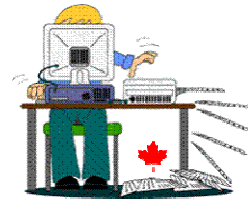


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

Policy and practice: Scroll down to [Specialist Publications](#) and 'Improving palliative care decision-making' (p.12), published in *Narrowing Gaps Between Vision & Reality*.

Canada

Manitoba will see surge in demand for end-of-life care

MANITOBA | *Winnipeg Free Press* – 4 December 2010 – Access to palliative care is still woefully inadequate for many Manitobans, according to advocates and experts who say the province needs to beef up its services before a critical shortage hits as baby boomers age. On any given day in Winnipeg, health officials estimate 30 people who are dying of terminal or chronic illnesses are lying in hospital beds on medical wards when their needs would be better met in palliative units or hospices devoted to pain management and end-of-life care. Some patients who want to die at home can't, because they don't have enough family support. Other times, the city's 16 hospice beds are full and patients have to be put up in the 45 palliative care beds available in Winnipeg hospitals. By 2030, reports estimate 45% of Manitobans will be over 65, and experts say it's only a matter of time before the health-care system faces a huge surge in patients approaching their final days. <http://www.winnipegfreepress.com/opinion/fyi/manitoba-will-see-surge-in-demand-for-end-of-life-care-111312254.html>

Of related interest:

- ALBERTA | *Calgary Herald* – 2 December 2010 – '**Hospice a first at city hospital: Advocates seek more options.**' While a new hospice at the Peter Lougheed Centre is being applauded, some health care advocates say the province needs to do more as Calgary's population ages. The Santuari Hospice opened ... with 20 beds for end-of-life care to patients and families. This increases the number of hospice beds from 88 to 108 across seven facilities... "This meets our population health needs for the next two years," said Dr. Francois Belanger medical director for Calgary. <http://www.calgaryherald.com/health/Hospice+first+city+hospital/3916312/story.html>
- CBC NEWS | Online report – 30 November 2010 – '**Cancer, heart disease cause more than half of Canadian deaths: StatsCan.**' Cancer accounted for 30% of deaths and heart disease 22%.¹ The third-most common cause of death, stroke, accounted for six per cent. The other seven leading causes of death were chronic lower respiratory diseases, accidents, diabetes, Alzheimer's disease, influenza and pneumonia, kidney disease and suicide. <http://www.cbc.ca/cp/health/OG0012.html>

1. '**Leading causes of death,**' Statistics Canada, 30 November 2010. <http://www.statcan.gc.ca/daily-quotidien/101130/dq101130b-eng.htm>

Funding end-of-life-care

Society would formalize hospice services

BRITISH COLUMBIA | *Trail Daily Times* – 30 November 2010 – Local palliative care volunteers are setting up a non-profit society aimed at stabilizing existing services and working to expand them. Talk of setting up a society began after the Interior Health Authority [IHA] eliminated a social worker position at Kootenay Boundary Regional Hospital. This has left the remaining social workers at the hospital and a 12-hour administrator funded by the IHA to coordinate the hospice program. The volunteers are concerned the administrative position "could go in the next round of cuts." http://www.bclocalnews.com/kootenay_rockies/traildailytimes/news/111022839.html

Assisted (or facilitated) death

- BRITISH COLUMBIA | *Vancouver Sun* – 3 December 2010 – **'Latimer banned from caring for disabled as part of his parole.'** Robert Latimer is not permitted to make decisions for "significantly disabled people" as it would elevate his risk to reoffend, the National Parole Board has ruled. <http://www.vancouversun.com/news/canada/Latimer+banned+from+caring+disabled+part+parole/3919679/story.html>
- ALBERTA | Global TV News (Edmonton) – 30 November 2010 – **'Murder or mercy?'** As the ongoing debate [in Quebec] on the morality of euthanasia and assisted suicide continues, Global News takes a look at other Canadian cases that have made national and international headlines. <http://www.globaltv Edmonton.com/Murder+mercy/3905582/story.html>

U.S.A.

Funeral home storeroom holds 407 forgotten souls

FLORIDA | *Miami Herald* – 6 December 2010 – Behind a bolted door, in the back of an old mortuary, is a purgatory on earth. Ashes of the dead sit in shoebox-sized containers on dusty shelves, cremated at the behest of loved ones who never retrieved them. So now, they are kept inside a cooled 10-by-10 room. They are sons and daughters of the poor, the rich and the middle-class. They lived through the Great Depression and Hurricane Andrew and 9/11, and run the gamut of South Florida's many cultures. They led robust lives before they were burned, then neglected. Funeral home owner Donald Van Orsdel holds out hope that someone might want them one day, so he keeps them in his central office just outside Miami's Design District in a room rarely unlocked to the public. There are hundreds of histories inside now, but Van Orsdel believes the future will bring many more. <http://www.miamiherald.com/2010/12/04/1958004/funeral-home-storeroom-holds-407.html>

Physicians Orders for Life-Sustaining Treatment

New state registry helps clear up 'do not resuscitate' confusion

OREGON | *Portland Tribune* – 1 December 2010 – The POLST [Physicians Orders for Life-Sustaining Treatment] Registry ... began pushing doctors, physicians assistants and nurse practitioners to have patients with advanced illness fill out special forms that would be also be signed by the physicians and posted in the database. Having the physician signature ... makes the forms a medical order, and makes it much more likely that a paramedic will follow the directions, even if it means withholding treatment. The 40,000 [to date] registrants far exceeds ... expectations. During the past 11 months, the registry has received 322 calls from paramedics, emergency departments and hospital intensive care units wanting immediate access to patient forms. http://portlandtribune.com/news/story.php?story_id=129114965203992200

End-of-life uncertainty

CALIFORNIA | *Los Angeles Times* – 29 November 2010 – Americans have a near obsessive interest in death and dying. Today's most popular television series is about violent crime investigators. The biggest movie of the year is likely to be 'Harry Potter and the Deathly Hallows: Part 1.' The bestseller list is packed with crime novels. And the latest hit video game revolves around Cold War assassins. And yet, Americans also are notoriously reluctant to confront the realities of death itself. In particular, how is it that so few people have taken steps to ensure that their wishes will be respected if they're too sick or injured to speak for themselves? That question is squarely posed by a recent study of end-of-life care for cancer patients. Researchers at the Dartmouth Atlas of Health Care looked at the treatment of Medicare patients over age 65, focusing on those suffering from especially lethal versions of the disease.¹

They found that "many hospitals and physicians aggressively treat patients with curative attempts they may not want, at the expense of improving the quality of their last few weeks and months." In Los Angeles, more than 40% of the cancer patients studied died in a hospital or intensive care unit – a setting few people would choose. <http://www.latimes.com/news/opinion/editors/la-ed-endoflife-20101129.0,4202446.story>

From the Dartmouth Atlas Project report:

In at least 50 academic medical centers, fewer than half of patients with a poor prognosis receive hospice services. And in some hospitals, patients were referred to hospice care so close to the day they died that it was unlikely to have provided much benefit.

1. *Quality of End-of-Life Cancer Care for Medicare Beneficiaries: Regional and Hospital-Specific Analyses*, The Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, November 2010. http://www.dartmouthatlas.org/downloads/reports/Cancer_report_11_16_10.pdf

N.B. Noted in Media Watch dated 22 November 2010.

International

We should not tolerate inadequate pain management for terminally ill

AUSTRALIA (NEW SOUTH WALES) | *Sydney Morning Herald* (OpEd) – 6 December 2010 – While Australia has not yet had its first case of a doctor and/or a hospital being sued for inadequate pain management, there have been several successful cases in the U.S. and it can be only a matter of time before the first case appears in the Australian courts. In fact, it could be sooner rather than later based on some recent examples I have observed with my colleagues, where inadequate pain management for terminally ill older people and a refusal to follow the instructions of their legally authorised decision makers have placed treating medical practitioners, nurses and hospitals at risk of a lawsuit. <http://www.smh.com.au/opinion/society-and-culture/we-should-not-tolerate-inadequate-pain-management-for-terminally-ill-20101205-1816r.html>



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers.

When it is time to say enough

AUSTRALIA (NEW SOUTH WALES) | *Sydney Morning Herald* – 6 December 2010 – Dialysis may, in a sense, save the lives of people with advanced kidney disease. But in Professor [Mark] Brown's observation, for the elderly it is most often simply not worth the price of relentless hospital visits – usually three a week – and their burden of physical and emotional distress. He has come to believe the alternative of keeping people comfortable while their kidney failure brings about their eventual death is ultimately better for many, if not most, people in that predicament." When you've got a technology available, the normal response is to use it," said Professor Brown, a renal specialist... of the dialysis machines now used to filter the blood of more than 10,000 Australians, at a cost approaching \$1 billion. By making explicit the option not to use the technology, and formally acknowledging a natural end-point for active therapy, Professor Brown has put himself and his patients at the centre of a gathering debate: where to draw the treatment line for the growing number of people who avoid cancer, stroke or heart attack, but still face inevitable death from the progressive failure of one of the body's essential organs.
<http://www.smh.com.au/lifestyle/lifematters/when-it-is-time-to-say-enough-20101205-18lex.html>

From Media Watch dated 18 January 2010:

- *CLINICAL JOURNAL OF THE AMERICAN SOCIETY NEPHROLOGY* | Online article – 14 January 2010 – **'End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease.'** Participants [in this study] ... had poor self-reported knowledge of palliative care options and of their illness trajectory. 61% ... regretted their decision to start dialysis. More patients wanted to die at home or in an inpatient hospice compared with in a hospital. Less than 10% of patients had a discussion about end-of-life care issues with their nephrologist in the past 12 months.
<http://cjasn.asnjournals.org/cgi/content/abstract/CJN.05960809v1?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=1&title=End-of-life+care+preferences+and+needs&andorexacttitle=and&andorexacttitleabs=and&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&sortspec=relevance&resourcetype=HWCIT>

Family database for the dying

AUSTRALIA (NEW SOUTH WALES) | *Sydney Morning Herald* – 5 December 2010 – If an ambulance is called to the Browns' Cranebrook home, Ben [diagnosed at age two with Hunter syndrome] can be taken straight to the Bear Cottage hospice ... under a pioneering program to support dying people and to acknowledge their wishes. Usual ambulance protocols require paramedics to resuscitate people and take them to the nearest suitable hospital. Now, 20 families have registered alternative instructions for their dying children in the ambulance service's dispatching database, in an initiative set to be extended to terminally ill adults. John Collins, of the Pain Management Unit, Children's Hospital, Westmead, which administers the program, said even when families elected to keep their child at home they might need an ambulance. "It's the unexpected," he said. "If you haven't previously cared for a dying person it can be a scary series of events ... it's an automatic reaction to call an ambulance." Paramedics had been called on five occasions, demonstrating the system's effectiveness, Dr. Collins said. The language of the ambulance alert was important, because parents might balk at ... "do not resuscitate" ... but find ... "allow a natural death" more acceptable. <http://www.smh.com.au/lifestyle/lifematters/family-database-for-the-dying-20101204-18kr0.html>

[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/>

Palliative Care Bill for terminally ill scrapped

U.K. (SCOTLAND) | BBC News – 5 December 2010 – Planned laws requiring Scottish health boards to provide specialist care for the terminally ill have been scrapped amid concern over the legislation. A backbench bill brought by SNP MSP [Scottish National Party Member of the Scottish Parliament] Gil Paterson aimed to secure high-quality palliative care on the NHS [National Health Service]. But he has now withdrawn it, after Holyrood's health committee said the move could make services less flexible. Mr. Paterson said his proposals had, nevertheless, sparked an important debate on palliative care. The West of Scotland MSP brought forward his bill amid concern over varying levels of care across Scotland. <http://www.bbc.co.uk/news/uk-scotland-11922595>

- U.K. (SCOTLAND) | Press Association – 29 November 2010 – **'Palliative care law bid questioned.'** The need for legislation to improve palliative care services has been questioned in a new [parliamentary] committee report.¹ The report concluded that the Bill did not establish a simple and unambiguous definition of palliative care ... [and] could prove more costly than predicted, and could lead to demands for other treatment areas to be given the same status as palliative care. <http://www.google.com/hostednews/ukpress/article/ALeqM5iyun3UVVw42oDQtbhO61zx0P-xhA?docId=N0333761291029896167A>
 - Stage 1 Report on the Palliative Care (Scotland) Bill, Health & Sport Committee, November 2010. <http://www.scottish.parliament.uk/s3/committees/hs/reports-10/her10-10-vol1.htm>

From Media Watch dated 4 October 2010:

- U.K. (SCOTLAND) | *The Herald* – 4 October 2010 – **'Bridging the care gap.'** Two years ago, the Government published *Living & Dying Well*,¹ an action plan requiring health boards to ensure all those with an incurable illness are identified and given a care plan covering their emotional, spiritual and physical needs. It came after a study by Audit Scotland revealed that most palliative care services were tilted towards cancer patients. The Palliative Care (Scotland) Bill ... will go through its first committee stage in the Scottish Parliament, the finance committee, before going forward for detailed scrutiny. It aims to put *Living & Dying Well* on a statutory footing by giving health boards a legal duty to provide palliative care to all patients and requiring the Government to report annually on the provision of that care. <http://www.heraldsotland.com/life-style/real-lives/bridging-the-care-gap-1.1059011>

1. *Living & Dying Well*: A national action plan for palliative and end of life care in Scotland, October 2008. <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

Plea for palliative care funding

AUSTRALIA (QUEENSLAND) | *Noosa News* – 3 December 2010 – The operators of the Sunshine Coast Community Hospice have made a passionate plea for the State Government to do more for the terminally ill. The three palliative care rooms at the Katie Rose Cottage at Doonan are full. Six people are on the waiting list, but many more may have died while waiting. Plans to open at least six other similar centres ... depend on funding. Katie Rose Cottage spokeswoman Sue Story said it cost \$200,000 a year to operate the service. "That includes insurance, food, water, electricity, rent and the wages of our registered nurses," Ms Story said. "Three guests equate to a cost of \$4000 a week. It is much cheaper than the cost of palliative care in public hospitals, where it is about \$1000 a day. The Sunshine Coast Community Hospice, like most palliative care organisations of this kind, has been relying entirely on community support." <http://www.noosanews.com.au/story/2010/12/03/hospice-pleads-for-more-palliative-care-funding/>

- AUSTRALIA (QUEENSLAND) | *Courier-Mail* (OpEd) – 6 December 2010 – **'Cruel, unpalatable care.'** It's hard to imagine this State Government would quibble over \$1.5 million when it's now throwing \$209 million at fixing a health payroll system that didn't cost a third of that for starters. And it's almost incomprehensible that the Bligh Government would target palliative care services in its bid to cut costs. <http://www.couriermail.com.au/news/opinion/cruel-unpalatable-care/story-e6frerhf-1225966300065>

Life goes online after death with 'memory boxes'

U.K. | BBC News – 3 December 2010 – The death of a close, elderly relative can often mean a sombre weekend or two going through old things, sorting through photographs, donating old clothes to charity. But in an age when so much of our lives are online, little thought has been given to how we handle a person's digital world when they are no longer with us. By the time the "Facebook generation" become old and grey, their whole lives may be spread out with a million updates on Twitter, thousands of photos on Flickr, hours and hours of video on YouTube and maybe their own website too. As a person dies, should their online presence end too? What should happen to all that personal information? <http://www.bbc.co.uk/news/technology-11900774>

Hospice is final home for homeless in Tokyo's Sanya district

JAPAN | Union of Catholic Asian News – 2 December 2010 – Until now, the final days of residents of Tokyo's Sanya district were likely to be marked by collapse in the streets and, with luck, a ride to a hospital. Those less fortunate were simply wrapped in blue plastic tarpaulins and put in a police car – end of story. Sanya is well-known as a neighborhood of day laborers and the homeless. But ever since the opening of Hope House ... the story has changed, if only a little. The center has so far cared for 120 people. Three years ago, Hope House purchased space in a public cemetery in Ina City, about 160 kilometers west of Tokyo in Nagano Prefecture. Anyone can obtain a grave there. So far this year, the remains of 18 people have found their final rest place there. <http://www.ucanews.com/2010/12/02/hospice-is-final-home-for-homeless-in-tokyos-sanya-district/>

N.B. Hope House (Kibô-no-lê): <http://www.kibounoie.info/index.html>

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 tool or change document.

Distribution

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

Links to Sources

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

Something Missed or Overlooked?

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

Palliative Care Funding Review

Review says National Health Service must ensure good palliative care

U.K. | BBC News – 2 December 2010 – The NHS [National Health Service] in England has failed to take responsibility for ensuring good end-of-life care, according to an independent review.¹ The analysis, by the head of Marie Curie Cancer Care, says this has led to a "postcode lottery" in funding and service quality. Tom Hughes Hallett's report calls for the NHS to provide key services such as round-the-clock community care. The theme of the report is how to ensure a good death on the NHS. The paper highlights some organisations that are doing "excellent" work. But it says funding and services have developed *ad hoc*. It cites a Department of Health survey in 2008 which revealed that palliative care expenditure across primary care trusts ranged from £154 to £1,684 per death. The report says this variation has had damaging consequences. "The 'postcode lottery' within palliative care means that patients with the same diagnosis in different geographical locations can

expect very different levels of service," it states. The review says although most people say they would like to be cared for and die in their own home or care home, the proportion who achieve this is "very small." <http://www.bbc.co.uk/news/health-11902757>

1. *Palliative Care Funding Review Interim Report*, December 2010. <http://www.palliativecarefunding.org.uk/interimReport.pdf>

"Postcode lottery"

The term "postcode lottery" refers to the way the allocation of postcodes, which often bears little relation to local government boundaries, can effect such things as insurance rates. The term is also used to refer to the way local budgets and decision-making can lead to different levels of public services in different places, especially with regard to health and social services.

Of related interest:

- U.K. | ComRes online posting – 3 December 2010 – **'MPs believe that people should have the right to die in their place of choice.'** Eighty-seven per cent of MPs believe that people should have the right to choose where they die according to research ... by ... Marie Curie Cancer Care. Almost the same proportions of MPs (86%) say this will only be possible with more community nursing care, particularly out-of-hours. <http://www.comres.co.uk/page188605123.aspx>
- U.K. | Department of Health online posting – 29 November 2010 – **'New end of life care service brings benefits for patients and health service.'** The year-long pilot exceeded expected referral numbers by 12% and exceeded targeted savings by 51%. During the year there were only three admissions to hospital out of 600 people referred to the service. The savings represent avoided hospital admissions and are calculated on the basis of figures from the three years before the service was introduced of an average of three admissions per patient in the last year of life. A key part of the service, which gives each patient a named family liaison officer, is a 24-hour care bureau staffed by nurses. http://www.dh.gov.uk/en/Aboutus/Features/DH_122168

N.B. Birmingham East & North Family Liaison Service case study:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@hc/@healthcarequality/documents/digitalasset/dh_121041.pdf

Lack of cash could mean closure for children's hospice

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 1 December 2010 – Fears are growing that the ... Children's Hospice may be forced to shut or severely cut services because of a lack of Government funding. Representatives of the charity ... met with Stormont's [parliament buildings] health committee to voice their concerns. Around £500,000 is allocated to the charity by the Government each year, but members say it takes £3 million to operate the hospice, built just eight years ago. <http://www.belfasttelegraph.co.uk/news/local-national/northern-ireland/lack-of-cash-could-mean-closure-for-childrensquo-s-hospice-15018415.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *The Herald* – 5 December 2010 – '**Kirk calls for end-of-life care debate after Margo's Bill fails.**' The Church of Scotland has called for a national debate on improving care standards for people who are close to death. Rev. Ian Galloway said the fall of MSP [Member of the Scottish Parliament] Margo MacDonald's bill on assisted suicide should mark the beginning of a conversation on end-of-life care. <http://www.heraldscotland.com/news/home-news/kirk-calls-for-end-of-life-care-debate-after-margo-s-bill-fails-1.1072534>

N.B. Kirk is the Scottish Gaelic name for the Church of Scotland.
- U.K. | *The Guardian* – 30 November 2010 – '**Assisted dying inquiry will be fair, Falconer vows.**' An inquiry into assisted dying in the U.K. will be objective and dispassionate, its chair, the former lord chancellor Lord Falconer, promised. The Commission on Assisted Dying, whose members also include the former Metropolitan police commissioner Lord Blair, will consider what system, if any, should exist to allow people to be helped to die and whether changes in the law should be introduced. It is funded by Terry Pratchett, the author and passionate euthanasia supporter who suffers from Alzheimer's disease, and businessman Bernard Lewis, with its formation overseen by Dignity in Dying. Critics, including the disability charity Scope, have raised concerns about its transparency and independence. <http://www.guardian.co.uk/society/2010/nov/30/assisted-dying-inquiry-promises-fairness>
- U.K. (SCOTLAND) | BBC News – 1 December 2010 – '**Margo MacDonald's End of Life Assistance Bill rejected.**' The Scottish Parliament has rejected plans to give terminally ill people the right to choose when to die, despite claims they were widely backed. Independent MSP Margo MacDonald's End of Life Assistance Bill aimed to make it legal for someone to seek help to end their life. Ms. MacDonald, who has Parkinson's disease, claimed there was wide public support for the legislation. But the bill was defeated by 85 votes to 16 with two abstentions. MSPs were allowed a rare free vote on the bill, rather than on party lines, and it was supported by a number of members from across the Holyrood [Scottish Parliament] parties. <http://www.bbc.co.uk/news/uk-scotland-11876821>

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/Usefullinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm>
(Scroll down to 'Newsletters/Media Updates')

U.S.A.

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

International

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/search/?tag=Media+Watch>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

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

'Yes, but it's somewhat difficult managing end of life care in primary health care'

AGEING | Online article – 1 December 2010 – A qualitative study was undertaken to investigate the perceptions of General Practitioners regarding the management of older people with heart failure, particularly at the end of life. Participants identified that the needs of older patients with heart failure could not be addressed in isolation from the wider issues which affect older people. This complexity influenced all components of patient need including the typical course of the disease, the provision of prognostic and end of life information, and how palliative care was provided, including referral to specialist services. Some participants also believed that older people's palliative care management should be approached differently to that of younger people stating, for example, that they were concerned about the amount of information older people could take in. A model which takes into consideration the experiences of the older person and fits them into, not a 'dying model' but a 'life model,' one that supports the natural transition to end of life is needed. A 'life planning model' used early in the management of patients would be a useful way forward and one which would allow the integration of the different paradigms of cardiology, gerontology, palliative care and nursing. <http://www.springerlink.com/content/64512p0u7022677g/>

Of related interest:

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2010;60(581):e449-e458. '**Advance care planning for cancer patients in primary care: A feasibility study.**' Findings suggest there were multiple barriers to earlier planning: prognostic uncertainty; limited collaboration with secondary care; a desire to maintain hope; and, resistance to any kind of 'tick-box' approach. A clear divide was found between U.K. policy directives and delivery of end-of-life care in the community that educational interventions targeting primary care professionals are unlikely to address. <http://rcgp.publisher.ingentaconnect.com/content/rcgp/bjgp/2010/00000060/00000581/art00001.jsessionid=23qwdxllwp2d1.alice>

Palliative care in the emergency department

ANNALS OF EMERGENCY MEDICINE, 2010;56(6):a17-a19. Palliative training for the ED [Emergency Department] doesn't mean that every emergency physician needs to become a full-fledged specialist. But Michael A. Gisondi, MD, director of the emergency residency program and assistant professor, Department of Emergency Medicine at Northwestern University Feinberg School of Medicine [Chicago, Illinois], wants all the physicians in his ED to have core competencies, the ability to provide what he calls "primary palliative care," including excellent care for patients who are dying in the ED. For complex cases, or for situations when palliative care needs can't be addressed in a frenetically busy, privacy-lacking, crisis-driven ED, Dr. Gisondi calls in the hospital's palliative care service for a consultation, forming a partnership that has deepened the skills and understanding of residents and attending physicians in both fields. <http://www.annemergmed.com/article/PIIS0196064410016409/fulltext>

From Media Watch dated 8 November 2010:

- *ANNALS OF EMERGENCY MEDICINE* | Online article – 29 October 2010 – '**Hospice care and the emergency department: Rules, regulations, and referrals.**' Traditional emergency medicine training may fail to address hospice as a system of care. When they are unfamiliar with the hospice model, emergency clinicians, patients, and caregivers may find it difficult to properly use and interact with these care services. This article reviews the hospice care service model and benefits offered, who may qualify for hospice care, common emergency presentations in patients under hospice care, and a stepwise approach to initiating a hospice care referral in the emergency department. [http://www.annemergmed.com/article/S0196-0644\(10\)01202-3/abstract](http://www.annemergmed.com/article/S0196-0644(10)01202-3/abstract)

N.B. The 8 November 2010 Media Watch lists additional articles on palliative care in the emergency department.

Palliative care in a multicultural society

Ethics of cancer palliative care in Sri Lanka: A cross-cultural perspective

AUSTRALASIAN MEDICAL JOURNAL, 2010;3(12):772-776. The diagnosis of cancer is associated with an unexpected breakdown of the physical, psychological and social well being. In addition to cancer related physical outcomes, cross-cultural issues are known to hasten patients' clinical deterioration and can impact upon orientation as a healthy human being in society. As members of a developing nation in the second world, to provide patient oriented quality care while maintaining high standards of ethical practice, health care workers in Sri Lanka have to be culturally competent. In Sri Lanka, the cross-cultural ethical issues related to patients with a diagnosis of cancer include, awareness of one's own cultural identity, gaining knowledge of different cultural issues, verbal and non-verbal communication skills, respect for patients' autonomy, involvement of the family and the relatives, addressing moral and spiritual backgrounds, development of effective communication skills and provision of social support. Therefore in the management of cancer patients in Sri Lanka, cultural issues should be given a high priority to maintain ethical standards and quality in palliative care. Culturally competent health care workers safeguard the rights of patients, as well as providing optimal medical and surgical care. <http://www.amj.net.au/index.php?journal=AMJ&page=article&op=viewFile&path%5B%5D=436&path%5B%5D=685>

Of related interest:

- **SUPPORTIVE CARE IN CANCER** | Online article – 26 November 2010 – '**A bridge between cultures: Interpreters' perspectives of consultations with migrant oncology patients.**' Three broad dilemmas faced by interpreters emerged [in this study]: accuracy versus understanding; translating only versus cultural advocacy and sensitivity; and professionalism versus providing support. Some saw themselves as merely an accurate conduit of information, while others saw their role in broader terms, encompassing patient advocacy, cultural brokerage and provision of emotional support. Perceived challenges in their role included lack of continuity, managing their own emotions especially after bad news consultations, and managing diverse patient and family expectations. <http://www.springerlink.com/content/a16531825q256254/fulltext.pdf>

Palliative care based on need not diagnosis: Challenges for nurses

BRITISH JOURNAL OF COMMUNITY NURSING, 2010;15(11):539-540. Across the U.K. and beyond, and in response to demographic changes and policy directives, palliative care services are transitioning. There is little doubt that district nurses, alongside general practitioners and other members of the multi-professional team, are essential to the provision of community palliative care and pivotal to implementation of palliative care policies and service plans. The End of Life Care Strategy,¹ *Living & Dying Well*,² and *Living Matters, Dying Matters*³ set out national plans for the development and maintenance of equitable, high quality and sustainable palliative and end-of-life care services for the future. These plans are based on equality, dignity and support to empower patients, carers and the voluntary sector to be full partners in planning services, improving quality and enhancing the experience of care. http://www.bjcn.co.uk/cgi-bin/go.pl/library/article.html?uid=79623;article=BJCN_15_11_539_540

1. *End of Life Care Strategy – promoting high quality care...* England & Wales, July 2008. http://www.dh.gov.uk/prod_consum_dh/groups/dh.digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf
2. *Living & Dying Well: A national action plan for palliative and end of life care in Scotland*, October 2008. <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>
3. *Living Matters Dying Matters, A Palliative & End of Life Care Strategy for Adults in Northern Ireland*, March 2010. http://www.dhsspsni.gov.uk/8555_palliative_final.pdf

Cont.

Of related interest:

- *NURSING TIMES* (U.K.) | Online report – 29 November 2010 – **'Nurses lack skills in end of life care.'** More than one in four nurses involved in end of life care do not feel competent to broach the subject of death with patients, a *Nursing Times* reader survey has revealed. The findings suggest a major skills gap and lack of support for nurses, despite recent drives to improve end of life care, such as the 2008 national end of life care strategy. Two thirds of respondents said they had been involved in nursing a dying patient on the Liverpool Care Pathway. However, 27% of nurses who had used the care pathway admitted in the anonymous survey that they did not feel competent to discuss end of life care issues with patients. That proportion rose to 33% among all respondents. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/nurses-lack-skills-in-end-of-life-care/5022455.article>

Palliative care: Earlier is better

JOURNAL OF FAMILY PRACTICE, 2010;59(12):695-698. Palliative care focuses on the prevention and treatment of pain and other debilitating effects of serious illness, with a goal of improving quality of life for patients and their families. Unlike hospice care, which requires a prognosis of less than 6 months of life to qualify for Medicare reimbursement, eligibility for palliative care is not dependent on prognosis. Indeed, palliative care can occur at the same time as curative or life-prolonging treatment. Palliative care programs include psychosocial and spiritual care for patient and family; management of symptoms such as pain, fatigue, shortness of breath, depression, constipation, and nausea; support for complex decisions, such as discussions of goals, do not resuscitate orders, and requests for treatment; and coordination of care across various health care settings. http://stg.jfponline.com/pdf%2F5912%2F5912JFP_PURL.pdf

Psychological and social profile of family caregivers on commencement of palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 2 December 2010 – Palliative care services are required to support patients who have advanced, life-threatening, non-curable disease, and their family caregivers. Comprehensive psychological and social support for bereaved family members also is expected. However, recent systematic reviews have demonstrated significant gaps in evidence-based approaches for such support. Furthermore, a comprehensive understanding of the psychological and social response to the family caregiver role is required for support to be optimized. The results [of this study] reinforce the need to develop suitable strategies for psychological and social support for family caregivers. [http://www.jpsmjournal.com/article/S0885-3924\(10\)00659-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(10)00659-7/abstract)

- *PROGRESS IN PALLIATIVE CARE*, 2010;18(6):335-340 **'Listening to the still small voice: The role of palliative care nurses in addressing psychosocial issues at end of life.'** It is argued that the often intangible aspects of practice, such as intuition, can inform decision-making and that relationship evolved over time with the patient and family enables issues of hope, suffering and loss to be tended to. Compassion as a relatively under-researched aspect of palliative care is posited as a framework in which the palliative nursing approach to psychosocial care can be better articulated. <http://www.ingentaconnect.com/content/maney/ppc/2010/00000018/00000006/art00003>

Incorporating routine survival prediction in a U.S. hospital-based palliative care service

JOURNAL OF PALLIATIVE MEDICINE | Online article – 3 December 2010 – The authors sought to incorporate predicted survival into the routine practice of their hospital-based palliative care team. The team recorded a predicted survival in 95% of new patient consults. Fifty-eight percent accuracy is in line with prior literature. Routinely incorporating survival prediction into palliative care consultation raised a number of questions. What decisions were made based on the 42% incorrect prognoses? Did these decisions negatively affect care? Survival prediction accuracy has potential as a quality measure for hospital-based palliative care programs, however, to be truly useful, it needs to be shown to be "improveable" and the downstream effects of predictions need to be better understood. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0152>

Policy and practice

Improving palliative care decision-making

NARROWING GAPS BETWEEN VISION & REALITY | Online report – Accessed 2 December 2010 – This study demonstrated that many, but not all, senior decision-makers do have a good conceptual understanding of palliative care; can describe at a high level how their health regions were delivering services to their respective populations; and, understand many of the challenges and opportunities facing them as they work to advance palliative care in their regional contexts. Many times the direct managers, who are also often the local palliative care champions, have an incredible vision about what they want their palliative care programs to look like and are able to articulate this vision well. Their challenging role is to work within their respective, complex health systems and regional contexts to bring this vision to life, in part, through their own leadership efforts – seeking to close gaps between the visions they hold and the realities they face. This study suggests that the field of palliative care needs to continue to build understanding both at senior management levels of healthcare systems, but also at a more general societal level. This is needed if we are to narrow the gap between the basic provision of palliative care at the very end of life, and a broader vision of palliative care as a philosophy of care that is integrated throughout chronic disease management and end-of-life care initiatives. Key messages on practice and policy implications relate to the conceptualization, operationalization and evaluation of palliative care in the context of a health system. <http://www.download.bham.ac.uk/hsmc/gail-mackean.pdf>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online report – 30 November 2010 – '**Assisted dying should be part of care package offered to terminally ill people, debate hears.**' Assisted dying should form part of a good palliative care service for terminally ill people in the U.K., said Ann McPherson, a GP and founder of a new group of medical professionals called Dignity in Dying: Healthcare Professionals for Change. <http://www.bmj.com/content/341/bmj.c6884.extract>
- *JOURNAL OF MEDICAL ETHICS* | Online report – 21 November 2010 – '**A test for mental capacity to request assisted suicide.**' The mental competence of people requesting aid-in-dying is a key issue for the how the law [in England & Wales] responds to cases of assisted suicide. A number of cases from around the common law world have highlighted the importance of competence in determining whether assistants should be prosecuted, and what they will be prosecuted for. Nevertheless, the law remains uncertain about how competence should be tested in these cases. <http://jme.bmj.com/content/early/2010/11/21/jme.2010.037564.abstract>
- *KING'S LAW JOURNAL*, 2010;21(3):425-443. '**Director of Public Prosecution's Prosecutorial Policy on Assisted Suicide.**' This article ... highlights the potential effect of the offence-specific policy [in England & Wales] and demonstrates that there are both strengths and weaknesses contained within it. How a person comes to view these depends largely on which particular side of the assisted suicide debate they favour. The author also suggests ... that there is no right not to be prosecuted. <http://www.ingentaconnect.com/content/hart/klj/2010/00000021/00000003/art00001>
- *MEDICAL LAW JOURNAL*, 2010;18(4):541-563. '**Assisted dying and the context of debate: 'Medical law' versus 'end of life law.'**' Considering both medical law as a discipline, and the study of end-of-life issues, the [author's] argument highlights the range of relevant issues that must be accounted for, and addresses the question of whether these are well conceived as ones of medical law. <http://medlaw.oxfordjournals.org/content/18/4/541.abstract>

Worth Repeating

Starting a prison hospice program

ILLNESS, CRISIS & LOSS, 2009;17(4):349-361. Starting in the late 1970s, the incarcerated population in the U.S. increased in large part due to the use and abuse of drugs. At the same time ... inmates came into the system sicker and more of them began to die while in prison. These concerns came to the attention of the late Florence Wald [1917-2008], a founder of the hospice movement in this country. With determination, discipline, and collaboration, Florence spearheaded the founding of a prison hospice and palliative care program in Connecticut, keeping in mind both the need for creating a long lasting and sustainable program and to act as a model for other states. Since 2001, with the use of trained inmate hospice volunteers, the program has provided compassionate care for over 50 inmates at three correctional facilities in Connecticut. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,9,13;journal,5,48;linkingpublicationresults,1:103734,1>

Angola's hospice program teaches convicts how to care

LOUISIANA | WAFB News – 6 December 2010 – Within the walls of Angola State Penitentiary there are an estimated 5,200 inmates. More than 95% of them will die there. Angola has a hospice program that is a part of the rehabilitation treatment offered to inmates. Warden Burl Cain said it is a way for people known as "selfish takers" to finally give back. In their final hours, some inmates at Angola tend to the needs of other convicted criminals. The prison's hospice program serves as a model for others across the country. In fact, Academy Award-winning actor Forest Whitaker is producing a film about the program, 'One Last Shot: A story of Redemption.' <http://www.wafb.com/Global/story.asp?S=13621310>

Of related interest:

- *ILLNESS, CRISIS & LOSS*, 2009;17(4):363-378. **'Caring for prison inmates the hospice way.'** This article describes the evolution of a prison hospice program. The article provides a historical background of the role of Florence Wald, a pioneer of the national hospice movement, and the natural extension of her role in the development of the Connecticut prison hospice program. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,10,13;journal,5,48;linkingpublicationresults,1:103734,1>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. For those interested in prison hospice, a compilation of these articles and reports in a single document is available on request (contact information below).

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