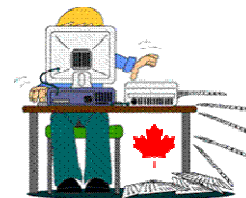


## Media Watch...

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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Compilation of Media Watch 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Parkinson disease patients' perspectives on palliative care needs' (p.12), in *Neurology*.

## Canada

### **The Globe & Mail wins best series award for home care investigation**

ONTARIO | *The Globe & Mail* – 5 April 2016 – A *Globe & Mail* investigation into Ontario's home care system has won the award for best series in a daily newspaper from the Registered Nurses' Association of Ontario. Reporters Kelly Grant and Elizabeth Church conducted a three-month investigation that found a system plagued by underfunding, inconsistent standards of care, and a lack of transparency that make it virtually impossible for patients and their family members to determine what government-funded health care they are entitled to in their houses or in community settings such as assisted-living centres.<sup>1,2,3</sup> Since the series was published, the pro-

vincial government has announced a policy to eliminate the bureaucratic middlemen in home care delivery – the Community Care Access Centres – and promised to establish new standards of care to ensure consistency in services across the province. <http://goo.gl/HNxjly>

### Specialist Publications

'Palliative and end-of-life care communication as emerging priorities in postgraduate medical education' (p.8), in *Canadian Medical Education Journal*.

1. 'Home care for Ontario seniors affected by move to non-profit agencies,' 13 July 2015. [Noted in Media Watch, 20 July 2015, #419 (p.1)] <http://goo.gl/JWYDLO>
2. 'Ontario shifting home care to private clinics as province seeks savings,' 13 July 2015. [Noted in Media Watch, 20 July 2015, #419 (p.1)] <http://goo.gl/EeDJf8>
3. 'No place like home? Investigating Ontario's home-care shortcomings,' 10 July 2015. [Noted in Media Watch, 13 July 2015, #418 (p.1)] <http://goo.gl/QFmBhW>

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.16.

Noted in Media Watch, 21 December 2015, #441 (p.1):

- ONTARIO | *The Globe & Mail* – 17 December 2015 – ‘**Ontario moves to scrap troubled health agencies, reorganize primary care.**’ Ontario is moving to scrap the troubled agencies responsible for home care and is proposing changes to the way primary care is organized to make it easier for people to find family doctors and get an appointment when they are sick. The move, made public ... in a discussion paper,<sup>1</sup> comes as the Liberal government faces mounting pressure to make changes to home care following a string of scathing reports. <http://goo.gl/4xWhXc>

1. ‘Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario: Discussion Paper,’ Ministry of Health & Long Term Care, Ontario Provincial Government, 17 December 2015, <http://goo.gl/XVoGO3>

### Caregivers are needed more than ever, but burning out

ONTARIO | *The Toronto Star* – 5 April 2016 – Distress among unpaid caregivers who bear the heavy burden of looking after ill, elderly or disabled relatives has doubled in four years, according to Health Quality Ontario, the provincial adviser on quality of health care.<sup>1</sup> A report ... suggests these factors, along with Ontario’s aging population, may be creating a perfect storm for the provincial health system: a growing need for family caregivers at a time when distress is making them increasingly unable to do the job. The proportion of family caregivers who had to stop looking after their loved ones due to stress more than doubled over four years ending in 2014, rising from roughly 7% to 14%, according to the report. The findings come from surveys conducted by community home-care workers who support patients and their families. This increase in family caregiver burnout occurred as

the population of patients needing at-home care in Ontario became older, more physically impaired and increasingly burdened by dementia. The research raises a troubling question: What happens to patients and the health system if unpaid caregivers are unable to provide care? <http://goo.gl/XXwdwe>

#### Extract from Health Quality Ontario report

An overall decline in the condition of long-stay home care patients is also indicated by statistics gathered by the Ontario Association of Community Care Access Centres. According to the association, the proportion of long-stay home care patients with multiple chronic and complex health issues increased to 68.5% in 2014/15 from 37.4% in 2009/10.

1. ‘The Reality of Caring: Distress among the caregivers of home care patients,’ Health Quality Ontario, April 2016. <http://goo.gl/xkSYRP>

**N.B.** No mention is made in the report of home care for people living with a terminal illness.

Noted in Media Watch, 6 October 2014, #378 (p.3):

- *THE GLOBE & MAIL* | Online – 2 October 2014 – ‘**Why Canada’s reliance on unpaid care is not sustainable.**’ According to Statistics Canada, 2.2 million individuals representing 8% of Canadians 15 years and older, received homecare in 2012.<sup>1</sup> Most [1.8 million] consider that over a one-year period they received all the services they required to help with their daily activities. Only a minority, approximately 15%, said they had unmet homecare needs. <http://goo.gl/qWHeDZ>

1. ‘Canadians with unmet home care needs,’ Statistics Canada, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.3)] <http://goo.gl/oBNrck>

**N.B.** See also ‘Family caregiving: What are the consequences?’ Statistics Canada, December 2013, <http://goo.gl/Qf796g>

#### [Media Watch: Back Issues](#)

Back issues of Media Watch are available on the International Palliative Care Resource Center website: <http://goo.gl/frPgZ5>

## Assisted (or facilitated) death

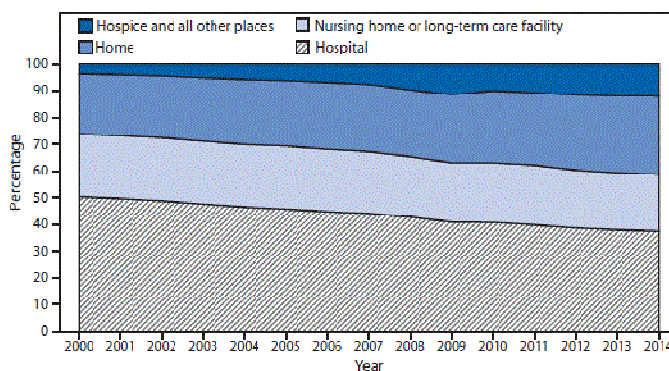
Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 8 April 2016 – ‘**Assisted dying law coming soon with strict limits, sources say.**’ The Trudeau government won’t be taking a permissive approach to medically assisted dying in long-awaited new legislation to be unveiled as early as next week, The Canadian Press has learned. Sources, who aren’t authorized to speak publicly about the imminent bill, say it won’t adopt some of the most controversial recommendations from a special parliamentary committee. That committee urged the government in February to place few obstacles in front of Canadians who want medical help to end their suffering. The legislation ... is expected to stipulate that only competent adults should be eligible to receive a doctor’s help to end their lives. It will not allow people diagnosed with competence-impairing conditions like dementia to make advance requests for medical help to die, which the committee advocated. Nor will it include mature minors, to whom the committee recommended extending the right to choose assisted death within three years. In rejecting those recommendations, the government appears to be sticking to the strict letter of a Supreme Court ruling... <http://goo.gl/0Ya9LJ>

## U.S.A.

### Percentage distribution of deaths by place of death – U.S., 2000-2014

CENTERS FOR DISEASE CONTROL & PREVENTION | *Morbidity & Mortality Weekly Report* – 8 April 2016 – The percentage of deaths that occurred in a hospital decreased 25.7%, from approximately half (50.2%) in 2000 to 37.3% in 2014. During 2000-2005, the percentage of deaths that occurred in a nursing home or long-term care facility remained relatively stable, and then decreased 10.1% during 2005-2014. The percentage of deaths that occurred at a decedent’s home increased 29.5% during 2000-2014. The percentage of deaths that occurred in hospice and all other places increased 242.9%, from 3.5% in 2000 to 12.0% in 2014. <http://goo.gl/0peclK>



### Six months to live? Most U.S. hospice spending goes for longer stays

FLORIDA | *The Palm Beach Post* – 8 March 2016 – By law, Medicare hospice spending is supposed to care for people diagnosed with six months or less to live, but an advisory group’s latest report to Congress shows well over half of the money goes for people who live longer than that.<sup>1</sup> Whether that’s perfectly appropriate or a wholesale “ripoff” of taxpayers depends on who is talking. Stays longer than 180 days accounted for nearly \$9 billion out of \$15.1 billion in total Medicare hospice spending in 2014, according to the Medicare Payment Advisory Commission. In addition, many people continue to leave hos-

pice without dying. More than 17% of U.S. enrollees were discharged alive from hospice care in 2014 ... and the rate has been slightly higher in past years. <http://goo.gl/NWTlyh>

#### Specialist Publications

‘A qualitative inquiry on palliative and end-of-life care policy reform’ (p.11), in *Journal of Palliative Medicine*.

1. ‘Report to Congress: Medicare Payment Policy,’ Medicare Payment Advisory Commission, March 2016. <http://goo.gl/Kq26KQ>

Cont.

Noted in Media Watch, 4 April 2016, #456 (p.3):

- **THE NEW YORK TIMES** | Online – 2 April 2016 – ‘**Medicare is often overbilled by hospices, and pays twice for some drugs.**’ Hospices often bill Medicare for a higher level of care than patients need, and Medicare often pays twice for the prescription drugs provided to people who are terminally ill, federal investigators say in a new report.<sup>1</sup> <http://goo.gl/3dd3Qh>

1. ‘Hospices Inappropriately Billed Medicare Over \$250 Million for General Inpatient Care,’ Office of Inspector General, March 2016. <http://goo.gl/vlOp6>

### **Editorial: Iowa's lax oversight of hospice care is a scandal**

IOWA | *The Des Moines Register* – 8 April 2016 – Five years ago, *The Des Moines Register* first reported that the state of Iowa was inspecting hospice-care facilities roughly once every 20 years. As one patient advocate said in 2011, Iowa’s oversight of hospice didn’t “even pass the laugh test.” Even the National Hospice & Palliative Care Organization ... acknowledged that 20 years between inspections was “completely unacceptable.” To make matters worse, hospice licensing was voluntary in Iowa. That’s right: You needed no license to provide end-of-life care to Iowa patients facing a terminal illness. What’s more, hospice facilities were immune from state fines, no matter how many people were injured or killed due to regulatory violations. So what did our governor and our state lawmakers do to address these problems? In a word: Nothing. <http://goo.gl/WYNY8a>

Noted in Media Watch, 28 October 2013, #329 (p.2):

- IOWA | *The Des Moines Register* – 21 October 2013 – ‘**Branstad reluctant to hire more hospice inspectors.**’ Governor Terry Branstad said he was unaware that Iowa inspects hospice providers about once every 20 years, but said he’s reluctant to hire new inspectors or take any action that would increase costs for those companies. <http://goo.gl/wMOVYM>

Noted in Media Watch, 23 April 2011, #198 (p.2):

- IOWA | *The Des Moines Register* – 24 April 2011 – ‘**Iowa hospices inspected only once every 20 years.**’ Hospice providers that care for hundreds of Iowans in the final stages of a terminal illness are now being inspected by the state on a schedule of one visit every 20 years. Patient advocates say that sort of inspection cycle “doesn’t even pass the laugh test.” <http://goo.gl/qXqMdm>

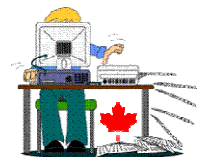
### **Loss and separation**

#### **On widower watch**

*THE NEW YORK TIMES* | Online – 7 April 2016 – Widowers are endangered beings, challenged by grief and its grim companions: loneliness, disorientation and a statistically high mortality rate. A 2012 study by a team at Rochester Institute of Technology showed that widowers are 30% more likely to die after the recent death of a spouse, compared to normal risks of mortality. The first six months after widowhood are the most challenging, but the effects of grief can last up to a decade. <http://goo.gl/5Kif1n>

### **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://goo.gl/5CHoAG>



## New push to keep seniors in home, community-based programs

ASSOCIATED PRESS | Online – 4 April 2016 – The federal government is pushing states to keep more low-income seniors out of nursing homes and, instead, enroll them in home and community-based programs. The shift comes as demand for long-term care is rising. By 2050, the number of people older than 85 is expected to triple to more than 18 million. These seniors tend to have the highest disability rate and the greatest need for long-term care. The tug-of-war between rising demand and controlling costs has advocates for seniors worrying about quality of care. Medicaid is one of the largest expenses for states, and it's a program they look to for savings when budgets are tight. Medicaid spending

on long-term care was \$146 billion in fiscal year 2013, including nearly \$89 billion just for seniors. <http://goo.gl/4mvtWq>

### Specialist Publications

'Interprofessional team building in the palliative home care setting: Use of a conceptual framework to inform a pilot evaluation' (p.10), in *Journal of Interprofessional Care*.

'Report suggests urgent need for policies to support family caregivers of aging and disabled Americans' (p.11), in *Medical Express*.

## International

### Court orders chemo for dying boy, 6, after parents refuse treatment

AUSTRALIA (West Australia) | *The West Australian* (Perth) – 7 April – 2016 – A Princess Margaret Hospital doctor took legal action after Angela Kiszko and Adrian Strachan refused chemotherapy and radiotherapy for their son, Oshin, who was diagnosed with medulloblastoma in December. The Swan View parents argued they could not bear to see their son suffer the side effects of cancer treatment like a “lab rat.” Instead they wanted palliative care to give the family quality time together. But West Australia’s Family Court ruled treatment should start the Sunday after Oshin’s planned birthday party. The couple have also been banned from taking their son out of the country. The court was told Oshin, who had surgery last year, would die within a few months without treatment. However, he had a 30% prospect of surviving for five years if chemotherapy started immediately and a 50% chance with both chemotherapy and radiotherapy. In his judgment Family Court chief justice Stephen Thackray said the evidence suggested Oshin’s parents had “tried to approach this matter on the basis of what is in the best interests of their child.” He said he did not discount the side effects of treatment. But the prospect of a long-term cure “is the matter that most heavily must weigh in the decision.” “One other matter that I think ought to be given weight is that the uncontested medical evidence is that the great majority of other parents faced with a similar decision would opt for the intervention that the hospital proposes,” he said. <https://goo.gl/Q8kAf3>

### End-of-life care in England

### New palliative care funding guidelines to be in place from April 2017

U.K. (England) | *National Health Executive* – 7 April 2016 – New palliative care (PC) guidelines to help decide how funding is allocated will be in place from April next year, National Health Service England and Public Health England announced. The set of developmental currencies, which are used to categorise adults and children receiving PC according to need and help decide how funding is allocated, will be announced later in the year. <http://goo.gl/p1ckwq>

### Media Watch: 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://goo.gl/8JyLmE>

## Living day by day: Britain's defiant elderly are NOT scared of death

U.K. (England) | *The Daily Express* – 5 April 2016 – The number of Britons in their 10th decade at the time of their death has tripled in the last 30 years as improvements in environment and lifestyles, as well as significant medical advances, mean more people are living longer [according to a University of Cambridge study].<sup>1</sup> Dr. Jane Fleming, who led the research, said: “Despite the dramatic rise in the number of people living into very old age, there is far too little discussion about what the ‘oldest old’ feel about the end of their lives. “We know very little, too, about the difficult decisions concerning their end-of-life care.” Researchers interviewed 33 people aged over 95 about their attitude towards death, dying and end-of-life care for the study... Dr. Fleming said the responses were at times poignant and occasionally humorous, but provide a “fascinating perspective” on the views of an “often overlooked” minority. She said the age of the older people was so great that most of their contemporaries had died, so death was a regular feature of life and many spoke of living on borrowed time. Many of the older people referred to “taking each day as it comes,” expressing thankfulness

for where they were in life and content, at this stage, to take life one day at a time, not worrying too much about tomorrow. <http://goo.gl/tAzsOO>

### Quote from University of Cambridge study

This study's rare data show 95-year-olds are willing to discuss dying and end-of-life care, but seldom do. Formal documentation of wishes is extremely rare and may not be welcome. Although being “ready to die” and preferring a palliative approach predominated, these preferences cannot be assumed.

### Specialist Publications

‘Caring for a dying spouse at the end of life: “It's one of the things you volunteer for when you get married”: A qualitative study of the oldest carers' experiences’ (p.7), in *Age & Ageing*.

‘Challenges and strategies for hospice caregivers: A qualitative analysis’ (p.7), in *The Gerontologist*.

1. ‘Death and the oldest old: Attitudes and preferences for end-of-life care: Qualitative research within a population-based cohort study,’ PLOS One, 5 April 2016. <http://goo.gl/UFaCvc>

Noted in Media Watch, 28 March 2016, #455 (p.6):

- *AGE & AGING* | Online – 24 March 2016 – ‘**A good death for the oldest old.**’ People aged over 85 are the fastest growing segment of the population, both in the U.K. and across all high-income countries. This is also the group of people who are most likely to die. So it is pertinent to consider how we can ensure that for the oldest old, their deaths, as well as their lives, are as good as we can help them to be. <http://goo.gl/jmj0yG>

### End-of-life care in Wales

#### **Abergele woman's life “unnecessarily prolonged” by pacemaker...**

U.K. (Wales) | *The Daily Post* (Llandudno Junction, Conwy) – 3 April 2016 –A widower says his dying wife's life was prolonged unnecessarily because a pacemaker-type device fitted in her chest kept her alive after all hope of recovery was lost. Ron Hastings' wife Patricia suffered from vascular dementia and organ failure, and died in a nursing home in Rhos-on-Sea. But Mr. Hastings, 87, said because staff at the home did not have the equipment to switch off her implantable cardioverter-defibrillator, her life was [unnecessarily] prolonged. Medical experts say while the devices have helped keep thousands of people alive, there are times when prolonging life is not appropriate. <http://goo.gl/hdy8no>

**N.B.** Selected articles on implantable cardioverter-defibrillators at end of life are noted in Media Watch of 1 February 2016, #447 (p.11).

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

### **Caring for a dying spouse at the end of life: “It’s one of the things you volunteer for when you get married”: A qualitative study of the oldest carers’ experiences**

*AGE & AGEING* | Online – 7 April 2016 – The oldest carers [i.e., study participants] demonstrated high levels of resilience and the ability to adapt to their caring role. Caring until death was accepted as an integral part of the commitment made to their partner as part of the “wedding contract.” Carers felt they benefited from the support provided by family, friends and care services; however, their own care needs were not always recognised by health and social care services. The findings of this study underscore the complexity of the oldest carers’ experiences and challenges in times of illness and end of life. Healthcare professionals should be alerted to the myriad ways caregiving is enacted in serious illness and seek opportunities for developing supportive interventions specifically for older carers. <http://goo.gl/MLIXKc>

#### **Related**

- *THE GERONTOLOGIST* | Online – 5 April 2016 – ‘**Challenges and strategies for hospice caregivers: A qualitative analysis.**’ Caregivers [i.e., study participants] shared narratives discussing challenges that included their frustrations with patient care issues, emotional challenges, frustrations with various health care systems, financial problems, and personal health concerns. They also discussed coping strategies involving patient care, self-care, and emotional support. The coping techniques were both problem and emotion based. <http://goo.gl/hldQN0>

### **Best practices for scholarly authors in the age of predatory journals**

*ANNALS OF THE ROYAL COLLEGE OF SURGEONS OF ENGLAND*, 2016;98(2):77-79. The focus of any academic or research author is to share his or her findings, and to gain respect and reward for publishing. The ideal journal is one that not only publishes an article quickly but also helps the author to improve the article before publication through peer review, selects only the best research so that the author’s article lies alongside other high quality articles, and provides maximum (and long-term) visibility and access to the article. Unfortunately, in the real world, authors need to make tradeoffs between high quality journals, those that work quickly, those that are willing to accept the article and those that provide the best access. Into this mix has come the potential of open access as a means of increasing visibility: journals publish the article without a subscription barrier so anyone, anywhere, can read the article. However, the growth of open access (pushed by institutions, grant bodies and governments as a means of improving human health and knowledge) has come with some unforeseen consequences. <http://goo.gl/8EanhK>

#### Literature search

#### **Update in hospice and palliative care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 April 2016 – The goal of this update in hospice and palliative care (PC) is to summarize and critique research published between 1 January and 31 December 2014 that has a high potential for impact on clinical practice. The authors searched 22 leading journals, the Cochrane Database of Systematic Reviews, and Fast Article Critical Summaries for Clinicians in Palliative Care. They also performed a PubMed keyword search using the terms “hospice” and “palliative care.” The authors ranked candidate articles based on study quality, appeal to a breadth of PC clinicians, and potential for impact on clinical practice. They have summarized the findings of eight articles with the highest ratings and make recommendations for clinical practice based on the strength of the resulting evidence. <http://goo.gl/ngCfG8>

**N.B.** Selected articles on predatory journals are noted in Media Watch of 29 February 2016, #451 (p.9), 23 November 2015, #437 (p.11), and 8 February 2016, #448 (p.9).

## Ethical challenges facing advance care planning

*ASIAN BIOETHICS REVIEW*, 2016;8(1):53-65. Advance Care Planning (ACP) was introduced as a means of empowering individuals to make informed decisions regarding their health and end-of-life care. It is a way for individuals to contemplate their own personal values and to exercise autonomy. However, there is reason to believe that ACP may not be widely taken up and, when adopted, may not be applied as intended. This essay focuses on two problematic ethical aspects of ACP: 1) Strict adherence to procedural formalism; and, 2) An over-emphasis on individualistic autonomy, which can lead to hindrances in its implementation. These may explain both the low uptake as well as its ineffectiveness. ACP should not be a compliance exercise and implementers will need to think hard about when and how to implement ACP, given cultural and perceptual sensitivities. By discussing the concept of “narrativism” and “relational autonomy,” the authors provide an avenue for solving the dilemmas faced and present a scenario that is closer to the ideal of what the ACP framework hopes to achieve. This would include patient preference as well as best interest and

family values. An increased uptake of ACP will be a useful health service delivery indicator, but this would also entail developing a more morally mindful and just society in a broader sense. <http://goo.gl/3MKvzm>

### Shared decision making: The need for patient-clinician conversation, not just information

*HEALTH AFFAIRS*, 2016;35(4):627-629. The growth of shared decision making has been driven largely by the understanding that patients need information and choices regarding their health care. But while these are important elements for patients who make decisions in partnership with their clinicians, the authors' experience suggests that they are not enough to address the larger issue: the need for the patient and clinician to jointly create a course of action that is best for the individual patient and his or her family. The larger need in evidence-informed shared decision making is for a patient-clinician interaction that offers conversation, not just information, and care, not just choice. <http://goo.gl/IRDNZg>

### Related

- *ASIAN BIOETHICS REVIEW*, 2016;8(1):4-19. **'Medical decision-making for minors: Using care ethics to empower adolescents and amend the current power imbalances.'** It is unjust to generalise and say that children are inexperienced and thus lack capacity to make decisions. It is also unjust if cultural notions disregard the child's voice. For children who have been ill their whole lives, it can be certain that they have a greater capacity to understand their situations than they are given credit for – it may even be reasonable for them to “prefer death” and voice that thought... I am writing from an “end-of-life” perspective where minors are severely ill, probably have been for a long time, and should have the opportunity to refuse treatment and have that decision respected. <http://goo.gl/AfYAGi>

## Palliative and end-of-life care communication as emerging priorities in postgraduate medical education

*CANADIAN MEDICAL EDUCATION JOURNAL* | Online – 31 March 2016 – Reliance on surveys and qualitative studies of trainees to guide postgraduate education about palliative and end-of-life (EOL) communication may lead to gaps in the curriculum. The authors aimed to develop a deeper understanding of internal medicine trainees' educational needs for a palliative and EOL communication curriculum and how these needs could be met. Surveyed trainees were least confident and least satisfied with teaching in counseling about the emotional impact of emergencies and discussing organ donation. Direct observation with feedback, small group discussion, and viewing videos of personal consultations were perceived as effective, yet infrequently identified as instructional methods. Focus groups and interviews identified goals of care conversations as the highest educational priority, with education adapted to learner needs and accompanied by feedback and concurrent clinical and organizational support. The authors work expands on previous research describing needs for postgraduate education in palliative and EOL communication to include the importance of support, culture change, and faculty development, and provides insight into why such needs exist. <http://goo.gl/Rc0Yaa>

Cont.



## Related

- *RHODE ISLAND MEDICAL JOURNAL*, 2016;99(4):20-25. '**Palliative and end-of-life care education among Alpert Medical School Students.**' The authors discovered less than half of Alpert Medical School (AMS) students have worked with dying patients, and almost a quarter of graduating medical students did not feel prepared to palliate common symptoms including pain, nausea, shortness of breath, and anxiety. They also found that exposure to dying individuals was significantly associated with many symptom management skills and more favorable attitudes toward palliative medicine. The authors, therefore, recommend that palliative care skills, which are relevant to all future physicians regardless of specialty, be incorporated throughout the AMS curriculum, and that more students be exposed to patients at end of life. <http://goo.gl/NvLuD2>

**N.B.** Link is to the journal contents page; scroll down to article to access full text.

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 1 April 2016 – '**Strategies for enhancing “person knowledge” in an older people care setting.**' Appreciative inquiry, an approach to research that focuses on discovering what works well and implementing strategies to help these aspects happen most of the time, was used [in this study]. Findings uncovered that knowledge of the person and ways of promoting this were key dimensions of compassionate caring. The attributes of “caring conversations” emerged through the analysis process, which we suggest are crucial to developing person knowledge. The political and public focus on compassionate care makes it opportune to raise discussion around this form of knowledge in academic and practice debates. <http://goo.gl/7DFTN2>

## Overcoming barriers to grief: Supporting bereaved people with profound intellectual and multiple disabilities

*INTERNATIONAL JOURNAL OF DEVELOPMENTAL DISABILITIES* (British Society of Developmental Disabilities) | Online – 28 March 2016 – Engaging people with profound intellectual and multiple disabilities (PIMD) in relation to issues of bereavement and loss is often seen as a complex therapeutic challenge. The author examines the barriers preventing them from engaging with the grieving process in supported ways. Although there are some similarities between people with PIMD and their more able peers, there are additional factors which may place people with PIMD at greater risk of complicated grieving. In addition, this paper identifies the socio-contextual factors that can mediate experiences of and reactions to loss in this group. <http://goo.gl/POczcq>

Noted in Media Watch, 7 December 2015, #439 (p.14):

- *INTELLECTUAL & DEVELOPMENTAL DISABILITIES* (American Association on Intellectual & Developmental Disabilities), 2015;53(6):394-405. '**A Delphi study on staff bereavement training in the intellectual and developmental disabilities field.**' Results showed that training should help staff identify and support service users experiencing grief. Importantly, staff also needs help in managing their own grief. Organizational policies and resources should be instituted to support the grief processes of both service users and staff. <http://goo.gl/YZx0ar>

## Mind the gap: Palliative care knowledge among cardiovascular clinicians

*JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2016;67(13\_S):1553-1553. In this survey, College members who care for patients with transcatheter aortic valve replacements and ventricular assist devices acquired palliative care (PC) knowledge through practical experience and/or independent learning, not training program didactics. Nonetheless, over half expressed interest in dedicated PC education. These results highlight an unmet need in cardiovascular training and provide a call for more structured PC-focused educational opportunities. <http://goo.gl/zQZVmJ>

**N.B.** Selected articles on palliative care and cardiology are noted in Media Watch of 11 January 2016, #444 (pp.9=10) and 19 January 2015, #393 (pp.11-12).

## **Interprofessional team building in the palliative home care setting: Use of a conceptual framework to inform a pilot evaluation**

*JOURNAL OF INTERPROFESSIONAL CARE*, 2016;30(2):262-264. The purpose of this evaluation was to explore the views of an interprofessional group of home care providers (occupational therapists, nurses, personal support work supervisors, community care coordinators and a team coordinator) regarding a pilot project encouraging teamwork in interprofessional palliative home care services. Findings suggest that encouraging practitioners to share past experiences and foster common goals for palliative care (PC) are important elements of team building in interprofessional PC. Also, establishing a team leader who emphasises sharing power among team members and addressing the need for mutual emotional support may help to maximise interprofessional teamwork in palliative home care. <http://goo.gl/BLYG1Q>

### **Related**

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 16 April 2016 – ‘**Systematic quality monitoring for specialized palliative care services: Development of a minimal set of Quality Indicators for Palliative Care Study (QPAC).**’ A minimal set of 31 indicators reflecting all the important issues in palliative care (PC) was created for PC services to assess the quality of their care in a quick and efficient manner. Additional topic-specific optional modules are available for more thorough assessment of specific aspects of care. <http://goo.gl/6qe1tz>

## **U.S. physicians’ opinions about accommodating religiously based requests for continued life-sustaining treatment**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 March 2016 – In 2010, the authors surveyed 1,156 practicing U.S. physicians from specialties likely to care for adult patients with advanced illness. The questionnaire included two randomized experimental vignettes: one where a family asked that life-sustaining treatment (LST) be continued for a patient that met brain death criteria and a second where the son of an elderly patient with cancer insists on continuing LST. In both, the authors experimentally varied the reasons that the family member gave to justify the request, to see if physicians are more likely to accommodate a request based on a religious requirement or hope for a miracle, compared to no mention of either. For physicians’ religious characteristics, they assessed their religious affiliation and level of religiosity. For the patient meeting brain death criteria, physicians were more likely to accommodate the request to continue LST when the family mentioned their Orthodox Jewish community... For the patient with metastatic cancer, physicians were more likely to accommodate the request when the son said his religious faith does not permit discontinuing LST, but not when he said he expected divine healing. <http://goo.gl/0doJ3i>

### **Selected articles on religious considerations in decision making in end-of-life care**

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING* (Hospice & Palliative Nurses Association), 2015;17(4):275-282. ‘**On the ethical issues that arise when religion and treatment collide in end-of-life decision making.**’ The article begins with a case study drawn from clinical experience that focuses on the need for a surrogate decision maker for a deeply religious patient in the intensive care unit with life-limiting cancer. The patient’s adult children, also religious, against the health care team’s clinical advice, want all life-extending measures taken as they await a divine miracle. [Noted in Media Watch, 3 August 2015, #421 (p.11)] <http://goo.gl/PCs0jx>
- *JOURNAL OF RELIGION & HEALTH* | Online – 10 January 2015 – ‘**Religious, ethical and legal considerations in end-of-life issues: Fundamental requisites for medical decision making.**’ With the influential development of patient autonomy and the right to self-determination, a patient’s religious affiliation constitutes a key component in medical decision making. This is particularly pertinent in issues involving end-of-life decisions such as withdrawing and withholding treatment, medical futility, nutritional feeding and do-not-resuscitate orders. [Noted in Media Watch, 19 January 2015, #393 (p.15)] <http://goo.gl/1kL0pF>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 June 2011 – ‘**Approaching patients and family members who hope for a miracle.**’ Belief in miracles is found to be common in the United States and is an important determinant of how decisions are made for those with advanced illness. There is a growing amount of evidence that suggests end-of-life outcomes improve with the provision of spiritual support from medical teams, as well as with a proactive approach to medical decision making that values statements given by patients and family members. [Noted in Media Watch, 13 June 2011, #205 (p.8)] <http://goo.gl/D4mAAa>

### Elder & end-of-life care in the U.S.

#### **A qualitative inquiry on palliative and end-of-life care policy reform**

*JOURNAL OF PALLIATIVE MEDICINE*, 2016; 19(4):400-407. There is increasing recognition of the role of palliative care (PC) in health care delivery, but priorities for state and federal policy to support PC are unclear and have sometimes engendered controversy. The authors canvassed experts to shed light on general recommendations for improving PC. Respondents identified four central challenges to advancing PC policies: 1) Knowledge about PC in the health care setting; 2) Cultural beliefs about PC; 3) Payment/reimbursement for PC services; and, 4) Public understanding of PC. Of the wide range of solutions proposed by respondents, the authors present the eight most frequently discussed solutions to these challenges targeted towards policymakers, health care professionals, research, and the general public. A qualitative approach of querying experts identified multiple significant challenges to improving and expanding PC, most of which are acknowledged in existing consensus statements. Proposed solutions were more numerous and diffuse than descriptions of the problems, signaling the need for fur-

ther consensus building around actionable policy, and better understanding of how to advance a PC policy agenda. <http://goo.gl/pbFmBC>

#### **Understanding an informed public’s views on the role of evidence in making health care decisions**

*HEALTH AFFAIRS*, 2016;35(4):566-574. Policy makers and practitioners increasingly believe that medical evidence plays a critical role in improving care and health outcomes, and lowering costs. However, public understanding of the role of evidence-based care may be different. The Community Forum Deliberative Methods Demonstration project, sponsored by the Agency for Healthcare Research & Quality, obtained informed public views on the role of evidence in health care decisions through seventy-six deliberative groups involving 907 people overall... Although participants perceived evidence as being essential to high-quality care, they also believed that personal choice or clinical judgment could trump evidence. <http://goo.gl/Vv1te3>

Noted in Media Watch, 7 March 2016, #452 (p.4):

- U.S. (Washington DC) | *The Hill* – 2 March 2016 – ‘**Reforming our end-of-life healthcare system.**’ Our society is in the midst of a profound shift in attitudes toward end-of-life healthcare. We are increasingly aware that too many suffer needlessly in their dying. Too many endure tests and treatments that increase suffering but do nothing to extend life. Too many carry memories of the pain, confusion and agony of a dying loved one. Every day, 10,000 people turn 65. The proportion of the population reaching age 85 is 48 times larger than a century ago. Increased life expectancy brings challenges of advanced illnesses among the aged. Our medical system focuses almost exclusively on extending life at any cost, often at the expense of its quality. <http://goo.gl/CvJZwz>

#### **Related**

- *MEDICAL EXPRESS* | Online – 7 April 2016 – ‘**Report suggests urgent need for policies to support family caregivers of aging and disabled Americans.**’ Family members and friends provide the vast majority of care for aging Americans experiencing chronic conditions, trauma or illness. Yet, according to a [new] study<sup>1</sup> ... current policy efforts at the federal and state levels have not adapted to address significant health and economic risks that these caregivers experience. <http://goo.gl/iIJT3F>

1. ‘Addressing the Needs of Caregivers at Risk: A New Policy Strategy,’ University of Pittsburgh Stern Center for Evidence-Based Policy, April 2016. <http://goo.gl/xO6SKO>

## Dead people and living interests

*MORTALITY* | Online – 7 April 2016 – Suppose that my dearest-of-all dies suddenly, and that instead of playing the piece of music she loved at her funeral, I play a song she despised. Have I wronged her and acted in contrast to her interests? In part I of this paper I criticise the prevailing attempts to prove that the dead have interests, and show that these attempts rest on a logical contradiction. I conclude that we cannot wrong the dead and that they have no interests. How then can we account for our strong feeling that we ought to respect the interests of the people who are dear to us, even when they are dead – and perhaps even more so? In part II I show that such a feeling does have a sound philosophical-moral basis, stemming from the interests of the living who remain behind. This feeling is based on our relationship with our dear ones while they were still alive and has to do with our being interested in their interests, and our obligation to represent these people when needed. When we represent them we, in a sense, re-present them. <http://goo.gl/mMGaxT>

## Parkinson disease patients' perspectives on palliative care needs

*NEUROLOGY* (American Academy of Neurology) | Online – 1 April 2016 – A growing body of literature suggests that patients with Parkinson disease (PD) have many unmet needs under current models of care that may be addressed through palliative care (PC) approaches. A first step in improving care for patients with PD through PC principles is to better understand patient perspectives on their perceived needs and care preferences. Patients [i.e., study participants] articulated major challenges in living with a diverse and complex set of motor and non-motor symptoms; feelings of loss; changes in roles, relationships, and concept of self; and, expressed concerns about the future. Participants discussed gaps in their care, including support at the time of diagnosis, education about the disease, and advance care planning (ACP). There was an expressed interest in and openness of participants to interdisciplinary approaches for addressing these needs. Patients were receptive to outpatient team-based PC services to address psychosocial issues, adjustment to illness (particularly at diagnosis and with progression), non-motor symptom control, and ACP as an adjunct to usual care. <http://goo.gl/KQV2dQ>

### Selected articles on palliative care for people living with Parkinson's disease

- *BMC PALLIATIVE CARE* | Online – 9 February 2016 – '**Interviews with Irish healthcare workers from different disciplines about palliative care for people with Parkinson's disease: A definite role but uncertainty around terminology and timing.**' Findings indicate that palliative care (PC) may be facilitated in this population by increased public awareness of the role of PC, education for healthcare workers (HCW) in both specialist and generalist settings, education for patients and families, better communication and integrated care models, and increased resources. [Noted in Media Watch, 15 February 2016, #449 (p.10)] <http://goo.gl/hCxhzq>

Noted in Media Watch, 30 March 2015, #403 (p.11):

- *CURRENT NEUROLOGY & NEUROSCIENCE REPORTS* | Online – 22 March 2015 – '**Palliative care for Parkinson's disease: Has the time come?**' Although Parkinson's disease is traditionally viewed as a movement disorder which affects quality of life, recent literature has revealed an increased mortality, a high burden of difficult-to-manage non-motor symptoms, high caregiver distress, and a high utilization of medical services especially in the last year of life. <http://goo.gl/09pTbj>

Noted in Media Watch, 15 July 2013, #314, (p.11):

- *PALLIATIVE MEDICINE* | Online – 9 July 2013 – '**Palliative care for Parkinson's disease: A summary of the evidence and future directions.**' Despite calls for improved access to palliative care (PC) for people with Parkinson's disease, services have been slow in developing. Obstacles include poor understanding and recognition of PC needs, the role for specialist PC services, and an agreed structure for sustainable PC provision. An integrated model of care is discussed. <http://goo.gl/dN4FFK>

## Pediatric palliative care

### **Caregivers' experiences of pathways to care for seriously ill children in Cape Town, South Africa: A qualitative investigation**

*PLOS ONE* | Online – 30 March 2016 – The experiences of caregivers guiding their critically ill children into and through a health system presents a unique perspective, with many issues congruent to those perceived and measured by clinicians such as delays within health facilities and in the referral process, early identification of critically ill children, and quality of care. These data provide insights into the difficulty and uncertainty facing caregivers about where and how to access emergency care for their sick children, the strategies they use to overcome these barriers, and the importance of good communication. This setting – the Western Cape of South Africa, where health services at all levels are overstretched and resources limited – represents one of the better scenarios found in this and other middle income countries. This report of the lived experiences of caregivers from the onset of illness to the highest level of care gives a clearer indication of the issues that need to be addressed in this context. <http://goo.gl/W3K7Ux>

#### **Related**

- *JOURNAL OF PEDIATRIC NURSING* (Society of Pediatric Nurses & Pediatric Endocrinology Nursing Society) | Online – 31 March 2016 – **'When technology fails: Community-based pediatric hospice.'** Perhaps we have become overly accustomed to the gifts of technology; life-saving devices emerge on a regular basis that provide hope to families of terminally ill patients. Unfortunately sometimes these gifts of technology fail, forcing an acceptance that death is inevitable. This is particularly heart-wrenching when the dying patient is a baby or child. This article reviews options for pediatric families at end of life such as community-based pediatric palliative care and hospice. The authors describe a movement in the U.K. which provides parents with a full-range of supportive options for their child including compassionate home extubation. <http://goo.gl/vsDtSd>

### **Life and death in the ICU: Ethics on the razor's edge**

*REVISTA BIOÉTICA*, 2016;24(1):54-63. This article seeks to address some ethical issues experienced on the borders of life and death in Intensive Care Units (ICUs). These are special places in hospitals, where there is the mandatory presence of cutting-edge medical technology and support for the preservation of life of a patient in a critical condition or risk. It is in this complex context that difficult ethical issues emerge: there are no objective criteria for admissions to the ICU, ICUs can be overcrowded with patients without diagnosis and there are difficulties in limiting treatment, which results in medical procedures that only prolong the dying process of the patient. The authors analyzed a case of assisted suicide, the young American Brittany Maynard, the need for palliative care, the ethical duty to care for pain and human suffering, the need to rediscover the paradigm of care, in search of an end to life without pain and suffering, and to avoid the practice of "medical futility," which only prolongs the dying process and only imposes more suffering on the patient, family members and health care professionals. <http://goo.gl/HMPohi>

**N.B.** Spanish language article.

#### **Related**

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2016;35(3):160-166. **'Family experiences during the dying process after withdrawal of life-sustaining therapy.'** The purpose of this investigation was to understand the experience of families when a family member had an unexpected life-threatening illness or injury and who died after life-sustaining therapy was withdrawn. Six categories evolved from the analysis [of interviews with family members]: 1) Preparing for the dying process; 2) The dying environment; 3) Perceptions of patient comfort; 4) The death vigil; 5) Essential aspects of care; and, 6) Together as a family. Families described the death vigil as extremely difficult. Family members described several aspects of care as very meaningful to them during the dying process. Families described how important it was for the family to be together as a family during the dying process. <http://goo.gl/lk9oBC>

## No matter the species

### **Veterinary hospice and palliative care: A comprehensive review of the literature**

*VETERINARY RECORD* (British Veterinary Association), 2016;178(15):369-374. In parallel with a rising interest in palliative medicine, hospice care and advance care planning within human medicine, increasing attention is currently being given to serious illness and death within veterinary medicine. Our ability to prolong life has created the need for thoughtful end-of-life discourse. Interest in hospice and palliative care (PC) for companion animals is on the rise, yet there has been limited scholarly research in these areas to date. This review concludes that veterinary hospice and PC is currently hindered by an inadequate amount of scholarly research to guide clinicians. Given a lack of prospective studies in veterinary hospice and PC to date, a significant opportunity exists for veterinary teaching institutions to contribute to the literature in an important and growing field. <http://goo.gl/zGG0kH>

Noted in Media Watch, 17 August 2015, #423 (p.10):

- U.K. (England) | BBC News – 9 August 2015 – ‘**The vet will see you now...**’ How does the care and compassion shown to animals when they are sick compare to the treatment patients receive in the National Health Service? <http://goo.gl/gmNnKl>

**N.B.** Selected articles on end-of-life care in veterinarian medicine are noted in Media Watch of 10 March 2014, #348 (p.6).

### **Palliative care and the humanities: Centralizing the patient at the end of life**

*YALE JOURNAL OF BIOLOGY & MEDICINE* (Yale University, New Haven, CT), 2016;89(1):105-108. While scientific advancements have broken new ground for the possibilities of end-of-life care, sensitive treatment of the patient as an individual has lagged behind and has frequently led to an unsatisfactory experience for patients, families, and the medical community at large. This essay argues that centralizing patients during the terminal phases of treatment by using humanistic perspectives has the potential to bring new meaning and improved effectiveness to patients and physicians alike. <http://goo.gl/7Rsjh>

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

Representative sample of recent news media coverage:

- *EUROPEAN SCIENTIFIC JOURNAL*, 2016;12(8):73-81. ‘**The debate over euthanasia and human rights.**’ This article analyzes the debate on issue of euthanasia (voluntary assisted suicide) and the relevance of international human rights norms to that debate. <http://goo.gl/QColwP>
- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 5 April 2016 – ‘**Legal standards for brain death and undue influence in euthanasia laws.**’ A major appellate court decision from the U.S. seriously questions the legal sufficiency of prevailing medical criteria for the determination of death by neurological criteria. There may be a mismatch between legal and medical standards for brain death, requiring the amendment of either or both. In South Australia, a Bill seeks to establish a legal right for a defined category of persons suffering unbearably to request voluntary euthanasia. However, an essential criterion of a voluntary decision is that it is not tainted by undue influence, and this Bill falls short of providing adequate guidance to assess for undue influence. <http://goo.gl/2wy1hV>
- *JOURNAL OF MEDICAL ETHICS* | Online – 30 March 2016 – ‘**Can facilitated aid in dying be permitted by “double effect”?**’ Some reflections from a recent New Zealand case.’ While the doctrine of double effect (DDE) remains controversial in ethical circles, it continues to be recognised in common law courts. In 2015, the High Court of New Zealand became the latest to acknowledge the existence of the DDE, in a case that challenged the prohibition on physician assisted dying. In so doing, the possibility was raised that the DDE could potentially be used in an untraditional way to provide a *prima facie* justification of “facilitated aid in dying” in some cases. <http://goo.gl/3PWFDY>

Cont.

- *RECENTI PROGRESSI IN MEDICINA*, 2016;107(3):127-139. **‘Forgoing treatments: A kind of euthanasia? A scientific approach to the debate about end-of-life decisions.’** In the last decade an extensive debate on the topic of end-of-life decisions has developed in western countries, obtaining a worldwide media relevance. Philosophers, theologians, legal experts and doctors, focus their attention on the three thorny issues of the topic: forgoing treatments, euthanasia, and assisted suicide. A thorough and respectful discussion on these issues should include all stakeholders – above all palliative care physicians – and should be encouraged in order to understand the views in favor or against the three practices, checking the different moral positions, and analyzing the cultural, social and legal aspects in the background on one hand, and, on the other, their impact on the health care systems. At present, in the fields of communications and politics, the debate related to the topic of these end-of-life practices is characterized by a confusion of terms and meanings. As an outcome, the term “euthanasia” is misused as a “container” including forgoing treatments, euthanasia and assisted suicide, while palliative sedation is wrongly considered as a procedure to cause death. This confusing approach does not permit to understand the real issues at the stake, keeping the debate at the tabloid level. Conversely, sharing the precise meaning of the words is the only way to provide tools to make rational, autonomous and responsible decisions, allowing individual informed choices in compliance with the principle of autonomy. <http://goo.gl/9Ym9h8>

**N.B.** Italian language article.

### 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, research and teaching tool.

### Distribution

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5. 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.
6. 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.

## Worth Repeating

### True to the principles of palliative care

#### **Politics and Policy**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 December 2009 – My message is that we have to be careful about how we explain ourselves, not only to our patients and families and to our colleagues, but to the public-at-large and that we need to keep our focus on palliative care (PC) as a means of matching medical care to patient and family goals. It is not about anybody's agenda other than that of the patient and family, and I think we must keep saying that. We should stop saying we want people to have a good death or that we want to be more efficient or we want to stop those other doctors from doing the wrong thing. If we keep our focus on the patient and the family in front of us and help them come to an understanding of their situation and help them identify the priorities that are meaningful for them, we are true to the principles of PC. I think that it is something that the public not only can understand, but will embrace. <http://goo.gl/0adSJ8>

#### Media Watch: Online

##### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/0Q1Mh4>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

##### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

##### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

##### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

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