# 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

Unintended consequences: Scroll down to <u>Specialist Publications</u> and 'Opioid campaigns' impact on advanced cancer and hospice and palliative care' (p.14), in *Rehabilitation Oncology*.

## Canada

# Future care for Canadian seniors: A primer on nursing supply and demand

CONFERENCE BOARD OF CANADA | Online -14 March 2017 - Given the increase in Canadian seniors who will need continuing care supports over the next 30 years, growth in demand for nursing will far outstrip general labour force growth and therefore require changes to the health system and nursing practices. Under a status quo scenario, the overall demand for nurses to provide continuing care to seniors in home, community, and facility living settings is projected to increase from just under 64,000 fullyear jobs to 142,000 full-year jobs by 2035 - an annual growth rate of 3.4%. The expansion of home and community care services and the implementation of dementia and palliative care strategies will all require sufficient numbers. skills, and expertise of nurses working in continuing care settings. Regardless if care is delivered in facility living establishments or in the home and community, meeting this demand requires changes to the health system and nursing practices. https://goo.gl/wL7c7h

# **Specialist Publications**

'Inuit interpreters engaged in end-of-life care in Nunavik, Northern Quebec' (p.8), in *International Journal of Circumpolar Health*.

# Health-care spending more than doubled since 2001: Projected to keep growing

FRASER INSTITUTE | Online - 14 March 2017 - Health-care spending by provincial governments has increased by 116% since 2001, and even though increases have slowed recently, health care is projected to consume an even larger portion of program spending over the next 15 years, according to a new study by the Fraser Institute, an independent, non-partisan Canadian public policy think-tank. The study finds that from 2001 to 2016, health-care spending increased across Canada by 116.4%. In Alberta, which had the largest increase over the 15-year period, health-care spending grew by a staggering 191% - almost doubling Gross Domestic Product (GDP) growth - followed by Saskatchewan (137%), Manitoba (123%) and Ontario (114%). By 2031, the study estimates health-care spending will consume 42.6% of all provincial program spending (on average), up from 40.1% in 2016 and 37.6% in 2001. In fact, over the next 15 years, four provinces are expected to eclipse the 45% mark - British Columbia (47.2), Prince Edward Island. (47.1), Ontario (45.4) and Nova Scotia (45.3). And when measured relative to the size of the economy, health-care spending is also on the rise. While provincial health-care spending (in total) represented only about 6.0% of Canada's GDP in 2001, it is projected to grow to 9.3% by 2031. https://goo.gl/fgi016

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

QUEBEC | CBC News – 14 March 2017 – 'Over 450 Quebec patients received medical aid in dying last year.' 461 patients were granted doctor-assisted death during the first year of Quebec's medical aid in dying law, according to data obtained by CBC's French-language Radio-Canada. The number of requests increased significantly in the second half of 2016. From December 2015 to the end of June 2016, 253 patients requested the procedure, and 166 of them underwent it. Between June and December 2016, 468 people made requests for medically assisted dying, with 295 of them undergoing it. <a href="https://goo.gl/TsKJsH">https://goo.gl/TsKJsH</a>

#### **Specialist Publications**

'Can medical assistance in dying harm rural and remote palliative care in Canada?' (p.15), in Canadian Family Physician.

# U.S.A.

## Study: When it comes to dying, it's better to be in Oregon

OREGON | The Oregonian (Newport) - 15 March 2017 - Twothirds of Oregonians die at home compared with about half in Washington state and nearly 40% nationwide, according to findings published recently. People want to be in their home – not hooked up to machines in a hospital, said co-author Dr. Susan Tolle, head of the Center for Ethics at Oregon Health & Science University. "Whenever anyone does a Gallup poll, a majority say they want to die at home," Tolle said. "Yet in much of the rest of the country that happens much less than in Oregon." The findings ... relied on Medicare statistics and defined "home" as wherever the person was living at the time of death, including nursing homes. They showed that Oregon has a relatively high rate of hospice use - 42%. That compares with 31% in Washington state and 17% in the rest of the country. The study also found that Oregon tends to have less intrusive end-of-life care than elsewhere. In the last month of life, for instance, 18% of Oregonians spend at least some time in intensive care units, compared with 23% in Washington and 29% in the rest of the country. https://goo.gl/ylEuB8

 'Lessons from Oregon in embracing complexity in end-of-life care,' The New England Journal of Medicine, published online 16 March 2017. https://goo.gl/oJqAUP

Noted in Media Watch 16 June 2014, #362 (p.3):

■ JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online - 9 June 2014 - 'Association between Physician Orders for Life-Sustaining Treatment (POLST) for scope of treatment and inhospital death in Oregon.' Nearly 18,000 of the decedents studied had such forms on file at time of death. In comparing the location of death with the medical treatment people requested on their forms, only 6.4% of patients who specified "comfort measures only," or allowing for a natural death while relieving pain and suffering, died in a hospital. Meanwhile, 22.4% of patients who chose "limited additional interventions" died in a hospital and 44.2% of patients who chose "full treatment" died there. Of people with no such form, 34.2% died in a hospital. https://goo.gl/QE2ozh

## **Specialist Publications**

'Variation in hospice services by location of care: Nursing home versus assisted living facility versus home' (p.10), in Journal of the American Geriatrics Society.

'Seeking a definition of medical futility with reference to the Louisiana Natural Death Act' (p.11), in Louisiana Law Review.

'An economic view on the current state of the economics of palliative and end-of-life care' (p.13), in *Palliative Medicine*.

## Bill that allows "right to try" medication for terminally ill passes lowa Senate

IOWA | The De Moines Register – 14 March 2017 – Iowans facing terminal illness would have access to medicines that have passed Phase I of the Food & Drug Administration's approval process, but are not yet on pharmacy shelves under a bill that passed the Iowa Senate. Under the bill, an eligible patient's doctor must acknowledge the patient's illness is terminal and recommend the patient for an investigatory drug trial and receive the patient's written, informed consent. The patient's insurance would not be required to pay for the treatment and any hospice would be allowed to decline the patient after treatment is provided. Expenses would be credited to the patient, including the patient's estate, unless another agreement is reached. If the patient dies during treatment, the patient's heirs would not be liable for any remaining debts unless otherwise required by law. Senate File 404 was approved 49-0, sending the measure to the House. <a href="https://goo.gl/OoeGaT">https://goo.gl/OoeGaT</a>

N.B. Additional articles on "right to try" laws are noted in Media Watch 6 March 2017, #502 (p.2).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW MEXICO | The Albuquerque Journal - 13 March 2017 -'End-of-life options bill sent to full Senate for consideration.' It's running short on time, but a bill that would allow terminally ill New Mexicans to seek help from a doctor to end their own lives is headed to the Senate floor. The measure cleared the Senate Judiciary Committee ... after the panel's chairman, Senator Richard Martinez, Democrat-Española, changed his vote and allowed it to advance with no recommendation. The legislation, officially known as the End-of-Life Options Act, has been one of the most emotional issues at the Roundhouse [the seat of the state government] during this year's 60-day session... This year's debate was prompted by a state Supreme Court ruling last year that said terminally ill patients don't have a right to a physician's help in dying under the law as it stands now. Senate Bill 252, would allow competent, terminally ill adult patients to obtain prescriptions from doctors for drugs the patients would have to self-administer. Death certificates for patients opting to use the program would list their underlying illness as the cause of death, not the prescribed medication. https://goo.gl/UGaZSU

#### **Specialist Publications**

'Implementing California's law on assisted dying' (p.15), in *The Hastings Report*.



## 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



Media Watch: Behind the Scenes http://goo.gl/XDjHxz

## International

#### End-of-life care in the U.K.

## National Health Service rationing "leaving dying patients to suffer in pain" report warns

U.K. (England, Northern Ireland, Scotland & Wales) | The Daily Telegraph - 14 March 2017 -National Heath Service rationing is leaving dying patients to suffer in pain, a leading think tank has warned. A report by The King's Fund found people at the end of their life are being left for hours without pain relief due to nursing shortages. The think tank looked at four areas where rationing has affected patient care - sexual health services, district nursing, planned hip operations and neonatal care. It said in some areas there is "clear evidence that access to and quality of patient care has suffered." District nurses support the care of people at home, including those who are housebound, suffering a longterm illness or who are at the end of their life. The report found services in this area are under "significant financial pressure," with funding either static or reducing, despite rising demand. https://goo.gl/JybU9p

#### Extract from The King's Fund report

The authors "heard that pressures in district nursing are affecting staff beyond those working directly in the service. For example, a hospice manager described that "sparse" end-of-life care provision by the local district nursing service had had a "tsunami" effect for their organisation, as they stepped in to perform basic palliative care tasks that would typically be done by district nurses."

#### **Specialist Publications**

'Law, ethics and end-of-life care: The policy and practice interface in England' (p.8), in *International Journal of Palliative Nursing*.

1. 'Understanding National Health Service financial pressures: How are they affecting patient care?' The King's Fund, March 2017. https://goo.gl/Fs4Hh1

## Related

- U.K. (England) | The Darlington & Stockton Times 16 March 2017 'Council investigates end-of-life care in North Yorkshire.' North Yorkshire County Council's scrutiny of health committee has drawn up a report highlighting the need for investment into a multi-agency, community-based provision for people in the final months of their lives, after it conducted a six month investigation into end-of-life care (EoLC) in the county. The report sets out a number of recommendations following consultation with patients, the public, service providers and commissioners. It highlights that while the majority of people, about 75%, experience good quality EoLC, whether that is at home, in a care home or in a hospital. However, 25% do not. It also found that while most people would prefer to die in their own home, 43% die in hospital, with all the associated, significant costs. https://goo.gl/pollKd
- U.K. (England, Northern Ireland, Scotland & Wales) | The Belfast Telegraph 16 March 2017 'Poor end-of-life care "taints" memories of loved ones for 35% of bereaved people.' Charity Marie Curie said it was sad to see so many memories were "tainted" by poor care. Its poll of 1,155 people who had lost a relative, friend or neighbour through terminal illness found that 35% felt the poor quality of end-of-life care (EoLC) had marred their memories. Nearly a fifth felt that better EoLC could have helped them preserve memories of happier times. The survey, which also polled a further 845 British adults who had not been bereaved, also quizzed participants on how they would like to be remembered by their loved ones. https://goo.gl/sEif9B

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Back Issues of Media Watch http://goo.gl/frPgZ5 U.K. (England, Northern Ireland, Scotland & Wales) | The Guardian – 13 March 2017 – 'Thousands of vulnerable people held unlawfully in care homes: Report.' Tens of thousands of vulnerable people with dementia and learning disabilities are being detained unlawfully in hospitals and care homes across Britain, the Law Commission has said. Replacing the "administrative and bureaucratic nightmare" system of deprivation of liberty safeguards would speed up checks and allow care workers to concentrate on those most at risk, the legal study recommends. https://goo.gl/2T95SP

## **Extract from Law Commission report**

We proposed that a separate scheme [regarding deprivation and liberty safeguards] would apply in general hospitals and palliative care. This scheme would have delivered safeguards in cases where a patient required (or there was a real risk the patient would require) care or treatment in his or her best interests that amounted to a deprivation of liberty, but the patient lacked capacity to consent to such care or treatment.

- 'Mental Capacity and Deprivation of Liberty,' Law Commission, March 2017. https://goo.gl/l2fGVD
- U.K. (England) | Isle of Wight Radio (Newport) 12 March 2017 'End-of-life care offers unique apprenticeships on the Isle of Wight.' As [the U.K.'s] National Apprenticeship Week draws to a close, the Isle of Wight's Earl Mountbatten Hospice says it is launching a new opportunity for two trainees to work alongside its clinical team. Two new Health & Social Care apprenticeships will give the opportunity to learn how to provide end-of-life care at the John Cheverton Centre and (eventually) within other areas of the Newport organisation. The hospice already offers apprenticeships in retail, administration and health and social care. <a href="https://goo.gl/jvqC51">https://goo.gl/jvqC51</a>

#### Photo essay

## Waiting to die: Uganda's untreated cancer patients

UGANDA | Aljazeera – 13 March 2017 – With his shoulders hunched forward and his hands curled over the curve of the steering wheel, James Isabirye scans a dusty road in southern Uganda for signs of life. The driver at Hospice Jinja is looking for a narrow inlet, somewhere between a neighbourhood shop and a primary school, that his colleague and passenger Esther Apolot is directing him to. "And you remembered to pack the morphine?" Esther asks. "This patient is very sick." James takes a hard left turn down a winding footpath carved in the dirt, which grows increasingly narrow until it dead-ends at two crumbling redbrick houses. "This is it," says Esther. "She's in-



side." Covered by a single sheet atop a foam mattress on the concrete floor is 32-year-old Harriet Namuwoya. The mother of seven has abdominal cancer. A watermelon-sized tumour protrudes from her stomach. "She's in a lot of pain," says Esther. "If it was caught earlier, she would've benefited from radiation." Harriet is not alone. She is one of hundreds of patients dying from treatable cancer in Uganda after the country's only external-beam radiotherapy machine broke last April. It has not been replaced. Too poor to travel to the nearest machine in Nairobi, Kenya, where treatment and living expenses for the duration of treatment often run upwards of \$5,000, Harriet and those like her are simply waiting to die in homes across Uganda. https://goo.gl/z0KBGi

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## 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.

## End-of-life care in Uganda

- BMC PALLIATIVE CARE | Online 9 April 2016 'A palliative care link nurse programme in Mulago Hospital, Uganda: An evaluation using mixed methods.' The programme demonstrates that nurses working in the wards of busy hospitals in sub-Saharan Africa can be trained and supported to provide generalist palliative care (PC) to patients, working with and referring to the specialist PC team as needed and working as a focal point for the core clinical teams. [Noted in Media Watch 18 April 2016, #458 (p.7)] <a href="https://goo.gl/id3vQa">https://goo.gl/id3vQa</a>
- NATIONAL PUBLIC RADIO (U.S.) | Online 3 January 2016 'How Uganda came to earn high marks for quality of death.' Food coloring, water, a preservative and a pound of morphine powder are the ingredients in Dr. Anne Merriman's recipe for liquid morphine. "It's easier than making a cake," says Merriman, a British palliative care specialist who founded Hospice Africa in Uganda in 1993 and helped design the formula that hospice workers in Uganda have used for 22 years to craft liquid morphine. [Noted in Media Watch 4 January 2016, #443 (p.6)] <a href="https://goo.gl/iNFhhF">https://goo.gl/iNFhhF</a>
- KENYA | The Mail & Guardian (Nairobi) 9 November 2015 'Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails.' The Quality of Death Index, highlights the advances that countries are making in taking care of their citizens at the end of life, as well as the remaining challenges and gaps in policy and infrastructure. It's morbid, but important stuff... The need for long-term, palliative care is set to rise significantly. [Noted in Media Watch 16 November 2015, #436 (p.8)] <a href="https://goo.gl/KzyOkf">https://goo.gl/KzyOkf</a>
  - Uganda was ranked 35th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in Media Watch 12 October 2015, #431 (p.6)] <a href="http://goo.gl/nuPWII">http://goo.gl/nuPWII</a>

# **Specialist Publications**

## To be a trained and supported volunteer in palliative care: A phenomenological study

BMC PALLIATIVE CARE | Online – 14 March 2017 – The findings of the present study highlight that volunteering is experienced as meaningful and satisfying, and that the volunteers have an independent and important role to play among seriously ill or dying people in the palliative care (PC) team by providing practical help and emotional support. This positive finding may be explained by the fact that the volunteers were trained and supported by a PC coordinator. When volunteers experience their volunteering as meaningful, and when they receive recognition for performing voluntary tasks, they frequently wish to continue as volunteers. To ensure that PC volunteers are available in the future, it is important to inform individuals about the benefits of volunteering in PC within public forums. Likewise, health care personnel have to be aware of the volunteers' roles in PC. Since PC coordinators are suitable for training and supporting volunteers, it is important that such a position is made available, and is filled, within the community health care services. In future research, it will be important to focus on the experiences of patients, their next of kin, and health care personnel, particularly as they relate to the trained and supported individuals who volunteer in PC settings within the community health care services. <a href="https://goo.gl/AJVbNh">https://goo.gl/AJVbNh</a>

## Related

MANAGEMENT COMMUNICATION QUARTERLY | Online – 12 arch 2017 – "People just don't understand": Challenges communicating home hospice volunteer role experiences to organizational outsiders.' Findings of this study demonstrate how role articulation inhibits volunteers from communicating the full scope and relevance of role experiences. Although volunteers used discursive strategies to alter perceptions of stigma, these strategies may also exaggerate insider-outsider differences, inhibit authentic role disclosure, and reduce value of service to personal benefit. <a href="https://goo.gl/VZqHPt">https://goo.gl/VZqHPt</a>

**N.B.** Additional articles on hospice and palliative care volunteers are noted in Media Watch 9 January 2017, #494 (p.9); 12 December 2016, #491 (p.8); 28 November 2016, #489 (p.8); and, 25 July 2016, #476 (pp.5-6,11).

## The demon in deeming: Medical paternalism and linguistic issues in the palliative care setting

CANADIAN FAMILY PHYSICIAN, 2017;63(3):191-194. Despite considerable efforts in public health policy since 1995 to promote and advance palliative care (PC) in Canada, no more than a third of Canadians access PC when they need it. This number is tragically low when compared with the 90% of Canadians who could benefit from PC in the final phases of their lives. Although the reasons for this are multifactorial, the authors submit that medical paternalism together with linguistic issues are important contributing factors. In addition to posing a barrier to accessing PC services in a timely fashion or at all, medical paternalism and linguistic inaccuracies and euphemisms might reflect a failure to act in a truly ethical and patient-centred manner. https://goo.gl/1tHPJQ

Noted in Media Watch 6 March 207, #502 (.7):

• AMERICA MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2017;19(3):234-237. 'To understand and be understood: The ethics of language, literacy, and hierarchy in medicine.' The tragedy of linguistic failures with respect to health outcomes is well known: low health literacy among patients is consistently associated with more hospitalizations, greater use of emergency care, lower receipt of critical preventative interventions, poorer ability to take medications properly, and, among seniors, poorer overall health status and higher mortality rates. <a href="https://goo.gl/5cbNAT">https://goo.gl/5cbNAT</a>

Noted in Media Watch 27 June 2016, #468 (p.11):

• NURSING IN CRITICAL CARE (British Association of Critical Care Nurses), 2016;21(4):193-194. 'Treatment withdrawal, allow a natural death, passive euthanasia: A care-full choice of words.' When we talk about concepts and care at the end of life, it is important to be clear to ourselves and to others about what we mean, what we say and what our motivations are behind the care given. When we talk to patients/families and to our colleagues, there can be no place for ambiguity or euphemisms. <a href="http://goo.gl/NsQAtS">http://goo.gl/NsQAtS</a>

Noted in Media Watch 22 February 2015, #450 (p.12):

JOURNAL OF MEDICAL ETHICS | Online – 18 February 2016 – 'Medical maternalism: Beyond paternalism and antipaternalism.' This paper argues that the concept of paternalism is currently overextended to include a variety of actions that, while resembling paternalistic actions, are importantly different. http://goo.gl/IODwGe

## Justifying clinical nudges

THE HASTINGS REPORT, 2017:47(2):32-38. The shift away from paternalistic decision-making and toward patient-centered, shared decision-making has stemmed from the recognition that in order to practice medicine ethically, health care professionals must take seriously the values and preferences of their patients. At the same time, there is growing recognition that minor and seemingly irrelevant features of how choices are presented can substantially influence the decisions people make. Behavioral economists have identified striking ways in which trivial differences in the presentation of options can powerfully and predictably affect people's choices. Choice-affecting features of the decision environment that do not restrict the range of choices or significantly alter the incentives have come to be known as "nudges." Although some have criticized conscious efforts to influence choice, we believe that clinical nudges may often be morally justified. The most straightforward justification for nudge interventions is that they help people bypass their cognitive limitations - for example, the tendency to choose the first option presented even when that option is not the best for them - thereby allowing people to make choices that best align with their rational preferences or deeply held values. However, the authors argue that this justification is problematic. They argue that, if physicians wish to use nudges to shape their patients' choices, the justification for doing so must appeal to an ethical and professional standard, not to patients' preferences. The authors demonstrate how a standard with which clinicians and bioethicists already are quite familiar - the best-interest standard – offers a robust justification for the use of nudges. https://goo.gl/mDEMxg

Noted in Media Watch 21 April 2014, #354 (p.8):

BMC MEDICAL ETHICS | Online – 17 April 2014 – "Nudge" in the clinical consultation – an acceptable form of medical paternalism? Overall the extremes of autonomy and paternalism are not compatible in a responsive, responsible and moral health care environment, and thus some compromise of these values is unavoidable. Nudge techniques are widely used in policy making and the authors demonstrate how they can be applied in shared medical decision making. https://goo.gl/wrlz2c

## Inuit interpreters engaged in end-of-life care in Nunavik, Northern Quebec

INTERNATIONAL JOURNAL OF CIRCUMPOLAR HEALTH, 2017;76(1). Inuit interpreters are key players in end-of-life (EoL) care for Nunavik patients and families. This emotionally intensive work requires expertise in French, English and Inuit dialects to negotiate linguistic and cultural challenges. Cultural differences among medical institutions and Inuit communities can lead to value conflicts and moral dilemmas as interpreters navigate how best to transmit messages of care at EoL. Inuit working as interpreters in Nunavik are hired to provide multiple services of which interpretation plays only a part. Many have no formal training and have few resources (e.g., visual aids, dictionaries) to draw upon during medical consultations. Given the small size of communities, many interpreters personally know their clients and often feel overwhelmed by moral dilemmas when translating EoL information for patients and families. The concept of moral distress is a helpful lens to make sense of their experience, including personal and professional repercussions. https://goo.gl/Qqldxc

Noted in Media Watch 13 February 2017, #499 (p.13):

JOURNAL OF PALLIATIVE MEDICINE | Online – 8 February 2017 – 'End-of-life care in Nunavik, Quebec: Inuit experiences, current realities, and ways forward.' Increasing longevity for Inuit living in Nunavik, northern Quebec, has resulted in heightened rates of cancers and chronic diseases necessitating complex treatments. Consequently, end-of-life care, once the domain of Inuit families and communities, has come to include professionalized healthcare providers with varying degrees of awareness of factors to consider in providing care to Inuit populations. <a href="https://goo.gl/HMbbgQ">https://goo.gl/HMbbgQ</a>

# Law, ethics and end-of-life care: The policy and practice interface in England

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Inprint – Accessed 13 March 2017 – Palliative care (PC) aims neither to hasten nor postpone death, but instead offers support to people with advancing, incurable somatic illness... At the same time, individual nurses hold a wide range of views on euthanasia and end-of-life (EoL) care, whilst the care-giving in clinical practice occurs in a social context in accordance with local and national policy. Policy and practice must conform to the law, which defines liability in the EoL phase. However ... the law has primarily focused on the criminalisation of euthanasia and less on the complex issues involved in the "good death" concept. As a result, contemporary policy that helps to shape and direct EoL care faces a tension between EoL liability and the way in which PC is developing. The authors of this paper are not suggesting as a response to this tension that euthanasia should be legalised nor equating it with a "good death." The central argument from the authors of this paper is different: that for EoL care to develop and progress, practice has to interface with law and policy to a greater extent. A better interface will facilitate policy and law to be shaped by the complexity and demands of practice decision-making, so allowing a better understanding of what the EoL process entails. This is not to suggest that all EoL issues should be driven singularly by PC practice, but that a better future for the EoL entails the linking of law, policy and practice. <a href="https://goo.gl/RineHa">https://goo.gl/RineHa</a>

- 'Nursing and euthanasia: A review of argument-based ethics literature,' Nursing Ethics, 2009;16(4): 466-486. https://goo.gl/2u5xGh
- 2. 'One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch 30 June 2014, #364 (p.7)] https://goo.gl/bCg4UY

Noted in Media Watch 30 January 2017, #497 (p.10):

INTERNATIONAL JOURNAL OF LAW IN CONTEXT | Online – Accessed 24 January 2017 – 'From dispassionate law to compassionate outcomes in healthcare law, or not.' This paper evaluates the extent to which law's traditional objectivity (dispassion) is undermined by the introduction of concerns about compassion into judicial and executive decisions. Focusing primarily on the law in England and Wales, but with reference to multi-jurisdictional case law and international instruments, it considers whether the law provides compassionate approaches and outcomes in end-of-life decision-making, and the implications of compassion for legal certainty. https://goo.gl/OhnQQ2

## Pediatric palliative care - a shared priority

JAMA ONCOLOGY | Online – 9 March 2017 – Seventeen years ago, Wolfe and colleagues demonstrated pervasive symptoms and suffering among children with cancer at the end of life. In this issue of JAMA Oncology, Levine and colleagues have extended this work by evaluating experiences of children with cancer and their parents in the first year after diagnosis. This work demonstrates that children with cancer report significant symptoms in their first month of cancer treatment, with a majority suffering from nausea, anorexia, pain, anxiety, and constipation, and half suffering from depression. These data suggest that pediatric oncologists such as myself do not sufficiently meet one of our fundamental obligations to these children – we are not adequately treating their suffering. We must think about how best to respond and remedy this gap. <a href="https://goo.gl/dmeFHC">https://goo.gl/dmeFHC</a>

- 'Symptoms and suffering at the end of life in children with cancer,' New England Journal of Medicine, 2000;342(5):326-333. https://goo.gl/xXofLP
- 2. 'Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology, 'JAMA Oncology, published online 9 March 2017. https://goo.gl/lwQYSJ

#### Related

- ARCHIVES DISEASE IN CHILDHOOD | Online 13 March 2017 "'I can't tell my child they are dying." Helping parents have conversations with their child.' This paper explores the challenges of resolving conflicting feelings around talking with a child about their terminal prognosis. When children are left out of such conversations it is usually done with good intent, with a parent wishing to protect their child from anxiety or loss of hope. There is however growing evidence that sensitive, timely, age appropriate information from those with whom children have a good relationship is helpful both for the child and their family. There is no evidence that involving children in sensitive and timely discussions creates significant problems, rather that withholding information may lead to confusion, frustration, distress and anger. <a href="https://goo.gl/nPNYLa">https://goo.gl/nPNYLa</a>
- NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online 14 March 2017 'Paediatric palliative care: Multidisciplinary and pro-active.' Every child with a life-limiting or threatening illness, and his or her family, has a right to palliative care (PC). PC is not limited to end-of-life care, but starts from the moment of diagnosis and is independent of whether there are curative options. To optimise quality of life of both the child and the family, the emphasis of care should be on both somatic and psychosocial and spiritual aspects from the very start, and goals should be set together with the child and the family. https://goo.gl/X9q5dw
  - N.B. Dutch language article.



## Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials. <u>http://goo.gl/OTpc8l</u>

#### End-of-life care in the U.S.

## Provision of palliative care services by family physicians is common

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2017;30(2):255-257. One third of family physicians (FPs) recertifying in the American Board of Family Medicine Maintenance of Certification in 2013 see themselves as palliative care (PC) providers, although this varies regionally, by physician demographics, and by clinic settings. It is concerning that physicians reporting that they provide PC are more likely to be older, white, male, and rural, as this may limit patients' access to primary PC. However, it is reassuring that those with or pursuing Patient-Centered Medical Home (PCMH) certification are more likely to report PC provision given the current policy emphasis on supporting PCMHs. This study used a broad, self-reported question of whether physicians provide PC in their routine practice and is therefore limited by self-reporting bias and potential ambiguity in the interpretation of PC by respondents. Further work needs to be done to understand the degree and quality of PC provided by FPs. The authors data source had the advantage of being a required survey for recertifying physicians, capturing responses from approximately 10% of all FPs. This study raises questions about what FPs perceive as their role in providing PC and what they need in order to better engage in PC. Future work is needed to understand the barriers to providing PC for FPs. <a href="https://goo.gl/w3fGMu">https://goo.gl/w3fGMu</a>

# Variation in hospice services by location of care: Nursing home versus assisted living facility versus home

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 14 March 2017 – There are significant differences between characteristics of hospice patients in different settings, as well as the mix of services they receive. Data from 32,605 hospice patients who received routine hospice care from 2009 to 2014 were analyzed. Minimal differences were found in overall intensity of service contacts across settings; however, the mix of services were different for patients living at home versus nursing home versus assisted living facility. Overall, more nurse care was provided at the beginning and end of the hospice episode; intensity of aide care services was higher in the middle portion of the hospice episode. Nearly 43% of the sample had hospice stays less than 2 weeks and up to 20% had stays greater than 6 months. Medicare hospice payment methodology was revised starting in 2016. While the new payment structure is in greater alignment with the U shape distribution of services, it will be important to evaluate the impact of the new payment methodology on length of stay and mix of services by different providers across settings of care. https://goo.gl/PWewbN

## Managing difficult patients: Roles of psychologists in the age of interdisciplinary care

JOURNAL OF CLINICAL PSYCHOLOGY IN MEDICAL SETTINGS | Online – 10 March 2017 – Various problems can occur during encounters between health providers and patients. In some instances, clinicians attribute these problems to patients being "difficult." Clinicians' perception of difficulties in the clinical encounter are also influenced by: clinicians' own attitudes, thoughts, and behavior; the specific setting in which patient and clinician interact; and properties of the healthcare organization in which they are embedded. This article explores how psychologists in medical settings can serve as a resource that improves patient care for difficult patients, supports provider wellness, provides relevant education to clinical providers, and reduces the stress difficult patients place on the healthcare system. The definition, scope, and impact of difficult patients in healthcare settings are reviewed, including an examination of patient, clinician, and systems factors that contribute to the etiology of difficult clinical encounters. Strategies are discussed that may prevent or limit the adverse impact of difficult patients in healthcare, with special emphasis on the roles of psychologists in interprofessional healthcare teams. https://goo.gl/0aP6j7

#### The role of psychologists in palliative care

■ EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(1):24-27. 'Psychological ideas in palliative care: Attachment theory.' There is growing recognition in the palliative care community of the emotional and psychological needs of patients ... as they reach the end of life. But not every patient needs, wants or has access to formal contact with a psychologist. What's more, all members of a multidisciplinary team are likely to experience the impact of psychological matters in their daily practice with patients and colleagues, whether or not their role is to explicitly address these. [Noted in Media Watch 27 February 2017, #501 (p.7)]

**N.B.** Access to this article requires a subscription to the journal. Contents page for the January/February 2017 issue: <a href="https://goo.gl/lzN0zd">https://goo.gl/lzN0zd</a>

• AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2014 – 'Psychosocial care and the role of clinical psychologists in palliative care.' The following themes were identified in this study: 1) The essential nature of the psychologists' care were caring and company; 2) The dynamic process included psychological assessment, intervention, and evaluation based on psychological knowledge; 3) They needed to modify their care using an integrative framework, by setting practical goals and using techniques with flexibility; and, 4) They faced external and internal challenges in this field. [Noted in Media Watch 21 July 2014, #367 (p.7)] https://goo.gl/05U3LR

# Standardized criteria for palliative care consultation on a solid tumor oncology service reduces downstream health care use

JOURNAL OF ONCOLOGY PRACTICE | Online – 17 March 2017 – Integration of palliative care (PC) improves symptom control and decreases unwanted health care use, yet many patients are never offered these services. In 2016, the American Society of Clinical Oncology called for incorporation of PC into oncologic care for all patients with metastatic cancer. To improve the quality of cancer care, the authors developed standardized criteria, or triggers, for PC consultation on the inpatient solid tumor service. To the authors' knowledge, this is the first study to demonstrate that among patients with advanced cancer admitted to an inpatient oncology service, the standardized use of triggers for PC consultation is associated with substantial impact on 30-day readmission rates, chemotherapy following discharge, hospice referrals, and use of support services following discharge. https://goo.gl/i9Ah1U

'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline – updated,' *Journal of Clinical Oncology*, published on line 31 October 2016. [Noted in Media Watch 7 November 2016, #486 (p.8)] <a href="https://goo.gl/zaRNuP">https://goo.gl/zaRNuP</a>

## Seeking a definition of medical futility with reference to the Louisiana Natural Death Act

LOUISIANA LAW REVIEW, 2017;77(3):755-803. The general question concerning the existence of a patient's right in the U.S. either to accept or refuse care at the end of life has largely been resolved through a fairly consistent body of jurisprudence, statutory schemes, and pronouncements of professional ethics. The principal statutory expression of this right in Louisiana is found in the Natural Death Act, in which the legislature recognized the right of patients under certain conditions either to withhold treatment at the outset of care or to withdraw treatment that had already been initiated. However, the legislature left open the ultimate scope of this right, which remains the subject of debate both in the courts and among physicians, bioethicists, and moral philosophers. One of the most significant and problematic of these unresolved questions involves the relationship between the Act and the elusive concept of "medical futility." Although the Act unambiguously reflects the traditional view of the patient's right of self-determination as a negative one, the contemporary variant of the question asks whether a patient's right to refuse recommended treatment necessarily encompasses the right to receive interventions that have not been offered, and, if so, what constraints might limit the scope of that positive right. Framed from the opposite perspective, the question would ask whether, and to what extent, the Act would recognize a physician's authority to withhold or withdraw life-sustaining treatment that a patient has expressly requested - whether directly or through a surrogate. https://goo.gl/Ak0uog

Noted in Media Watch 2 January 2017, #493 (pp.13-14):

- JOURNAL OF CLINICAL ETHICS | Online 30 December 2016 'Medical futility: A contemporary review.' Although living in a pluralistic society presents one of the major reasons as to why, despite 30 years of intense discussion, no consensus has been made, the issue of medical futility will always be complex as it is, by nature, multifaceted, and numerous elements including possible risks, evidence of the probability of benefit, the wishes of the patient (and family), professional standards, and cost interact. Nevertheless, the global medical community has seen the development of two distinctly different approaches to medical futility: one in which the autonomy of patients is of paramount importance in the decision whether or not to pursue a treatment; and, one in which beneficence and primum non nocere first do no harm are almost entirely the clinician's prerogative, and whereby he/she has a duty to refuse any treatment for which the potential risks outweigh the potential benefits for the patient. https://goo.gl/2Rq13L
- MEDSCAPE | Online 23 December 2016 'Medscape Ethics Report 2016: Life, death, and pain.' Every day, physicians grapple with wrenching life-and-death decisions. They often must weigh many factors (some conflicting), such as patient wishes, laws, right and wrong, one's sense of duty... There are enough shades of gray such that the best course of action may not be obvious and often there is no optimal course of action at all. Medscape's Ethics Report premiered in 2010. Here, in its fourth report, more than 7,500 physicians from more than 25 specialties shared their often clashing views on issues about life, death, and patient suffering, with some notable shifts in attitude over the years. https://goo.gl/L3ybuU

Would you recommend life-sustaining therapy if you believed it would be futile?



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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.

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# **Something Missed or Overlooked?**

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

## An economic view on the current state of the economics of palliative and end-of-life care

PALLIATIVE MEDICINE, 2017;31(4):291-292. Investing in palliative and end-of-life care (P&EoLC) services improves our chances of living well towards the end of life, and in accordance with our wishes. However, the global provision of P&EoLC is hampered by the absence of health economics research demonstrating value for money. Despite increasing interest in the economics of P&EoLC. research into priority setting, costs and outcomes, supply and demand, the planning and funding of services, economic evaluation and broader health system analysis in this setting is relatively scarce. This special issue of Palliative Medicine aims to explore the many economic facets of providing and funding P&EoLC. While the call for papers sought a wide variety of topics and methods, the vast majority of papers submitted to, and accepted for, the special issue concern the costs of P&EoLC. These include a number of important papers covering challenging issues around capturing accurate data in a complex area; measuring costs in P&EoLC is notoriously difficult. https://goo.gl/wMHxin



This issue focuses on the economic facets of providing and funding palliative and end-of-life care. Journal contents page: <a href="https://goo.gl/sK9yLi">https://goo.gl/sK9yLi</a>

#### Related

PALLIATIVE MEDICINE, 2017;31(4):293-295. 'Current state of the economics of palliative and end-of-life care: A clinical view.' It is essential that economic research in our field continues to grow, and in particular that it addresses the challenges posed by a rapidly expanding older population. If palliative care is a complex response to a complex problem, then the evidence to underpin its provision must also be sophisticated, thoughtful and rigorous. Clinicians, researchers and policymakers alike must be flexible in responding to the many different facets of changing patterns of need and delivering appropriate healthcare responses built on this evidence. <a href="https://goo.gl/HKyT6W">https://goo.gl/HKyT6W</a>

## New guidance for an old problem: Early release for seriously ill and elderly prisoners in Europe

THE PRISON JOURNAL | Online – 10 March 2017 – Early release of seriously ill and elderly prisoners is possible in several countries, but only few prisoners gain such exemption. The authors identified hurdles to the implementation of early release laws in Europe by analyzing legal requirements for such release... Provisions are based on prisoners' health status and the ability to care for them in prison. Interviews [with forty stakeholders] revealed three barriers: 1) Practical hurdles; 2) Penological goals; and, 3) Multiple interests. Finally, early release is obstructed because three justifications are often confounded: 1) Compassion; 2) The principle of equivalence; and, 3) Practical concerns, such as costs and overcrowding. <a href="https://goo.gl/gbRif6">https://goo.gl/gbRif6</a>

**N.B.** End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report is available at: <a href="http://goo.gl/ZpEJyQ">http://goo.gl/ZpEJyQ</a>

#### End-of-life care in Denmark

Pre-loss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study

*PSYCHO-ONCOLOGY* | Online – 7 March 2017 – Severe grief symptoms in family caregivers (FCGs) during end-of-life (EoL) cancer trajectories are associated with complicated grief and depression after loss. Nevertheless, severe grief symptoms during EoL caregiving in caregivers to cancer patients have been scarcely studied. The authors aimed to explore associations between severe pre-loss grief symptoms in caregivers and modifiable factors such as depressive symptoms, caregiver burden, preparedness

Cont.

for death and EoL communication. Severe pre-loss grief symptoms were significantly associated with distress, low preparedness and little communication during caregiving. Thus, severe pre-loss grief symptoms may be a key indicator for complications in caregivers of cancer patients in an EoL trajectory. Targeted interventions are needed to support FCGs with severe pre-loss grief symptoms. <a href="https://goo.gl/xydlKp">https://goo.gl/xydlKp</a>

#### Related

■ INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online — 9 March 2017 — 'Perceived stigma of sudden bereavement as a risk factor for suicidal thoughts and suicide attempt: Analysis of British cross-sectional survey data on 3,387 young bereaved adults.' People who experience sudden bereavement report feeling highly stigmatised by the loss, potentially influencing access to support. The authors tested the association of high versus low perceived stigma ... with post-bereavement suicidal ideation and suicide attempt, using random effects logistic regression, adjusting for socio-demographic factors, pre-bereavement psychopathology, and mode of sudden bereavement (natural causes/unnatural causes/suicide). https://goo.gl/XEAGga

# Opioid campaigns' impact on advanced cancer and hospice and palliative care

REHABILITATION ONCOLOGY | Online – 27 February 2017 – Opioids effectively manage pain, but increasing misuse has resulted in significant abuse, addiction and even death. This misuse has accelerated to the point that an "opioid epidemic" has been declared. Several government agencies and professional associations ... are developing well-meaning programs to address opioid abuse. Recent national opioid campaigns may have significant, unintentional, and adverse consequences on the medical management of patients with advanced cancers or those receiving hospice and palliative care (H&PC). New guidelines are likely to impose even tighter controls on opioids, further reducing accessibility to these drugs for these individuals. There is concern that these well-meaning public initiatives may have unintended consequences for end-of-life care if the H&PC community is not vigilant in its advocacy. <a href="https://goo.gl/Qw3dYU">https://goo.gl/Qw3dYU</a>

## Training generalist doctors for rural practice in New Zealand

RURAL & REMOTE HEALTH | Online - 8 March 2017 - Targeted postgraduate training increases the likelihood young doctors will take up careers in rural generalist medicine. This article describes the postgraduate pathways that have evolved for these doctors in New Zealand. The Cairns consensus statement 2014 defined rural medical generalism as a scope of practice that encompasses primary care, hospital or secondary care, emergency care, advanced skill sets and a population-based approach to the health needs of rural communities. Even as work goes on to define this role different jurisdictions have developed their own training pathways for these important members of the rural healthcare workforce. In 2002 the University of Otago developed a distance-taught postgraduate diploma aimed at the extended practice of rural general practitioners (GPs) and rural hospital medical officers. This qualification has evolved into a 4-year vocational training program in rural hospital medicine, with the university diploma retained as the aca-

demic component. The intentionally flexible and modular nature of the rural hospital training program and university diploma allow for a range of training options. The majority of trainees are taking advantage of this by combining general practice and rural hospital training. Although structured quite differently the components of this combined pathway looks similar to the Australian rural generalist pathways. https://goo.gl/cz12ly

## Extract from Rural & Remote Health article

This article adds to existing knowledge by describing the structure and evolution of the rural hospital medicine training program in New Zealand, highlighting the key features of its success. New Zealand's rural population is spread thinly over a terrain that is not vast but is rugged. Also, its institutions and communities of interest are relatively small.

1. 'Cairns Consensus Statement on Rural Generalist Medicine,' International Steering Group for the World Summit on Rural Generalist Medicine, November 2013. https://goo.gl/GLJvEE

Cont.

Noted in Media Watch 23 January 2017, #496 (p.12):

PALLIATIVE MEDICINE | Online – 20 January 2017 – 'Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review.' A total of 27 articles (22 rural/remote studies) from developed and developing countries were included, reporting rural end-of-life care (EoLC) experiences and perspectives of patients and family caregivers. Greatest needs were informational (developed countries) and medications (developing countries). Influence of rural location included distances, inaccessibility to EoLC services, strong community support and importance of home and "country." Articulation of the rural voice is increasing; however, there still remain limited published rural studies reporting on patient and family caregivers' experiences and perspectives on rural. https://goo.gl/jiAPA0

**N.B.** Additional articles on end-of-life care in rural communities and remote regions are noted in Media Watch 26 September 2016, #481 (p.8); 22 August 2016, #476 (p.11); 16 May 2016, #462 (p.18); and, 18 April 2016, #459 (p.4).

# Assisted (or facilitated) death

Representative sample of recent journal articles:

- CANADIAN FAMILY PHYSICIAN, 2017;63(3):186-190. 'Can medical assistance in dying harm rural and remote palliative care in Canada?' The authors argue that medical assistance in dying (MAiD) presents a unique set of challenges to rural and remote physicians, particularly those who endeavour to provide high-quality palliative services to patients suffering from terminal illness. As most medically assisted deaths traditionally occur in the community, there is no doubt that this intervention will be requested of Canada's rural and remote physicians. However, if these physicians are simultaneously committed to the provision of high-quality palliative care, should rural and remote GPs also be expected to provide MAiD? <a href="https://goo.gl/7lmN7Z">https://goo.gl/7lmN7Z</a>
- THE HASTINGS REPORT, 2017;47(2):7-8. 'Implementing California's law on assisted dying.' On 5 October 2015, Governor Jerry Brown approved bill ABX2 15, the End of Life Option Act, making California the fifth state in the country to allow physician-assisted dying. The law was modeled after Oregon's 1997 Death with Dignity Act. When the legislative special session ended on 10 March 10 2016, California health care providers had only ninety days to respond to the state mandate before the law would take effect on 9 June 2016. Experience with the law so far suggests several challenges with implementation. <a href="https://goo.gl/ANVZnk">https://goo.gl/ANVZnk</a>

# **Worth Repeating**

# Developing organizational guidelines for the prevention and management of suicide in clients and carers receiving palliative care in Australia

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 December 2014 –This article describes the process of developing a suicide guideline in palliative care (PC). Little literature was available, but utilizing the partnership model, a working party consulted with each discipline regarding specific requirements. The working party experienced significant challenges in creating policy that would adequately cover the diverse needs of all members of the PC team, as it was recognized that all staff needed guidance. The final guideline incorporated specific action plans for each discipline; mandatory training for all staff was endorsed through a recognized suicide alertness training program; advanced training in suicide intervention skills for key clinical staff will be required; and a 'Rapid Plan Team' was recommended. This policy development has required significant work and the combined expertise of many disciplines. [Noted in Media Watch 5 January 2015, #391 (p.5)] <a href="https://goo.gl/l9EqVX">https://goo.gl/l9EqVX</a>

## **Media Watch: Online**

#### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/dxmEdJ

N.B. Of additional interest: <a href="https://goo.gl/Q8ilBP">https://goo.gl/Q8ilBP</a> (scroll down to 'Media Watch celebrates 500th edition')

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: <u>HTTP://GOO.GL/JNHVMB</u>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <a href="https://goo.gl/JL3j3C">https://goo.gl/JL3j3C</a>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): https://goo.gl/lOSNC7

**Europe** 

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

HUNGARY | Hungarian Hospice Foundation: http://goo.gl/5d1l9K

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

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