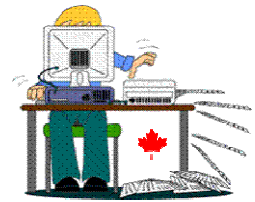


## Media Watch...

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

Uncommon prototype for hospice care: Scroll down to **U.S.** and 'Social model hospice homes may revolutionize end-of-life care in the U.S' (p.3), in *The Huffington Post*.

## Canada

### Elder care in Ontario

#### Growing seniors population taxes homecare services in northeastern Ontario

ONTARIO | CBC News – 26 June 2015 – The Northeast Community Care Access Centre [CCAC] says it's feeling the demand of seniors needing more complex home care. The agency serves 16,000 patients in the region, and more than half of them are elderly. CCAC CEO Richard Joly said hospitals aren't keeping the elderly as long as they used to – and that means they're going home and needing more complicated support." [The] complexity has dramatically increased," he said. "I would say, in the 30-40% range, that we service more complex patients in the community." But while demand for services is up, the CCAC's budget is staying the same. "A lot of the time, financial resources don't allow" for the full range of care that more than 8,000 seniors at home, and in the community, Joly noted. <http://www.cbc.ca/news/canada/sudbury/growing-seniors-population-taxes-homecare-services-in-northeastern-ontario-1.3128739>

Noted in Media Watch, 18 May 2015, #410 (p.1):

- ONTARIO | *The London Free Press* – 14 May 2015 – '**Community Care Access Centres may be on way out.**' Health Minister Eric Hoskins may be weeks away from changes that would take power and money away from 14 large bureaucracies that act as gatekeepers to home care... Hoskins said he wanted to make changes but would wait until Auditor General Bonnie Lysyk releases her report... <http://www.lfpress.com/2015/05/14/ccacs-may-be-on-way-out>

Noted in Media Watch, 16 March 2015, #401 (p.1):

- ONTARIO | *The Toronto Star* – 12 March 2015 – '**Ontario's home care system should be overhauled now: Editorial.**' A study by the Ontario Health Coalition, an advocacy group, is calling for a complete overhaul of the home care system.<sup>1</sup> If their message isn't strong enough to be heard by the Ontario government, many of the group's findings are reinforced by a second report on home care by a group of experts commissioned by the provincial government.<sup>2</sup> <http://www.thestar.com/opinion/editorials/2015/03/12/ontarios-home-care-system-should-be-overhauled-now-editorial.html>

Cont.

1. 'The Care We Need: Ontarians Speak Out on the State of Home Care – A Proposal for Reforming Home Care in the Public Interest,' Ontario Health Coalition, March 2015. <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>
2. 'Bringing Care Home,' Report of the Expert Group on Home & Community Care,' March 2015. [http://health.gov.on.ca/en/public/programs/ccac/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf)

## Cancer society makes first ever public pitch to parties ahead of election

*THE GLOBE & MAIL* | Online – 23 June 2015 – The Canadian Cancer Society is delivering a blunt indictment of the federal Conservative government's record on cancer care, saying a lack of strong national leadership on the prevention and treatment of the disease is threatening Canada's health-care system. For the first time in its 77-year history, Canada's largest health charity, is making a public pitch to political parties before a federal election, calling for commitments to cancer care and research to be written into campaign platforms and pointing to gaps it says have been created by "Ottawa's broader disengagement from health issues." In a report<sup>1</sup> ... the cancer society says cases of the disease ... are expected to climb by 40% over the next 15 years as a result of the aging population. "Without a strong national response," the report says, "there is a risk that the rising number of cancer cases will overwhelm our

health care system, compromising the quality of care available and crowding out the investments required to better prevent and treat the disease tomorrow." The report says the government has taken some important steps to reduce the incidence of cancer, but those actions have been undermined by contradictions and missed opportunities. <http://www.theglobeandmail.com/news/politics/cancer-society-makes-first-ever-public-pitch-to-parties-ahead-of-election/article25068834/>

### Extract from The Canadian Society report

One of the federal government's most important obligations is to ensure that all Canadians have access to affordable, high-quality healthcare. Of the areas where Ottawa has failed to meet this responsibility, palliative care is one of the clearest and most pressing. (See p.19 of the report.)

1. 'Wake-up Call: National Priorities for Patients, Families, and a Healthier Future,' a federal election platform, released by The Canadian Cancer Society, on the 23 June 2015. <http://www.cancer.ca/~media/cancer.ca/CW/for%20media/Media%20releases/2015/ccs-election-platform-June-2015-EN.pdf>

Representative sample of news media coverage of the Canadian Cancer Society report:

- *CBC NEWS* | Online – 23 June 2015 – '**Cancer fight needs federal leadership, Canadian Cancer Society says.**' Lack of federal leadership in health care is undermining the effort to fight cancer, Canada's largest health charity says. The Canadian Cancer Society says there's a risk the projected increase in cancer cases among the growing and aging population will overwhelm families, health-care providers and the economy, unless there's a strong national response. <http://www.cbc.ca/news/health/cancer-fight-needs-federal-leadership-canadian-cancer-society-says-1.3125198>
- *THE NATIONAL POST* | Online – 23 June 2015 – '**Next government must address controversial issue of end-of-life care: Canadian Cancer Society.**' The Canadian Cancer Society is calling on the next federal government to take immediate action to address the thorny issue of end-of-life care. The group is releasing an election-campaign platform today that calls on the winner of the federal election this October to promptly introduce legislation to establish a comprehensive national palliative care strategy. <http://news.nationalpost.com/news/canada/next-government-must-address-controversial-issue-of-end-of-life-care-canadian-cancer-society>

**N.B.** 'Canadian Cancer Statistics 2015: Predictions of the Future Burden of Cancer in Canada,' Canadian Cancer Society, Statistics Canada. [Noted in Media Watch, 1 June 2015, #412 (p.2)] <https://www.cancer.ca/~media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2015-EN.pdf>

## U.S.A.

### **Social model hospice homes may revolutionize end-of-life care in the U.S.**

*THE HUFFINGTON POST* | Online – 23 June 2015 – The “social model” hospice home, an uncommon prototype for hospice care, may have great promise for resolving some future end-of-life issues in the U.S. The number of social model hospices in this country is currently small but growing at a steady pace as communities grapple with the question of how best to provide care for their dying members.<sup>1,2</sup> However, the social model hospice home is not a new idea at all: The first social hospices were created during the AIDS epidemic in the 1980s to house AIDS patients as they were nearing the end of life and in desperate need of terminal care. Many of these homes were literally private residences with multiple bedrooms where a small number of patients could be cared for and comforted through the dying process. In reviewing the current and future issues surrounding end-of-life care in the U.S. it appears that this model of community-based social care homes may offer solutions for some of the problems that lie ahead. Under the social model of care for the dying there is no federal or state funding because these homes do not function as

medical facilities. They tend to be cost-effective organizations that provide care for free or at low-cost and on a sliding scale. [http://www.huffingtonpost.com/karen-m-wyatt-md/social-model-hospice\\_b\\_7641916.html](http://www.huffingtonpost.com/karen-m-wyatt-md/social-model-hospice_b_7641916.html)

#### **Extract from *The Huffington Post* article**

While there are no perfect solutions to the issues facing end-of-life care in the U.S., the community-based social model seems to offer an important and viable addition to the current system of hospice care. This model encourages communities to take responsibility for the needs of their own citizens and provides an opportunity for creative involvement in end-of-life care for everyone.

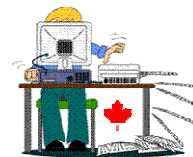
#### **Specialist Publications**

**‘A legal and ethical analysis of the effects of triggering conditions on surrogate decision-making in end-of-life care in the U.S.’** (p.10), in *HealthCare Ethics Committee Forum*.

1. Clarehouse, Tulsa, Oklahoma: <http://www.clarehouse.org/education/social-model-hospice/>
2. Social Hospice Network: <http://socialhospicenetwork.org/>

#### **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>



## International

### **Dementia in Ireland – Condition could bankrupt us**

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 26 June 2015 – The magnitude and challenge of dementia cannot be over-estimated. Across the world, every four seconds, a new case of dementia occurs and over the next 35 years, in the absence of a cure, dementia prevalence rates are set to triple globally and to reach 135 million by 2050. Like in other countries, the prevalence of dementia will rise in Ireland in the foreseeable future, from current estimates of 48,000 to circa 150,000 by 2051. Dementia is a chronic, progressive, and often devastating illness, since it not only affects the individual but also significant others, including close family members, colleagues, communities, and society at large. Although age is by far the single strongest risk factor for dementia, there are about 4,000 Irish men and women with younger-onset dementia. These are an exceptionally vulnerable group of people who do not fit easily into service systems and structures generally established for older people. In 2010, the economic cost of Alzheimer's disease (AD) was estimated to be €500 billion globally. In Ireland, the figure was €1.69 billion <http://www.irishexaminer.com/viewpoints/analysis/special-report-dementia-in-ireland--condition-could-bankrupt-us-339113.html>

### **U.K. Ministers promise action to help grieving families forced to wait months to bury dementia victims who die in care homes**

U.K. | *The Telegraph* – 22 June 2015 – Ministers have ordered an urgent review into why some relatives of dementia sufferers who die in nursing homes are having to wait weeks before they can bury them because of legal red tape. Families are being caught up in regulations that require inquests into the deaths of Alzheimer's sufferers before funerals can take place – even when there is little mystery over the cause of death. Alistair Burt, the social care minister, has ordered the Law Commission to carry out an urgent review of the law to see if the system is working properly. The review will report back next year, with a new draft law expected to be published by December 2016. Delays are linked to Deprivation of Liberty Safeguards, which make sure people in care homes and hospitals are looked after in a way that does not inappropriately restrict their freedom. <http://www.telegraph.co.uk/news/politics/11687701/Ministers-promise-action-to-help-grieving-families-forced-to-wait-months-to-bury-dementia-victims-who-die-in-care-homes.html>



### [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 pp.13-14.

## End-of-life care in England

### **New information collated by the National End-of-Life Care Intelligence Network**

U.K. (England) | National End-of-Life Care Intelligence Network – 26 June 2015 – The report, 'What we know now 2014,' summarises the key findings of the network and its partners over the last year. Although much of the research has been published previously, this is the first time it has been brought together in one place. New findings show there is a growing understanding within the health sector of what is important to people at the end of life: 1) The proportion of people dying at home or in care homes continues to increase; 2) Patients with an Electronic Palliative Care Co-ordination System record and those receiving palliative care services, such as hospice at home, Gold Standards Framework or Macmillan services are more likely to die in the place of their preference; 3) Two in five people with dementia die in hospital, indicating that the trend towards increasing hospital deaths for people living with dementia has reversed; 4) Factors most importance to people at the end of their life were; having pain and other symptoms managed effectively, being surrounded by loved ones and being treated with dignity; and, 5) More GPs are having conversations with people about their end-of-life care wishes but 25% still say they have never initiated such a conversation.

Link to 'What we know now 2014'

[http://www.endoflifecare-intelligence.org.uk/resources/publications/what we know now 2014](http://www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now_2014)

Of related interest:

- U.K. (England) | *The Telegraph* – 26 June 2015 – '**Doctors forced to continue treating Sunni Muslim who is in a "minimally conscious" state.**' Hospital bosses had asked Mr. Justice Newton to allow doctors to stop treating the man – who is in his 40s and has suffered brain damage. Relatives wanted treatment to continue and said they had seen "purposeful responses" – and the judge praised them for their "persistence." He said it was unfortunate that relations between hospital bosses and the man's family had become "increasingly polarised." <http://www.telegraph.co.uk/news/health/11702431/Doctors-forced-to-continue-treating-Sunni-Muslim-who-is-in-a-minimally-conscious-state.html>

## End-of-life care in Singapore

### **Manpower crunch poses challenges for home hospice**

SINGAPORE | AsiaOne – 25 June 2015 – Home hospice care is the type of end-of-life care that most people hope for. But it will be a struggle to sustain this type of care if the manpower crunch keeps up, palliative care doctors cautioned. "If there are fewer medical and nursing resources

### Paediatric palliative care in the U.K.

#### **Terminally ill children let down by poor end-of-life care**

U.K. (England, Scotland, Wales & Northern Ireland) | Royal College of Nurses – 23 June 2015 – The College has found terminally ill children are being let down by a lack of staff, training and resources in children's community health services. A survey of children's nurses ... found that many children are not being given the choice to die at home as there are not enough trained staff to provide 24/7 care in this setting. Almost all children's nurses (97%) work with infants, children and young people with limited life expectancy each year. However, fewer than half (48%) said they have the time, skills and resources to deliver the right levels of palliative care for children. <http://www.rcn.org.uk/newsevents/news/article/uk/terminally-ill-children-let-down-by-poor-end-of-life-care>

### Specialist Publications

'Hospice care for children with cancer: Where do these children die?' (p.12), in *Journal of Pediatric Hematology/Oncology*.

'Paediatric palliative care' (p.12), in *Paediatrics & Child Health*.

Cont.

available to support 24/7 services, and the burnout and turnover rate are higher in the home care setting, this type of care will be difficult to sustain...” said Dr. Ong Yew Jin, medical director of Singapore Cancer Society. There are 51 accredited specialists in palliative medicine in Singapore, but only an estimated 34 of them work full-time. This works out to less than one full-time palliative consultant per 100,000 people – less than half the ratio recommended by Palliative Care Australia, added Dr. Ong. Adding to the strain is the distribution of resources, he pointed out.” Most (palliative care nurses and doctors) are based in the hospitals or inpatient facilities.” <http://yourhealth.asiaone.com/content/manpower-crunch-poses-challenges-home-hospice-care>

Noted in Media Watch, 14 April 2014, #353 (p.7):

- SINGAPORE | National News Agency of Malaysia – 8 April 2014 – ‘**Survey: 77% of Singaporeans wish to die at home.**’ Singaporeans want to die at home, die affordably, and not leave financial burdens behind.<sup>1</sup> And it would help to have well-trained doctors and nurses guide them about hospice palliative care. They also want a platform to talk about death in the community – national conversations and public education on hospice palliative care to discuss issues on death and dying. <http://www.bernama.com.my/bernama/v7/wn/newsworld.php?id=1028961>

1. ‘Death Attitudes Survey,’ The Lien Foundation, Singapore, April 2014. [http://lienfoundation.org/sites/default/files/Death%20survey%20Presser%20Final%20-%20Combined\\_0.pdf](http://lienfoundation.org/sites/default/files/Death%20survey%20Presser%20Final%20-%20Combined_0.pdf)

Of related interest:

- SINGAPORE | *The Straits Times* – 26 June 2015 – ‘**Give more thought to when to stop medical treatment.**’ The news that they have only a few months to live further augments feelings of resentment. Often, the doctor does not want to reveal this prognosis, for the rescue credo is ingrained in the medical profession... But not telling the patient would also be tantamount to a dereliction of duty. <http://www.straitstimes.com/premium/forum-letters/story/give-more-thought-when-stop-medical-treatment-20150626>

#### End-of-life care in Northern Ireland

#### **Charity calls for Executive to improve palliative care**

U.K. (Northern Ireland) | *The Belfast Telegraph* – 23 June 2015 – All healthcare workers involved in end-of-life care should receive mandatory training in palliative care, a leading charity has said. Marie Curie has called on the Executive [the administrative branch of the Northern Ireland Assembly] to improve the skills of medical professionals and develop a stronger palliative care strategy. In Northern Ireland, 75% of the 15,000 people who die each year need palliative care and over the next 22 years the number of people dying is set to increase by 28%. In a new report ... the charity highlights the limited understanding of what palliative care can do, who it benefits and when to introduce it. The report, ‘Triggers in Palliative Care,’ indicates that professionals do not have enough awareness and often miss the opportunity to consider whether that form of care is needed. It is estimated that there are 3,000 people in the region who could benefit from palliative care every year, but are not

currently receiving it. People with conditions including chronic obstructive pulmonary disease, dementia, end stage liver disease, and motor neurone disease are currently less likely to receive palliative care than those with terminal cancer because their illnesses can be more unpredictable. <http://www.belfasttelegraph.co.uk/news/health/charity-calls-for-executive-to-improve-palliative-care-31322269.html>

#### **‘Triggers in Palliative Care’ report/s**

As well as the main report, Marie Curie has produced brief reports for England, Scotland, Wales and Northern Ireland which set the findings in a nation specific context. These reports include recommendations which take account of the prevailing palliative care and disease environment. <https://www.mariecurie.org.uk/policy/publications/#june2015>

Cont.

Noted in Media Watch, 9 March 2015, #400 (p.5):

- U.K. (Northern Ireland) | *The Belfast Telegraph* – 3 March 2015 – ‘**New poll reveals concerns over cancer treatment in Northern Ireland.**’ 7 out of 10 people in Northern Ireland have concerns over how the pain of a terminally ill loved one would be managed during cancer treatment. A Marie Curie poll shows 45% of Northern Ireland respondents also worry a loved one would not have access to round-the-clock care and support if diagnosed with a terminal illness.<sup>1</sup>  
<http://www.belfasttelegraph.co.uk/news/northern-ireland/new-poll-reveals-concerns-over-cancer-treatment-in-northern-ireland-31035292.html>

1. ‘Marie Curie: U.K. Public Opinion on Taking Care of a Loved One with a Terminal Illness,’ ComRes, 2 March 2015. <http://comres.co.uk/wp-content/uploads/2015/02/Marie-Curie-Terminal-Illness-Survey.pdf>

### Elder care in China

#### **Beijing to set up care home in the city for old people whose only children have died**

CHINA | *The South China Morning Post* – 22 June 2015 – Beijing is to set up a care home in the city for elderly people whose only children have died and who have nobody to provide for them in their old age, according to a newspaper report. A home in the capital with about 450 beds will specifically care for this class of senior citizens, the *Beijing Youth Daily* reported, citing the city’s civil affairs bureau. Old people already living in the home will stay, but in future all new arrivals will be pensioners who have lost their children, the report said. Children are expected to be the main providers for their parents when they grow old in China and the latest initiative highlights the difficulties faced by pensioners if their only child, born under the one-child policy, dies before them. The

capital has an estimated 4,809 people aged over 70 whose only children have died and who are incapable of living in their own homes, the newspaper quoted a spokesperson for the civil affairs bureau as saying. <http://www.scmp.com/news/china/society/article/1824760/beijing-set-care-home-city-old-people-whose-only-children-have>

#### **China’s one-child policy**

Initiated in the late 1970s and early 1980s, the policy was intended to limit families to one child each. The rationale was to reduce the growth rate of the country’s population, presently estimated at 1.4 billion people, almost 20% of the world’s population.

#### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:


- U.K. | *The Economist* – 27 June 2015 – ‘**The right to die.**’ The argument is over the right to die with a doctor’s help at the time and in the manner of your own choosing. As yet only a handful of European countries, Colombia and five American states allow some form of doctor-assisted dying. But draft bills, ballot initiatives and court cases are progressing in 20 more states and several other countries. In Canada the Supreme Court recently struck down a ban on helping patients to die; its ruling will take effect next year. In the coming months bills will go before parliaments in Britain and Germany. The idea fills its critics with dismay. For some, the argument is moral and absolute. Deliberately ending a human life is wrong, because life is sacred and the endurance of suffering confers its own dignity. For others, the legalisation of doctor-assisted dying is the first step on a slippery slope where the vulnerable are threatened and where premature death becomes a cheap alternative to palliative care. These views are deeply held and deserve to be taken seriously. But liberty and autonomy are sources of human dignity, too. Both add to the value of a life. In a secular society, it is odd to buttress the sanctity of life in the abstract by subjecting a lot of particular lives to unbearable pain, misery and suffering. And evidence from places that have allowed assisted dying suggests that there is no slippery slope towards widespread euthanasia. <http://www.economist.com/news/leaders/21656182-doctors-should-be-allowed-help-suffering-and-terminally-ill-die-when-they-choose>

Cont.

Of related interest:

- U.K. | *The Economist* – 27 June 2015 – ‘**Doctor-assisted dying: Final certainty.**’ Campaigns to let doctors help the suffering and terminally ill to die are gathering momentum... <http://www.economist.com/news/leaders/21656182-doctors-should-be-allowed-help-suffering-and-terminally-ill-die-when-they-choose>
- U.K. | *The Economist* – 22 June 2015 – ‘**The president of the British Medical Association argues against legalisation.**’ Iora Finlay has specialised in the care of the dying for more than 27 years. An independent member of the House of Lords and current president of the British Medical Association, she co-chairs Living and Dying Well, a think-tank, and opposes the Assisted Dying bill brought before the House of Lords by Lord Falconer last year. <http://www.economist.com/news/international/21654933-iora-finlay-president-british-medical-association-argues-against-legalisation-assisted>
- NEW ZEALAND | New Zealand Radio (Wellington) – 26 June 2015 – ‘**Eyes of world on euthanasia hearing.**’ Parliament’s Health Select Committee has agreed to hold an inquiry into whether or not the law should be changed to allow voluntary euthanasia. <http://www.radionz.co.nz/news/national/277258/eyes-of-world-on-euthanasia-hearing>
- AUSTRALIA (Victoria) | *The Age* – 21 June 2015 – ‘**Andrews to reform medical treatment laws, but won’t back voluntary euthanasia.**’ Premier Daniel Andrews has revealed he does not support voluntary euthanasia, but concedes momentum is building to change the law. As state parliament begins a sweeping inquiry into end-of-life treatment, Mr. Andrews has spoken out for the first time as Premier about whether terminally ill people should have the right to die with the help of a doctor, warning that “we need to be very careful to get the balance right.” “I don’t support, at this stage ... making the sort of change that some people would like to make, but I do readily acknowledge that there is certainly more momentum, and there is perhaps more public support for this change than there has ever been,” he said. “My objection is not a faith-based objection, it’s not a matter of me imposing my personal values on the Victorian community – I’m loath to do that on any issue. But there are some safeguard issues, and there some balance issues I’m troubled by.” <http://www.theage.com.au/victoria/andrews-to-reform-medical-treatment-laws-but-wont-back-voluntary-euthanasia-20150620-ghsya4.html>

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Barry R. Ashpole, Guelph, Ontario, CANADA  
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**MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care**

Download the complete issue (PDF 450 KB) 

*CHEST | Online – 5 March 2015* | The tendency toward “either/or” thinking (either cure or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. [read more...](#)

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<http://www.ipcrc.net/archive-global-palliative-care-news.php>



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

### **The expert-generalist: A contradiction whose time has come**

*ACADEMIC MEDICINE* | Online – 16 June 2015 – The author suggests that the creation of expert-generalists to help provide the additional cost-effective access to care necessitated by increased insurance coverage under the [U.S.] Affordable Care Act. Expert-generalists, a concept drawn from an extant Canadian model [see sidebar], would be a cohort of primary care physicians who obtain additional training in a sub-specialty area, which would widen their practice portfolio and bring enhanced infrastructure to primary care settings. Expanding the reach of primary care into the realm of more advanced sub-specialty practice could be a way to enhance both access to and quality of care in a cost-effective fashion, in part because the educational framework for additional training already exists. Trainees could opt for an extra year of training after traditional residency or return to training after years in practice. Properly trained, an expert-generalist would benefit both the quality of the patient experience and also the bottom line by expertly

triaging patients to determine who will truly benefit from specialty consultations, decreasing specialists' engagement with cases that do not require their higher-tier care. [http://journals.lww.com/academicmedicine/Abstract/publishahead/The\\_Expert\\_Generalist\\_A\\_Contradiction\\_Whose\\_Time.98771.aspx](http://journals.lww.com/academicmedicine/Abstract/publishahead/The_Expert_Generalist_A_Contradiction_Whose_Time.98771.aspx)

**N.B.** Click on 'Article as PDF' to access the full text of article.

#### **Extracted from *Academic Medicine* article**

To provide specialty care in rural Canada, where the population density is unable to support specialists and there is patchy access to specialty care, the Royal College of Physicians & Surgeons of Canada created a new training pathway called the Areas of Focused Competence (Diploma) Program (AFC Diploma Program). [http://www.royalcollege.ca/portal/page/portal/rc/credentials/discipline\\_recognition/afc\\_program](http://www.royalcollege.ca/portal/page/portal/rc/credentials/discipline_recognition/afc_program).

Noted in Media Watch, 11 March 2013, #296 (p.10):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 6 March 2013 – '**Generalist plus specialist palliative care – creating a more sustainable model.**' The demand for palliative care specialists is growing rapidly, since timely palliative care consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity. As in any medical discipline, some core elements of palliative care, such as aligning treatment with a patient's goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms. <http://www.nejm.org/doi/full/10.1056/NEJMp1215620>

### **Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review**

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 22 June 2015 – This paper reports findings relating to previously developed approaches which capture the financial costs and implications of caring for family members receiving palliative/end-of-life care. Twelve articles met the inclusion criteria for the review. Various approaches to capturing data on the financial costs of care-giving at the end of life were noted; however, no single tool was identified with the sole purpose of exploring these costs. The majority of approaches used structured questionnaires and were administered by personal interview, with most studies using longitudinal designs. Calculation of costs was most often based on recall by patients and family caregivers, in some studies combined with objective measures of resource use. While the studies in this review provide useful data on approaches to capturing costs of care-giving, more work is needed to develop methods which accurately and sensitively capture the financial costs of caring at the end of life. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12253/abstract>

## **A legal and ethical analysis of the effects of triggering conditions on surrogate decision-making in end-of-life care in the U.S.**

*HEALTHCARE ETHICS COMMITTEE FORUM* | Online – 18 June 2015 – The central claim of this paper is that American states' use of so-called "triggering conditions" to regulate surrogate decision-making authority in end-of-life care leaves unresolved a number of important ethical and legal considerations regarding the scope of that authority. The paper frames the issue with a case set in a jurisdiction in which surrogate authority to withdraw life-sustaining treatment is triggered by two specific clinical conditions. The case presents a quandary insofar as the clinical facts do not satisfy the triggering conditions, and yet both the appropriate surrogates and the care team agree that withdrawal of life-sustaining treatment is in the best interest of the patient. The paper surveys applicable law across the 50 states and weighs the arguments for and against the inclusion of such triggering conditions in relevant legal regimes. The paper concludes by assessing the various legal and policy options states have for regulating surrogate decision-making authority in light of the moral considerations (including epistemic difficulties), and notes the possibility for conflict within ethics teams arising from the potential tension between prudence, risk-aversion, and moral obligation. <http://link.springer.com/article/10.1007/s10730-015-9279-3>

## **The changing nature of end-of-life-care**

*INDIAN JOURNAL OF MEDICAL & PAEDIATRIC ONCOLOGY* | Online – 16 June 2015 – Frameworks such as the Liverpool Care Pathway (LCP) have often been helpful in guiding good care at the end of life. However, in the past year, the LCP has been phased out of use in the U.K., following concerns that it was poorly implemented. This review describes the LCP's origins, its strengths and limitations, and the concerns that prompted a review of its use. It describes the recommendations for change made by an independent review, and the alternative strategies now being developed in the U.K. to guide good end-of-life care. Although the LCP is still being widely used worldwide, the lessons learned from the U.K. can be widely applied in other countries. [http://www.ijmpo.org/temp/IndianJMedPaediatrOncol36294-3541423\\_095014.pdf](http://www.ijmpo.org/temp/IndianJMedPaediatrOncol36294-3541423_095014.pdf)

## **Characteristics of prison hospice patients medical history, hospice care, and end-of-life symptom prevalence**

*JOURNAL OF CORRECTIONAL HEALTH CARE*, 2015;21(3):298-308. Increasing numbers of prisoners in the U.S. are dying from age-related and chronic illnesses while incarcerated. This study is among the first to document characteristics of a population of prison hospice patients. Retrospective review of medical records for all patients admitted to the Louisiana State Penitentiary prison hospice program between 1 January 2004, and 31 May 2012 examined demographics, medical history, hospice diagnosis, length of stay, and end-of-life symptom prevalence on admission and during final 72 hours before death. Resulting data were contrasted with community-based end-of-life care study data, demonstrating a unique clinical profile of this group. As prisons consider adopting programs to meet the growing

need for inmate end-of-life care, more research concerning the particular characteristics and unique needs of prison hospice patients will inform these efforts. <http://jcx.sagepub.com/content/21/3/298.abstract>

### **[Prison Hospice Backgrounder](#)**

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

## **Redefining the poet as healer: Valerie Gillies's collaborative role in the Edinburgh Marie Curie Hospice Quiet Room Project**

*LITERATURE & MEDICINE*, 2015;33(1):184-201. This article examines the contribution of Valerie Gillies, Edinburgh Makar (poet of the city) from 2005-2008, to the Edinburgh Marie Curie Hospice Quiet Room, a contemplation space for patients, families, and staff. In collaboration with others, Gillies created a transitional space for the Quiet Room, centered on the display of her sonnet, 'A Place Apart.' This functions to comfort visitors to the Quiet Room by relocating them in their surroundings, offering the solace provided by nature and history. With this project, her first as Edinburgh Makar, Gillies redefines the role of the poet as healer and advocates for newer forms of palliative care that focus on patients' spiritual and emotional, as well as physical, well-being. [http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/literature\\_and\\_medicine/v033/33.1.severin.html](http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/literature_and_medicine/v033/33.1.severin.html)

### **Metaphor in End-of-Life Care Project**

#### **Metaphors for "good" and "bad" deaths: A health professional view**

*METAPHOR AND THE SOCIAL WORLD* | Online – Accessed 23 June 2015 – This paper discusses the metaphors used by sixteen palliative healthcare professionals from around the U.K. The interviews, conducted for the large-scale Metaphor in End-of-Life Care project, are set against the background of contemporary practices and discourses around end-of-life care, dying and quality of death. To date, the use of metaphor in descriptions of different types of deaths has not received much attention. The authors find that the difference between good and bad deaths is partly expressed via different frequencies of contrasting metaphors, such as "peacefulness" and "openness" as opposed to "struggle" and "pushing away" professional help. They show how metaphors are used to: evaluate deaths and the dying; justify those evaluations; present a remarkably consistent view of different types of deaths; and, promote a particular "framing" of a good death... The authors discuss the implications of these consistent evaluations and framings in broader end-of-life care contexts, and reflect on the significance of their findings for the role of metaphor in communication about sensitive experiences. <http://eprints.lancs.ac.uk/74105/>

Noted in Media Watch, 16 March 2015, #401 (p.6):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 March 2015 – '**The online use of violence and journey metaphors by patients with cancer, as compared with health professionals: A mixed methods study.**' A blanket rejection of violence metaphors and an uncritical promotion of journey metaphors would deprive patients of the positive functions of the former and ignore the potential pitfalls of the latter. Instead, greater awareness of the function ... of patients' metaphor use can lead to more effective communication about the experience of cancer. <http://spcare.bmj.com/content/early/2015/03/05/bmjspcare-2014-000785.abstract>
- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 4 March 2015 – '**Inside patients' homes: A metaphorical analysis of home hospice nurses' experiences working with dying patients.**' Interviews revealed four main metaphors emphasizing how home hospice nurses conceive and communicate their experiences working with patients: a calling, hallowed ground, going with the flow, and life lessons. These metaphors highlight how home hospice nurses transcend organizational role descriptions, feel empowered to make a difference, appreciate the inevitable unpredictability of their work, and draw upon patient interactions for self-reflection. <http://ome.sagepub.com/content/early/2015/03/04/0030222815575282.abstract>

#### **Media Watch posted on Palliative Care Network-e Website**

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

## Paediatric palliative care

*PAEDIATRICS & CHILD HEALTH* | Online – 2 June 2015 – Children with palliative care needs are increasing in prevalence and complexity of need. 49,000 children (under 19 years) were estimated to be living in the U.K. in 2012 with a life limiting/life threatening condition that might require palliative care. Palliative care requires a total and active approach, with transparent, communicated, agreed provision of appropriate and proportionate care. Planning improves care, supported by documentation of plans. Advance planning enables management of both reversible and chronic aspects of the condition, as well as utilising parallel planning when end of life approaches. Challenges in palliative care include the commissioning of sustainable services across organisations to deliver, often over years, but sometimes briefly and rapidly, 24/7 access to skilled palliative care, including hands on care at the end of life. Care is integrally intertwined with other clinical, social, education and voluntary services to ensure families receive the spectrum of care required throughout their journey. [http://www.paediatricsandchildhealthjournal.co.uk/article/S1751-7222\(15\)00109-2/abstract](http://www.paediatricsandchildhealthjournal.co.uk/article/S1751-7222(15)00109-2/abstract)

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 June 2015 – **‘Pediatric palliative care pilot curriculum: Impact of “pain cards” on resident education.’** Prior research has shown that less than 40% of pediatric program directors believe their graduating residents competent in palliative care. While many curricula have been developed to address this need, few have demonstrated improved comfort and/or knowledge with palliative care principles. The purpose of this study was to test a pocket card educational intervention regarding resident knowledge and comfort with palliative care principles. Knowledge of palliative care principles improved in part, with only a few survey questions reaching statistical significance. 100% of respondents recommended the cards be provided to their colleagues. <http://ajh.sagepub.com/content/early/2015/06/15/1049909115590965.abstract>
- *JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY*, 2015;37(5):373-377. **‘Hospice care for children with cancer: Where do these children die?’** Many children who die of cancer enroll in hospice programs. How frequently such children remain in hospice to die at home, or disenroll from hospice and die in the hospital, has not been described. A child’s location of death has important implications for quality of life... This ... sub-analysis [is] of a retrospective study of 202 consecutive oncology patients who died at a single center... Further studies are warranted to explore the hospice experience in children, and to address modifiable factors that may impact a family’s choice to withdraw from hospice care. [http://journals.lww.com/jpho-online/Abstract/2015/07000/Hospice\\_Care\\_for\\_Children\\_With\\_Cancer\\_Where\\_Do.7.aspx](http://journals.lww.com/jpho-online/Abstract/2015/07000/Hospice_Care_for_Children_With_Cancer_Where_Do.7.aspx)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *SWISS MEDICAL WEEKLY* | Online – 22 June 2015 – **‘Time-trends in assisted and unassisted suicides completed with different methods: Swiss National Cohort.’** The aim of our study was to compare time trends in rates of assisted and unassisted suicide from 1991–2008. A total of 7,940,297 individuals and 24,842 suicides were included. In women, rates changed little in the younger age groups but increased in 65 to 94-year-olds, due to an increase in suicide by poisoning. An increase in suicides by poisoning was also observed in older men. Most suicides by poisoning were assisted. In men, suicide rates declined in all age groups, driven by declines in suicide with firearms. Research is needed to gain a better understanding of the reasons for the tripling of assisted suicide rates in older women, and the doubling of rates in older men, of attitudes and vulnerabilities of those choosing assisted suicide, and of access to palliative care. Rates of assisted suicide should be monitored; including data on patient characteristics and underlying co-morbidities. <http://www.smw.ch/content/smw-2015-14153/>

## Media Watch: Editorial Practice

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

### Distribution

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

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/06/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](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

Cont.

## **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>

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