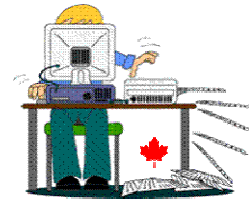


Media Watch...

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.

5 December 2011 Edition | Issue #230



Compilation of Media Watch 2008, 2009, 2010, 2011 ©

Compiled & Annotated by Barry R. Ashpole

Quality of relationships: Scroll down to [U.S.A.](#) and 'In caregiving, bond is often more important than blood' (p.4), published in the *Chicago Tribune*.

Canada

Economics of end-of-life care

How much does dying cost Canadians?

GLOBE & MAIL | Online series – 29 November 2011 – Of all the financially grim statistics confronting Canadian health care, this ranks among the grimmest: About 25% of all health-care costs are devoted to caring for patients in their last year of life. Provincial governments are scrambling to contain health-care spending, even as an aging population begins to place increasing demands on the system. Yet there is also a growing recognition among policy makers that they cannot make efficient spending decisions without a better understanding of the economics of death. Almost 70% of people die in the hospital, including some in high-tech intensive-care beds, which cost about \$1-million a year to operate. Many patients fail to complete advance directives or communicate preferences to their families, meaning they could be subject to costly, invasive treatments they did not actually want. "The bottom line is if you don't know how much something costs, then it's really difficult to say how much we should spend," said Konrad Fassbender, an

assistant professor at the University of Alberta's oncology department, and one of the few researchers who has attempted to quantify the cost of various end-of-life procedures. "In health, we somehow have bought into the fact that we need to provide this level of care at any cost, without any real data of its effectiveness, without any knowledge of how much it costs." http://www.theglobeandmail.com/life/health/end-of-life/calculating-the-spiralling-costs-of-dying/article2252845/?utm_medium=Feeds%3A%20RSS%2FAtom&utm_source=Home&utm_content=2252845

Extract from *Globe & Mail* article

Research shows it costs the health-care system about \$39,947 to treat a patient with organ failure near the end of life; \$36,652 for a terminal illness; and \$31,881 for frailty. Sudden death is the least costly at \$10,223.

N.B. Link to *Globe & Mail* series: <http://www.theglobeandmail.com/life/health/end-of-life/> (noted in Media Watch dated 28 November 2011).

Hassan Rasouli case

Supreme Court asked to hear end-of-life case

GLOBE & MAIL | Online report – 29 November 2011 – For 13 months, Hassan Rasouli has been in a critical care unit at a Toronto hospital, where machines do all the things his body cannot: breathe, feed and hydrate him. The 60-year-old is in a permanent vegetative state, utterly unaware he is in the middle of a divisive debate that could reshape the way decisions are made in Canadian hospitals on when to remove patients from life support. Two doctors at Sunnybrook Health Sciences Centre are now asking the Supreme Court of Canada to hear their case; they see no medical purpose in keeping Mr. Rasouli on life support and propose shifting him to palliative care – but his family disagrees. Although the country's highest court has yet to decide whether it will hear the case, it is being watched by physicians, lawyers and health-

care leaders as this ethical dilemma is expected to arise frequently as the population ages. If the court declines to hear the appeal, there will be no national guidance when families fight with physicians in hospitals and courtrooms over end-of-life issues. http://www.theglobeandmail.com/life/health/end-of-life/supreme-court-asked-to-hear-end-of-life-case/article2254394/?utm_medium=Feeds%3A%20RSS%2FAtom&utm_source=Life&utm_content=2254394

Extract from *Globe & Mail* article

At issue is whether extraordinary medical interventions save lives or merely prolong the dying process.

From Media Watch dated 21 November 2011:

- ONTARIO | *Jewish Tribune* – 14 November 2011 – **'End of life decisions – do doctors have the right to decide?'** This case depends on the definition of 'treatment' in the Ontario Health Care Consent Act and the steps set out by the act to resolve disagreements between doctors and substitute decision makers about treatment plans. Key ... is the legal meaning of the word 'treatment.' Also fundamental to the decision-making process are the real wishes of the patient. The substitute decision-maker's wishes were unimportant – it's what the patient wanted to do that is key. http://www.jewishtribune.ca/TribuneV2/index.php?option=com_content&task=view&id=5062&Itemid=53

From Media Watch dated 26 September 2011:

- *THE MEDICAL POST* | Online article – 21 September 2011 – **'Vegetative patient dispute forces rethink of term 'treatment.'** Words are what law is made of. So it comes as no surprise that judges often interpret words and decide what they mean. A good example is a recent case from the Ontario Court of Appeal involving the word "treatment." The case ... deals with the perennial and difficult question of how a doctor can legally pull the plug on someone who has entered a permanent vegetative state. <http://www.canadianhealthcarenetwork.ca/physicians/magazines/the-medical-post/september-20-2011/vegetative-patient-dispute-forces-rethink-of-term-treatment-18209>



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. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Parliamentary Committee on Palliative & Compassionate Care

Ottawa urged to push for national plan

ONTARIO | *Windsor Star* – 29 November 2011 – Canadians are not well served when it comes to end of life care for the dying, the parliamentary committee on palliative and compassionate care has concluded.¹ [Local] MP Joe Comartin ... said ... between 16-30% of the population has access to the level of palliative care needed. "It's clear we have a low rate of service in the country and that reflects a need for more research," said Comartin, who co-chaired the [bi-partisan] committee. Comartin stressed the high level of service available in this community [Windsor] is not the norm across Canada, where even pockets of major cities like Toronto and Montreal ... are under-served. "We're one of the few communities in the country that has a sophisticated system," said Comartin. "There are different postal codes that have no service at all." <http://www.windsorstar.com/health/Report+finds+gaps+palliative+care/5781281/story.html>

1. *Not to be Forgotten: Care of Vulnerable Canadians*, Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care, 17 November 2011. <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf> (noted in Media Watch dated 21 November 2011).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *Le Magazine de L'île des Soeurs* – 3 December 2011 – '**Defending dignity in death.**' The Royal Society of Canada ... recently recommended that the Criminal Code of Canada be amended so that people in poor health (usually a terminal illness) would have the right to physician-assisted suicide or euthanasia.¹ And just like that, Canadians have, once again, found themselves immersed in another heated debate on the issue. Cue the predictable fear mongering. <http://www.westmountexaminer.com/Opinion/Columns/2011-12-02/article-2823092/Defending-dignity-in-death/1>
 1. *Royal Society of Canada Expert Panel: End of Life Decision Making*, November 2011: http://www.rscsrc.ca/documents/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf (noted in Media Watch dated 21 November 2011).
- ASSOCIATED PRESS | Online report – 30 November 2011 – '**Canada woman pursues doctor-assisted suicide.**' One of Gloria Taylor's greatest fears is suffocating before she dies. It's part of the reason the 63-year-old grandmother has "gripped her teeth" to appear before a British Columbia Supreme Court judge ... in her quest for the right to a doctor-assisted suicide. Taylor has Lou Gehrig's disease [i.e., ALS – amyotrophic lateral sclerosis]. She is the reason the hearing on assisted suicide has been accelerated. <http://www.sfexaminer.com/news/health/2011/11/canada-woman-pursues-doctor-assisted-suicide>

U.S.A.

Economics of end-of-life care

Not ready to die, but prepared

CALIFORNIA | *Los Angeles Times* – 4 December 2011 – Susan Enguidanos, an assistant professor of gerontology at University of Southern California, specializes in end-of-life care. She said a study of Kaiser's in-home palliative program about 10 years ago showed a 45% reduction in patient costs due to the avoidance of emergency room and hospital visits, and more important, there was also a sharp increase in patient satisfaction. Other such studies, she said, have shown that 71% of palliative care patients die at home, as most people say they would prefer to do, as opposed to only 50% of those not in such programs. The national implications are enormous, given that a large portion of the debt crisis in the U.S. is due to rising healthcare costs. <http://www.latimes.com/news/local/la-me-1204-lopez-hospice-20111204,0,3841288.column>

Aging out of health care?

Ever-increasing costs prompt some doctors to ask if a patient can be too old for a lifesaving but expensive procedure

ILLINOIS | *Chicago Tribune* – 30 November 2011 – Earlier this year, a pair of influential bio-ethicists argued in an essay in *The New Republic* that the amount of money the country spends on Medicare is unsustainable.¹ With senior citizens the fastest-growing age group in the country, they say, the only way to control the ballooning costs is to try to bring the entire population up to a life expectancy of 80 and stop using most expensive technologies and medicines to extend life beyond that, even if some people will die. The Medicare program – unlike health plans in other countries – is not permitted to factor in the price of medical services, only the health benefit to the patient. No proposal is being discussed to change that. But Sherwin Nuland and Daniel Callahan believe there should be. "If you want to save all lives, you're in trouble," said Callahan, co-founder of The Hastings Center, a bioethics research institute in New York, and a faculty member at Harvard Medical School, in an interview. "And if you want to save all lives at any cost, you're really in trouble." Callahan and co-author Nuland, a retired professor of surgery at Yale School of Medicine who wrote the best-selling *How We Die*, were both 80 when the article was published. "We need to stop thinking of medicine as an all-out war against death, because death always wins," said Callahan. <http://www.chicagotribune.com/health/ct-x-surgery-for-old-20111130,0,4147104.story>

1. 'The quagmire: How American medicine is destroying itself,' *The New Republic*, 19 May 2011. <http://www.tnr.com/article/economy/magazine/88631/american-medicine-health-care-costs?passthru=ZDY1YmFhOTg2YzhmMWE2Njg2MTMzMmM1OWUyYmUyMDQ>

Quality of relationships

In caregiving, bond is often more important than blood

ILLINOIS | *Chicago Tribune* – 30 November 2011 – Many caregivers are not related to the people they are looking after. But that doesn't have to be a drawback. What's important ... is the bond between the caregiver and the person in need of care. In fact, "quality of relationship" is more important than "family ties," said Lawrence Ganong, a University of Missouri professor who asked 3,500 adults ages 18 to 89 nationwide about the topic. The study participants were given scenarios with aging parents and caregivers who were children or stepchildren. "For 25% of the participants, they said blood is thicker than water, and it is the children's responsibility to do the caregiving for older relatives," said Ganong. "But 75% said relationships mattered more than family." The participants were asked about helping older folks with housing, finances and daily tasks. Ganong said that stepchildren were just as likely as children to care for their parents "if they had a good relationship," he said. "They'd be more likely to care for the

stepparent they've lived with for years than the biological parent they never see." Factors that affect the caregiving decision, said Ganong, are hardships facing the caregivers, how close the two were before the older person got sick and mutual help in the past. "More baby boomers are reaching the point where they need caregivers," said Ganong. "Divorce and remarriage ... mean families rethink who will care for their kin." <http://www.chicagotribune.com/news/local/ct-x-caregiver-decision-20111130,0,4754352.story>

Specialist Publications

Of particular interest:

'Study shows hospice caregivers need routine care interventions' (p.15), published in *Qualitative Health Research*.

N.B. The Canadian Hospice Palliative Care Association definition of 'family' is "those closest to the patient in knowledge, care and affection."

Pending legislation would make it easy to bring together patients, their physicians, and their families to map out how patients want to spend their last days

NEW JERSEY | NJ Spotlight – 29 November 2011 – End-of-life care is always a difficult issue. In New Jersey it's also one that is both costly and aggressively pursued: The latest Medicare study by the non-profit Dartmouth Atlas,¹ which analyzes nationwide variations in healthcare, found that nearly 25% of New Jerseyans spent a week or more in the hospital intensive care unit in their last six months, compared with the national average of 15%. In that time they saw an average of 11 doctors, compared with eight for the nation. Medicare spending averaged \$65,436 in the last two years of life in New Jersey, compared with \$53,441 for the U.S., according to the Dartmouth Atlas review of 2003 to 2007 Medicare data. Experts say the cost of end-of-life treatments can be reduced if patients diagnosed with a terminal illness were encouraged to write an end-of-life plan in consultation with physician and family. Legislation now on track ... would bring to New Jersey a relatively new model of end-of-life planning known as the Physician Orders for Life Sustaining Treatment [POLST]. <http://www.njspotlight.com/stories/11/1129/0024/>

1. *Trends & Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, April 2011 (noted in Media Watch dated 18 April 2011). http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

From Media Watch dated 31 October 2011:

- *WALL STREET JOURNAL* | Online article – 24 October 2011 – '**Informed patient: Advance directives cut unwanted hospitalizations.**' Frail elderly patients who have advance directives through a program to communicate treatment preferences have fewer unwanted hospitalizations, according to a new study.¹ The program ... Physician Orders for Life-Sustaining Treatment ... [was] launched in Oregon almost 20 years ago... Efforts to expand use of the forms, currently in use in about 14 states, with about 20 programs in development were the subject of an Informed Patient column earlier this year. <http://blogs.wsj.com/health/2011/10/24/informed-patient-advance-directives-cut-unwanted-hospitalizations/>
1. 'The consistency between treatments provided to nursing facility residents and orders on the Physician Orders for Life-Sustaining Treatment form,' *Journal of the American Geriatric Society*, published online 22 October 2011. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03656.x/abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | *The Atlantic* – 2 December 2011 – '**Will Massachusetts legalize physician-assisted suicide?**' Should the terminally ill have the right to physician-assisted suicide? Some think the question would give voters the opportunity to play God. Others think it's long overdue. The legislation is titled the Death With Dignity Act. It would allow adults who have been given less than six months to live by two different doctors the opportunity to terminate their lives. There are many hurdles that a patient would need to clear. For starters, the first request by the patient must be in writing, and then it must be made verbally – twice . The patient must be advised on alternative options, such as hospice care. And if the patient ultimately decides to go through with it, someone other than a doctor must administer the prescription. (Involving the medical profession would raise a completely different set of legal issues.) <http://www.theatlantic.com/national/archive/2011/12/will-massachusetts-legalize-physician-assisted-suicide/249346/>

[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>

International

Cost of dying

Family of dying Kent man refused life insurance money

U.K. | BBC News – 2 December 2011 – A terminally ill man's family could lose their home in Kent after his life insurers denied him a payout of more than £200,000 because his policy was in its final year. Paul Holland was diagnosed with a brain tumour four months before his deal ended with Royal Liver. The company claim they only pay out if a terminal illness is diagnosed 12 months before the policy ends. His family said they would not be able to keep their home without the money. <http://www.bbc.co.uk/news/uk-england-kent-16010848>

Of related interest:

- U.K. | *Private Health* – 30 November 2011 – '**Can you afford to die?**' According to the 2011 Annual Cost of Dying Report from Sun Life Direct, the cost of dying (including death-related costs such as funerals, probate, headstones and flowers) has increased to an average of £7,248, representing an increase of 20% since 2007, and over £400 more than last year. Discretionary funeral costs have increased 6.7% from an average of £1,746 in 2010 to £1,864 in 2011. <http://www.privatehealth.co.uk/news/november-2011/sun-life-funeral-plans-36251/>

Audit of palliative care services

Loved ones not always told their relative is on controversial 'death pathway'

U.K. | *Daily Telegraph* – 2 December 2011 – Tens of thousands of patients with terminal illnesses are being placed on a "death pathway," almost double the number just two years ago, a [new] study ... shows.¹ Health service guidance states that doctors should discuss with relations whether or not their loved one is placed on the scheme which allows medical staff to withdraw fluid and drugs in a patient's final days. In many cases this is not happening, an audit has found. As many as 2,500 families were not told that their loved ones had been put on the so-called Liverpool Care Pathway, the study disclosed. In one hospital trust, doctors had conversations with fewer than half of families about the care of their loved one. In a quarter of hospital trusts, discussions were not held with one in three families. Under the guidance, patients who are close to death can be placed on the Liverpool Care Pathway [developed at the Royal Liverpool Hospital in the 1990s].¹ <http://www.telegraph.co.uk/health/healthnews/8928182/Loved-ones-not-always-told-their-relative-is-on-controversial-death-pathway.html>

Patients dying in pain needlessly: NHS drugs body

U.K. | *Daily Telegraph* – 3 December 2011 – In draft guidance on the use of opioids in palliative care, the National Institute for Health & Clinical Excellence, said patients were being 'undertreated'. It comes after an audit of palliative care services ... found that relatives were not always being told when their loved ones were being placed on the controversial 'death pathway,' known as the Liverpool Care Pathway. <http://www.telegraph.co.uk/health/healthnews/8931041/Patients-dying-in-pain-needlessly-NHS-drugs-body.html>

N.B. Scroll down to '**National Institute for Health & Clinical excellence publishes new end of life care quality standard**' (p.8).

1. 'National Dying of the Care Audit – Hospitals (2011-2012),' Marie Curie Palliative Care Institute Liverpool, November 2011 (executive summary). <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/NCDAH%20Docs/NCDAH%20ROUND%203%20EXEC%20SUMMARY%20%20FINAL.pdf>

Cont. next page

From Media Watch dated 25 October 2010:

- *BRITISH MEDICAL JOURNAL* | Online letter – 19 October 2010 – '**Good death for all remains distant goal.**' Ellershaw and colleagues again defend their Liverpool Care Pathway.^{1,2} The pathway has obvious appeal, but it has proved controversial, and reports of misuse remain disturbingly frequent. Despite decades of research in the care of patients with cancer, the accurate prediction of dying ... remains difficult. <http://www.bmj.com/content/341/bmj.c5815.extract>
 1. *BRITISH MEDICAL JOURNAL* | Online article – 16 September 2010 – '**Achieving a good death for all.**' <http://www.bmj.com/content/341/bmj.c4861.extract>
 2. Liverpool Care Pathway website: <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

Senate announces palliative care inquiry

AUSTRALIAN AGEING AGENDA | Online report – 1 December 2011 – Australia's palliative care system will be the subject of a new, full-scale Senate inquiry, which boasts broad terms of reference spanning all facets of service provision, from the factors influencing access and choice to funding and the system's interface with the aged care sector. The inquiry ... will be conducted by the Senate's Community Affairs References Committee... The terms of reference point to eight factors the committee will review ... the efficient use of palliative health and aged care resources; the effectiveness of various palliative care arrangements; the composition of the palliative care workforce; the adequacy of standards applying to palliative care provision; and the availability and funding of research, information and data about palliative care in Australia. Matters surrounding advance care planning will also be addressed, like end-of-life communication conversations between health care professionals and dying patients; national consistency in law and policy supporting advance care directives; and scope for including advance care plans in personal electronic health records. Never before has the Senate launched such a broad ranging inquiry into the entire Australian palliative care system. The broad scope of inquiry means the committee will also examine and make recommendations on the system's ability to serve the needs of those in rural and regional areas; Indigenous people; individuals from culturally and linguistically diverse backgrounds; people with disabilities, and children and adolescents. <http://www.australianageingagenda.com.au/2011/12/01/article/Senate-announces-palliative-care-inquiry/RKITDATLYH>

Prolong life or allow it to end?

AUSTRALIAN AGEING AGENDA | Online article – 29 November 2011 – To provide treatment and prolong a life that may have otherwise ended or to withhold treatment and allow death to take its natural course – that is the question which medical and aged care professionals face on a daily basis, yet receive very little evidence-based guidance on. In attempt to fill the research void which currently exists around this topic, Queensland University of Technology (QUT) will undertake a study into why futile medical treatment is, at times, provided to dying patients. The study ... will be conducted by a cross-disciplinary team ... from QUT and the University of Queensland, in partnership with the Royal Brisbane and Women's Hospital. The research, lead by Professor Lindy Willmott and Associate Professor Ben White from QUT's Health Law Research Program, aims to reveal why treatment – which is considered unnecessary from a strictly medical point of view – is sometimes provided when a person is dying. "It's a topic that people have been talking about for some time but there's not a good-evidence base on the extent to which futile treatment is being provided," said Professor White. "There is some overseas evidence – not a great deal though – but none from Australia. <http://www.australianageingagenda.com.au/2011/11/29/article/Prolong-life-or-allow-it-to-end/UHOVPZBXZJ.html>

From Media Watch dated 28 November 2011:

AUSTRALIA (QUEENSLAND) | *Health Canal* – 24 November 2011 – '**Queensland University of Technology [QUT] to study appropriate level of medical treatment for dying patients.**' The research will reveal why treatment which is considered unnecessary from a strictly medical point of view is sometimes provided. Limited research had been conducted in the U.S. and Canada and anecdotal evidence collected in Australia, this would be the first comprehensive study to determine the size of the issue and the best ways of dealing with it. <http://www.healthcanal.com/public-health-safety/23810-QUT-study-appropriate-level-medical-treatment-for-dying-patients.html>

Elder care

Councils slash their home help services: 12,000 elderly and vulnerable no longer qualify

U.K. | *Daily Mail* – 1 December 2011 – The number of old and vulnerable folk given help to live decently in their own homes dropped by 120,000 last year, an official report revealed. It said local councils had told many thousands of the elderly and disabled they were not sick enough to qualify to have meals delivered, get help with dressing or have their cleaning done. Thousands of others were simply told their local social workers no longer provided the service. The report, from the Department of Health, showed the fast accelerating scale of the withdrawal of home help from the elderly by councils. It said last year alone the number of adults given assistance fell by 8%. Official confirmation of suspicions of widespread cuts follows a series of alarms over the deepening failure in care for the elderly. <http://www.dailymail.co.uk/news/article-2068382/Councils-slash-home-help-services-12-000-elderly-vulnerable-longer-qualify.html?ito=feeds-newsxml>

From Media Watch dated 28 November 2011:

- U.K. (ENGLAND) | BBC News – 23 November 2011 – **'Basic home care help 'breaching human rights.'** Basic care for the elderly in their own homes in England is so bad it breaches human rights at times, an inquiry says.¹ <http://www.bbc.co.uk/news/health-15836500>
 1. *Close to home: An inquiry into older people and human rights in home care*, Equality & Human Rights Commission, November 2011. http://www.equalityhumanrights.com/uploaded_files/homecareFI/home_care_report.pdf

National Institute for Health & Clinical Excellence publishes new end of life care quality standard

U.K. (ENGLAND) | National Institute for Health & Clinical Excellence (NICE) – 30 November 2011 – NICE quality standards are a set of specific, succinct statements and measures that describe aspirational but achievable care for adult patients across the NHS [National Health Service] in England. They are developed in collaboration with the NHS and social care sectors, using the best available evidence, such as NICE guidance or other NHS evidence accredited sources. Around half a million people die each year in England and the issues considered to be important at this time can differ enormously from one person to another. Preparation for death, communication with carers and physicians that is sensitive and responsive, and being treated with dignity and respect are often deemed significant. This new quality standard includes 15 statements for the care of adults ... with advanced, progressive, or incurable conditions who are approaching the end of their life and are expected to die within the next 12 months.¹ <http://www.nice.org.uk/newsroom/pressreleases/EndOfLifeCareQualityStandard.jsp>

The quality standard statements include:

People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

1. Statements for the care of adults approaching the end of their life: <http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp>

An image of Dickensian poverty

Tragedy of 100,000 buried in paupers' graves over past five years

U.K. | *Daily Mail* – 28 November 2011 – At least 100,000 pensioners who died penniless and alone have been buried in paupers' graves in the past five years. Soaring funeral prices and the breakdown of families mean about 21,000 pensioners die every year without the money for funeral bills and with no relatives willing or able to pay. Their funerals are paid for by councils, many of which have admitted they inter the bodies in communal plots or cremate them to save costs. Such paupers' mass graves conjure an image of Dickensian poverty. But this has become the reality for some of the 40,000 people a year in Britain who receive state-funded funerals – of which about 21,000 are pensioners. <http://www.dailymail.co.uk/news/article-2066991/Tragedy-100-000-buried-paupers-graves-past-years.html?ito=feeds-newsxml>

- U.K. (SCOTLAND) | *Daily Record* (Glasgow) – 28 November 2011 – **'Esther Rantzen calls for minister for the elderly as it's revealed 5,500 Scots die every year 'friendless and penniless.'** Scotland has the second highest number of state-funded funerals in the whole of the U.K. Each year around 5,500 people north of the Border die "penniless" and have their funerals arranged by their local authority. <http://www.dailyrecord.co.uk/news/scottish-news/2011/11/28/esther-rantzen-calls-for-minister-for-the-elderly-as-it-s-revealed-5500-scots-die-every-year-friendless-and-penniless-86908-23594008/>

The art and science of the embalmer

Respect for the dead

IRELAND | *Irish Times* – 26 November 2011 – Embalming: the word makes you think of holy oils; ancient unguents; the Egyptian mummies, their leathery bodies swaddled for eternity, made benign by time and distance. But the reality is different. Modern embalming is seen primarily as a hygienic practice, keeping the body fresh and clean in the days before burial. More than that, it's about restoring and enhancing the deceased person's appearance so that the family can say goodbye. <http://www.irishtimes.com/newspaper/magazine/2011/11/26/1224307977116.html>

Of related interest:

- U.S. | *Forbes* – 2 December 2011 – **'The burial industry takes a turn to eco-friendliness.'** Burial and cremation are the most common ways we dispose of the dead, but while these methods are steeped in tradition, they're far from environmentally friendly. <http://www.forbes.com/sites/economics/2011/12/02/the-burial-industry-takes-a-turn-to-eco-friendliness/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *Irish Times* – 1 December 2011 – **'Research reveals shifting attitudes towards euthanasia.'** Almost 60% of final year medical students in one Irish university are in favour of euthanasia, according to a new survey. The study of students at University College Cork [UCC] forms part of a research project by Canadian medical student Matthew Carere. He revealed some of his findings at a Law Society conference in UCC, on Assisted Dying & Euthanasia in Ireland. <http://www.irishtimes.com/newspaper/ireland/2011/12/01/1224308417523.html>
- THE NETHERLANDS | *Dutch News* – 30 November 2011 – **'Mobile euthanasia teams not ruled out, says minister.'** People who are faced with unbearable suffering and want to end their lives can be referred by their doctors to special mobile euthanasia teams if necessary, health minister Edith Schippers told MPs. Although the minister said she would prefer if people are helped to die by their own doctors, there is a place for referral to other specialists if the doctor objects to euthanasia. http://www.dutchnews.nl/news/archives/2011/11/minister_has_no_objections_to.php

Cont.

- U.K. | *Daily Telegraph* – 30 November 2011 – '**Disabled man asks High Court: "please let me die."**' Lawyers want a ruling that a doctor could intervene to end Tony Nicklinson's "indignity" and have a "common law defence of necessity" against any murder charge. They expect a judge ... of the High Court to begin hearing arguments in the near future and say the case will be a "test" which raises "difficult" questions about euthanasia. <http://www.telegraph.co.uk/news/uknews/law-and-order/8923114/Disabled-man-asks-High-Court-please-let-me-die.html>

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

Understanding why older people develop a wish to die: A qualitative interview study

CRISIS: JOURNAL OF CRISIS INTERVENTION & SUICIDE PREVENTION, 2011;32(4):204-216. In-depth interviews with people with a wish to die were carried out. The wish to die had either been triggered suddenly after traumatic life events or had developed gradually after a life full of adversity, as a consequence of aging or illness, or after recurring depression. The respondents were in a situation they considered unacceptable, yet they felt they had no control to change their situation and thus progressively "gave up" trying. Recurring themes included being widowed, feeling lonely, being a victim, being dependent, and wanting to be useful. Developing thoughts about death as a positive thing or a release from problems seemed to them like a way to reclaim control. People who wish to die originally develop thoughts about death as a positive solution to life events or to an adverse situation, and eventually reach a balance of the wish to live and to die. <http://www.sciencedirect.com/science/article/pii/S0227591011600421>

From the archives:

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. '**Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.**' Health professionals may struggle to determine whether a 'desire to die' statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, the authors have prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. <http://pmj.sagepub.com/cgi/content/abstract/20/7/703>

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?mediawatch=1>

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/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

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

Primary Palliative Care in Ireland

GPs want more training in care of dying

IRISH HEALTH | Online report – 30 November 2011 – The average GP practice cares for up to 20 dying patients every year and this figure is expected to double over the next two decades due to an ageing population, the Irish College of General Practitioners (ICGP) has said. It made its comments following the launch of a major new report, which aims to enhance the way in which GPs care for people dying in the community. *Primary Palliative Care in Ireland – Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life* was compiled by the ICGP, the Irish Hospice Foundation (IHF) and the Health Service Executive (HSE). Last year, these three organisations established the Primary Palliative Care Programme in an attempt to identify different ways that GPs could support the management of people who were expected to die within a year. The findings of that programme's research are contained in this new report. It showed that most people working in the area of primary care would like more training in palliative care, including symptom control and caring for patients who are just days or hours away from dying. The report contained a number of initiatives, which the Primary Palliative Care Programme aims to pursue over the next 12 months, including the development of a system which identifies and responds to

patients in need of palliative care in the community. It also recommended a number of other things that need to be done in the longer term, such as more psychological support for patients and their families and more timely access to specialised equipment. <http://www.irishhealth.com/article.html?id=20093>

2011 Humanism in Medicine Essay Contest

First place: Palliation

ACADEMIC MEDICINE, 2011;86(12):1558-1559. During the summer months following my first year of medical training, I found myself walking the halls of our city's regional medical center with its palliative care team. I had taken the rotation as part of an elective track, hoping to see firsthand what medical care looked like at the end of life. It was here that I met Lauren Johnson, the nurse practitioner who co-chaired the team and served as my mentor during the experience. She was a small woman, unimposing, and yet her cordial affect was such that one could not help but feel a sense of camaraderie and ease after even the smallest of interactions. Over the course of our weeks together, she introduced me to the life and obligations of a palliative care provider. http://journals.lww.com/academicmedicine/Fulltext/2011/12000/2011_Humanism_in_Medicine_Essay_Contest_First.22.aspx

1. *Primary Palliative Care in Ireland – Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life*, Irish College of General Practitioners, Irish Hospice Foundation, and Health Service Executive, November 2011. <http://www.lenus.ie/hse/bitstream/10147/192381/1/Primary%20Palliative%20Care%20in%20Ireland.pdf>

Of related interest:

- *PALLIATIVE MEDICINE* | Online article – 29 November 2011 – '**Classroom-based and distance learning education and training courses in end-of-life care for health and social care staff: A systematic review.**' Classroom-based education and training is useful for enhancing professionals' skills and perceived preparedness for delivering end-of-life care but should be reinforced by actual practice experience. <http://pmj.sagepub.com/content/early/2011/11/23/0269216311429496.abstract>

Is an advance care planning model feasible in community palliative care?

JOURNAL OF ADVANCE NURSING | Online article – 27 November 2011 – This article reports a [multi-site] study to determine the feasibility of an advance care planning model developed with Australian community palliative care services [i.e., one regional, two regional services]. The services demonstrated that it was feasible to embed the model into their organizational structures. Advance care planning conversations and involvement of family was an important outcome measure rather than completion rate of advance care planning documents in community settings. Services adapted and applied their own concept of community, which widened the impact of the model. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2011.05892.x/abstract>

Patients' diverse beliefs about what happens at the time of death

JOURNAL OF HOSPITAL MEDICINE | Online article – 28 November 2011 – One belief, that death separates the dead from the living, was widespread. Majorities of all three ethnic group samples [in this study]¹ and of 5 of the 6 gender sub-samples expressed this belief, saying the dead "go" or "leave" from this life. Other beliefs differed by ethnic group or gender. More EAs (50%) than others said death is a momentary event, and more MAs (35%) than others said death involves "being taken" by an external force (always God or Jesus). Considerably more EA women (45%) than others said some senses persist after death. In contrast, the physiologic signs that participants cited as defining the exact time of death varied from individual to individual with no ethnic or gender pattern, and no one sign predominated. A few beliefs about what happens at the time of death may characterize Americans in general; many other beliefs may characterize only certain ethnic groups, genders, or individuals. To identify such beliefs and to use them to guide end-of-life care, hospitalists and other health professionals may have to elicit them directly from patients or survivors. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.947/abstract>

1. Mexican-American (MA), 18 Euro-American (EA), and 14 African-American (AA)

Terminal sedation: An emotional decision in end-of-life care

JOURNAL OF MEDICAL ETHICS | Online article – 2 December 2011 – A patient with end-stage motor neurone disease was admitted for hospice care with worsening bulbar symptoms. Although he initially walked onto the ward he became very distressed and asked for sedation. After much discussion, this man was deeply sedated, and after some harrowing days, died. Was it right to provide terminal sedation? What should the threshold be for such treatment? How should our personal reservations affect how we approach the distressed patient in an end-of-life situation? <http://jme.bmj.com/content/early/2011/12/01/medethics-2011-100213.abstract>

Emergency medicine physicians' perspectives of providing palliative care in an emergency department

JOURNAL OF PALLIATIVE MEDICINE | Online article – 2 December 2011 – Overall, [study] respondents felt that palliative care is not prioritized appropriately, leading patients to be unaware of their options for end-of-life care. Providing educational materials and courses that have been developed from the ED [emergency department] perspective should be included in ongoing continuing medical education. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0106>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2011;42(5):657-662. 'A rapid two-stage screening protocol for palliative care in the emergency department: A quality improvement initiative.' The project shows unmet needs among elderly emergency department patients, and the feasibility of rapid screening and referral using a quality improvement approach. At its peak, the project accounted for half the referrals to the palliative care consultation service. [http://jpsmjournal.com/article/S0885-3924\(11\)00403-9/abstract](http://jpsmjournal.com/article/S0885-3924(11)00403-9/abstract)

Cont.

From Media Watch dated 21 November 2011:

- **CRITICAL CARE MEDICINE** | Online article – 10 November 2011 – **'Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit (IPAL-ICU) Project Advisory Board and the Center to Advance Palliative Care.'** Physicians, nurses, and other team members in surgery, critical care and palliative care (if available) should be engaged collaboratively to identify challenges and develop strategies. http://journals.lww.com/ccmjournal/Abstract/publishahead/Integrating_palliative_care_in_the_surgical_and.98189.aspx

The impact of culture and religion on truth telling at the end of life

NEPHROLOGY DIALYSIS TRANSPLANTATION, 2011;26(12):3838-3842. Truth telling, a cardinal rule in Western medicine, is not a globally shared moral stance. Honest disclosure of terminal prognosis and diagnosis are regarded as imperative in preparing for the end of life. Yet in many cultures, truth concealment is common practice. In collectivist Asian and Muslim cultures, illness is a shared family affair. Consequently, decision making is family centred and beneficence and non-maleficence play a dominant role in their ethical model, in contrast to patient autonomy in Western cultures. The 'four principles' are prevalent throughout Eastern and Western cultures, however, the weight with which they are considered and their understanding differ. The belief that a grave diagnosis or prognosis will extinguish hope in patients leads families to protect ill members from the truth. This denial of the truth, however, is linked with not losing faith in a cure. Thus, aggressive futile treatment can be expected. The challenge is to provide a health care service that is equable for all individuals in a given country. The British National Health Service provides care to all cultures but is bound by the legal principles and framework of the U.K. and aims for equity of provision by working within the U.K. ethical framework with legal and ethical norms being explained to all patients and relatives. This requires truth telling about prognosis and efficacy of potential treatments so that unrealistic expectations are not raised.

<http://ndt.oxfordjournals.org/content/26/12/3838.abstract>

Palliative care and oncology partnerships in real practice

ONCOLOGY | Online article – 30 November 2011 – Integrating PC [palliative care] into the outpatient oncology setting introduces palliative medicine and the PC team earlier in the course of a patient's illness, allowing for a smoother transition from curative to palliative goals of care when needed. Patients also will benefit from expert symptom management in the outpatient setting, which may result in fewer hospital admissions for severe symptoms, such as intractable pain or vomiting. The PC team can help to coordinate outpatient services, such as home health agencies and hospice services, or other resources available based on the patient's needs. As a result of this combination ... patients will have the opportunity to receive the highest quality of care possible. Several programs in cancer centers offer successful models of concurrent PC and oncology care. The most readily applicable one is the U.S. Oncology model, which provides a PC physician or APN [advance practice nurse] within an oncology practice. This appears to have a good effect on symptom scores, and it benefits the practice. Truly interdisciplinary care including a chaplain, social worker, and psychologist is difficult given the medical reimbursement model in the U.S. <http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/1994333?pageNumber=2>

Of related interest:

- *ONCOLOGY* | Online article – 30 November 2011 – **'The oncologist as primary palliative care provider.'** <http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/1995330>
- *ONCOLOGY* | Online article – 30 November 2011 – **'Palliative care: Meaningful benefit in oncology care.'** <http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/1994307>

The need for new perspectives on evaluation of palliative care

PALLIATIVE MEDICINE, 2011;25(8). This special edition of *Palliative Medicine* considers different approaches to palliative care evaluation. It has its origin in a meeting organized in 2010 by the Capacity Building & Methodology Themes of the Cancer Experiences Collaborative, reflecting an increasing recognition that the traditional randomized controlled trial design does not always provide the best approach to much needed evaluation in palliative care. Part of the problem in evaluating palliative care is that we are almost always dealing with a complex intervention. Complex interventions are interventions containing several interacting components, and their complexity may relate to the complexity, number, and flexibility of the components of the intervention itself and/or the groups, organizational levels, and outcomes targeted.

Editorial: <http://pmj.sagepub.com/content/25/8/737.full>

Contents page: <http://pmj.sagepub.com/content/25/8.toc>

Of related interest:

- *JOURNAL OF MEDICINE & MEDICAL SCIENCES*, 2011;2(11):1225-1234. **'Improving the coordination of palliative care.'** This study will discuss the principles and difficulties with palliative care coordination by carrying out an examination of international literature on the importance and effectiveness of various palliative care models and interventions that impact on the coordination of palliative care services. Evidence-based recommendations are made on how to improve care coordination. <http://interesjournals.org/JMMS/Abstracts/2011%20Abstract/November/Chan%20and%20Nichols.htm>

European trends in medical practice

Out-of-hours medical care for terminally ill patients: A survey of availability and preferences of general practitioners

PALLIATIVE MEDICINE | Online article – 29 November 2011 – Continuity of care is one of the core values of good medical care for terminally ill patients. The availability of one's own general practitioner (GP) out of hours is regarded as important for personal continuity. The reported out-of-hours availability of GPs [i.e., study participants] for terminally ill patients is still high. GPs' perception of their duty of care might change in the next generations, and the increasing number of salaried GPs, living far from their practice, might threaten out-of-hours availability for terminally ill patients. <http://pmj.sagepub.com/content/early/2011/11/23/0269216311428527.abstract>

From Media Watch dated 19 September 2011:

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE*, 2011;2(9):70. **'Heartsink encounters: A qualitative study of end-of-life care in out-of-hours general practice.'** The authors' interpretation distinguished the term 'heartsink' from its usual context, the "heartsink patient," to a different meaning, that of the imminent palliative care encounter triggering a sensation of heartsink for some out-of-hours doctors. <http://shortreports.rsmjournals.com/content/2/9/70.short>

From Media Watch dated 25 April 2011:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 20 April 2011 – **'What challenges good palliative care provision out-of-hours? A qualitative interview study of out-of-hours general practitioners.'** Out-of-hours doctors [i.e., study participants] were not confident about their palliative care knowledge and expressed a wish for more education. Lack of familiarity with patients requiring acute palliative care, compared with the closer bonds formed within the in-hours general practice setting, was perceived as troublesome and problematic, and lack of follow-up was felt to be a major factor. <http://spcare.bmj.com/content/early/2011/04/21/bmjspcare-2011-000015.abstract>

Study shows hospice caregivers need routine care interventions

QUALITATIVE HEALTH RESEARCH |
Online article – 30 November 2011 – A study led by the University of Kentucky researcher Elaine Wittenberg-Lyles found hospice family caregivers are "second order patients" themselves and require their own unique care needs. Study participants were asked to identify and describe the most pressing problems or concerns they faced. Researchers coded participants' responses in one of three categories: primary stressors, which included talk that related to the performance of caregiving tasks; secondary stressors, talk about the personal impact of performing caregiving tasks; and, intrapsychic stressors, talk about their thoughts, feelings and awareness of the caregiving role. Clinicians should assume that anyone going through the stress and chaos of caring for a terminally ill family member has low health literacy and high needs for education and support."
http://www.sciencecodex.com/read/study_shows_hospice_caregivers_need_routine_care_interventions-82316

From the archives

Palliative care for families: Remembering the hidden patients

CANADIAN JOURNAL OF PSYCHIATRY, 2004; 49(6):359-365. Families of patients receiving palliative care are profoundly affected by the challenges of the illness. They observe care that the patient receives, provide care for the patient, and receive support from health professionals in the form of information, counselling, or practical assistance. As they witness and participate in the patient's care, they judge the quality of care that the patient receives. They often see themselves as the patient's care advocates and may harbour regret and guilt if they believe that the patient did not have the best possible care. The illness experience profoundly affects family members' psychological and physical health; recognition of this has coined the term "hidden patients."
<https://ww1.cpaapc.org/Publications/Archives/CJ/P/2004/june/kristjanson.pdf>

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.

Worth Repeating

Sharing death and dying: Advance directives, autonomy and the family

BIOETHICS, 2004;18(2):87-103. This paper critically examines the liberal model of decision making for the terminally ill and contrasts it with the familial model that can be found in some Asian cultures. The contrast between the two models shows that the liberal model is excessively patient-centred, and misconceives and marginalises the role of the family in the decision making process. The paper argues that the familial model is correct in conceiving the last journey of one's life as a sharing process rather than a process of exercising one's prior or counterfactual choice, and concludes by suggesting a policy framework for the practice of familialism that can answer the liberal challenge that familialism cannot safeguard the patient from abuse and neglect.
<http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2004.00383.x/abstract>

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca