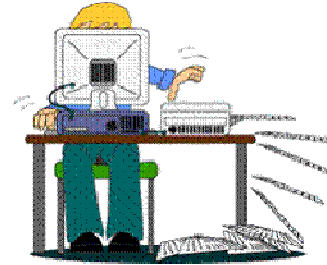


Media Watch

...is distributed weekly to colleagues active or with a special interest in **hospice and 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.

30 March Edition | Issue #90



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Compiled & Annotated by Barry R. Ashpole

Towards a less invasive, more family-centered end to life: Scroll down to [U.S.A.](#) and 'In search of the peace a patient may need most as death approaches.'

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *Montreal Gazette* – 30 March 2009 – **'The push for euthanasia could be the death of us all.'** How far do we want laws to go on 'death with dignity' and assisted suicide? <http://www.montrealgazette.com/news/push+euthanasia+could+death/1443039/story.html>
- ONTARIO | *Ottawa Citizen* – 25 March 2009 – **'Allow assisted suicide, expert on law, health urges Canada.'** Assisted suicide should be decriminalized ... to allow competent and informed people to make decisions about how they die ... because current laws are inconsistent, ineffective. <http://www.ottawacitizen.com/news/Allow+assisted+suicide+expert+health+urges+Canada/1423971/story.html>

Compassionate care leave

Canada's top 100 employers

ONTARIO | *Financial Post* – 25 March 2009 – The best companies to work for in Canada. Word search the article for 'compassionate care leave' for a representative sample of current company policies. <http://www.financialpost.com/careers/story.html?id=1426269>

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.

End of life decisions

The ethics of allowing babies to die

QUEBEC | *Montreal Gazette* (OpEd) – 25 March 2009 – Phebe Mantha is a 17-month-old baby girl who was injured during birth and as a result is brain damaged. Shortly after her birth, she was transferred to the Montreal Children's Hospital and placed on life support. The physicians told her parents that she would be deaf, blind, unable to take food orally, and would never walk. Her parents consented to the withdrawal of life-support treatment to allow Phebe to die. However, when the respirator was removed, Phebe started to breathe on her own. The issue, then, was removal of the feeding tube. The hospital's ethics committee advised it and other necessary treatment should be continued. Ten weeks later, Phebe was discharged into the care of her parents, still needing the feeding tube and other care. The parents are now suing the hospital and its ethics committee for not abiding by their decision to let Phebe die. The baby Phebe case could help clarify the ethical and legal rights of disabled babies and disabled people in general.

<http://www2.canada.com/montrealgazette/features/viewpoints/story.html?id=4248bae3-5cc1-4bde-9bf2-9caae367c018&p=1>

From Media Watch dated 03.16.09.

- *NATIONAL POST* | Online report – 14 March 2009 – **'Hospital sued for keeping infant alive.'** A Quebec couple has launched a \$3.5-million lawsuit against Montreal Children's Hospital for putting their severely disabled infant daughter back on life support without seeking their consent. <http://www.nationalpost.com/most-popular/story.html?id=1387994>

Family dynamics

Family skeletons detrimental to healing

QUEBEC | Université de Montréal's Department of Family Medicine press release – 24 March 2009 – University of Montreal professor finds family secrets lead to feelings of guilt, anger and helplessness. Family secrets such as alcoholism, abuse and unwanted pregnancies are quite common and an obstacle to healing when disease strikes, according to Marie-Dominique Beaulieu, a professor at the Université de Montréal's Department of Family Medicine. "I see it in my practice," says Beaulieu.¹ "Family secrets lead to feelings of guilt, anger and helplessness. These feelings have a considerable impact on health, specifically on the capacity to adapt and find a balance in times of disease." http://www.eurekalert.org/pub_releases/2009-03/uom-fsd032409.php

1. Université de Montréal | *UdeM Nouvelles* – 16 March 2009 – **'Les secrets de famille nuisent à la guérison.'** <http://www.nouvelles.umontreal.ca/recherche/sciences-de-la-sante/les-secrets-de-famille-nuisent-a-la-guerison.html>

U.S.A.

Children's hospice in danger of closing

CALIFORNIA | *Los Angeles Times* – 28 March 2009 – George Mark Children's House, which is funded through donations and is the only free-standing hospice and respite-care center for children in the U.S., has only enough money to operate through June. "It would be devastating for the whole newly emerging field of pediatric palliative care," said Dr. Barbara Sourkes, director of palliative care at Lucille Packard Children's Hospital at Stanford. "Across the country, George Mark stands for so much. It would send an absolutely terrible message."

<http://www.latimes.com/news/local/la-me-children-hospice28-2009mar28,0,2200801.story>

Courage in the face of death is a reaction to loss

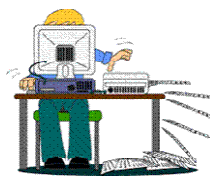
UTAH | *Desert News* (OpEd) – 28 March 2009 – I just learned that a friend is not doing well. We all know what that means: She is dying. The cancer has returned and has taken over her whole body. I do not want her to die. I also don't want to see her dying. But I have to. I want to show her I am not afraid of her dying, and I am not scared of what the cancer has done to her. She is melting away: muscle, sinew, shape and form. It is this wasting that scares me more than her actual last breath. It is the cachexia that makes cancer or other terminal infections like AIDS or TB so frightening. The diseases produce wasting molecules or turn on internal machinery that consumes the whole being. It is why TB used to be called consumption. It literally, like some cancers, will end in a patient being only skin and bones. This is what I do not want to see. Of course it is not what I want, but if knowing I am not afraid would be of any solace, I would like to think I had the courage to do that for her and her husband. Courage is not just testing myself against by own fears of death and dying. <http://deseretnews.com/article/705293589/Courage-in-the-face-of-death.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MINNESOTA | *Star Tribune* – 27 March 2009 – '**Desperate act from a weary caregiver.**' In older couples, murder-suicide is often committed by the husband who sees it as an act of mercy. http://www.startribune.com/local/south/41952717.html?elr=KArks7PYDiaK7DU2EkP7K_V_GD7EaPc:iLP8iUiD3aPc: Yyc:aUU
- CALIFORNIA | *Los Angeles Times* – 27 March 2009 – '**Different assisted-suicide groups, one goal.**' The (*Los Angeles Times* wrongly sees a difference between the Final Exit Network and the assisted-suicide laws promoted by organizations such as Compassion & Choices.¹ http://www.latimes.com/news/opinion/opinionla/la-oev-price-use27-2009mar27_0_2537665.story
 1. '**Sense and suicide.**' Laws allowing the ill to die with dignity are fine ... some groups, though, step over the line. <http://www.latimes.com/news/opinion/editorials/la-ed-suicide23-2009mar23%2C0%2C4285278.story>
- WASHINGTON | *South Whidbey Record* (Letter) – 26 March 2009 – '**So you voted to have your doctor lie.**' Initiative-1000 requires physicians to lie on the death certificate, putting another cause of death rather than physician-assisted suicide. <http://www.pnwlocalnews.com/whidbey/swr/opinion/letters/41921517.html>

Barry R. Ashpole



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses and facilitating issue specific workshops for frontline care providers.

Does faith prolong suffering for cancer patients?

ILLINOIS | *Christianity Today* – 26 March 2009 – A recent study in the *Journal of the American Medical Association* finds that cancer patients who use "positive religious coping," or collaborating with God to overcome illness, are more likely to seek heroic measures in an attempt to prolong life.¹ <http://www.christianitytoday.com/ct/2009/marchweb-only/112-42.0.html>

1. *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2009;301(11):1140-1147. **'Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer.'** <http://jama.ama-assn.org/cgi/content/abstract/301/11/1140>

From Media Watch dated 03.23.09.

- MASSACHUSETTS | *Boston Globe* – 18 March 2009 – **'Religious dying patients more likely to get aggressive care.'** Patients who rely heavily on their religious faith to cope with terminal cancer are more likely to receive intensive life-prolonging measures in their last week of life. http://www.boston.com/news/health/articles/2009/03/18/religious_dying_patients_more_likely_to_get_aggressive_care/

Representative sample of faith-based media coverage of study findings:

- MASSACHUSETTS | Religion News Service – 28 March 2009 – **'Religious may suffer more in fight against cancer.'** People who employ faith in their battle against the deadly disease may also be more likely to exacerbate their own suffering in the final days of life and to leave behind caregivers who have a hard time adjusting to bereavement. http://www.satrib.com/faith/ci_12011557
- WASHINGTON DC | *Christian Post* – 18 March 2009 – **'Highly religious patients fight to live longer.'** Previous research has shown that more religious patients often prefer aggressive end-of-life treatment ... but, the new study is the first to examine patients in their final days. http://www.christianpost.com/Education/Polls_reports/2009/03/highly-religious-patients-fight-to-live-longer-18/

Alzheimer's costs triple that of other elderly

ILLINOIS | Associated Press – 24 March 2009 – The health care costs of Alzheimer's disease patients are more than triple those of other older people, and that doesn't even include the billions of hours of unpaid care from family members, a new report suggests.¹ Compared with people aged 65 and older without Alzheimer's, those with the mind-destroying disease are much more often hospitalized and treated in skilled-nursing centers. Their medical costs also often include nursing home care and Medicare-covered home health visits. That all adds up to at least \$33,007 in annual costs per patient, compared with \$10,603 for an older person without Alzheimer's. <http://www.google.com/hostednews/ap/article/ALeqM5hxEVLOBQNV1lqgHqjPijA7XilsbAD9745VU00>

1. Alzheimer's Disease: Facts & Figures, Alzheimer's Association, 2009. http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf

[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. PCN-e link: <http://www.pcn-e.com/>

Many resuscitation orders faulted

KENTUCKY | *Lexington Herald-Leader* – 24 March 2009 – The question of whether to resuscitate a dying patient is supposed to be resolved by checking the patient's orders. But the *Lexington Herald-Leader* reports a gap in Kentucky law has led to errors at the bedsides of the dying. Sadiqa Reynolds, of the Cabinet for Health & Family Services, said there is no uniform regulation for denoting a patient's wishes regarding resuscitation in a long-term care center or a hospital. <http://nky.cincinnati.com/apps/pbcs.dll/article?AID=/AB/20090324/NEWS0103/903240356/>

Of related interest (from the archives):

- *RESUSCITATION*, 2008;79(3):490-498. **'Cardiopulmonary resuscitation: Knowledge and opinions among the U.S. general public.'** Inaccurate perceptions regarding resuscitation and survival rates exist among the lay public, and participants indicated strong preferences regarding resuscitation and advance directives. [http://www.resuscitationjournal.com/article/S0300-9572\(08\)00605-9/abstract](http://www.resuscitationjournal.com/article/S0300-9572(08)00605-9/abstract)

In search of the peace a patient may need most as death approaches

MARYLAND | *Baltimore Sun* – 24 March 2009 – When Peggy Murphy succumbed to her five-year battle against breast cancer this month after a fight that included just about every treatment she or her doctors could find, those who eulogized her in print called her a "pioneer" and a patient with the unwavering "courage and strength" to endure almost anything in her struggle to live. Nearly lost in the story of her death ... was one sad detail – that the final month of (her) life was spent in an intensive care unit in New York, in the most clinical setting modern medicine has to offer. Ms. Murphy, ever the warrior patient, lived on a sterile unit, most likely hooked up to myriad machines, her family and friends' visits restricted by the confines of ICU protocol. Yes, her struggle against breast cancer and her desire to help those looking for a cure were noble and inspiring. But we have to wonder about that last month of her life. We hope that her decision to keep fighting came after an honest and thorough discussion of her end-of-life options. We hope that Ms. Murphy knew there were alternatives that could provide a less invasive, more family-centered end to her life. And we hope someone told her that choosing to seek a more peaceful death could, in fact, help extend her life. http://www.baltimoresun.com/news/opinion/oped/bal-op.endoflife24mar24_0_6294082.story

Louisiana State Penitentiary's Hospice Program

'Grace Before Dying'

LOUISIANA | *Fraction* (Online magazine) – 6 March 2009 – Louisiana's maximum-security prison in Angola is the backdrop for the launch of Lori Waselchuk's exhibition 'Grace Before Dying,' an award-winning photo essay that chronicles the Louisiana State Penitentiary's Hospice Program. The program was created in 1998 at the Louisiana State Penitentiary in Angola. Prison officials say that the program has helped to transform one of the most violent prisons in the South into one of the least violent maximum-security institutions in the United States. Waselchuk spent two years photographing the program. The result is an eye-opening and moving portrayal of prisoners that goes far beyond the stereotypes. <http://fractionmag.blogspot.com/2009/03/lori-waselchuk-grace-before-dying.html>

From Media Watch dated 03.02.09.

- WISCONSIN | *Wisconsin State Journal* – 1 March 2009 – **'Dodge Correctional Institution hospice program gives 'comfort care' to dying inmates.'** Kaos Metz, who has end-stage liver disease, won't live to finish his 10-year sentence ... but, he's considered a success story, along with the 26 other prisoners who came to the Dodge Correctional Institution hospice to die before him. <http://www.madison.com/wsj/topstories/440697>

International

Life, death and the contentious limits of the law

AUSTRALIA | *The Age* (OpEd) – 30 March 2009 – *The Age* reported the story of Angie Belecciu, a 57-year-old sufferer from bone-marrow cancer who chose to end her life rather than endure what she described as slow euthanasia in hospital.¹ In other words, she wished to feel in control of her life until the end, rather than gradually relinquish that control to carers even as the drugs they administered to relieve pain shortened her life anyway. The choice she made was for what she called a death with dignity. <http://www.theage.com.au/opinion/editorial/life-death-and-the-contentious-limits-of-the-law-20090330-9fs6.html>

1. **'Angie's choice.'** Angie Belecciu knew the rules of death. <http://www.theage.com.au/national/angies-choice-20090324-98yu.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *WA Today* – 29 March 2009 – **'Patients don't die in pain: doctors.'** A retired palliative care nurse's decision to take her life last week, ending years of illness, has reinvigorated the euthanasia debate, but specialists say they seldom see people dying in pain. <http://www.watoday.com.au/national/patients-dont-die-in-pain-doctors-20090329-9fkk.html>
 - U.K. | *The Guardian* | 29 March 2009 – **'My father deserved a better way to die.'** By turning a blind eye to those choosing assisted suicide abroad, we ignore the wishes of many here. <http://www.guardian.co.uk/commentisfree/2009/mar/29/john-humphrys-assisted-suicide>
 - AUSTRALIA | *Herald-Sun* – 27 March 2009 – **'Philip Nitschke leaves trail of lonely dead.'** Giving the likes of Philip Nitschke licence to kill could create all sorts of horror for the lonely, scared, helpless and impressionable. <http://www.news.com.au/heraldsun/story/0,21985,25247235-5000117,00.html>
 - MALTA | *Malta Independent* – 25 March 2009 – **'What is euthanasia and what is not?'** The fact that morality stops just short of direct killing ... keeps many confused between what is actually euthanasia and what is not. <http://www.independent.com.mt/news.asp?newsitemid=85227>
 - U.K. | *The Times* – 25 March 2009 – **'Depression and assisted dying.'** Serious requests for assisted dying usually stem from a desire for autonomy or personal control ... but, a second group of patients will request assisted dying whose motivations are different: those with terminal disease and concurrent depression. <http://www.timesonline.co.uk/tol/comment/letters/article5970024.ece>
 - U.K. (Scotland) | *Scotsman* – 25 March 2009 – **'Optimistic Margo unveils right-to-die Holyrood Bill.'** Member of the Scottish Parliament Margo MacDonald revealed details of her right-to-die Bill and the safeguards she wants to put in place. <http://news.scotsman.com/scotland/39Optimistic39-Margo-unveils-righttodie-Holyrood.5105966.jp>
 - FRANCE | *The Connexion* – 24 March 2009 – **'Case closed on assisted suicide.'** Investigation into the assisted suicide of a women with an incurable brain tumour ... closed a year after her death; her ordeal was given much coverage in the media, stirring strong public opinion and re-launching the debate on euthanasia. http://www.connexionfrance.com/news_articles.php?id=716
 - U.K. | *Daily Telegraph* – 24 March 2009 – **'Majority of doctors opposed to assisted suicide.'** Research shows doctors rarely help anyone who is terminally ill to die, while two-thirds are opposed to changing the law.¹ <http://www.guardian.co.uk/society/2009/mar/24/assisted-suicide-euthanasia-doctors>
1. Scroll down to [Journal Articles](#) and **'Legalisation of euthanasia or physician-assisted suicide: (U.K.) Survey.'**

'It's hard to say the actual words, especially when people who don't know ask about my mam and I have to say she died'

IRELAND | *Independent* – 26 March 2009 – Families in this country have to face the fact that there are few professional bereavement supports available, as Peter Nolan discovered after his wife's death from cancer four years ago. "Google became my support network", he says. "There's massive help available when someone is terminally ill between social workers and medics. But once the body is removed from hospital, that's it. The last piece of advice I got was 'You're now a widower.' Boom, just like that". <http://www.independent.ie/lifestyle/parenting/its-hard-to-say--the-actual-words-especially-when-people-who-dont-know-ask-about--my-mam-and-i-have-to-say-she-died-1686428.html>

Doctors to be "struck off" if they do not listen to dying patients

U.K. | *Daily Telegraph* – 26 March 2009 – Updated guidance puts greater emphasis on establishing the wishes of the patient at the end of their life and says doctors must stick to 'advance directives' refusing care, or so-called 'living wills,' which state under which circumstances life support should be turned off. However patients who have actively requested that treatment – particularly artificial feeding and hydration – continue until their death, can be overruled by doctors if it is felt the care would be futile and impose unacceptable discomfort during the final hours or days of life. High profile court cases and new laws such as the Mental Capacity Act 2005 have prompted the General Medical Council to review advice to doctors on end of life care and a consultation on new draft guidance will be launched tomorrow to run until July. <http://www.telegraph.co.uk/health/healthnews/5050669/Doctors-to-be-struck-off-if-they-do-not-listen-to-dying-patients.html>

From Media Watch dated 03.09.09.

- *BRITISH MEDICAL JOURNAL* | Online report – 2 March 2009 – **'General Medical Council is to reconsider guidance on end of life care.'** Guidance for doctors on care at the end of life, including difficult decisions on when to provide, withhold, or withdraw life prolonging treatment, will go out for consultation from the GMC. http://www.bmj.com/cgi/content/extract/338/mar02_1/b875

Hindu demands right to be cremated in open-air funeral pyre

U.K. | *Daily Telegraph* – 25 March 2009 – Davender Ghai admits his demand is controversial ... but, he insists that traditional open-air cremations would not offend members of the public if they were held on secluded sites away from homes. The 70-year-old, from Gosforth, Newcastle-upon-Tyne, told London's High Court that his "soul is in jeopardy" until the legality of his dearest wish is established. After he dies, he wants his body to be placed on logs and his eldest son Sanjay to light the pyre while the rest of his family watches. He believes the ceremony, which Hindus in India have been observing for thousands of years, is essential for the release of his soul. <http://www.telegraph.co.uk/news/newstoppers/religion/5043564/Hindu-demands-right-to-be-cremated-in-open-air-funeral-pyre.html>

- U.K. | *The Times* – 24 March 2009 – **'Hindu seeks High Court ruling for funeral pyres in Newcastle.'** The irony that an average Indian's carbon footprint may actually be larger in death than in life is certainly not lost on Vinod Kumar, head of an environmental group based in Delhi ... (who) recently devised a raised pyre that reduces the amount of wood required and, thus, the greenhouse gases emitted by over 60%. <http://timescolumns.typepad.com/gledhill/2009/03/hindu-seeks-high-court-ruling-for-funeral-pyres-in-newcastle.html>

Doctors rarely help terminally-ill patients to die, survey reveals

U.K. | *The Guardian* – 25 March 2009 – Doctors very rarely help those who are terminally ill to die and two in three oppose changing the law to allow them to do so, research reveals. In only one in 200 deaths have doctors given a drug with the explicit intention of hastening death, according to a survey published in *Palliative Medicine*.¹ Where doctors help a patient escape pain or distress, most say they have not shortened life by more than twenty-four hours and nine out of 10 say their actions hastened death by less than a week. Doctors who admit to it (i.e., hastening death) say they had the full collaboration of the patient and family. A survey of 4,000 doctors on their attitudes towards euthanasia indicated that 34% are in favour of legalisation and 35% in favour of assisted suicide.² That contrasts with 82% and 62% respectively of the public questioned by the survey. <http://www.guardian.co.uk/society/2009/mar/25/terminally-ill-patients-assisted-suicide>

1. *PALLIATIVE MEDICINE*, 2009;23(3):198-204. 'End-of-life decisions in the U.K. involving medical practitioners.' <http://pmj.sagepub.com/cgi/content/abstract/23/3/198>
2. *PALLIATIVE MEDICINE*, 2009;23(3):205-212 (2009). 'Legalisation of euthanasia or physician-assisted suicide: (U.K.) Survey.' <http://pmj.sagepub.com/cgi/content/abstract/23/3/205>

N.B. Scroll down to [Journal Articles](#) for abstracts of the *Palliative Medicine* articles.

In light of the deteriorating economic situation

Taking care of how we die

IRELAND | *Irish Times* – 24 March 2009 – The Irish Hospice Foundation will meet the Health Service Executive (HSE) and the Department of Health & Children in an effort to clarify the status of the HSE's National Action Plan for Palliative Care Services (2009-2013), in light of the deteriorating economic situation. The plan identified priorities and actions required to address the deficits in palliative care service provision. The unpublished plan (would) almost double the €75 million annual palliative care budget, build nine new hospices and increase the number of hospice beds from 153 to 356 ... a capital investment of €237.34 million over the five-year duration of the plan. <http://www.irishtimes.com/newspaper/health/2009/0324/1224243309762.html>

Cabinet passes bill on cancer palliative care

KOREA | *The Korea Herald* – 24 March 2009 – A bill of a law that supports the introduction of a palliative care system for cancer patients in the terminal stage has been passed by Cabinet. The Ministry for Health, Welfare & Family Affairs said it will develop and distribute guidebooks that provide directions on terminal cancer patients and nurture professionals that could take part in the effort. The ministry plans to designate some hospitals as palliative care medical centers and give them partial or full financial support. Those medical facilities will be mandated to offer a clear explanation to the patients' families about the procedures of palliative treatment and the patients will be allowed to withdraw their treatment requests whenever they wish to, ministry officials said. http://www.koreaherald.co.kr/NEWKHSITE/data/html_dir/2009/03/25/200903250028.asp

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.

Journal Articles (In-print & On-line)

Should hospices be exempt from following national (U.K.) cardiopulmonary resuscitation guidelines?

No

BRITISH MEDICAL JOURNAL | Online article – 26 March 2009 – It is tempting to view hospices as unique therapeutic environments that demand special treatment. However, hospices have no desire to work outside national guidelines on good practice. The current cardiopulmonary resuscitation guidelines uphold essential core principles and values that particularly apply in end of life care and are coherent with the Mental Capacity Act (England & Wales) and the Adults with Incapacity Act (Scotland), which govern decisions for patients who lack capacity. The guidelines reflect the good practice expected of hospices. http://www.bmj.com/cgi/content/full/338/mar26_2/b986

Yes

BRITISH MEDICAL JOURNAL | Online article – 26 March 2009 – The patient population in U.K. hospices is changing. Patients with malignant and non-malignant diseases, increasing disease complexity, and multiple co-morbidities are attending from earlier in their illness for management of symptoms and supportive care. Indeed, almost half of hospice patients are now discharged. Yet, despite these trends we must remember that hospice patients have illnesses that are not curable. Hospices should be exempt from applying blanket national cardiopulmonary resuscitation guidelines because the needs and treatment goals of hospice patients differ from those of patients in other care settings. http://www.bmj.com/cgi/content/full/338/mar26_2/b965?maxtoshow=&HITS=10&hits=10&RESULTFORMAT=&fulltext=hospice&searchid=1&FIRSTINDEX=0&volume=338&resourcetype=HWCIT

Broadening the scope of palliative care

Rethinking and integrating nephrology palliative care

CANADIAN ASSOCIATION OF NEPHROLOGY NURSES & TECHNOLOGISTS JOURNAL, 2009;19(1):36-44. Kidney disease presents challenges (and) its chronicity and associated morbidity, often including difficult and intractable symptoms, make palliative care a natural accompaniment to its management. This patient population wants and needs an improved approach to symptom assessment and management, as well as advanced care planning. http://findarticles.com/p/articles/mi_m5PMC/is_1_19/ai_n31418718?tag=content;col1

Of related interest:

- *CRITICAL CARE MEDICINE*, 2009;37(3):946-950. **'Developing guidelines that identify patients who would benefit from palliative care services in the surgical intensive care unit.'** The authors offer a set of consensus guidelines derived from expert opinion, and the criteria discussed can be used to educate surgeons at large on the variety of clinical scenarios where palliative care specialists can offer support. <http://www.ccmjournal.com/pt/re/ccm/abstract.00003246-200903000-00021.htm;jsessionid=JJJRS1G2QsZ8q4qv34hJ2GnBFpVYYK0YQ6FpspC1GWfDRPCchDpK!-269263472!181195628!8091!-1>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2009;15(3):120-127. **'A neurological care pathway for meeting the palliative care needs of people with life-limiting neurological condition.'** This paper describes the development process and the resulting care pathway for meeting the palliative care needs of people living with neurological conditions. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41090;article=IJPN_15_3_120_127

Deciding in the dark: Advance directives and continuation of treatment in chronic critical illness

CRITICAL CARE MEDICINE, 2009;37(3):919-925. The authors report that most chronically critically ill patients (in the study group) failed to designate a surrogate decision-maker or express preferences regarding life-sustaining treatments (and) despite burdensome symptoms and poor outcomes, limitation of such treatments was rare and occurred late, when patients were near death. <http://www.ccmjournal.com/pt/re/ccm/abstract.00003246-200903000-00017.htm;jsessionid=JJJRS1G2QsZ8q4qv34hJ2GnBFpVYYK0YQ6FpspC1GWfDRPCchDpK!-269263472!181195628!8091!-1>

Of related interest:

- *PALLIATIVE MEDICINE* | Online journal article – 26 March 2009 – '**Advance care planning in care homes for older people...**' Managers face intrinsic and extrinsic challenges related to the ascertaining – and the implementing – of wishes as they address advance care planning in the care home context. <http://pmj.sagepub.com/cgi/content/abstract/0269216309103802v1>

Can the palliative care services of today keep up and match the expectations of the 'baby boomer' generation?

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(3):108-109. Much has been written in the popular media about the so-called 'baby boomer' generation; those people born in the 1950s and 1960s who, in many respects, are a unique generation. While the rise in smoking-related cancers, obesity, coronary heart disease and other lifestyle-related health issues have tragically cut short many lives, the average 'baby boomer' can confidently expect to live longer and with better quality than has ever been experienced before. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41088;article=IJPN_15_3_108_109

Providing comfort to patients in their palliative care trajectory: experiences of female nurses working in an acute setting

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(3):134-141. This study aims to explore the lived experience of nurses who provide comfort to palliative care patients in an acute setting in a small urban hospital in the west of Ireland. The main findings revealed four major themes (with sub-themes): time needed to provide comfort, emotional cost to the nurse in providing comfort, a holistic approach in the provision of comfort, and the role of education and the expert team in providing comfort. The study findings ... contribute to a greater understanding of the difficulties and challenges that general non-specialized nurses in the acute setting have to understand and apply the philosophy of palliative care to patients in an acute care setting. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41092;article=IJPN_15_3_134_141

Home away from home? A case study of bedside objects in a hospice

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2009;15(3):148-152. This is a descriptive case study employing a photographic survey of the numerous objects that patients and their social networks bring to a hospice setting. These objects ranged from assorted food and drink, greetings cards and magazines, to more specific personal items such as family photos, children's drawings, and religious icons. There were two principle findings. First, patients appeared to bring objects to a hospice setting that reflected their desire to partially recreate their home settings or functions, however modestly. Second, despite a major diversity of objects, and the fact that most objects underlined desires for distraction, entertainment and social contact, almost every individual patient harboured at least one personally unique object. These two observations – creating some semblance of 'home' and the existence of uniqueness amid a plethora of expected patient paraphernalia – suggest important reconsideration of both hospice settings and the possibility of new ways to engage patients about meaning, illness and loss. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41095;article=IJPN_15_3_148_152

Communicating with seriously ill patients: Better words to say

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2009;301(12):1279-1281. Words matter. What clinicians say and how they say it hugely affect patients. Communicating about emotionally and medically complex topics such as advance care planning, preferences for care, prognosis, and death and dying is challenging. Doing so requires clinicians to attend to their own and the patient's cognitive reactions, tone, affect, and non-verbal cues. Communicating goals of care is so important that in California it is now the law. Although poor communication may harm patients by leading to unwanted invasive procedures, generating unnecessary anxiety, or creating feelings of abandonment, good communication can improve outcomes for patients and their families by promoting shared decision making and addressing patient concerns. A recent study described a novel communication model and a process through which it could be adopted by clinicians. <http://jama.ama-assn.org/cgi/content/extract/301/12/1279>

Efficacy of a self-study programme to teach spiritual care

JOURNAL OF CLINICAL NURSING, 2009;18(8):1131-1140. Although U.S. and U.K. accrediting bodies mandate nurses learn how to assess and support patient spiritual health, there is a paucity of evidence to guide educators regarding how to teach spiritual care to nurses. It is unknown if aspects of spiritual care can be taught using formal approaches. The authors investigated the efficacy of a self-study programme designed to teach nurses about how to talk with patients about spirituality. Findings suggest learning occurred for both students and RNs, regardless of whether they were at a religious institution or not. Data indicate that this self-study programme was an effective approach to teach nurses about how to converse with patients about spirituality. <http://www3.interscience.wiley.com/journal/121571685/abstract?CRETRY=1&SRETRY=0>

Of related interest:

- *NURSING PHILOSOPHY*, 2009;10(2):71-80. **'Nursing and spirituality.'** It is argued that when we take into consideration the great diversity among religious and spiritual ideas, the lack of rational means of deciding between them when they conflict, and the practicalities of nursing, we find that a spiritual viewpoint is less useful than a naturalistic one, when offering palliative care. <http://www3.interscience.wiley.com/journal/122246646/abstract>

Advancing palliative care

Change management: The secret sauce of successful program building

JOURNAL OF PALLIATIVE MEDICINE, 2009;12(4):329-330. The field of palliative care is somewhat "counterculture" to mainstream biomedicine. In conventional biomedicine, symptoms are used merely as a means to an end, i.e., symptoms are used as clues to diagnose the underlying culprit, the disease. Once identified, all energy is devoted to annihilating the culprit. In contrast, in the field of palliative care, the symptom ... itself is the focus and much effort is directed at alleviating the symptom. Understandably, this premise of palliative care sets it apart from the rest of mainstream biomedicine. Additionally, hospice and palliative medicine being the "newest kid on the block" of medical subspecialties fundamentally represents change. Therefore, effecting and sustaining change is a key survival skill for all palliative care professionals. Effecting change is a process (not an event) and requires both strategic thinking and ongoing hard work. The Center for Advancement of Palliative Care (CAPC) founded by the pioneering efforts of Dr. Diane Meier offers a framework, requisite tools, and support for clinicians who want to change their local health care systems for the better by building new and expanding existing palliative care programs. Additionally, clinicians have to become skilled in the process of change management in order to harness the full power of the CAPC tools to create successful palliative care programs. <http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2009.9645>

End-of-life decisions in the U.K. involving medical practitioners

PALLIATIVE MEDICINE, 2009;23(3):198-204. This study estimates the frequency of different medical end-of-life decisions (ELDs) made in the U.K. in 2007-2008, comparing these with 2004. Postal survey was carried out with 8857 medical practitioners, of whom 3733 (42%) practitioners replied, with 2869 having attended a person who died in the previous year. The proportion of U.K. deaths involving (1) voluntary euthanasia, (2) physician-assisted suicide, and (3) ending of life without an explicit request from the patient is low. Better questions about ELDs showed both non-treatment decisions and double effect measures to be much less common than suggested in earlier estimates, rarely involving intent to end life or being judged to have shortened life by more than a day. Continuous deep sedation is relatively common in the U.K. medical practice, particularly in hospitals, home care settings and with younger patients. Survey research in this area requires careful control over question wording if valid estimates and comparisons of the prevalence of ELDs are to be made. <http://pmj.sagepub.com/cgi/content/abstract/23/3/198>

Of related interest:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online journal article – 23 March 2009 – '**Patient involvement in decisions to limit treatment: The crucial role of agreement between physician and patient.**' The aim of this study was to describe, first, the decision-making process concerning limitation of life-prolonging treatment; second, the extent to which patients are involved in these decisions; and third, to detect medical and ethical factors that affect patient involvement. http://www.ncbi.nlm.nih.gov/pubmed/19307508?ordinalpos=7&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum
- *PALLIATIVE MEDICINE* | Online journal article – 26 March 2009 – '**Hospital staff attributions of the causes of physician variation in end-of-life treatment intensity.**' When end-of-life treatment depends on the doctor, patient and family preferences may be neglected. <http://pmj.sagepub.com/cgi/content/abstract/0269216309103664v1>
- *WESTERN JOURNAL OF NURSING RESEARCH* | Online journal article – 25 March 2009 – '**Doing what's best: Decisions by families of Acutely ill nursing home residents.**' When nursing home residents experience acute illness, the preference of family members is a major consideration in the choice between aggressive treatment and palliative care. <http://wjn.sagepub.com/cgi/content/abstract/0193945909332911v1>

Legalisation of euthanasia or physician-assisted suicide: (U.K.) Study

PALLIATIVE MEDICINE, 2009;23(3):205-212. This study reports doctors' opinions about legalisation *vis-a-vis* medically assisted dying (euthanasia and physician-assisted suicide), and comparing this with the general public's opinion). In a survey of 3733 medical practitioners, the majority opposed legalisation, in contrast with the general public. Palliative medicine specialists are particularly opposed (and) strong religious belief is independently associated with opposition to assisted dying. <http://pmj.sagepub.com/cgi/content/abstract/23/3/205>

Clinical dilemmas in children with life-limiting illnesses: decision making and the law

PALLIATIVE MEDICINE, 2009;23(3):238-247. Decision making about interventions for children and young people with life-limiting illnesses is fraught with difficulties but faced regularly by staff in children's hospices and paediatric wards. The perspectives of the child, various family members and professionals may all be different. The process of discussion and negotiation and the mechanism by which a decision is arrived at is complex, and various laws have recently changed in the U.K. that have impact on this process. This article discusses several clinical scenarios to better understand these decisions and the effects of changes in the law. The author also discusses how multidisciplinary teams in children's hospices (and other supportive clinical systems) can best support young people and families with and without recourse to the law. <http://pmj.sagepub.com/cgi/content/abstract/23/3/238>

Comparison of bereavement services provided in hospice and palliative care settings in Australia, the U.K. and the U.S.

PROGRESS IN PALLIATIVE CARE, 2009;17(2):69-74. Bereavement support services are recognised as an integral part of hospices and palliative care services. Exploratory surveys on the nature of such services have been conducted in recent years in several countries. The purpose of this paper is to compare the main findings of these surveys and to offer preliminary suggestions on how to improve this component of care both within and across these three countries. Through this comparison, a number of common aspects of service delivery were highlighted. Common difficulties were also found, including low numbers of paid staff, variations in specialist training, insufficient levels of funding, and the lack of the use of validated bereavement assessment tools. <http://www.ingentaconnect.com/content/maney/ppc/2009/00000017/00000002/art00003>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2009;15(3):110-118. **'Effecting positive change with bereaved service users in a hospice setting.'** This qualitative study aimed to gain a deeper understanding of service user experiences of an adult bereavement group in a hospice setting in Northern Ireland. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=41089;article=IJPN_15_3_110_118

A systematic review

What are the unmet supportive care needs of people with cancer?

SUPPORT CARE CANCER | Online journal article – 25 March 2009 – Of 94 articles or reports identified, 57 quantified the prevalence of unmet need. The most frequently reported unmet needs were those in the activities of daily living (1-73%), followed by psychological (12-85%), information (6-93%), psychosocial (1-89%) and physical (7-89%). Needs within the spiritual (14-51%), communication (2-57%) and sexuality (33-63%) domains were least frequently investigated. Unmet needs appear to be highest ... during treatment, however, a greater number of individuals were likely to express unmet need post-treatment compared to any other time. http://www.ncbi.nlm.nih.gov/pubmed/19319577?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum

Worth Repeating

Truth may hurt but deceit hurts more: Communication in palliative care

PALLIATIVE MEDICINE, 2002;16(4):297-303. Healthcare professionals often censor their information giving to patients in an attempt to protect them from potentially hurtful, sad or bad news. Less than honest disclosure is seen from the moment that a patient reports symptoms, to the confirmation of diagnosis, during discussions about the therapeutic benefits of treatment, at relapse and terminal illness. This desire to shield patients from the reality of their situation usually creates even greater difficulties for patients, their relatives and friends and other members of the healthcare team. Although the motivation behind economy with the truth is often well meant, a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion not one of calm and equanimity. Ambiguous or deliberately misleading information may afford short-term benefits while things continue to go well, but denies individuals and their families opportunities to reorganize and adapt their lives towards the attainment of more achievable goals, realistic hopes and aspirations. <http://pmj.sagepub.com/cgi/content/abstract/16/4/297>