14 January 2015 – Research evidence is used to support different assumptions about the effects of public policies on end-of-life practices. It is, however, unclear whether reliable international practice comparisons can be conducted between different policy contexts. The authors developed a descriptive classification of end-of-life practices that distinguishes practices according to their legal status. They focused on the intentional use of lethal drugs by physicians because of international variations in the legal status of this practice. In sum, 329 empirical studies on the intentional use of lethal drugs by doctors were identified, including studies from 19 countries. Studies on the intentional use of lethal drugs were conducted in jurisdictions with permissive (62%) and restrictive policies (43%). The most common study objectives related to the frequency of end-of-life practices, determinants of practices, and doctors' adherence to regulatory standards. Large variations in definitions and research methods were noted across studies. The use of a descriptive classification was useful to translate end-of-life practice definitions across countries. A few studies compared end-of-life practice in countries with different policies, using consistent research methods. The authors identified no comprehensive review of end-of-life practices across different policy contexts. <http://hsr.sagepub.com/content/early/2015/01/14/1355819614567743.abstract>

What can we do to help Australians die the way they want to?

MEDICAL JOURNAL OF AUSTRALIA, 2015;202(1):10-11. Australians are not dying as they would wish. Surveys consistently show that between 60% and 70% of Australians would prefer to die at home, and that residential care facilities are their least preferred option. Dignity, control and privacy are important for a good death. Choice over who will be present, where people will die and what services they will get, matters. People want their symptoms to be well managed, and they want personal, social and psychological support. It is important to have the opportunity to say goodbye and leave when it is time to go without pointlessly prolonging life. But dying is now highly institutionalised. Over the past century, the proportion of deaths at home has declined and that of deaths in hospitals and residential aged care has increased. Today only about 14% of people die at home in Australia. Fifty-four per cent die in hospitals and 32% in residential care. Home and other non-institutional deaths are about half as prevalent in Australia as they are in New Zealand, the U.S., Ireland, and France. <https://www.mja.com.au/journal/2015/202/1/what-can-we-do-help-australians-die-way-they-want>

Of related interest:

- *AUSTRALIAN HEALTH REVIEW* | Online – 22 January 2015 – '**Advance care planning in palliative care: A national survey of health professionals and service managers.**' The survey shows improvements on past small-scale research showing advance care planning is supported by health professionals; however, the organisational processes and systems did not support best practice in this regard. <http://www.publish.csiro.au/nid/270/paper/AH14118.htm>
- *AUSTRALIAN HEALTH REVIEW* | Online – 22 January 2015 – '**Palliative care health professionals' experiences of caring for patients with advance care directives.**' Advance care directives (ACDs) facilitate communication and advance care planning, help establish trust between health professionals, patients and their families, and make multiple aspects of care easier for health professionals. Processes surrounding ACDs ... limit adherence and application. <http://www.publish.csiro.au/nid/270/paper/AH14119.htm>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(1):26-29. '**Making it easier for people to die at home – an innovative programme in New South Wales, Australia.**' The discrepancy between the number of people who would prefer to die at home and those who actually do is thought to be due a lack of access to well-trained care workers and the perceived lack of knowledge and skills in non-specialist doctors and nurses.

N.B. Access to this article requires a subscription. Journal contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=519

On the death of a colleague

NEW ENGLAND JOURNAL OF MEDICINE, 2015;372(3):207-209. Straining to do her job after a friend and mentor dies, a physician marvels that in a hospital that routinely and efficiently deals with life, death, and all the intervening drama, the passing of a colleague can shatter the established structure for coping with loss. <http://www.nejm.org/doi/full/10.1056/NEJMp1410385>

Current challenges in palliative care provision for heart failure in the U.K.: A survey on the perspectives of palliative care professionals

OPENHEART | Online – 16 January 2015 – This is the first study, to the authors' knowledge, to document the difficulties surrounding implantable cardioverter defibrillator (ICD) deactivation throughout the U.K. It is disappointing to find that difficulties still persist in palliative care (PC) provision for heart failure (HF) in 2014. They hope that their findings will reinvigorate the debate on PC in HF among cardiologists, particularly on: reassessment of contemporary PC needs as new HF therapies emerge, optimal timing for initiating PC discussions or needs assessment, and ideal interdisciplinary working arrangements to deliver efficient care. The fact remains that cardiologists are often the gatekeepers to PC services for the patient with HF. Therefore, improvement of PC provision in HF must first start with raising awareness of its benefits among cardiologists and encouraging interdisciplinary dialogue. <http://openheart.bmj.com/content/2/1/e000188.full>

Noted in Media Watch, 12 January 2015, #392 (p.9):

- *INTERNATIONAL JOURNAL OF CARDIOLOGY* | Online – 5 January 2015 – **'Defibrillator patients should not be denied a peaceful death.'** The objective of this study was to investigate end of life in ICD patients, with respect to location of death; duration between do-not-resuscitate-orders (DNR); and, deactivation of ICD therapy or DNR and time of death. [http://www.internationaljournalofcardiology.com/article/S0167-5273\(15\)00037-6/abstract](http://www.internationaljournalofcardiology.com/article/S0167-5273(15)00037-6/abstract)

N.B. Listed in this issue of Media Watch are selected articles on defibrillator deactivation in end-of-life care noted in past issues of the weekly report. Additional articles of interest on palliative care in cardiology are noted in Media Watch of 19 January 2015, #393 (pp.10-11).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC MEDICAL ETHICS* | Online – 22 January 2015 – **'Psychosocial determinants of physicians' intention to practice euthanasia in palliative care.'** Euthanasia remains controversial in Canada and an issue of debate among physicians. Most studies have explored the opinion of health professionals regarding its legalization, but have not investigated their intentions when faced with performing euthanasia. These studies are also considered atheoretical. The purposes of the present study were to fill this gap in the literature by identifying the psychosocial determinants of physicians' intention to practice euthanasia in palliative care and verifying whether respecting the patient's autonomy is important for physicians. Overall, physicians have weak intentions to practice euthanasia in palliative care. Nevertheless, respecting patients' final wishes concerning euthanasia seems to be of particular importance to them and greatly affects their motivation to perform euthanasia. <http://www.biomedcentral.com/content/pdf/1472-6939-16-6.pdf>

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[Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

- *JOURNAL OF MEDICAL ETHICS* | Online – 22 January 2015 – '**Physician-assisted death with limited access to palliative care.**' Even among advocates of legalising physician-assisted death, many argue that this should be done only once palliative care has become widely available. Meanwhile, according to them, physician-assisted death should be banned. Four arguments are often presented to support this claim, which the authors call the argument of lack of autonomy, the argument of existing alternatives, the argument of unfair inequalities, and the argument of the antagonism between physician-assisted death and palliative care. The authors argue that although these arguments provide strong reasons to take appropriate measures to guarantee access to good quality palliative care to everyone who needs it, they do not justify a ban on physician-assisted death until we have achieved this goal. <http://jme.bmj.com/content/early/2015/01/22/medethics-2013-101953.abstract>
- *JOURNAL OF MEDICAL ETHICS* | Online – 21 January 2015 – '**Finnish physicians' attitudes towards active euthanasia have become more positive over the last 10 years.**' In 2003, 61% of the [survey] respondents were against the legalisation of euthanasia and 29% supported it. In 2013, both groups were of equal size (46%). The willingness to perform active euthanasia has not, however, increased significantly, even in a legalised setting. <http://jme.bmj.com/content/early/2015/01/21/medethics-2014-102459.abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/01/media-watch/>

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

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

Australia

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

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://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Worth Repeating

Literature review

Dying with dignity: The good patient versus the good death

JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2004;21(2):116-120. Death is a unique experience for each human being, yet there is tremendous societal pressure on a dying person to be a "good patient" while trying to experience the "good death." These pressures shape patient, caregiver and family choices in end-of-life situations. The purpose of this review was twofold: first, to develop an understanding of "dying with dignity" to enhance the end-of-life care received by dying patients and, second, to contribute to a concept analysis of dignity to improve the clarity and consistency of future research related to dignity in aging individuals. Articles pertaining to dying with dignity from the disciplines of nursing, medicine, ethics, psychology, and sociology were reviewed... A dichotomy surrounding dying with dignity emerged... The definition of dignity in dying identifies not only an intrinsic, unconditional quality of human worth, but also the external qualities of physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection. For many elderly individuals, death is a process, rather than a moment in time, resting on a need for balance between the technology of science and the transcendence of spirituality. <http://ajh.sagepub.com/content/21/2/116.short>

Media Watch: Editorial Practice

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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.

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