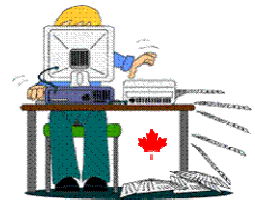


Media Watch...

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

In the face of terminal illness: Scroll down to **U.S.A.** and 'Knowing how doctors die may help patients at end of life' (p.3), broadcast on Southern California Public Radio.

Canada

The high cost of dying

ONTARIO | *The Ottawa Citizen* – 20 May 2015 – A study by an Ottawa researcher offers some new and compelling numbers about the high cost of dying.¹ In Ontario, it costs the health care system an average of \$14,000 for the last month of a person's life. In all, Ontario spends \$4.7 billion annually on final year of life care, with \$1.3 billion of that in the final month of life. Nearly 10% of the health care budget is spent on care in the last year of life. The study ... is the first to tally end of life numbers in Ontario. It also offers insight into how the health system can save millions of dollars while serving patients better. Hospitals accounted for 43% of end-of-life costs with long term care palliative services taking another 15.5%. As it happens, these are the two most expensive places to

die. In fact, Ontario takes the preferred hierarchy for end-of-life care and turns it upside down. Instead of giving the most weight to services that rate high on patient preference and cost-effectiveness, our province puts the largest portion of its end of life money into hospitals, the costliest place to die. <http://ottawacitizen.com/opinion/columnists/denley-the-high-cost-of-dying>

Specialist Publications

'Choosing Wisely Canada cancer list: Ten low-value or harmful practices that should be avoided in cancer care' (p.12), in *Journal of Oncology Practice*.

1. 'The health care cost of dying: A population-based retrospective cohort study of the last year of life in Ontario, Canada,' *PlosOne*, 26 March 2015. The study ... does not directly address quality of care; nevertheless, it can be inferred that a proportion of health care utilization near the end of life ... are potentially preventable and burdensome for the patient. [Noted in Media Watch, 13 April 2015, #405 (pp.1-2)] <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0121759>

Ontario falling short on fixing home-care mess

ONTARIO | *The Toronto Star* – 16 May 2015 – At last, Ontario Health Minister Eric Hoskins seems to get it. After nearly a year of insisting Ontario's much-criticized home-care system is performing just fine, Hoskins is now admitting that the system is an utter mess and in desperate need of fixing. He made the concession ... in unveiling a 10-point "road map" to improve home- and community-care... The program is a small, first step in the right direction, but lacks real details and falls far short of what is required to reform a system in such disarray. The most important step was taken by Hoskins when he adopted a new attitude toward home care, a key part of the overall health-care system that has suffered from severe underfunding, political neglect and too much bureaucracy. <http://www.thestar.com/opinion/commentary/2015/05/16/ontario-falling-short-on-fixing-home-care-mess-hepburn.html>

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

- ONTARIO | *The Globe & Mail* – 13 May 2015 – **“Self-directed” home-care projects planned for Ontario following scathing report.** Ontario is moving to provide some home-care clients with pots of money they could spend as they choose on various in-home health services, a model known as “self-directed care,” that would be a first in Canadian home care. <http://www.theglobeandmail.com/news/national/ontario-health-minister-expected-to-address-scathing-report-on-home-care/article24415170/>

U.S.A.

Caring for the dying, behind bars

MASSACHUSETTS | *The Boston Globe* – 21 May 2015 – Every year, more than 4,000 inmates nationwide die inside jails or prisons, and many more are in the process of dying. The implications of dying while incarcerated extend far beyond any theoretical grappling ... ethical ideals. The mortality rate behind bars is rising. As America “grays,” there is a parallel aging of the prison population, with a 234% increase in prisoners over age 55 in the past 14 years – from 43,300 in 1999 to 144,500 in 2013. According to recent data from the federal Bureau of Justice Statistics, the death rate in jails jumped 8% between 2011 and 2012, the first uptick since 2009. Deaths – mostly from heart disease and cancer – are highest among prisoners and jail detainees over age 50. As increasing numbers of prisoners require end-of-life care, states bear an inordinate financial burden – it costs at least twice as much to care for inmates over age 55 than

younger ones. In an effort to curb the tremendous expense and effort needed to care for dying inmates, some correctional systems divert end-of-life care back to communities. <http://www.bostonglobe.com/opinion/2015/05/21/caring-for-dying-in-mates/WNispkkTY8MoI6zYP8tSRO/story.html>

Prison Hospice Backgrounder

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

Of related interest:

- ILLINOIS | WIFR News (Rockford) – 20 May 2015 – **‘Findings of report on medical care in Illinois prisons.’** A new report by a court-approved medical panel sharply criticizes health care at Illinois prisons, though the state Department of Corrections disputes many of its conclusions. Among its findings: Some terminally ill inmates sign do-not-resuscitate orders but suffer needlessly from the inattention of staff. The report says, “do not resuscitate” does not mean, “do not treat.” <http://www.wifr.com/home/headlines/Findings-of-Report-on-Medical-Care-in-Illinois-Prisons-304433071.html>

Knowing how doctors die may help patients at end of life

CALIFORNIA | Southern California Public Radio (Pasadena) – 19 May 2015 – Los Angeles doctor Ken Murray first started thinking about how doctors die roughly ten years ago, when a physician he knew passed away. “He had died at home and it occurred to me I couldn’t remember any of our colleagues ... who had actually died in the hospital,” he says. “That struck me as quite odd because I know that most people do die in hospitals.” Murray then began talking about it with other doctors. “And I said, ‘Have you noticed this phenomenon?’” he recalls. “They thought about it and they said, ‘You know? You’re right.’” Five years later, the retired family practice physician shared his observations in an article...¹ It quickly went viral. In it, Murray told the world that doctors don’t typically die like the rest of us and he doesn’t plan to, either. “I fit with the vast majority of physicians that want to have a gentle death and don’t want extraordinary measures taken when they have no meaning,” he says. Stanford University Medical School published a study showing a similar finding: 88% of 1,081 doctors surveyed said they would not want aggressive treatment or resuscitation if facing a terminal disease.² Murray and others say that many Americans might alter their approach to end-of-life care if they were aware most doctors feel this way. <http://www.scpr.org/news/2015/05/19/51633/knowning-how-doctors-die-may-help-patients-at-end-o/>

1. ‘How doctors die: It’s not like the rest of us, but it should be,’ Zócalo Public Square, 30 November 2011. <http://www.zocalopublicsquare.org/2011/11/30/how-doctors-die/ideas/nexus/>
2. ‘Do unto others: Doctors’ personal end-of-life resuscitation preferences and their attitudes toward advance directives,’ *PLOS ONE*, 28 May 2014 [Noted in Media Watch, 2 June 2014, #360 (p.11)] <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0098246>

Physician perspectives on end-of-life care

‘How doctors die: Showing others the way,’ *The New York Times*, 19 November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.5)] <http://www.nytimes.com/2013/11/20/your-money/how-doctors-die.html>

‘How to die like a doctor,’ *Forbes*, 7 March 2012. [Noted in Media Watch, 12 March 2012, #244 (p.3)] <http://www.forbes.com/sites/carolynmccclanahan/2012/03/07/how-to-die-like-a-doctor/>

‘Doctors do die differently...,’ *Forbes*, 2 March 2012. [Noted in Media Watch, 5 March 2012, #243 (p.2)] <http://www.forbes.com/sites/carolynmccclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/>

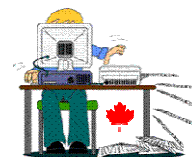
‘How doctors choose to die,’ *The Guardian* (U.K.), 19 February 2012. [Noted in Media Watch, 27 February 2012, #242 p.8] <http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors>

‘Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine’s big taboo,’ *The Daily Mail* (U.K.), 14 February 2012. [Noted in Media Watch, 27 February 2012, #242 (p.8)] <http://www.dailymail.co.uk/health/article-2100684/Why-doctors-like-die-endure-pain-treatment-advanced-cancer.html>

‘What doctors know – and we can learn – about dying,’ *Time Magazine*, 16 January 2012. [Noted in Media Watch, 23 January 2012, #237 (p.2)] <http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit>

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>



Ending “the war” and giving up “the fight”: How *not* to talk about cancer

MASSACHUSETTS | WBUR News (Boston) – 18 May 2015 – A new theme in medicine has emerged: How to talk about dying. As a field, oncology has been at the forefront of this movement. Some suggest making exposure to end-of-life encounters mandatory during medical school. Others stress creating systems and providing more resource for patients and doctors to encourage earlier planning for death. But in order to facilitate and advance this difficult conversation, we must first change the very words we use to discuss cancer. When the National Cancer Act was signed in 1971, our nation’s political and social will was focused on a “war on cancer.” Our widespread use of this language is rooted in a propagandist history promoting the belief that, with enough resources, this is a conflict we will win. Consequently, victory became defined only by “defeating cancer,” or finding a cure. A visit to the American Cancer Society website asks

you to join the “fight against cancer”; and a majority of public cancer-related media is packed with more war imagery. While the war description of cancer has resulted in unprecedented attention and fundraising for cancer care, research and survivorship, a balance should be reached between these successful efforts and language that is a realistic assessment of what can be accomplished today, for the patient, right now. <http://commonhealth.wbur.org/2015/05/ending-war-cancer-language>

Specialist Publications

‘Dying for advice: Code status discussions between resident physicians and patients with advanced cancer – A national survey’ (p.14), in *Journal of Palliative Medicine*.

Noted in Media Watch, 10 November 2014, #383 (p.8):

- U.K. | *The Independent* – 3 November 2014 – ‘**Mind your language: “Battling” cancer metaphors can make terminally ill patients worse.**’ Media portrayals of cancer as a “battle to be fought” are leading to feelings of failure and guilt among terminally ill patients, experts in language and end-of-life care have said. <http://www.independent.co.uk/life-style/health-and-families/health-news/mind-your-language-battling-cancer-metaphors-can-make-terminally-ill-patients-worse-9836322.html>

Of related interest:

- *THE WALL STREET JOURNAL* | Online – 18 May 2015 – ‘**How doctors deliver bad news.**’ Doctors are trying new ways of solving an old problem – how to break bad news, which is as much a staple of doctors’ lives as ordering blood work and reviewing scans. Research into the effectiveness of training doctors in how to deliver bad news has turned up mixed results, with patients often not noticing the benefits. <http://www.wsj.com/articles/how-doctors-deliver-bad-news-1431970796>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | ABC News – 20 May 2015 – ‘**California Medical Association changes aid-in-dying position.**’ The Association, which for decades has been against a law allowing physicians to help patients with terminal illnesses die, announced that it has become the first state medical association in the U.S. to change this position. “As physicians, we want to provide the best care possible for our patients. However, despite the remarkable medical breakthroughs we’ve made and the world-class hospice or palliative care we can provide, it isn’t always enough,” said California Medical Association President Dr. Luther Cobb. “The decision to participate in the End of Life Option Act is a very personal one between a doctor and their patient, which is why CMA has removed [its] policy that outright objects to physicians aiding terminally ill patients in end of life options.” <http://abcnews.go.com/Health/california-medical-association-aid-dying-position/story?id=31172740>

International

End-of-life care in New Zealand

\$76.1 million more for palliative care and hospices

NEW ZEALAND | Scoop (Wellington) – 21 May 2015 – An extra \$76.1 million will be invested over four years to provide more hospice and palliative care services ... Health Minister Jonathan Coleman says. In 2013, more than 15,000 people received care and support from hospice services throughout New Zealand, and hospice staff made over 145,000 home visits. Just over 20% of people using hospice services were under 60 and three-quarters had a cancer-related disease. The Government announced the additional investment over four years to support hospices during the election campaign last year. From 1 July 2015, \$13 million is being allocated each year to help hospices expand their community palliative care services so they can better support terminally ill people at home and in aged-care facilities. An additional \$3.1 million in 2015/2016, rising to \$7 million from 2016/2017, will support the recruitment of 60 new nurse specialists, palliative care educators and other roles at hospices. <http://www.scoop.co.nz/stories/PA1505/S00328/761m-more-for-palliative-care-and-hospices.htm>

Noted In Media Watch, 17 November 2014, #384 (p.5):

- NEW ZEALAND | Radio New Zealand (Wellington) – 10 November 2014 – ‘**Call for more focus on end-of-life care.**’ Medical specialists say New Zealand is in the grip of a workforce crisis in palliative care, with 55 palliative care specialists, 42 of whom are working full time. The Palliative Medicine Training & Coordination Committee says a stock take ... shows 12 positions are vacant and 18 more vacancies will occur with five years from retirement. <http://www.radionz.co.nz/news/national/259060/call-for-more-focus-on-end-of-life-care>

Health professionals launch Wirral End-of-Life Care Charter

U.K. (England) | *The Wirral Globe* – 20 May 2015 – A Wirral End-of-Life Charter setting out 12 pledges of care people can expect to receive when they are terminally ill has been officially launched.¹ The charter has been introduced following a damning independent review of the so-called Liverpool Care Pathway (LCP) for end-of-life patients.² The LCP approach to care for the dying, developed at the Marie Curie Hospice Liverpool and the Royal Liverpool University Hospital in the late 1990s, was supposed to mean doctors could stop treatment if it would result in a more comfortable death, or withdraw food and drink if patients declined it. But ministers announced in 2013 that the LCP would be phased out after an independent review uncovered evidence of abuse – including patients being unnecessarily sedated and denied food and water. Instead, every patient would in future receive individual end of

life care plans, following the inquiry led by Baroness Julia Neuberger. Health professionals throughout the country are creating their own guidelines in response to the recommendations made by the Neuberger Review. The local charter is supported by Wirral End-of-Life & Palliative Care Partnership Group, and Cheshire & Merseyside Palliative and End-of-Life Care Clinical Network... http://www.wirralglobe.co.uk/news/12960682_Health_professional_launch_Wirral_End_of_Life_Care_Charter/

Specialist Publications

‘Life after the Liverpool Care Pathway (LCP): A qualitative study of critical care practitioners delivering end-of-life care’ (p.10), in *Journal of Advanced Nursing*.

1. ‘Wirral End-of-Life Charter: Care, Kindness & Understanding.’ http://www.cmcsenate.nhs.uk/files/8714/3171/0511/wirral_end_of_life_care_charter_march_2015.pdf

Cont.

2. 'Review of Liverpool Care Pathway for dying patients,' Department of Health, 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

End-of-life care in England

Dying without dignity

U.K. (England) | Parliamentary & Health Service Ombudsman Report – 19 May 2015 – By definition, the Ombudsman only sees those cases it has not been possible to resolve locally. However, its casework adds insight into what goes wrong in the most complex cases and what learning there might be for the National Health Service (NHS) to prevent similar situations occurring again. Its casework shows there is a need for the NHS to get better at: 1) recognising people are dying – cases in this report show if clinicians better recognise the risk of approaching death, important conversations can take place to establish the patient's preferences, needs can be assessed and planned for, and crisis interventions can be avoided; 2) making sure symptoms are properly controlled – the greatest fear expressed by people about dying is being in pain. Yet with good care it is unusual for pain not to be controlled acceptably. This report illustrates some clinicians need to be more confident with established good practice, such as the skilled use of morphine and other opiate drugs; 3) communicating with people, their families and each other – cases in this report show health care professionals need to be supported to be better at having open discussions about care towards the end of life. There is a need to

communicate in a way both sensitive but also makes clear the prognosis and what options there are for care based on the outcomes individuals may want for themselves. Patients, but also their families, should have opportunities to discuss their concerns and fears; 4) providing out of hours services – casework shows the harrowing results when patients cannot get the services they need. For the benefit of their comfort, dignity and wellbeing, all in need should have access to specialist palliative care services whenever they need it; and, 5) making sure service delivery and organisation help people have a good death – the importance of linking up people with services and ensuring the service they do receive is timely and appropriate is clear from the cases in this report. http://www.ombudsman.org.uk/_data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf

Specialist Publications

'The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012' (p.13), in *Palliative Medicine*.

Representative sample of media coverage of the Ombudsman report:

- *The Independent*, 20 May 2015. **'Many have a fear of dying – this report shows why.'** <http://www.independent.co.uk/voices/many-have-a-fear-of-dying--this-report-shows-why-10262052.html>
- *The Times*, 20 May 2015. **'Scandal of "appalling" end-of-life National Health Service care.'** <http://www.thetimes.co.uk/tto/health/news/article4445579.ece>

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. | *The Guardian* – 18 May 2015 – **‘Few Britons discuss dying or make plans in event of their death, finds survey.’** Few Britons have discussed their death ... according to a [recent] survey. While more than 30% of people think about their death at least once a week, nearly three-quarters believe fellow Britons are uncomfortable discussing dying and bereavement, according to a poll by the Dying Matters Coalition... A mere 7% had discussed what sort of care they might want if they are unable to make their own decisions, while only 18% said they had spoken to a family member about the way they might want to end their life. <http://www.theguardian.com/lifeandstyle/2015/may/18/few-britons-discuss-dying-and-plans-after-their-death-finds-survey>
- U.K. | *The Independent* – 18 May 2015 – **‘While medicine gets better, dying gets worse: Doctors are so good at saving lives that we forget about death.’** Our desertion of the dying is a relatively modern phenomenon. At the start of last century, doctors had so little up their sleeves with which to do their doctoring that much of what they did was palliate, tend to the dying. But during the 20th century things changed. There were enormous and rapid social, economic and medical advances, and as a consequence the average human life span almost doubled. We doctors quickly became good at something that we had never been good at before: saving lives. The trouble is, so good have we become at life-saving, and so reliant on the increasing sophistication of medical science in everything we do, that we seem to have forgotten that in every life there will come a point where it is un-saveable. We are all going to die. <http://www.independent.co.uk/voices/comment/while-medicine-gets-better-dying-gets-worse-doctors-are-so-good-at-saving-lives-that-we-forget-about-death-10257927.html>

Noted in Media Watch, 13 April 2015, #405 (p.5):

- U.K. (England, Northern Ireland & Wales) | BBC News – 8 April 2015 – **‘End-of-life care for terminally ill “needs major overhaul.”** The U.K.’s care system for dying patients with terminal illnesses is lacking and needs a major overhaul, says a damning new report.¹ According to London School of Economics researchers, more than 100,000 people a year who would benefit from palliative care are not getting it. <http://www.bbc.com/news/health-32201594>

1. ‘Equity in the provision of palliative and end of life care in the U.K.: Review,’ Personal Social Services Research Unit, London School of Economics & Political Science, April 2015. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

End-of-life care in Australia

Dying at home: Thousands of Victorians unable to receive community-based palliative care, while hospitals attract funding

AUSTRALIA (Victoria) | ABC News (Melbourne) – 18 May 2015 – Fifteen-thousand Victorians ... receive palliative care in their own homes, which is subsidised according to their needs and the funding restraints of service providers. A majority of palliative care funding is spent at hospital – approximately 70%. Palliative Care Victoria estimates the cost of caring for a chronically or terminally ill person in hospital is between 40 and 300% higher for the taxpayer. Chief executive of Palliative Care Victoria, Odette Waanders, says there is an urgent need for investment in community-based palliative care as a viable alternative to hospital care. Aside from it being substantially more expensive for the Government to house chronically ill people in hospitals and nursing homes, it is also against the desires of most Victorians. A recent auditor-general report into palliative care found that 70% of terminally ill Victorians wish to die at home, yet only 14% do.¹ <http://www.abc.net.au/news/2015-05-18/home-based-palliative-care-limited-by-funding/6473178?section=vic>

1. ‘Palliative Care,’ Victorian Auditor-General, 2015 [Noted in Media Watch, 2015, #406 (p.5)] <http://www.audit.vic.gov.au/publications/20150415-Palliative-care/20150415-Palliative-care.pdf>

End-of-life care in Ireland

Patients “disempowered” at point of death, says Senator John Crown

IRELAND | *The Irish Times* (Dublin) – 18 May 2015 – A lack of investment in palliative care services means many people are being “disempowered” at the point of death, according to a cancer specialist who is also a Senator. Professor John Crown said a lack of co-operation between hospitals and hospices was making it more difficult to provide top-notch end-of-life care. “We see it too often in hospitals all around the country that patients are disempowered at the point of death. Often hospitals are not hospice friendly,” said the Independent Senator. “Some see their duty as being done where the patient has survived a medical crisis, and the links and pathways to hospice care are not suitably explored. The patients of cardiologists, geriatricians, neurologists and other specialities need to have the same access to specialist hospice and palliative services that cancer patients do.” His thoughts largely echo the findings of a report from the Irish Hospice Foundation last December which found two-thirds of Irish people wishing to die at home were not facilitated in doing so.¹ <http://www.irishtimes.com/news/health/patients-disempowered-at-point-of-death-says-senator-john-crown-1.2215993>

1. ‘Enabling More People to Die at Home...’ The Irish Hospice Foundation, December 2014. [Noted in Media Watch, 8 December 2014, #387 (p.5)] <http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf>

Noted in Media Watch, 28 October 2013, #329 (p.5):

- IRELAND | *The Irish Times* (Dublin) – 22 October 2013 – **‘Lack of hospice beds leaves terminal patients out in the cold.’** More than a decade ago a report from the National Advisory Committee on Palliative Care recommended there should be one hospice bed per 10,000 of the population. According to the latest report from the Irish Hospice Foundation, just “just two regions come close to fulfilling government policy.”¹ <http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194>
 1. ‘Access to Specialist Palliative Care Services...’ The Irish Hospice Foundation, 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

End-of-life care in India

Palliative care in villages

INDIA (Bangalore) | *The Deccan Herald* (Bengaluru) – 16 May 2015 – The Kurian Foundation and Bangalore Baptist Hospital have joined hands to provide palliative care services to villages in Devanahalli Taluk in Bengaluru Rural district. Two palliative care teams, comprising of a specialised and trained doctor, nurses and a counsellor, visit patients at home within a radius of 25 km from the hospital covering the city and villages in the limits of Bangalore Rural district. Continuous support is provided through a 24-hour helpline. Every month ... as many as 130 patients receive palliative care. The need of the hour is to provide expanded cover to over 200 villages of Devanahalli Taluk in the next two years and 900 villages in Bengaluru Rural district within the next five years. <http://www.deccanherald.com/content/477984/palliative-care-villages.html>

Of related interest:

- INDIA | *The Times of India* – 19 May 2015 – **‘India needs a complete law on “end-of-life” care.’** India does not have a comprehensive legal framework that lets patients and families take control of their last days and do the right things. As a default option, doctors tend to follow the safest option, which is to do nothing. As a society we avoid discussing an issue that affects all of us and leads to unnecessary trauma, prolonged grief and a huge wastage of scarce resources. Remember most individuals, especially in cities die in hospital, not at home. <http://timesofindia.indiatimes.com/india/India-needs-a-complete-law-on-end-of-life-care/articleshow/47336216.cms>

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

A survey of older peoples' attitudes towards advance care planning

AGE & AGEING, 2015;44(3):371-376. Seventeen per cent [1,823] of the respondents had prepared an advance care planning (ACP) document, of whom 4% had completed an Advance Decision to Refuse Treatment. Five per cent of respondents stated they had been offered an opportunity to talk about ACP. Predictors of completing an ACP document included: 1) being offered the opportunity to discuss ACP; 2) older age; 3) better physical function; and, 4) male gender. Levels of trust were higher for families than for professionals. Preferences were for informal discussions with family rather than professionals. <http://ageing.oxfordjournals.org/content/44/3/371.abstract>

Of related interest:

- *RESEARCH ON AGING* | Online – 22 – May 2015 – ‘**Future time perspective and end-of-life planning in older adults.**’ This study explores the extent to which cognitive processes, specifically perceptions of one’s distance to death, are associated with informal and formal advance care planning ... Persons who perceive remaining life span to be expansive or limited have significantly lower odds of formally planning for the end of life, relative to those in the middle category. Death anxiety and having a family confidante partially explain these associations. <http://roa.sagepub.com/content/early/2015/05/21/0164027515585172.abstract>

Therapeutic education in improving cancer pain management: A synthesis of available studies

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 May 2015 – Recent studies indicate a growing interest in evaluating patients’ skills and attitudes; these include satisfaction with cancer pain treatment, patient-reported improvement, and patient participation – all of which could be dependable benchmarks for evaluating the effectiveness of educational programs. Besides pain measurement, recent studies advance support for the importance of assessing newly developed outcome criteria. In this sense, patients’ active participation and decision making in their pain management are probably the most relevant goals of pain education. <http://ajh.sagepub.com/content/early/2015/05/18/1049909115586394.abstract>

The preferences and perspectives of family caregivers towards place of care for their relatives at the end of life. A systematic review and thematic synthesis of the qualitative evidence

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 19 May 2015 – Home is often reported as the preferred place of care for patients at the end of life. The support of family caregivers is crucial if this is to be realised. However, little is known about their preferences. A greater understanding would identify how best to support families at the end of life, ensuring more patients are cared for in their preferred location. Eighteen studies were included... Two themes were identified. 1) Preferences and perspectives: most family caregivers preferred home care, although a range of perspectives were reported. Both positive and negative perspectives of home, hospices and hospitals emerged. At times, family caregivers reported feeling obligated to provide home care. 2) Impact of facilitating home care; both positive and negative effects on family caregivers were reported. <http://spcare.bmj.com/content/early/2015/05/19/bmjspcare-2014-000794.abstract>

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

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

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 20 May 2015 – **‘Place of death of people living with Parkinson’s disease: A population-level study in 11 countries.’** The proportion of deaths in hospital ranged from 17% in the U.S. to 75% in South Korea. Hospital was the most prevalent place of death in France (40%), Hungary (60%), and South Korea; nursing home in New Zealand (71%), Belgium (52%), U.S. (50%), Canada (48%), and Czech Republic (44%); home in Mexico (73%), Italy (51%), and Spain (46%). The chances of dying in hospital were consistently higher for men (Belgium, France, Italy, U.S., Canada), those younger than 80 years (Belgium, France, Italy, U.S., Mexico), and those living in areas with a higher provision of hospital beds (Italy, U.S.). In several countries a substantial proportion of deaths from Parkinson’s disease (PD) occurs in hospitals, although this may not be the most optimal place of terminal care and death. Unless place of death becomes a major focus for quality end-of-life care persons with serious progressive illnesses, such as those who suffer from PD, will continue to need to rely on hospitals for terminal care. <http://www.biomedcentral.com/content/pdf/s12904-015-0021-3.pdf>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 May 2015 – **‘Caregiver expectations: Predictors of a worse than expected caregiving experience at the end of life.’** Of the 1,628 active caregivers for people at the end of life (i.e., study participants), almost half (48.3%) reported a worse or much worse than expected experience. This was associated with gender and with level of care provided. Women who provided daily hands-on care were significantly more likely to have a worse than expected experience compared with women who provided intermittent care or rare care. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00239-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00239-0/abstract)

Let’s stop “staging” persons who are coping with loss

ILLNESS, CRISIS & LOSS | Online – 21 May 2015 – This article offers a critical analysis of Elisabeth Kübler-Ross and David Kessler’s *On Grief & Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. The goal is to delineate the strengths and limitations of the book’s ostensible framework. Although the five stages of grief are described in Chapter 1, they play little role thereafter. Further, readers are told these stages are neither universal nor linear. Consequently, it would be desirable to stop staging persons who are coping with loss or at least be extremely cautious in using this stage-based model in appreciating their unique journeys. <http://icl.sagepub.com/content/early/2015/05/20/1054137315585423.abstract>

Of related interest:

- *JOURNAL OF ADVANCED GENERALIST SOCIAL WORK PRACTICE*, 2015;12(1):20-25. **‘Coping strategies of parentally bereaved children.’** Coping is a skill that can be developed in children when the social environment gives them support. Coping can also relate to resiliency. http://www.springfieldcollege.edu/Assets/pdfs/ssw/SSWJournal_vol12_1.pdf

N.B. Scroll down to p.20.

Life after the Liverpool Care Pathway (LCP): A qualitative study of critical care practitioners delivering end-of-life care

JOURNAL OF ADVANCED NURSING | Online – 13 May 2015 – The LCP was widely used with an aim to improve communication and care for dying individuals and their relatives. However, widespread media criticism prompted a review, which resulted in the discontinuation of the LCP across U.K. clinical settings.¹ Three key themes emerged: 1) “lessons learned”; 2) “uncertainties and ambivalences”; and, 3) “the future.” Critical care practitioners reported life after the LCP ... often involved various clinical ambivalences, uncertainties and inconsistencies in the delivery of end-of-life care (EOLC), especially for less experienced practitioners. They had “become accustomed” to the components of the LCP, which still guide them in principle to ensure quality EOLC.

Cont.

The LCP's format was perceived to be a useful clinical tool, but was criticized as a "tick-box exercise," and for lacking family involvement. Despite experienced practitioners being able to deliver quality EOLC without using the LCP, junior nursing and medical staff need clear guidelines and support from experienced mentors in practice. Evidence-based guidelines related to family involvement in EOLC planning in critical care settings are needed to avoid future controversies. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12680/abstract;jsessionid=0BD5CAB39B38E9261F3DAD2B89443C3E.f02t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

1. 'Review of Liverpool Care Pathway for dying patients,' Department of Health, 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 18 May 2015 – ‘**Effectiveness of the LCP for the dying in residential care homes: An exploratory, controlled before-and-after study.**’ When implemented with adequate staff training and support, the LCP may be a useful tool for providing end-of-life care of elderly people at the end of life in non-cancer settings. <http://pmj.sagepub.com/content/early/2015/05/18/0269216315588007.abstract>

Noted in Media Watch, 11 May 2015, #409 (p.6):

- *BMC PALLIATIVE CARE* | Online – 9 May 2015 – ‘**Development of the care programme for the last days of life for older patients in acute geriatric hospital wards: A phase 0-1 study according to the Medical Research Council Framework.**’ The effects of the LCP have never been investigated in older patients dying in acute geriatric hospital wards and its content and implementation have never been adapted to this specific setting. Moreover, the LCP has recently been phased out in the U.K. hospitals. For that reason, this study aims to develop a new care programme to improve care in the last days of life for older patients dying in acute geriatric wards. <http://www.biomedcentral.com/content/pdf/s12904-015-0025-z.pdf>

Noted in Media Watch, 23 February 2015, #398 (pp.14-15):

- *PALLIATIVE MEDICINE* | Online – 17 February 2015 – “**Less ticking the boxes, more providing support**”: **A qualitative study on health professionals’ concerns towards the Liverpool Care of the Dying Pathway.**’ The authors explore views of professionals who, during the implementation of the Italian version of the LCP, voiced or showed concerns towards it. Furthermore, difficulties were reported which were not linked to the programme but rather to end-of-life care. <http://pmj.sagepub.com/content/early/2015/02/14/0269216315570408.abstract>

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Please feel free to share this weekly report with your colleagues.
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MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care

Download the complete issue (PDF 450 KB)

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

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

Choosing Wisely Canada cancer list: Ten low-value or harmful practices that should be avoided in cancer care

JOURNAL OF ONCOLOGY PRACTICE, 2015;11(3):e296-e303. Choosing Wisely Canada, modeled after Choosing Wisely in the U.S., is intended to identify low-value or potentially harmful practices relevant to the Canadian health care environment. A Task Force convened by the Canadian Partnership Against Cancer included physician representation from the Canadian Society of Surgical Oncology, Canadian Association of Medical Oncologists, and Canadian Association of Radiation Oncology... Sixty-six potentially relevant cancer-related practices were identified. The long list (41 practices) was reduced to a short list of 19 practices. Of the 10 practices on the final list, five are completely new, and five are revisions or adaptations of practices from previous U.S. society lists. Using knowledge translation and exchange efforts, this list should empower patients with cancer and physicians to assist in a targeted conversation about the appropriateness and quality of individual patient care. <http://www.jop.ascopubs.org/content/11/3/e296.abstract>

Hospital palliative care support teams in France: A nationwide descriptive study

MÉDECINE PALLIATIVE | Online – 23 May 2015 – Hospital palliative care support teams have been widely developed in France since 1987. However, very few studies have been conducted to evaluate and measure this development... This study shows that in France, hospital palliative care support teams face many challenges with limited resources. Although these transversal services have a great potential for disseminating the palliative care approach in various settings this study raises important questions regarding the effectiveness and the sustainability of small and isolated teams. <http://www.sciencedirect.com/science/article/pii/S1636652215000409>

N.B. French language article

The moral courage of nursing students who complete advance directives with homeless persons

NURSING ETHICS | Online – 14 May 2015 – Before meeting with homeless persons, participants [in this study] reported that they expected to experience two fears and a challenge: fear of behaving in ways that a homeless person would deem inappropriate, fear of discussing a homeless person's dying and death, and the challenge of adequately conveying the advance directive's meaning and accurately recording a homeless person's end-of-life wishes. In contrast, after their meetings with homeless persons, relatively few participants reported having encountered those obstacles. So, while participants required moral courage to assist homeless persons with advance directives, they required greater moral courage as they anticipated their meetings than during those meetings. The authors' findings cannot be generalized, but portions of their approach are likely to be transferable to similar social contexts. For example, because homeless persons are misunderstood and marginal-

ized throughout the U.S., the authors' design for training nursing students to provide this service is also likely to be useful across the U.S. Internationally, however, it is not yet known whether the participants' fears and the challenge they faced are experienced by those who assist homeless persons or members of other vulnerable populations in documenting healthcare wishes <http://nej.sagepub.com/content/early/2015/05/13/0969733015583926.abstract>

Extract from *Nursing Ethics* article

The authors' study breaks new ground at the intersection of nursing, moral courage, and advance directives. It might also have important implications for how to improve the training that U.S. nursing students receive before they provide this service.

Cont.

Noted in Media Watch, 16 March 2015, #401 (p.10):

- *PALLIATIVE MEDICINE* | Online – 11 March 2015 – ‘**Chronically homeless persons’ participation in an advance directive intervention: A cohort study.**’ Participants were more likely to complete an advance directive if they reported thinking about death on a daily basis, believed thinking about their friends and family was important, or reported knowing their wishes for end-of-life care but not having told anyone about these wishes. A counselor-guided intervention can achieve a high rate of advance directive completion among chronically homeless persons. <http://pmj.sagepub.com/content/early/2015/03/05/0269216315575679.abstract>

Careful considerations in end-of-life care

NURSING & RESIDENTIAL CARE, 2015;17(6). Keeping a focus on “care” is imperative. Staff providing end-of-life care in a care home may be taking on the role of a resident’s family member, providing emotional support in addition to other duties. Where there are family or friends, these visitors too may need support. It is no surprise that care work is sometimes talked about as “emotional labour.” Recognising that staff may feel bereaved or distressed is part of a manager’s many jobs. Managers themselves need support, as they are also likely to have known the resident and their family, as well as having responsibilities for staff support. “Who supports the supporters?” is one question we are left to consider when thinking about end-of-life care. Key points: 1) Providing end-of-life care is likely to be a core part of a care home’s business. There are various definitions; therefore, it is helpful to find out what a person means by this term; 2) It is important for new residents and their family members to know what the care home offers in terms of end-of-life care; 3) Staff should be helped to understand what is meant by end-of-life care in the care home environment, and why early identification of people approaching end of life may be helpful to all concerned with their care and support; 4) Care homes should offer bereavement care to staff, as well as residents; and, 5) Care home managers themselves may need support when working in a care home providing end-of-life care. <http://eprints.kingston.ac.uk/31619/1/Vandrevala-T-31619.pdf>

Of related interest:

- *NURSING ETHICS*, 2015;22(2):176-187. ‘**Ethical challenges when caring for dying children.**’ The essence of caring for dying children was likened to a musically attuned composition, comprising five constituents: 1) Presence; 2) Self-knowledge; 3) Injustice in dying; 4) Own suffering; and, 5) In need of others. In this study, presence was found to be a prerequisite for caring when a child is dying. Self-knowledge and support from others can be of help when struggling with emotional pain and injustice. Emotional pain and suffering accompanied caring ...but, an atmosphere in which it is possible to give and get support from colleagues and to have time to grieve and time to focus on the patient’s needs may ease the burden, as can having time to process thoughts about life and death, and a possibility to grow in self-knowledge. <http://nej.sagepub.com/content/22/2/176.abstract>

The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012

PALLIATIVE MEDICINE | Online – 19 May 2015 – Studies ... have suggested inequality of hospice provision with respect to factors such as age, diagnosis and socio-economic position. How this has changed over time is unknown. The annual number of hospice deaths increased from 17,440 in 1993 to 26,032 in 2012, accounting for 3.4% of all deaths in 1993 and 6.0% in 2012. A total of 50.6% of hospice decedents were men; the mean age was 69.9 years. The likelihood of hospice decedents being in the oldest age group increased over time. Just 5.2% of all hospice decedents had non-cancer diagnoses, though the likelihood of non-cancer conditions increased over time. The likelihood of hospice decedents being resident in the least deprived quintile increased over time. The increase in non-cancer conditions among hospice decedents is encouraging although absolute numbers remain small. Deprivation trends are concerning and require further exploration. <http://pmj.sagepub.com/content/early/2015/05/06/0269216315585064.abstract>

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 May 2015 – **‘Evaluation of the patterns of care provided to patients with COPD compared to patients with lung cancer who died in hospital.’** The authors compared the end-of-life care provided patients with chronic obstructive pulmonary disease [COPD] versus patients with lung cancer who died in hospital over a 12-month period in the authors’ institution [the Gold Coast University Hospital, Queensland, Australia]. Patients with COPD received less palliative care services ... and underwent more diagnostic tests and received more life-prolonging measures. <http://ajh.sagepub.com/content/early/2015/05/15/1049909115586395.abstract>

Conditions of palliative home care: The case of family physicians in Switzerland

PRIMARY HEALTH CARE, 2015;5(1). Aim of this article is to identify, how family physicians (FPs) can be supported in palliative home care in Switzerland by the availability of guidelines and advance directives, community-based palliative care structures, education and training, as well as remuneration of palliative home care services. The availability and use of guidelines as well as advance directives is rather small in general practice, and FPs care and treatment at the end of life is only marginally supported by ambulant care structures, especially in rural areas. Also the coordination of services and collaboration between specialists and generalists is poorly developed. Furthermore FPs possibilities to acquire competencies in palliative care are strongly limited, and palliative home care provided by FPs is poorly financed. The results [if this case based study] draw a rather bleak picture with respect to the support of FPs palliative home care services in Switzerland today. Though considerable steps towards implementing palliative care have been made in recent years, in general, conditions for FPs medical services have to get improved strongly. Major efforts have to be made to foster the recognition and implementation throughout Switzerland. <http://omicsgroup.org/journals/conditions-of-palliative-home-care-the-case-of-family-physicians-inswitzerland-2167-1079-1000180.pdf>

Cardiopulmonary resuscitation beyond the technique

REVISTA COLOMBIANA DE ANESTESIOLOGIA (Colombian Journal of Anaesthesiology), 2015;43(2):142-146. This reflective article presents the current state of cardiopulmonary resuscitation (CPR) and reviews it from a bioethical standpoint. It starts with the ineffectiveness of CPR and the reasons why today it is a universally applied procedure, sometimes without taking into consideration the wishes or condition of the patient. Possible courses of action for the continuous improvement of cardiopulmonary resuscitation are proposed, especially from the humanistic point of view. Greater involvement of patients and their families in medical decisions, particularly in the planning of medical management rather than in the acute phase of the disease ... is encouraged. <http://www.revcolanest.com.co/en/cardiopulmonary-resuscitation-beyond-the-technique/articulo/90406162/>

N.B. English language article.

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 May 2015 – **‘Dying for advice: Code status discussions between resident physicians and patients with advanced cancer – A national survey.’** Patients with treatment-resistant advanced cancer rarely benefit from cardiopulmonary resuscitation (CPR) but infrequently discuss end-of-life care with physicians until hospitalized. Admitting resident physicians may conduct initial code status discussions, but may elicit patients’ preferences without providing necessary guidance. U.S. internal medicine resident physicians are unlikely to discuss prognosis or offer recommendations on CPR in treatment-refractory cancer principally because of a conflict with their concept of patient autonomy. Given the futility associated with CPR in this setting, these data define an unmet need in training and practice. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0373>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MEDICAL EXPRESS* | Online – 21 May 2015 – ‘**European court to rule on right-to-die case.**’ Europe’s human rights court will on 5 June rule on whether a man in a vegetative state can be taken off life support, a case that has ignited a fierce euthanasia debate in France. <http://medicalxpress.com/news/2015-05-european-court-right-to-die-case.html>
- *MEDICAL JOURNAL OF AUSTRALIA*, 2015;202(9):480-481. ‘**A minimalist legislative solution to the problem of euthanasia.**’ Despite differences of religious and philosophical convictions and ethical values, there is widespread community agreement people with terminal illnesses are entitled to adequate treatment, and should also be allowed to make basic choices about when and how they die. A problem with the current law [in Australia] is that doctors who follow current best practice cannot be confident they will be protected from criminal prosecution. The authors propose changes to Commonwealth and state legislation that recognise community concerns and protect doctors acting in accordance with best current practice. <https://www.mja.com.au/journal/2015/202/9/minimalist-legislative-solution-problem-euthanasia>
- *SOCIAL SCIENCE & MEDICINE* | Online – 13 May 2015 – ‘**Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living.**’ The essential meaning of the phenomenon [among study participants] is understood as “a tangle of inability and unwillingness to connect to one’s actual life,” characterized by a permanently lived tension: daily experiences seem incompatible with people’s expectations of life and their idea of whom they are. While feeling more and more disconnected to life, a yearning desire to end life is strengthened. The experience is further explicated in its five constituents: 1) a sense of aching loneliness; 2) the pain of not mattering; 3) the inability to express oneself; 4) multidimensional tiredness; and, 5) a sense of aversion towards feared dependence. This article ... raises questions about a close association between death wishes and depression in this sample. <http://www.sciencedirect.com/science/article/pii/S0277953615002889>

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

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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.

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/05/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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