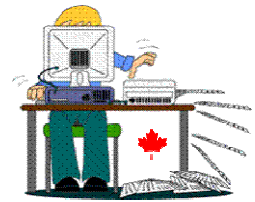


Media Watch...

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.

6 July 2015 Edition | Issue #417



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

With this issue of Media Watch, the weekly report begins its 9th year of publication.

End-of-life care for vulnerable populations: Scroll down to [Specialist Publications](#) and 'When dying at home is not an option: Exploration of hostel staff views on palliative care for homeless people' (p.11), in *International Journal of Palliative Nursing*.

Canada

Hospital kept patient alive for 10 days because family's culture did not accept brain death

BRITISH COLUMBIA (B.C.) | *The National Post* – 28 June 2015 – A Vancouver-area hospital was asked to keep a brain-dead patient's heart beating for 10 days until the person could be flown – on life support – to his country of origin – all because the family's culture [undisclosed] did not accept brain death, a British Columbia bio-ethicist has revealed. In the wake of the unusual episode, the province declined to register the death, ruling that the man "must have been alive" if he left Canada connected to a ventilator. Details of the case, which was discussed at a recent conference, are sketchy, and both hospital administrators and provincial government officials refused to fill in any of the gaps. But the situation raises questions about who should cover the cost of keeping a brain-dead person partially "alive" – and the distress that doing so could have on healthcare workers, Bethan Everett, a Vancouver Coastal Health ethicist, said in

a *précis* of her presentation. In the past, people were considered officially dead only when their hearts stopped beating. The notion of brain death, an irreversible loss of all brain function, emerged in the 1960s in response to technology that could keep the heart and lungs functioning mechanically. <http://news.nationalpost.com/health/vancouver-area-hospital-paid-to-keep-brain-dead-patient-alive-for-10-days-for-cultural-reasons>

Extract from *The National Post* report

In recent years, Canadian hospitals have repeatedly clashed with families over whether to maintain life-preserving treatment for patients considered on the verge of death or vegetative – but still actually alive. The Vancouver case was different as it involved a middle-aged man who had already been declared brain-dead...

Cont.

Noted in Media Watch, 13 April 2015, #405 (p.11):

- *SEMINARS IN NEUROLOGY*, 2015;35(2):139-144. **‘Brain death: The European perspective.’** The authors describe the considerable variations in when brain death determinations are made between and within individual European countries, and propose that they are due to differences in the end-of-life care practices in patients with irreversible brain injuries, medical attitudes, and organ donation practices. <https://www.thieme-connect.de/DOI/DOI?10.1055/s-0035-1547533>

Noted in Media Watch, 28 July 2014, #368 (p.6):

- *AMERICAN JOURNAL OF BIOETHICS*, 2014;14(8):3-8. **‘Whither brain death?’** The publicity surrounding the recent McMath and Muñoz cases^{1,2} has rekindled interest in brain death: the familiar term for human death determination by showing the irreversible cessation of clinical brain functions. It is established medical practice and laws permit it in all U.S. jurisdictions. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.925153?queryID=%24%7BresultBean.queryID%7D>
 1. ‘Jahi McMath, Ariel Sharon, and the Valley of Death,’ *Time Magazine*, 9 January 2014. Today, more and more of us face the uncanny valley of the shadow of death. It’s the domain of those like Jahi [McMath] ... who suffer grievous injury and are kept on this side of life by elaborate and increasingly heroic medical procedures. [Noted in Media Watch, 13 January 2014, #340 (p.1)] <http://content.time.com/time/magazine/article/0,9171,2162277,00.html>
 2. ‘Case of Marlise Muñoz serves as launch pad for future rulings,’ *The Daily Cougar* (Houston, Texas), 12 February 2014. Some of the Republican candidates running for Texas lieutenant governor have stated Judge Wallace was wrong to have let Muñoz be taken off life support and promised, if they were elected, to “tighten state law” to not let something like this happen again. Is it prudent to make a fixed ruling in such matters – to tie the hands of hospitals and families? [Noted in Media Watch, 17 February 2014, #345 (p.4)] <http://thedailycougar.com/2014/02/12/case-marlise-munoz-serves-launchpad-future-rulings/>

N.B. The focus of this issue of the *American Journal of Bioethics* is on brain death. Journal contents page: <http://www.tandfonline.com/toc/uajb20/current>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 29 June 2015 – **‘Doctors’ group proposes assisted death protocols in absence of rules from government.’** The nation’s most powerful doctors’ lobby – once long opposed to euthanasia in any form – is proposing its own aid-in-dying protocols that include death by lethal injection. In a draft document, the Canadian Medical Association (CMA) sets out the terms under which Canadians should qualify for assisted dying and the processes to be followed... The proposed scheme calls for several cooling off periods, or time for sober second thought. Someone seeking aid in dying would have to make two oral requests – at least 15 days apart – followed at least seven days later by a completed written request on a special declaration form. Two doctors would have to agree that the person is competent, acting voluntarily, and has made an informed decision. The patient must be informed of the “right to rescind” his or her request at any time... <http://news.nationalpost.com/news/canada/doctors-group-proposes-assisted-death-protocols-in-absence-of-rules-from-government>

Specialist Publications

‘Respecting a new right: What are physicians’ responsibilities?’ (p.15), in *BC Medical Journal*.

‘What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators’ (p.9), in *BMJ Open*.

‘Cultural influences on palliative family caregiving: Service recommendations specific to the Vietnamese in Canada’ (p.7), in *BMC Research Notes*.

U.S.A.

Recent Office of Inspector General audits of home health and hospice surveys may signal increased scrutiny on worker qualifications

LEXOLOGY | Online – 1 July 2015 – Recent audits by the Department of Health & Human Services Office of Inspector General conclude that state survey agencies in a number of states and a leading national accrediting agency serving the home health and hospice industry failed to identify a significant number of deficiencies related to worker qualifications. Based on these findings, OIG concluded that reliance on these surveyors by the Center for Medicare & Medicaid Services could be inadequate to ensure quality of care and protection of Medicare beneficiaries receiving home health, hospice and nursing facility services. regarding professional licensing, criminal background checks and training. <http://www.lexology.com/library/detail.aspx?g=567752b5-db19-4176-a0b2-75f8635e46a5>

Of related interest:

- NEW JERSEY | NJ.com – 3 July 2015 – **‘Feds audit accuses New Jersey of failing to monitor hospice workers.’** More than half of the hospice workers whose records were examined in a federal audit had failed to be screened for measles or tuberculosis, hadn’t had their health screened at all, or had no health records on file. The audit¹ ... concluded the federal government could not count on the state of New Jersey to oversee the background of hospice workers. http://www.nj.com/healthfit/index.ssf/2015/07/feds_audit_accuses_nj_of_failing_to_monitor_hospic.html
 1. ‘Centers for Medicare & Medicaid Services’ Reliance on New Jersey Licensure Requirements Could Not Ensure the Quality of Care Provided to Medicaid Hospice Beneficiaries,’ Office of Inspector General, U.S. Department of Health & Human Services, July 2015. <https://oig.hhs.gov/oas/reports/region2/21101024.asp>

Family eldercare: Survival in the “Big Apple”

NEW AMERICA MEDIA | Online – 1 July 2015 – The profile of the family caregiver in the U.S. is changing. A new study¹ ... finds that although the typical family caregiver is a woman, age 49, who takes care of a relative, caregivers are becoming as diverse as the American population. It is often assumed that “elders” and “family caregivers” are homogenous groups, but it only takes a walk down any urban block today to realize how far that is from the truth. New York City alone, for example, now has nearly 1.5 million older adults, which is growing. By 2030, there will be more older New Yorkers than elementary school children for the first time. Increasingly, family caregivers, may find themselves squeezed by their ethnic ties and cultural expectations on the one hand, and modern struggles with work, the high cost of city living and their own needs – and those of their children – on the other. <http://newamericamedia.org/2015/07/family-eldercare-survival-in-the-big-apple.php>

1. ‘Caregiving in the U.S. 2015,’ National Alliance for Caregiving, and the American Association for Retired Persons, June 2015. <http://www.caregiving.org/caregiving2015/>

Of related interest:

- RHODE ISLAND | *The Providence Journal* – 28 June 2015 – **‘Law will ease burden on caregivers.’** With the bill’s passage, caregivers will get help at a vital moment in the care of a loved one – when being released from a hospital. The legislation is part of a national campaign by American Association for Retired Persons to get states to adopt its CARE (Caregiver Advise, Record & Enable) Act. Rhode Island is now among about a dozen states that have embraced it. <http://www.providencejournal.com/article/20150628/NEWS/150629322>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *Washington Business Journal* – 2 July 2015 – ‘**DC Council committee to weigh “death with dignity.”**’ District officials will consider whether terminally ill patients should be allowed the right to die. [A proposed] bill is among a collection of end-of-life issues coming up in public hearings before the Health & Human Services Committee in advance of the D.C. Council’s upcoming summer recess. <http://www.bizjournals.com/washington/blog/2015/07/d-c-council-committee-to-weigh-death-with-dignity.html>
- CALIFORNIA | *San Gabriel Valley Tribune* (San Covina) – 29 June 2015 – ‘**Assisted suicide bill hits roadblock.**’ A high-profile bill that recently passed out of the state Senate without much trouble is facing a much tougher road in the Assembly. Senate Bill 128 would legalize physician-assisted suicide for terminally ill patients in California. The two authors of SB 128 have canceled a vote on the bill in the Assembly Health Committee because there is currently not enough support. The sponsors might be hoping that if they delay the vote long enough, the passage of time may change the minds of some committee members. Where is the opposition coming from? Hundreds of organizations and citizens are vehemently opposed to physician-assisted suicide. This includes the American Medical Association and the physicians who treat cancer patients: oncologists. <http://www.sgvtribune.com/opinion/20150629/assisted-suicide-bill-hits-roadblock-bob-huff>

International

Elder and end-of-life care in Ireland



Health Information Quality & Authority nursing home report finds improvement but room for more

IRELAND | Newstalk (Dublin) – 3 July 2015 – The Health Information Quality & Authority (HIQA) has released its annual overview of public and private nursing homes, finding there were 3,436 non-compliances registered in 2014.¹ HIQA received 5,485 legally-required notifications of “certain adverse events in nursing homes in 2014.” This figure is a 2.2% increase on 2013, when 5,362 were recorded. There were 625 notifications in relation to unexpected deaths in 2014, and 357 notifications of suspected or confirmed abuse of a resident. Over the course of the year there were four events of a member of staff at a centre being subject of review by a professional body. The authority had to issue 470 corrective actions in relation to end-of-life care, and food and nutrition. <http://www.newstalk.com/LISTEN:-HIQA-nursing-home-report-finds-improvement-but-room-for-more>

1. ‘Annual overview report on the regulation of designated centres for older people – 2014,’ Health Information Quality & Authority, June 2015 (see p.48). <http://www.hiqa.ie/publications/annual-overview-report-regulation-designated-centres-older-people-%E2%80%93-2014>

Members of the Scottish Parliament launch inquiry into “end of life” care

U.K. (Scotland) | BBC News – 2 July 2015 – Members of the Scottish Parliament (MSPs) are to launch an inquiry into the quality of palliative and end-of-life care in Scotland. It comes after problems with palliative care were highlighted during scrutiny of the Assisted Suicide Scotland bill. The bill, which would have allowed those with terminal illnesses to seek the help of a doctor to end their own life, was rejected by MSPs in May. Those who opposed the legislation said improvements should be made to palliative care instead. Holyrood’s Health Committee will be seeking views on how to provide high quality care for the terminally ill. It will also examine whether access to care varies across the country and if those with certain conditions are more likely to get support. <http://www.bbc.com/news/uk-scotland-scotland-politics-33351327>

Do not attempt to resuscitate orders: East trial could go nationwide

U.K. (England) | BBC News – 29 June 2015 – New guidelines that aim to improve end-of-life care could be issued nationwide following a trial in hospitals in the East of England. Dr. Zoe Fritz, who oversaw the project, said the current *ad hoc* arrangement often led to an “undignified death.” She wants nationwide guidelines, based on what was trialled, covering Do Not Attempt to Resuscitate Orders (DNAR). Legally, doctors do not need patient consent to issue a DNAR, but they must have consulted the patient beforehand. Dr. Fritz, a consultant physician who has studied DNARs ... said: “Different doctors have different ways of deciding when someone should be for resuscitation. The worst case is you start (to resuscitate) and someone who has had a peaceful death then wakes up briefly to find all these people around them, tubes in them, blood everywhere and then dies. And unfortunately, I’ve seen that on more than one occasion.” The number of DNAR hospital complaints in the East of England has risen from seven in 2012 to forty-five in 2014. <http://www.bbc.com/news/uk-england-cambridgeshire-33167692>

Noted in Media Watch, 19 January 2015, #393 (p.9):

- *BMJ OPEN* | Online – 13 January 2015 – ‘**Variation in local trust Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.**’ There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council (U.K.) record form (or a modification of the form). There was variation in the terminology used, which included DNAR (do not attempt resuscitation), DNACPR (do not attempt CPR), CPR, and AND (allow natural death). <http://bmjopen.bmj.com/content/5/1/e006517.full>

End-of-life care in the England

Let elderly die “surrounded by love” at home – not in hospitals, says minister

U.K. (England) | *The Telegraph* – 27 June 2015 – Elderly people should be allowed to spend the final hours of their lives at home “surrounded by love” rather than stuck on hospital wards, the minister for National Health Service [NHS] productivity has said. Lord Prior of Brampton ... called for more to be done to make sure those who choose to spend their dying days at home can be sure of the finest palliative care from the NHS. It is the strongest indication since the election that the government is preparing to use public money to improve health support dramatically for dying pensioners who reject the chance to enter care homes. The remarks came in a House of Lords debate about palliative care amid concerns the NHS is failing to provide sufficient end-of-life care for those who choose to die at home. He said NHS

England is “reviewing this whole area” and would report back later in the year – hinting the government was ready to change policy on the back of the recommendations. Should the government decide to commit more funds to providing end-of-life care at home the money would need to be found from an increasingly tight NHS budget. <http://www.telegraph.co.uk/news/health/11702137/Let-elderly-die-surrounded-by-love-at-home-not-in-hospitals-says-minister.html>

Specialist Publications

‘*One Chance to Get it Right: Understanding the new guidance for care of the dying person*’ (p.9), in *British Medical Bulletin*.

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.

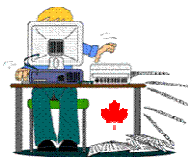
Of related interest:

- U.K. (England) | *The Solihull Observer* – 3 July 2015 – ‘**Solihull patients to receive treatment at home in final months of life as part of new pilot scheme.**’ Cancer patients across the borough will be able to receive medical treatments usually only delivered in hospital or a hospice at home as part of a groundbreaking project to improve end-of-life care. It will mean that up to ten people across Solihull who are facing their last few months of life will now be able to receive drugs called bisphosphonates through an intravenous drip, without having to travel to hospital or a hospice. <http://solihullobservers.co.uk/news/solihull-patients-to-receive-treatment-at-home-in-final-months-of-life-as-part-of-new-pilot-scheme-5651/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *Dutch News* (Amsterdam) – 3 July 2015 – ‘**Rise in euthanasia requests sparks concern as criteria for help widen.**’ Since 2002, euthanasia has been effectively decriminalised in The Netherlands, as long as certain criteria are met. The Dutch position is considered by many to be the blueprint for other countries struggling with right to die issues. <http://www.dutchnews.nl/features/2015/07/rise-in-euthanasia-requests-sparks-concern-as-criteria-for-help-widen/>
- GERMANY | *Deutsche Welle* (Bonn) – 2 July 2015 – ‘**German parliament opens debate on assisted suicide.**’ The Bundestag has begun debating on whether to expand the right to assisted suicide as some of their European neighbors have done. Four competing draft laws have been presented for consideration. <http://www.dw.com/en/german-parliament-opens-debate-on-assisted-suicide/a-18558626>
- COLOMBIA | *Colombia Reports* (Medellin) – 1 July 2015 – ‘**Colombia to proceed with euthanasia after chaos in 1st case.**’ Colombia’s Health Minister on Wednesday called for doctors to continue with euthanasia procedures after a controversial last minute suspension of the country’s first ever procedure last week. The statement gave additional guidelines surrounding the manner in which these euthanasia cases must be handled after doctors cancelled what would have been the country’s first ever procedure just 15 minutes before implementation. <http://colombiareports.com/colombia-to-proceed-with-euthanasia-after-chaos-in-1st-case/>
- *THE ECONOMIST* | Online – 27 June 2015 – ‘**Attitudes towards assisted dying.**’ In June *The Economist* and Ipsos MORI polled attitudes towards doctor-assisted dying in 15 countries. They found that majorities thought doctor-assisted dying should be legal for adults in 13 of the 15 countries polled. Western Europe was broadly more supportive than eastern Europe. Large majorities were in favour in Belgium and The Netherlands, where doctor-assisted dying is legal, and – much more surprisingly – in France and Spain, where it is not, and the Catholic church’s influence is strong. When people were asked to think about the specifics of how a life should be taken, support fell considerably, though in nine countries it remained above 50%. <http://www.economist.com/news/briefing/21656121-idea-whose-time-has-come-attitudes-towards-assisted-dying>



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

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

Culturally responsive end-of-life care

Perspectives of health care providers on U.S. South Asians' attitudes toward pain management at end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 June 2015 – A lack of research on pain management among seriously ill South Asians reveals a critical gap in the knowledge base regarding culturally responsive end-of-life care. This ... study investigated the perspectives of health care providers ... on the attitudes of U.S. South Asians toward the management of pain experienced at end of life, and the factors that influenced these attitudes. Thematic analysis of interviews and focus group discussions with 57 health care providers indicated providers perceive South Asian patients and families to be generally reluctant to use medications to treat pain experienced at end of life. Detailed description of patient-related and culturally based reasons for this reluctance is provided with implications for hospice and palliative care. <http://ajh.sagepub.com/content/early/2015/06/25/1049909115593063.abstract>

Of related interest:

- *BMC RESEARCH NOTES* | Online – 30 June 2015 – ‘**Cultural influences on palliative family caregiving: Service recommendations specific to the Vietnamese in Canada.**’ We know little about the end-of-life experiences of Vietnamese-Canadian families. Consequently, there is a lack of understanding around how to best meet the needs of Vietnamese care recipients, caregivers, and their families via the health service system, whose services of which we know they have limited access. Ten main recommendations have been vetted with service provider leaders and confirmed as being appropriate for uptake. <http://www.biomedcentral.com/1756-0500/8/280>

“First, do no harm”: A solution-focused approach to pain measurement and management

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;21(6):190-193. Asking patients to rate their pain using formal pain scoring tools can make symptoms worse, as it draws patients' attention to them. The validity of pain scoring tools is questionable. In contrast with a whole-person approach, the sensory-based paradigm that has become dominant has encouraged dualistic and ultimately reductionist approaches to pain management. A solution-focused approach to pain management concentrates on promoting whole-person well-being, with a focus on what patients hope for and can still achieve. In a solution-focused approach, success is defined as movement towards where patients want to be, building on their expertise.

N.B. Access to this article requires a subscription. Journal contents page: http://www.haywardpublishing.co.uk/year_search_revew.aspx?JID=4&Year=2015&Edition=540

[Media Watch: Back Issues](#)

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MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE

Please feel free to share this weekly report with your colleagues.
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Media Watch Archives

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- 2011, January - June
- Current

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

Lessons about dying and death from the classroom of the bedside

ANNALS OF BEHAVIORAL SCIENCE & MEDICAL EDUCATION, 2015;21(1):3-5. Medical education about care of the dying is not always conducted systematically at the patient's bedside. Unfortunately, neither life experience nor lecture style pedagogy is an adequate substitute for teaching medical students and residents about caring for the terminally ill. Obstacles to involving trainees in the bedside care of the dying include a general cultural avoidance of death, discomfort among faculty mentors when dealing with death, and uneven application of established rubrics for conveying the art of bedside care of the dying. Valuable lessons about dying and death can be taught if medical educators will model for trainees the delivery of sensitive, compassionate care of the dying and involve them in active learning by convening the "classroom of the bedside." <http://www.absame.net/annals/ojs/index.php/annals/article/view/230>

Facebook helps to get the palliative care message across to future doctors

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(4):178-181. Despite decades of educating professionals and the public, the palliative care message remains unclear; little teaching time is devoted to palliative care in undergraduate medical curricula. Three lecturers from Monash University in Melbourne, Australia, created a Facebook page complementing a one-day palliative care course undergone by all undergraduate medical students. The Facebook page helps to reach and engage students, but also to disseminate information about palliative care more widely. The Facebook page also provides an opportunity for patients and families to get involved in educating healthcare professionals.

N.B. Access to this article requires a subscription to the journal: Contents page: http://www.haywardpublishing.co.uk/year_search_revew.aspx?JID=4&Year=2015&Edition=540

Noted in Media Watch, 2 June 2014, #360 (pp.8-9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2014;311(19):1971-1972. '**Bedside teaching rounds reconsidered.**' Barriers to bedside teaching ... are insufficient time to teach, dependence of diagnosis on technology, obstacles created by infection control, and distractions from clinical responsibilities at distant computer stations. Many teachers find bedside teaching inherently difficult: <http://jama.jamanetwork.com/article.aspx?articleid=1872820>

N.B. Several articles on bedside teaching in the context of end-of-life care noted in past issues of Media Watch are listed in this issue of the weekly report.

Media Watch: Reach & Frequency

Media Watch is international in scope and reach. The weekly report is distributed via e-mail – at no cost to recipients – to 1,600-plus academics, educators and researchers; frontline health professionals; and, government policy makers and research staff. Approximately 20% of recipients reside in Canada; 20% in the U.S.; 25% in the U.K., and Eastern & Western Europe; 15% in Africa; and, 20% in the Asia-Pacific region, including Australia & New Zealand.

An informal survey in early 2014 indicated that on average each edition of Media Watch is read by between 3-5 individuals, indicating a potential readership of somewhere between 4,800 and 8,000. One palliative care association in Australia, for example, distributes the weekly report to all of its individual and institutional members.

In addition, Media Watch, or a link to the weekly report, is posted on a number of websites that serve the hospice and palliative care communities-at-large, for example, the International Association for Hospice & Palliative Care, the International Palliative Care Resource Center, and the Asia Pacific Hospice Palliative Care Network (see complete listing on p.16); it is difficult, however, to calculate with any degree of accuracy its reach via the Internet. Feedback from colleagues indicates that social media has become another factor in extending Media Watch's reach. **BRA**

What matters most for end-of-life care? Perspectives from community-based palliative care providers and administrators

BMJ OPEN | Online – 29 June 2015 – There has been little research conducted to understand the essential meaning of quality, community-based, end-of-life (EOL) care, despite the expansion of these services. The authors used interviews to explore the perceptions of providers and administrators from 14 specialised palliative care teams in Ontario, Canada. Participants were prompted with the question “What matters most for EOL care?” Data from 107 respondents were obtained and analysed, from which 40 formulated concepts emerged; these were further grouped into 9 themes. The most predominate concept was that patient’s wishes are fulfilled, cited by almost half the respondents. The most prominent themes were addressing the non-physical needs, healthcare teams’ nature of palliative care delivery, patient wishes are honoured, addressing the physical needs, preparing for

and accepting death, communication and relationship development, and involving and supporting the family. Tailoring the provision of care to consider these important elements plays a critical role in supporting a positive EOL experience for patients and families. <http://bmjopen.bmj.com/content/5/6/e007492.full>

Provider difficulties with spiritual and forgiveness communication at the end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 July 2015 – [Survey] participants ... reported the highest level of difficulty in spiritual communication when talking with family after the death of a patient, followed by conducting a spiritual history with a patient. <http://ajh.sagepub.com/content/early/2015/07/02/1049909115591811.abstract>

Of related interest:

- *CONNECT* (Oncology Nursing Society) | Online – Accessed 5 July 2015 – ‘**How can palliative care discussions occur earlier in patients’ diagnoses?**’ Our overarching goal ... is to discuss palliative care sooner in the disease trajectory and even plant the seed when patients are first diagnosed with a chronic or terminal illness. Our biggest challenge in palliative and end-of-life care is educating nurses, physicians, staff, and families. Presently, our healthcare model [in the U.S.] is medically focused, meaning the goal is to treat patients by curing and fixing everything. Crucial conversations are difficult, and physicians, nurses, and families don’t always want to discuss palliative care. Patients need to be able to make informed choices, but discussions of statistics and numbers need to be balanced with patients’ quality-of-life goals. <http://connect.ons.org/issue/june-2015/another-perspective/how-can-palliative-care-discussions-occur-earlier-in-patients%E2%80%99-diagnoses>

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

One Chance to Get it Right: Understanding the new guidance for care of the dying person

BRITISH MEDICAL BULLETIN | Online – 4 July 2015 – Following criticism of the Liverpool Care of the Dying Pathway, widely used to guide care of dying people in British health-care settings, the U.K. Government set up an independent review which in 2013 recommended that use of the LCP be discontinued. In response, the Leadership Alliance for the Care of Dying People, a coalition of a wide range of stakeholders, recently published guidance entitled *One Chance to Get it Right*.¹ This guidance contains five Priorities of Care for the dying person that are intended to guide clinical staff and will inform Care Quality Commission inspections of health-care providers. This article summarizes the background to One Chance to Get it Right and the guidance it contains. <http://bmb.oxfordjournals.org/content/early/2015/07/04/bmb.ldv030.abstract>

1. ‘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://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Where children die: Obstacles to quality end-of-life care

CLINICAL PEDIATRICS | Online – 26 June 2015 – Fifty thousand children die annually in the U.S., and 500,000 more live with chronic diseases. Nationally, after accidental/unanticipated mortalities, 5% of childhood deaths are secondary to cancer and 16% more to other chronic conditions between ages 0 and 24 years. The location of death varies depending on age, rural/urban location, and socio-economic circumstances, but the majority die in hospitals. This heterogeneous situation starkly contrasts with that for adults where the availability and delivery of end-of-life care services is more consistent. The authors discuss how and where pediatric patients die in America and identify deficiencies in their end-of-life care that remain to be remedied. <http://cpj.sagepub.com/content/early/2015/06/24/0009922815591891.extract>

Noted in Media Watch, 29 June 2015, #416 (p.12):

- *JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY*, 2015;37(5):373-377. ‘**Hospice care for children with cancer: Where do these children die?**’ Many children who die of cancer [in the U.S.] enrol in hospice programs. How frequently such children remain in hospice to die at home, or disenroll from hospice and die in the hospital, has not been described. A child’s location of death has important implications for quality of life... http://journals.lww.com/jpho-online/Abstract/2015/07000/Hospice_Care_for_Children_With_Cancer_Where_Do.7.aspx

Integration of palliative care services in the intensive care unit: A road map for overcoming barriers

CLINICS IN CHEST MEDICINE | Online – 27 June 2015 – Current evidence promotes the integration of palliative care services within the intensive care unit (ICU) setting. Palliative care [PC] bridges the gap between comfort and cure, and these services are growing in the U.S. This article discusses the benefits and barriers to integration of ICU and PC services, and a stepwise approach to implementation of PC services. [http://www.chestmed.theclinics.com/article/S0272-5231\(15\)00071-4/abstract](http://www.chestmed.theclinics.com/article/S0272-5231(15)00071-4/abstract)

Of related interest:

- *CRITICAL CARE NURSING CLINIC* | Online – 27 June 2015 – ‘**Pediatric palliative care in the intensive care unit.**’ Health care providers in the neonatal intensive care unit and pediatric intensive care unit should integrate fundamental pediatric palliative care principles into their everyday practice. [http://www.ccnursing.theclinics.com/article/S0899-5885\(15\)00040-4/abstract](http://www.ccnursing.theclinics.com/article/S0899-5885(15)00040-4/abstract)
- *CRITICAL CARE NURSING CLINIC* | Online – 26 June 2015 – ‘**Priorities for evaluating palliative care outcomes in intensive care units.**’ Evidence suggests that some aspects of intensive care unit care improve when palliative care is integrated; consensus is lacking concerning the outcomes that should be measured. [http://www.ccnursing.theclinics.com/article/S0899-5885\(15\)00036-2/abstract](http://www.ccnursing.theclinics.com/article/S0899-5885(15)00036-2/abstract)
- *CURRENT ANESTHESIOLOGY REPORTS* | Online – 30 June 2015 – ‘**Ethical challenges in caring for cancer patients in the intensive care unit: Advanced care pathways and avoidance of futility.**’ Predicting benefit and assessing futility is a process that continues throughout ICU and influences decisions such as change from curative to supportive intent. The fundamentals of collaborative communication between practitioners and patients and their families are pivotal to enhancing high quality end-of-life care. Advance care directives (ACDs) encompass these tenets and provide a template to enlist the cooperation of the patient into active planning for all possible outcomes. <http://link.springer.com/article/10.1007/s40140-015-0116-7>

Cont.

Noted in Media Watch, 22 September 2014, #376 (p.10):

- *CURRENT OPINION IN CRITICAL CARE* | Online – 17 September 2014 – ‘**Integrating palliative care in the ICU.**’ Although providing palliative care in the intensive care unit (ICU) has become a priority, the success of different methods to integrate palliative care into the ICU has varied. This review examines the current evidence supporting the different models of palliative care delivery and highlights areas for future study. http://journals.lww.com/criticalcare/Abstract/publishahead/Integrating_palliative_care_in_the_ICU_.99474.aspx

Bereavement care provision in Europe: A survey by the European Association for Palliative Care Bereavement Care Taskforce

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;21(6):185-189. The Bereavement Care Taskforce of European Association for Palliative Care (EAPC) has surveyed bereavement support within palliative care services in EAPC member countries; of the 370 services that responded, 302 provide bereavement support. The prioritisation of bereavement support as a core part of care was not evident in all palliative care services, and a substantial minority (18%) offered no bereavement support at all. Services had few bereavement-specific roles; less than two thirds formally trained their staff; only a quarter conducted formal risk assessments; and only a third applied formal policies or guidelines. To optimise support for bereaved relatives, it seems timely for the EAPC and palliative care services in Europe to formalise the planning of bereavement care. The next step for the Taskforce is to develop an EAPC statement of best practice in this area.

N.B. Access to this article requires a subscription. Journal contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=540

Dynamics in the sense of dignity over the course of illness: A longitudinal study into the perspectives of seriously ill patients

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 27 June 2015 – While there is a small group of patients for whom dignity remains unaffected by their disease experiences, most patients go through difficult times during which they struggle to maintain or regain their sense of dignity in the face of progressive loss. Three different trajectories over time could be distinguished: 1) A dynamic equilibrium in which the individual's sense of dignity was temporarily diminished followed by a return to previous levels; 2) A downward trend in which the sense of dignity was diminished with progression of the disease without a return to previous levels; and, 3) Stability in which the sense of dignity remained unaltered despite changes in circumstances. <http://www.sciencedirect.com/science/article/pii/S0020748915002047>

When dying at home is not an option: Exploration of hostel staff views on palliative care for homeless people

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 24 June 2015 – The Department of Health in the U.K. suggest that hostel staff are the most appropriate key workers for their dying homeless residents and that hostel-based palliative care may be the best way forward. However, little is known about the views of hostel staff with regard to this. Eight main themes emerged[in this study]: 1) Understanding palliative care; 2) Working with limited medical information; 3) Taking responsibility; 4) Building rapport; 5) Upholding residents' dignity; 6) Recognising physical deterioration; 7) Managing environmental challenges; and, 8) Role limitations and support needs of hostel staff. Discussion [during interviews] centred around the following four topics: 1) Policy, principles and practice of palliative care; 2) Professional boundaries as a threat to holism and a hindrance to dignity; 3) The social undesirability and invisibility of homeless people; and, 4) “community living” as a barrier to hostel-based palliative care and a new concept of family. <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2015.21.5.236>

Cont.

Noted in Media Watch, 16 February 2015, #397 (p.10):

- **DEATH STUDIES** | Online – 12 February 2015 – ‘**What constitutes a good and bad death? Perspectives of homeless older adults.**’ The themes for a good death were: 1) dying peacefully; 2) not suffering; 3) experiencing spiritual connection; and, 4) making amends with significant others. Themes for a bad death were: 1) experiencing death by accident or violence; 2) prolonging life with life supports; 3) becoming dependent while entering a dying trajectory; and, 4) dying alone. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629>

N.B. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: http://www.sophie-project.eu/pdf/ENHW_2014.pdf. Several articles on end-of-life care for the homeless are noted in Media Watch, 3 February 2014, #343 (p.4).

Dying to Talk Project

Australians with intellectual disability in the dark about death

MEDICALXPRESS | Online – 29 June 2015 – In a world-first, the Dying to Talk Project is developing a research-based toolkit to support staff and caregivers to deliver individual information to adults with intellectual disability, and discuss end-of-life planning in everyday contexts. Professor Roger Stancliffe from the University’s Centre for Disability Research & Policy said access to information about death is a fundamental human right, but those with an intellectual disability have frequently been marginalised and disempowered to make decisions about end-of-life care. “Around three per cent of the Australian population has intellectual disability and if we fail to openly discuss dying, we are setting them on a path towards a “disenfranchised” death,” said Professor Stancliffe. “It’s a common misconception that people with intellectual disability don’t know about death, but benevolent exclusion does not help a person with an intellectual disability manage their grief or cope with loss. All too often death isn’t discussed until people with intellectual disability face the end of their own life or the death of a close loved one, and this can be very traumatic, leading to prolonged grief or adding to mental health issues.” The Project is important because life expectancy for people with intellectual disability is increasing with many confronting the death of ageing parents and planning their own end of life without the support of close family. <http://medicalxpress.com/news/2015-06-australians-intellectual-disability-dark-death.html>

N.B. Dying to Talk Project website: http://sydney.edu.au/health-sciences/cdrp/projects/community_living-staff.shtml

End-of-life care in Norway

To die at home or to end life in an institution

OPEN JOURNAL OF NURSING, 2015;5(6):538-547. This study aimed to determine the main causes for the low proportion of deaths at home in Norway. A retrospective cohort study was conducted in six municipalities. This study showed how challenging it was for the family and health personnel ... in the last steps of life. However, when physical distress is under control, and when a dying patient and his significant other genuinely wish for death at home, it is necessary to control physical distress. Greater holistic well-being may then be achieved at home than in the hospital. <http://www.scirp.org/Journal/PaperInformation.aspx?paperID=57370&#abstract>

N.B. Click on ‘Download as PDF’ to access complete text.

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

Two worlds: Adolescents' strategies for managing life with a parent in hospice

PALLIATIVE & SUPPORTIVE CARE | Online – 1 July 2015 – Five stages through which adolescents [i.e., the study participants] manage their worlds [i.e., the “well world” of normal adolescence and the “ill world” of having a parent near the end of life] were identified: 1) Keeping the ill world and the well world separate; 2) Having the ill world intrude into the well world; 3) Moving between the ill world and the well world; 4) Being immersed in the ill world; and, 5) Returning to the well world having been changed by the ill world. The explanatory model of “managing two worlds” outlines a complex and nuanced process that changes over time. The model can be used by health professionals who seek to help adolescents navigate this critical time when their parents are dying or have recently died. These results can also be used to inform the development of interventions that assist families with strategies tailored to an adolescent's specific needs. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9817358&fulltextType=RA&fileId=S1478951515000735>

Understanding and managing cystic fibrosis

PRIMARY HEALTH CARE, 2015;25(6):18-24. Cystic fibrosis (CF) ... is a multi-system disease, mainly affecting the lungs and gastrointestinal tract, but also the liver, pancreas, joints, sinuses and male reproductive system. Diagnosis is commonly through screening newborns, although older children and adults are also diagnosed with CF. Treatment is daily, complex and time-consuming and, although most of it is conducted at home, there is an increasing need for hospital admission as individuals age and the disease progresses. CF is life-limiting, with no cure. However, life expectancy throughout Europe is improving thanks to early and aggressive treatment, specialist centre care and novel therapies. Of the 32,248 patients registered in Europe with CF, 49.3% are more than 18 years old, although the median age of death across Europe is 28 years ... based on the latest available figures. Children born with CF today are expected to live into their fifties and sixties. <http://journals.rcni.com/doi/abs/10.7748/phc.25.6.18.e714>

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

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(6):277-281. '**Palliative care and cystic fibrosis – the benefits of integrated working.**' Palliative care and cystic fibrosis (CF) teams can work together to provide synergistic care and treatment for CF patients and their families, and when this is done well there are huge benefits for patients and families/carers, as well as for health care professionals. Palliative care involvement for CF patients, and indeed other patients whose disease progression is complex, may benefit from being viewed as a fluid interface rather than a finite transition from one team to another.

N.B. Access to this article requires a subscription. Journal contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=540

Pathways through grief to hospice volunteering

QUALITATIVE SOCIOLOGY | Online – 1 July 2015 – Most individuals volunteer for hospice following a death in their own life. While grief can be incapacitating to individuals, bereavement can also have pro-social and life-affirming dimensions including discovering new meaning in life and developing compassion and a desire and capacity to care for others. The desire to return the care a dying family member received from hospice is frequently cited in the literature, although no study to date has systematically analyzed the diverse ways personal encounters with death bring individuals to volunteer for hospice. Drawing on in-depth interviews with volunteers from a variety of settings in the U.S. and Germany, the [author's] analysis illuminates three central processes linking experiences with death and grief to the draw to volunteer for hospice: 1) Developing and discovering caring capacities and emotional capital; 2) Transforming suffering and extending compassion through continuing bond; 3) and, Exploring and learning from grief. <http://link.springer.com/article/10.1007/s11133-015-9307-2>

Cont.

Noted in Media Watch, 30 March 2015, #403:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 26 March 2015 – ‘**Hospice volunteers: Bridging the gap to the community?**’ This article focuses on ... the place that volunteers occupy between the hospice and the community beyond its walls. External changes and pressures in society were impacting on volunteer management, but were viewed as requiring a careful balancing act to retain the "spirit" of the hospice philosophy. Honouring the developmental history of the hospice was vital to many respondents, but viewed less positively by those who wished to modernise. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12232/abstract>

N.B. Selected articles on hospice volunteers noted in past issues of Media Watch are listed in the issue of the weekly report dated 16 February 2015, #397 (pp.8-9).

Hospital executives' perceptions of end-of-life care

SAGE OPEN | Online – 25 June 2015 – This study utilized in-person interviews to explore executives' opinions and beliefs. The sample consisted of 14 individuals in the roles of medical center directors, chiefs of staff, chief medical officers, hospital administrators, hospital risk managers, and regional counsel in Arkansas, Louisiana and Texas. Hospital executives acknowledged that end-of-life care (EOL) care was a very important issue, and more attention should be paid to it in the hospital setting. Their comments and suggestions for improvement focused on 1) Current EOL care; 2) barriers to changing EOL care; and, 3) enhancing provision of EOL care in the hospital setting. The findings of this study suggest that hospital executives, although key change agents, may have insufficient EOL information to implement steps toward cultural and infrastructural change and should therefore be included in any EOL discussions and education. <http://sgo.sagepub.com/content/spsgo/5/2/2158244015590610.full.pdf>

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Media Watch: Editorial Practice

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

Distribution

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

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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.

Of related interest:

- *ASIA PACIFIC JOURNAL OF CANCER PREVENTION*, 2015;16(11):4653-4658. **'Evaluation of managerial needs for palliative care centers: Perspectives of medical directors.'** Potential barriers in providing palliative care (PC) and integrating PC into health systems were perceived as institutional by most of the doctors (97%) and nurses (96%) [that participated in the surveys]. Social barriers were reported by 54% of doctors and 82% of nurses. Barriers due to interest and knowledge of health professionals about PC were reported by 76% of doctors and 75% of nurses. An independent PC unit was suggested by 27.7% of participants and there was no difference between the hospitals [surveyed]. To overcome the barriers for integration of PC into health systems, providing education for health professionals and patient relatives, raising awareness in society, financial arrangements and providing infrastructure were suggested. http://www.apocpcontrol.org/paper_file/issue_abs/Volume16_No11/4653-4658%203.7%20Didem%20Kafadar.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BC MEDICAL JOURNAL*, 2015;57(6):248-249. **'Respecting a new right: What are physicians' responsibilities?'** A pan-Canadian strategy to improve access to high-quality palliative care is essential, as is education about palliative care and what it can do to improve the quality and quantity of life for those with a life-limiting illness. Integrating palliative care into life-limiting disease will require implementing accreditation standards for palliative care into chronic disease management. This is an opportunity for physicians to review what palliative care can do for those with advanced illness and how they can provide or access it for their patients. Canada has the opportunity to develop physician-assisted dying regulations that improve upon those in other jurisdictions and ensure safeguards are in place. Concerns about safeguards pertain to the lack of processes to assess capability, the impact of medical and mental illness on capacity, coercion as a factor in decision making, and dealing with conflict among assessing physicians. <http://www.bcmj.org/council-health-promotion/respecting-new-right-what-are-physicians%E2%80%99-responsibilities>
- *BRITISH JOURNAL OF NURSING* | Online – 25 June 2015 – **'Nurses' attitudes to assisted suicide: Socio-demographic factors.'** This literature review seeks to explore the factors that influence nurses' attitudes towards assisted suicide. A poll conducted by the Royal College of Nursing showed that 49% of nurses supported assisted suicide while 40% were opposed to it. A literature review resulted in 16 articles being identified for data synthesis using a recognised critiquing framework. The articles revealed four key themes: 1) Nursing specialty; 2) Level of education; 3) Geographical location; and, 4) Religion. These four themes are key to understanding a nurse's attitude towards assisted suicide. Nursing staff need to be aware of their own influences on this topic, since they will inevitably be involved in the process in some way or another... <http://www.magonlinelibrary.com/doi/abs/10.12968/bjon.2015.24.12.629>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(4):161. **'Assisted suicide has no place in medical care.'** Repeated surveys of British doctors have shown that the majority are opposed to the legalisation of "assisted dying," the latest euphemism for physician-assisted suicide (PAS). The general public appears to support PAS, although even its support wanes to equal numbers for and against when the facts are made clear. Only one in five doctors would be personally prepared to participate actively in causing a patient's death. Among those who support legislative change in theory, over one third would not want to participate in practice

N.B. Access to this article requires a subscription to the journal: Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=540

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/06/media-watch/>

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

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

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

Asia

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

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

Australia

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

Canada

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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

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