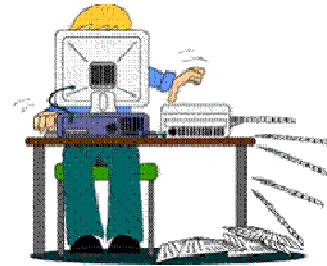


Media Watch

...is distributed weekly to colleagues active or with 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 inform discussion and encourage further inquiry. Following is an annotated listing of recent articles, reports, etc., with links to the original source.

22 September Edition | Issue #63



Compilation of Media Watch 2008 ©

Compiled & Annotated by Barry R. Ashpole

Hospice palliative care and end-of-life issues, and the Internet:
Scroll down to **Books & Resources** and 'More palliative care blogs!'
and (of related interest)'Wikipedia and palliative medicine: A call to arms.'

Canada: National

Federal election

Home care: a critical election issue

CANADIAN HOME CARE ASSOCIATION (CHCA) | CHCA press release – 19 September 2008 – Federal support and leadership is key to ensuring that Canadians across the country have equitable access to timely and appropriate community-based health care in order to remain independent at home for as long as possible. Federal support is also vital to the 4 million family caregivers who contribute over \$5 billion dollars of unpaid care to the health care system.
<http://www.newswire.ca/en/releases/archive/September2008/19/c6292.html>

- National Democratic Party (NDP) press release: '**Layton will introduce National Home Care Plan.**' <http://www.marketwatch.com/news/story/layton-introduce-national-home-care/story.aspx?guid=%7B01626E63-EA8D-4715-A441-239E0AB64DED%7D&dist=hpr>

Of related interest:

- Canadian Caregiver Coalition (CCC) press release: '**Call on all federal parties to support family caregivers.**' <http://www.ccc-ccan.ca/media.php?mid=151>
- Health Charities Coalition of Canada (HCCC) press release: '**Response to ... announcement regarding catastrophic drug coverage for Canadians.**' <http://www.newswire.ca/en/releases/archive/September2008/17/c5766.html>
- Service Employees International Union (Canada) press release: '**Ontario home care workers running on empty.**' <http://www.marketwire.com/press-release/Seiu-Canada-Service-Employees-International-Union-Canada-901910.html>
- *Toronto Star*: '**High price of compassionate care.**' <http://www.thestar.com/comment/article/502805>

Euthanasia and assisted suicide

Euthanasia: Whether to welcome death

TORONTO STAR | Online report – 19 September 2008 – Angelique Flowers ... speaks just above a whisper ... in her poignant plea to Australian Prime Minister Kevin Rudd to legalize euthanasia. Flowers, a writer who has suffered with debilitating Crohn's disease for 16 years, died in August after she was diagnosed in May with advanced, aggressive colon cancer. She spent much of those final, precious months on the Internet searching for ways to kill herself. All she wanted, she says in (a YouTube) video, is a pain-free, peaceful death. Every so often, a profoundly sad story sparks public and political debate about the ethics of death. In Australia, following Flowers' video, the leader of the Greens introduced a bill that would allow the country's territories to legalize euthanasia. In Canada, euthanasia and assisted suicide are not issues in the election campaign, but they contentiously loom on the political horizon. <http://www.thestar.com/living/article/501835>

Of related interest (with link to YouTube video discussed in the *Toronto Star* article):

- Australia (*Sydney Morning Herald*): **'Robbed of my living and dying.'** <http://www.smh.com.au/news/national/robbed-of-my-living-and-dying/2008/09/12/1220857835038.html>

Beliefs and values

Denying doctors free conscience unconscionable

CALGARY HERALD | Online report – 18 September 2008 – The practice of medicine ... involves ethical and moral issues. It's only when something goes wrong or there is a conflict of values that the ethical issues flash up on the big screen. Treating physicians as mere technicians fails completely to take that omnipresent ethical aspect into account. It is also the antithesis of the traditional concept of a physician, as a professional with ethical and legal obligations to exercise good judgment. Most notable among those obligations is to first do no harm, which means that a physician may not simply fulfil a patient's request, but must make an independent judgment as to its acceptability. <http://www.canada.com/calgaryherald/news/story.html?id=3794616b-c515-4a87-84a2-6773c0f2c6cb&p=2>

From Media Watch dated 08.25.08.

- *Calgary Herald*: **'Doctors must always have right to follow conscience.'** <http://www.canada.com/calgaryherald/news/theeditorialpage/story.html?id=1cfb5887-cc16-4d70-881a-652920d7718b>

From Media Watch dated 08.18.08.

- *The National Post*: **'College of Physicians & Surgeons of Ontario: Proposed rules could end right to follow conscience.'** <http://www.nationalpost.com/news/story.html?id=727686>

Canada: Provinces

Health centre and University Health Network establish world-class community hospice

ONTARIO | University Health Network (UHN) press release – 18 September 2008 – UHN will share its latest knowledge, research and expertise in end-of-life care to assist Kensington Health Centre long-term care home in establishing a world-class centre through a formal affiliation between UHN's palliative service and the academic palliative unit at Princess Margaret Hospital, and the newly established Kensington Hospice Home on the Toronto-based health centre's site. <http://www.marketwire.com/press-release/Kensington-Health-Centre-University-Health-Network-Princess-Margaret-Hospital-901309.html>

Roadside shrines spark debate on displays of grief

B.C. | *Times-Colonist* – 16 September 2008 – Several jurisdictions limit the length of time that a memorial may stand. Hawaii lets them stay for no more than 30 days, and not incorporate any reflective materials. Wyoming provides signs that may stay up for five years. In 2003, Washington decided to have its highways department remove all roadside shrines; families have the option of paying for an official memorial sign instead. B.C. Ministry of Transport allows memorials, as long as they aren't a hazard Police and highways officials don't always apply the letter of the law, though. <http://www.canada.com/victoriatimescolonist/news/sports/story.html?id=ef752477-d8c6-4e82-90a2-25d391568abd&p=2>

From Media Watch dated 07.28.08.

- Saskatchewan (*Prince Albert Daily Herald*): **'Roadside memorials dealt with in various ways.'** <http://www.paherald.sk.ca/index.cfm?sid=155979&sc=4>

N.B. Listing in the 28 July weekly report includes additional links to several related articles, reports, etc.

Alberta sees huge HIV jump

ALBERTA | *Calgary Sun* – 12 September 2008 – People on the front lines of the AIDS fight say they're concerned by a 29% jump in the number of new HIV cases in Alberta in 2007, compared to two years before. And Calgary has virtually traded places with Edmonton for having the largest portion of that increase – 43.8% of the cases versus 39.8%. It's difficult to pinpoint why Calgary's rate of new infections has overtaken Edmonton's, which is highly unusual, said AIDS Calgary's Capri Rasmussen. "It's possibly it's due to an increase in Calgary's population, young people coming to work," said Rasmussen. In 2007, newly reported HIV infections in Alberta totalled 225 – up from 175 two years previously. <http://calsun.canoe.ca/News/Alberta/2008/09/12/6744456-sun.html>

Of related interest:

- Scroll down to [U.S.A.](#) and **'U.S. AIDS epidemic far from over.'**

Province should fund community hospices

NEW BRUNSWICK | *Telegraph-Journal* – 8 September 2008 – Hospice of Greater Saint John is moving ahead with plans to renovate a community home into a centre that can accommodate 10 palliative care patients at a time. To operate this hospice, the organization will require \$800,000 in annual government funding, a pledge the Department of Health has not yet been willing to make. In Ontario, the community hospice model has been embraced as a cost-effective way of serving all patients better. It offers dying residents appropriate end-of-life care in calm surroundings where family members can be present, and it makes more acute care beds available for patients who need the treatment only a hospital can provide. Hospices establish a partnership in medicine at the community level - one that involves patients and their families, medical professionals, non-profit organizations and the provincial hospital system – the kind of health care innovation New Brunswick so desperately needs. <http://telegraphjournal.canadaeast.com/opinion/article/419100>

[Links](#)

Please alert this office if you encounter any difficulty. Every effort will be made to find an alternative means of access. Alternatively, copy/paste the URL into the address bar of your browser. All links are confirmed as being active before Media Watch is distributed; they remain active, however, for only a limited period of time.

U.S.A.

State can't afford to ignore data on end of life care

NEW YORK | Syracuse.com – 19 September 2008 – Examination of end-of-life care in Central New York raises a number of valid concerns that require community-wide reflection. It is common knowledge that, in general, the last year of life is the most expensive to the health care economy and the most intensive in its use of medical resources. There is wide geographic variation in terms of the expense, sites and types of care provided to patients at the end of life. Survey research shows that when asked what people want for end-of-life care, 83% said that they would like to spend their last days at home. This contrasts sharply with the fact that only about 25% of Americans actually die there. <http://www.syracuse.com/opinion/index.ssf?/base/opinion-4/1221814554213540.xml&coll=1>

- Minnesota (*Star-Tribune*): 'We're aging, but our care system isn't keeping pace.'
http://www.startribune.com/opinion/commentary/28625154.html?elr=KArksc8P:Pc:UthPacyPE7iUiD3aPc:_Yyc:aUU
- New York (*Ithaca Journal*): 'The cost, choices of health care in final months.'
<http://www.theithacajournal.com/apps/pbcs.dll/article?AID=/20080919/OPINION02/809190302>

Muslim faith and end of life care

Teaching diversity in medical care

FLORIDA | *Tampa Tribune* – 17 September – When it comes to medical care, not all people are comfortable with the same treatments and procedures. To better treat patients of varying ethnic, cultural and religious backgrounds, University Community Hospital's Palliative Care Team recently started a cultural diversity program. The program revolves around a lecture series in which prominent men and women of different faiths will address the hospital community and answer questions about medical requirements, preferences and restrictions. At the first lecture, Imam Muhammad Sultan of the Islamic Society of Tampa Bay spoke about health care and the Muslim community. <http://northeast2.tbo.com/content/2008/sep/17/ne-teaching-diversity-in-medical-care/>

Decision making

Long-ignored legislation would ease suffering

NEW YORK | *Buffalo News* – 17 September 2008 – For the past 15 years, the New York State Legislature has failed to pass a bill so sensible that most New Yorkers probably believe it already to be law. The Family Health Care Decisions Act, introduced in 1993, would allow families and guardians to make medical decisions for patients who can no longer decide for themselves. In the vast majority of states, it is the law, but not in New York. Because of that, helpless patients are suffering and dying miserable deaths. <http://www.buffalonews.com/149/story/441121.html>

U.S. AIDS epidemic far from over

ILLINOIS | MedLineNews.com – 16 September 2008 – Statisticians for the Centers for Disease Control & Prevention had predicted that about 40,000 new cases of HIV ... would be diagnosed each year in the U.S. alone, but the grim reality is that as many as 56,300 Americans became infected in 2006. <http://medheadlines.com/2008/09/16/cdc-us-aids-epidemic-far-from-over/>

- Centers for Disease Control (Fact sheet):
http://www.cdc.gov/nchhstp/newsroom/docs/CDC_Incidence_MMWR.pdf

Family caregiver writing study

IOWA | University of Iowa College of Nursing press release – 16 September 2008 – For families who provide care to a loved one with cancer, stress and isolation can be a burden that's hard to carry. A University of Iowa College of Nursing researcher is conducting a study to see if adults, age 55 and older, can use writing about their thoughts and feelings about care giving as a strategy to help manage stress. http://media-newswire.com/release_1073000.html

Tools for dying

NEW YORK | Core77 – 16 September 2008 – The Brooklyn-based design collective Thwart Design have just announced the launch of Tools for Dying, a site that parodies the modern furniture company Design Within Reach and its forthcoming Tools for Living stores. Rob Price and Kathy Park describe their project as follows: "Five of the world's most iconic designs are interpreted with a comical twist. Whether you're lounging (forever) in the Eames Plywood Lounge Coffin or settling into the Graves urn, one can celebrate the transition to death with the right design aesthetic." http://www.core77.com/blog/news/tools_for_dying_11101.asp

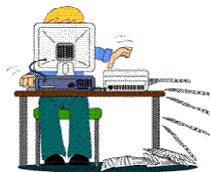
No rest – even in death

TEXAS | Associated Press – 16 September 2008 – Hurricane Katrina chased bluesman Clarence 'Gatemouth' Brown from his adopted home in New Orleans to his hometown here on the Texas Gulf Coast, where he died in exile. Now, another hurricane has disturbed his rest. The 1982 Grammy Award winner's casket was one of dozens belched up from the ground when gulf and rain waters from Hurricane Ike flooded Hollywood Cemetery, an all-black burial ground on the west side of this city on the Sabine River. Two days after Ike's landfall, water gurgled and bubbled ominously from submerged graves, and an invisible cloud of formaldehyde stung the eyes and throat. The only water left was filling now empty graves and vaults. Debris from the storm littered the ground. The top of Brown's vault had popped off, and his bronze casket had floated away. <http://www.edmontonsun.com/News/World/2008/09/16/6778211-sun.html>

Quotable Quotes

The worst thing about grief is the length of time during which the experience lasts. For the first weeks one is in a state of shock. But the agony lasts long after the state of shock comes to an end. After a year, or about two, the agony gives way to a dull ache, a sort of void. During the night in one's dreams, and in the morning when one wakes, one is vaguely aware that something is wrong and, when waking is complete, one knows exactly what it is." **Lord Halisham of St. Marylebone, A Sparrow's Flight** (Collins, 1990)

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 workshops for frontline care providers.

Euthanasia and assisted suicide: Washington's Initiative 1000

Initiative 1000 would let patients get help ending their lives

WASHINGTON | *Seattle Times* – 21 September 2008 – One woman shudders and chokes back tears as she recounts the agony of her husband's slow death. Another recalls with wonder and affection the many precious months she and her husband shared before he finally succumbed. After intimate encounters with death, these two came to opposite conclusions about Initiative 1000, which would allow doctors to prescribe lethal doses of medication for terminally ill patients seeking to hasten their deaths. Oregon is the only state that allows the dying to get medical help explicitly to end their lives. No other such proposals are on the ballot this fall in other states. Voters' experiences and fears about death are triggering powerful emotions as they consider I-1000. http://seattletimes.nwsourc.com/html/politics/2008193092_death21m.html

- Catholic News Agency: **'Washington assisted suicide ballot push is part of national plan, critics claim.'** <http://www.catholicnewsagency.com/new.php?n=13847>
- Washington (Enterprise Newspapers): **'Terminally ill deserve our compassion.'** <http://www.enterprisewspapers.com/article/20080917/ETP21/709179964/-1/ETPZoneLT&template=ETPZoneLTart>
- Washington (*Olympian*): **'Personal beliefs weigh in on fate of assisted-suicide measure in State.'** <http://www.theolympian.com/southsound/story/591449.html>
- Washington (Seattle.pi.com): **'Initiative 1000 is not a slippery slope.'** (Editorial by former Governor of Oregon.) http://seattlepi.nwsourc.com/opinion/379211_robertsoregon16.html
- Washington (*Whitworthian*): **'Don't let assisted suicide measure die this November.'** <http://media.www.whitworthian.com/media/storage/paper1220/news/2008/09/16/Opinions/Opinion.Dont.Let.Assisted.Suicide.Measure.Die.This.November-3432010.shtml>

Of related interest (representative sample):

- American Family News Network: **'Euthanasia victim survives, fights back.'** <http://www.onenewsnow.com/Legal/Default.aspx?id=251746>
- California (Sacbee.com): **'Doctor's torn by end-of-life philosophies.'** <http://www.sacbee.com/107/story/1248325.html>
- Oregon: (*Oregonian*): **'Aid in dying, Oregon-style.'** <http://www.oregonlive.com/editorials/oregonian/index.ssf?/base/editorial/1221863106315720.xml&coll=7>

Lawmakers introduce Bill to put hold on cut to hospice Medicare reimbursement

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Press release – 15 September – Lawmakers have introduced the Medicare Hospice Protection Act of 2008, which prevents a Centers for Medicare & Medicaid Services (CMS) rule that would effectively cut hospice Medicare reimbursement rates from going into effect for one year. Earlier this year, CMS announced that it will cut Medicare reimbursement rates for hospice, forcing many hospice providers across the country to either significantly scale back care at the bedside or to shut their doors altogether. <http://www.nhpc.org/i4a/pages/index.cfm?pageid=5729>

From Media Watch dated 09.08.08.

- NHPCO press release: **'Largest U.S. hospice member organization files suit against Bush Administration.'** <http://www.nhpc.org/i4a/pages/index.cfm?pageid=5718>

Decision making

Parents of dying newborns need clearer explanation of options

MARYLAND | Johns Hopkins Children's Center press release – 15 September 2008 – Parent-doctor discussions about whether to maintain or withdraw life support from terminally ill or severely premature newborns are so plagued by miscommunication and misunderstanding that they might as well be in different languages, according to a small but potentially instructive new study from Johns Hopkins Children's Center. In-depth interviews with 26 mothers of babies who died shortly after birth at three mid-Atlantic hospitals revealed that what mothers said they were told by doctors was often at odds with what physicians recorded in the medical chart with respect to options offered and accepted. Results of the interviews show that few mothers recalled discussing the full range of options, from aggressive resuscitation to palliative care through the end of life. In fact, few recalled discussing resuscitation as an option at all, while the written medical records often indicated that such options were discussed. Many mothers found doctors' language confusing. Few recalled being offered comfort end-of-life care, even when the discussion was noted in the medical charts. <http://newswire.ascribe.org/cgi-bin/behold.pl?ascribeid=20080915.102815&time=11%2054%20PDT&year=2008&public=0>

Of related interest:

- *New York Times*: 'ER patients often left confused after visits.'
http://www.nytimes.com/2008/09/16/health/16emer.html?_r=1&ref=science&oref=slogin
- TeachingExpertise.com: 'Risking painful treatment to improve a child's life.'
<http://www.teachingexpertise.com/articles/legal-case-notes-risking-painful-treatment-improve-childs-life-3505>

Perhaps death is proud: More reason to savor life

NEW YORK TIMES | Online article – 9 September 2008 – That's hardly our intention, but they die nonetheless. Usually it's at the end of a long struggle – we have done everything modern medicine can do and then some, but we can't save them. Some part of their body, usually their lungs or their heart or their liver, has become too frail to function. These are the "good deaths," the ones where the family is present and knows what to expect. Like all deaths, these deaths are difficult, but they are controlled, unsurprising, anticipated. And then there are the other deaths: quick and rare, where life leaves a body in minutes. In my hospital these deaths are 'Condition A's.' The 'A' stands for arrest, as in cardiac arrest, as in this patient's heart has all of a sudden stopped beating and we need to try to restart it.
<http://www.nytimes.com/2008/09/09/health/09case.html>

Letter to the editor in response:

'Trying to save the patient.'

http://www.nytimes.com/2008/09/16/health/16lett-TRYINGTOSAVE_LETTERS.html?ref=science

*Death be not proud, though
some have called thee
Mighty and dreadfull, for,
thou art not soe,
For, those, whom thou
think'st, thou dost overthrow,
Die not, poore death, nor yet
canst thou kill mee...*

John Donne [1572-1631]

N.B. The metaphysical poetry of Donne (pronounced Dunn) is a theme of the movie *Wit*: see Media Watch dated 06.02.08., and 'Top 10 palliative care movies.'

International

Euthanasia and assisted suicide

Push for fresh vote on euthanasia

AUSTRALIA (NORTHERN TERRITORY) | News.com.au – 17 September 2008 – Greens leader Bob Brown will introduce a bill to overturn the ban on the territory governments' right to legalise euthanasia. Senator Brown's bill aims to repeal the commonwealth Euthanasia Laws Act 1997 and thereby allow the Northern Territory and the Act to make legislation permitting voluntary euthanasia. The new bill amends Senator Brown's earlier euthanasia bill, introduced in February. A Senate committee delivered a report on the original bill in June with Labour senators saying they would support it with some amendments. "Yesterday, the new opposition leader, Malcolm Turnbull, declared the Liberal Party stood for freedom of choice and respect for the individual," Brown said. The Greens' bill will restore the rights of territory parliaments to assist terminally ill people choose a death with dignity. <http://www.news.com.au/story/0,23599,24359016-17001,00.html>

- Australia (ABC News): **'Territories' euthanasia bill gets cold reception.'** <http://www.abc.net.au/news/stories/2008/09/17/2367486.htm?section=australia>

Of related interest (representative sample):

- Australia (*Consult Magazine*): **'A defence of physician-assisted death.'** <http://www.consultmagazine.net/StoryView.asp?StoryID=269813> Reference page: <http://www.consultmagazine.net/StoryView.asp?StoryID=269812>
- Columbia (*Espectator*): **'Euthanasia clears historic hurdle in Columbia.'** <http://colombiareports.com/colombian-news/news/1264-euthanasia-now-legal-in-colombia.html>
- Columbia (Catholic News Agency): **'Crime of euthanasia will always be immoral, warns Colombian cardinal.'** <http://www.catholicnewsagency.com/new.php?n=13850>
- India (*Wall Street Journal*): **'The Law Commission in India recently recommended that euthanasia be legalized.'** <http://www.livemint.com/2008/09/09004317/A-right-to-dignified-death.html>
- U.K. (*Daily Telegraph*): **'Dementia sufferers may have a 'duty to die.'** <http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html>

N.B. Editorial in response to *Daily Telegraph* report (*Calgary Herald*, Canada): **'Euthanasia call termed 'barbaric.'** <http://www.canada.com/calgaryherald/news/story.html?id=441cef53-bafe-4409-9884-7732a4c5d4a3>

- U.K. (Regional Film & Video – 4rfv.co.uk): **'Internet suicide' laws to be made clearer.'** <http://www.4rfv.co.uk/nationalnews.asp?id=82428>
- United Press International: **'Euthanasia advocate avoids prison by death.'** http://www.upi.com/Top_News/2008/09/19/Euthanasia_advocate_avoids_prison_by_death/UPI-46131221874258/

Was Something Missed or Overlooked?

If you come across a media report, journal article, etc., relevant to hospice palliative care or end-of-life issues not mentioned in this edition of Media Watch, please alert this office so that it can be included in a future issue of the weekly report. Thank you.

Warning on HIV surge

AUSTRALIA | *Sydney Morning Herald* – 17 August 2008 – HIV rates in Australia have increased by almost 50% in the past eight years, pushing the number of new cases diagnosed each year to more than 1000 and prompting a call for more funding to fight the disease. Researchers at the National Centre of HIV Epidemiology & Clinical Research, at the University of New South Wales, found that 1051 new cases were diagnosed last year – up from 998 in 2006 and 718 in 1999. <http://www.smh.com.au/news/life--style-home/health/warning-on-hiv-surge/2008/09/16/1221330837139.html>

A human right to palliative care



U.K. | *The Guardian* (letter to the editor) – 16 September 2008 – The theme of this year's World Hospice & Palliative Care Day (11 October) is that palliative care is a human right, highlighting that without access to the care they need, people coping with serious and terminal illness suffer in ways that amount to a breach of their human rights. Now is the time to lobby MPs and others in all health and social care settings to the effect that we need to move on from laudable and very welcome aspirations to practical plans to increase resources, create partnerships and make hospice and palliative care – whether delivered in people's homes, in hospice buildings or elsewhere – available to all. <http://www.guardian.co.uk/society/2008/sep/16/longtermcare>

N.B. The letter was in response to an article in an earlier issue of the newspaper, **'The long game.'** <http://www.guardian.co.uk/society/2008/sep/10/ageing.population>

- Link to World Hospice & Palliative Care Day website: <http://www.worldday.org/>

From Media Watch dated 08.04.08.

- U.K. (*Medical News Today*): **'Organisations call for recognition of palliative care and pain treatment as human rights.'** <http://www.medicalnewstoday.com/articles/117069.php>

Survey reveals people want to die at home

U.K. | *Epping Forest Guardian* – 15 September 2008 – Most people would prefer to die at home rather than in a hospice or hospital, according to a new study. An audit of the choices of 100 people who recently died revealed that 76 wanted to die at home, 23 in a hospice, and one at hospital. It also found that 88 of those who took part died in their preferred location. The study was carried out ... following the publication of the National Health Service (NHS) End of Life Strategy last month. The strategy includes a Preferred Place of Care document which is aimed at helping people to have more control over where they die by improving trust and communication between patients and their families and health professionals. http://www.guardian-series.co.uk/news/3674889.EPPING_FOREST_Survey_reveals_people_want_to_die_at_home/

N.B. Link to NHS Preferred Place of Care document: <http://www.cancerlancashire.org.uk/leaflet.pdf>

Of related interest:

- Ireland (*Herald*): **'Allow terminally ill to die with a little dignity.'** <http://www.herald.ie/national-news/allow-terminally-ill-die-with-a-little-dignity--byrne-1475775.html>

[Back Issues of Media Watch](#)

Back issues of Media Watch are held on file for a limited time and available on request.

Journal Articles

Family Preferences Index

Helping family members who want to participate in the care of a hospitalized older adult

AMERICAN JOURNAL OF NURSING, 2008;108(9):52-59. Family members are an important but often underappreciated resource in caring for hospitalized older adults. The Family Preferences Index is a 14-item approach to exploring caregivers' personal choices for participating in the hospital care of older adult family members. It can be administered as a structured interview or as a questionnaire. Higher scores indicate a greater preference to participate in care. The nurse can use the responses to the index to plan care that builds a partnership with the family.

<http://www.nursingcenter.com/pdf.asp>

N.B. To watch a video demonstrating the use of the index: <http://links.lww.com/A296>

Modified Caregiver Strain Index

Helping those who help others

AMERICAN JOURNAL OF NURSING, 2008;108(9):62-69. The Modified Caregiver Strain Index can be given to family members caring for disabled older adults. It helps to determine their level of strain – a combination of stress and burden that has consequences on caregivers' overall health. The index assesses 13 aspects of physical health, family finances, social interactions, time demands, and employment. By pinpointing the sources and degree of strain, the index can guide in the selection of interventions that might be used to alleviate caregivers' strain and improve the lives of caregivers and care recipients. <http://www.nursingcenter.com/pdf.asp>

N.B. To watch a video demonstrating the use and interpretation of the Modified Caregiver Strain Index: <http://links.lww.com/A291>

Of related interest

- *American Journal of Nursing*, 2008;108(9):Supplement. '**Professional partners supporting family caregiving.**' <http://www.nursingcenter.com/library/static.asp?pageid=809507>

Resource:

- The Pallium Project (Barry R. Ashpole): '**Initiating a dialogue with family.**' http://www.pallium.ca/infoware/Ashpole_22Sep05.pdf. Link to podcast: <http://palliativeinsight.net/2007/10/25/initiating-a-dialogue-with-family-hospice-palliative-care.aspx>

Caregivers' active role in palliative home care – to encourage or to dissuade?

BMC PALLIATIVE CARE, 2008, 7:15. Spouses' involvement in palliative care is often a prerequisite for home death, but it is unclear whether active involvement of the spouse, e.g., administering and being in charge of oral or subcutaneous medication or taking care of the patient's personal hygiene, could be harmful or have negative effects on the spouse's experience of the palliative course of disease. The study identified important issues whenever spouses take an active part in medical treatment and physical care of critically ill patients in palliative care. The results question the previous research that active involvement of family caregivers could be harmful and add preconditions to a positive outcome. More research into these preconditions is needed. <http://www.biomedcentral.com/content/pdf/1472-684x-7-15.pdf>

Of related interest:

- Pennsylvania (*Central Daily Times*): '**When feminism meets elder care, results are tense.**' <http://www.centredaily.com/living/story/843441.html>

A funeral liturgy: Death rituals as symbolic communication

JOURNAL OF LOSS & TRAUMA, 2008;13(5):406-421. This performative ethnography pulls together ethnography, autoethnography, and interview accounts to explore and exemplify the liturgical and narrative symbolism inherent in funerals. Funerals are the ultimate in final stories. This article looks at funerals as a communicative event and addresses questions of the performative nature of funerals and the meaning and reality constructed by funerals. The author concludes with an argument for seeing funerals as an opportunity to bridge the liminal space between dead and alive and the sacred and the human, and to bring together the past, present, and future of the deceased and their "surviving" loved ones. **N.B.** Link unavailable.

General practitioners' experiences of the psychological aspects in the care of a dying patient

PALLIATIVE & SUPPORTIVE CARE, 2008;6:125-131. General practitioners (GPs) play an integral role in addressing the psychological needs of palliative care patients and their families. This qualitative study investigated psychosocial issues faced by GPs in the management of patients receiving palliative care and investigated the themes relevant to the psychosocial care of dying patients. The significant themes that emerged related to perceived barriers to exploration of emotional concerns, including spiritual issues, and the discussion of prognosis and dying, the perception of patients' responses/coping styles, and the GP's personal experience of the care (usually expressed in terms of identification with patient). The findings indicate the significant challenges facing clinicians in discussions with patients and families about death, to exploring the patient's emotional responses to terminal illness and spiritual concerns for the patient and family. <http://journals.cambridge.org/action/displayAbstract;jsessionid=C0ADF284138A686E442B80905F3D96A7.tomcat1?fromPage=online&aid=1885868>

Books & Resources

VON Canada launches bilingual web website for Canada's family caregivers

CANADA | Victorian Order of Nurses (VON) press release – 16 September 2008 – VON Canada has launched 'Caregiver Connect ... from Caring to Sharing' (<http://www.caregiver-connect.ca/en-us/Pages/Home.aspx>). Bilingual, the new website "... will provide access to information and resources that caregivers need to care for themselves, to provide better quality care to their family members or friends, and to connect and share with other caregivers." <http://www.newswire.ca/en/releases/archive/September2008/16/c4826.html>

Cancer pain management training for healthcare professionals on CD-ROM

U.K. | *British Journal of Healthcare Computing & Information Management* – 16 September 2008 – The Institute of Cancer Research has produced an interactive CD-ROM, 'Breaking Barriers: management of cancer-related pain, for medical professionals to help manage their patients' pain.' Developed in collaboration with the Royal Marsden Hospital it describes accurate ways of measuring pain, the combination of drug treatments that may assist in pain management, how to tailor treatments to individual patients and the importance of communication skills. 'Breaking Barriers' is the first CD-ROM to combine such depth with a user-friendly interface that maximises a healthcare professional's understanding of cancer pain management. Animations, videos and interactive elements all combine to rapidly educate and assist the user. The first 10,000 copies were produced with the help of a donation and allow them to be made available free to medical professionals worldwide. <http://www.bjhcim.co.uk/news/2008/n809020.htm>

Hospice palliative care and end-of-life issues, and the Internet

More palliative medicine blogs!



U.S. | PalliMed.org – 15 September 2008 – The world of hospice and palliative medicine related blogs has been slower to grow than in other fields of healthcare. Two blogs highlighted by PalliMed.org are 'Dethmama Chronicles: The true adventures of a hospice nurse,' and DNR/DNI. <http://www.pallimed.org/2008/09/more-palliative-medicine-blogs.html>

- Dethmama Chronicles: <http://dethmama.blogspot.com/>
- DNR/DI: <http://micunurse.blogspot.com/>

Of related interest:

- PalliMed.org: **'Wikipedia and palliative medicine: A call to arms.'** <http://www.pallimed.org/2008/09/wikipedia-and-palliative-medicine-call.html>

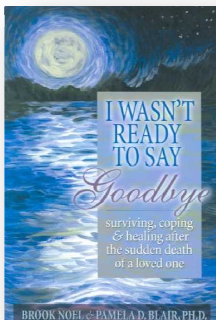
Sample YouTube broadcast:

- TalkBlogRadio.com: **'What dying people want: practical wisdom for the end of life.'** Interview with Dr. David Kuhl. <http://www.blogtalkradio.com/yourmentalhealth/2008/09/19/dr-david-kuhl-what-dying-people-want-practical-wisdom-for-the-end-of-life>

N.B. A journalism student at the University of Sydney (Australia) argues that YouTube gives a voice to those who would otherwise not be heard: <http://webdiary.com.au/cms/?q=node/2527>

Grief after sudden death

Recent tragedies draw new chapters from grief author



U.S. | *Houston Chronicle* (Texas) – 15 September 2008 – After the sudden death of her 27-year-old brother in 1997, Wisconsin resident Brook Noel hit the bookstore for resources to cope with grief. She found plenty of books on grieving after losing someone to age or to a terminal illness, but zero on how to grieve a sudden death. So Noel, the author of 19 self-help books, decided to write her own. She co-authored *I Wasn't Ready to Say Goodbye* with Pamela Blair in 2000. An updated version was recently released. Noel talked with writer Kim Morgan about people who have lost a loved one suddenly, something she said happens to about 8 million Americans each year. <http://www.chron.com/disp/story.mpl/health/6003503.html>

Worth Repeating

"Doctor, am I dying."

IRELAND | IrishHealth.com – 9 November 2001 – Maybe I should have bitten the bullet earlier and told Lilly the truth about her condition. Perhaps a more experienced doctor would have been more skilled and avoided the trap of being entangled in a web of inconsequential conversation. However, my overriding instinct tells me that Lilly posed the question when she was ready to hear the answer. <http://www.irishhealth.com/index.html?level=4&id=3190>

Arts & Entertainment

Film about terminally ill comedian not a typical cancer survivor's story

That's My Time

CANADA | *Chronicle-Herald* (Halifax) – 17 September – Dying is easy, comedy is hard, according to the famous last words of stage actor Sir Leonard Wolfitt. Imagine tackling both simultaneously. When comedian and writer Irwin Barker was diagnosed with leiomyosarcoma – a rare and aggressive strain of cancer — he was given 12 months to live. "But my lawyer says he can get it down to eight," he adds in his stage act. That's funny stuff, and as anyone connected to the Canadian comedy scene will tell you, Barker isn't your average comic. And his day-to-day struggle with cancer isn't your typical survivor's story. That's why documentary filmmaker Adamm Liley has chronicled that fateful first year in *That's My Time*, which premiered at the Atlantic Film Festival. The film follows Barker as he travels to comedy festivals, works on material for *This Hour* and his current gig at *The Rick Mercer Report*, and undergoes treatment. There are tough, tearful moments, but more often than not you're laughing at the comments of comedic friends like John Wing and Shaun Majumder, or Barker himself, who sighs, 'Phew, tough crowd!' after a perfectly timed awkward silence that follows telling one crowd of his terminal cancer diagnosis. <http://thechronicleherald.ca/ArtsLife/1079170.html>

N.B. Irwin Barker website: <http://www.irwinbarker.com/>

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