Media Watch...

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

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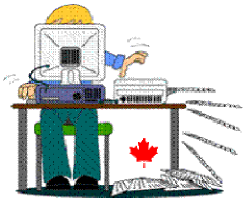


Compiled & Annotated by Barry R. Ashpole

Everyday life close to death: Scroll down to Specialist Publications and 'Being me and being us in a family living close to death at home' (p.12), published in *Qualitative Health Research.*

Canada

Journalism project reflects on death and dying

ONTARIO | *Western News* (University of Western Ontario) – 12 April 2011 – Western's Graduate Journalism Program and London palliative care providers are celebrating their innovative partnership in a groundbreaking journalism project addressing death and dying. 'Miles to Go' results from a first-ever journalism course on dying, and involves students visiting palliative care units in the London area to interact with an array of terminally-ill patients, as well as their families and health care providers. Together, the students have created 16 personal, multi-media stories culminating in a moving, at times unsettling, and very revealing examination of dying in Canada in 2011. Stories range from a look at how our health care system fails dying children and who gets access to palliative care, to how our system responds to the needs of different cultural groups at end of life, as well as recent legal debates about who gets to decide when to 'pull the plug.' http://communications.uwo.ca/western_news/stories/2011/April/journalism_project_reflects_on_death_and_dying.html

From Media Watch dated 5 July 2010:

- *SOCIAL SCIENCES & MEDICINE* | Online article – 19 June 2010 – **'How the mass media report social statistics: A case study concerning research on end-of-life decisions.'** This case study contributes to existing knowledge about the ways in which mass media establish, exaggerate and otherwise distort the meaning of statistical findings. The expectation that accuracy and comprehen-siveness should be the sole criteria for judging journalists' reports is, finally, considered to be unrealistic and it is argued that social scientists need to understand and adapt to the conditions under which mass media reporting operates if they are to succeed in introducing the findings of social research into public debates.http://linkinghub.elsevier.com/retrieve/pii/S0277953610004685

Specialist Publications

Of particular interest:

'Quality of reporting on the vegetative state in Italian newspapers' (p.11), published online by PLoS ONE.

Home care and house calls

Canada's seniors: The doctor will see you now

GLOBE & MAIL | Online article – 11 April 2011 – Seniors are the fastest-growing segment of the population, with 4.8 million Canadians aged 65 and older. The figure that will double to 10.4 million in 2036 and by 2051 one in four will be older than 65. But who will be their doctors?Today, there are only 238 certified geriatricians in Canada, and experts say an additional 500 more are required, plus more family physicians to treat the elderly. Inferior pay is partly the reason this field is suffering. Perhaps more important, though, is the way it attracts future physicians. Few medical students see the elderly at their best – in their own homes. Instead they are often tended to in a full-fledged medical crisis in an emergency room or chronic care ward. The answer for the future may be the past. Reviving the old-fashioned house call is one way to entice more doctors – and improve the system. http://www.theglobeandmail.com/news/national/canadas-seniors-the-doctor-will-see-you-now/article1981281/

U.S.A.

New push to improve end-of-life care in Massachusetts

MASSACHUSETTS | *Boston Globe* – 13 April 2011 – There is often a significant gap between the type of care patients want at the end of their lives and what they actually receive, says a new report that recommends Massachusetts adopt a standardized form for patients to communicate and document their wishes. The report, written by a committee of public policy and medical specialists and detailed today at a meeting of state health leaders, said patients lack a way to express their specific wishes in a format that can be readily understood and followed by health care providers in a variety of settings, such as hospitals and nursing homes. The new suggested form, dubbed a MOLST – Medical Orders for Life-Sustaining Treatment – is two pages and allows patients to check whether they want to be hooked to various machines to allow them to feed, breathe, and keep their kidneys functioning. http://articles.boston.com/2011-04-13/news/29414601_1_end-of-life-care-health-care-care-providers

> **N.B.** 'Surrogate-decision maker (or agent)' substitute decision-maker' and 'heath care proxy' are common terms used to describe the individual designated to make decisions in the event that the patient is no longer able to or chooses not to do so.

Of related interest:

- CONNECTICUT | *Yale Daily News* (Yale University) – 13 April 2011 – **'Professor rethinks end-of-life issues.'** Studies have shown that surrogates simply are not good decision-makers; in an experiment where patients and surrogates were placed in separate rooms and then asked what they thought the patient would have wanted, the surrogates picked the wrong decision 33% of the time. Surrogates also undergo an incredible amount of stress ... which can make them feel as if they were signing a death warrant and which often leads to depression, anxiety, or post-traumatic stress disorder. http://www.yaledailynews.com/news/2011/apr/13/professor-rethinks-end-of-life-issues/

Specialist Publications

Of particular interest:

'Patients' perspectives of the substitute decision maker: Who makes better decisions?' (p.11), published in the *Journal of Medical Ethics.*

Bill removes barriers to hospice, palliative care

VERMONT JOURNALISM TRUST | Online report – 13 April 2011 – Supporters of a bill that passed unanimously in the House [of Representatives] hope it will increase the number of Vermonters who take advantage of hospice. The intent of H.201, 'An Act Relating to Hospice and Palliative Care,' was to remove obstacles that discourage patients from choosing the service by: a) directing the state – and urging private insurers – to take the steps needed to provide an "enhanced hospice access" benefit; b) removing the barriers of access to Choices for Care[1] for hospice patients; c) taking measures to ensure that patients do not receive unwanted treatment, and do receive desired treatment, in a medical emergency; and, d) providing that practitioners of medicine and surgery complete 10 hours of continuing medical education to renew their licenses. http://vtdigger.org/2011/04/13/bill-removes-barriers-to-hospice-palliative-care/

1. Choices in Care, Division of Disability & Aging Services, Department of Disabilities, Aging & Independent Living, Vermont. http://www.ddas.vermont.gov/ddas-programs/programs-cfc/

Dartmouth Atlas Project

Hospital care at life's end: A disparity

NEW YORK TIMES | Online article – 11 April 2011 – At the end of life, people with chronic diseases like cancer get more aggressive medical care in the New York area than anyplace else in the country, continuing a trend going back decades, according to a report released ... by researchers at Dartmouth College.[1] The study, which looked at federal data from 2007, the most recent year available, found that 46% of chronically ill patients in the Manhattan hospital region, which also covers most of Brooklyn and Staten Island, were being treated at hospitals when they died, as opposed to dying at home or in hospices or nursing homes. That rate was the highest in the country. The region covering Long Island and Queens was second, with 42%; the Bronx region was third, at 40%; and the New Brunswick, N.J., region was fourth, at 39%. Nationally, 28% of hospitals' chronic patients were being treated at hospitals when they died. Dr. Elliott S. Fisher, a co-author of the new study, said that some of the disparity might be driven by financial incentives for keeping patients in New York-area hospitals while neglecting the true wishes of the patients. http://www.nytimes.com/2011/04/12/nyregion/12hospitals.html

1. *Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, A report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, April 2011. http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

Representative sample of news coverage of the Dartmouth Atlas Project report:

- COLORADO | *Trinidad Times* – 12 April 2011 – **'Health rankings put county 53rd among state's counties.'** Las Animas County ranks 53 out of the 57 counties in Colorado in health rankings, according to a recent survey. Still, the county ranks highly in the quality of its environment. http://trinidad-times.com/health-rankings-put-county-rd-among-states-counties-p1805-1.htm

- MINNESOTA | *Star Tribune* (Minneapolis) – 14 April 2011 – **'University leading evolution of end-of-life care.'** Chronically ill patients at the University of Minnesota Medical Center are far less likely to die in the hospital than those at most other academic medical centers, according to a new national study of end-of-life care. That may reflect a change in care patterns taking place across the country, with doctors less likely to press for expensive, invasive and sometimes unwanted care for dying patients. http://www.startribune.com/local/119878869.html

- *TEXAS TRIBUNE* (Austin) | Online report – 12 April 2011 – **'How Texas cities rank on end-of-life care.'** Want to die comfortably? Move to Corpus Christi. A study of national hospice and hospitalization trends shows the percentage of Medicare patients dying in hospitals there, as opposed to at home or in hospice, is dropping fast. http://www.texastribune.org/texas-health-resources/health-reform-and-texas/how-texas-cities-rank-on-end-of-life-care/

Cont.

- UTAH | *Salt Lake Tribune* – 11 April 2011 – **'Study: Utah again tops on end-of-life care measures.'** Utahns at the end of their lives are less likely to die in hospitals than other Americans, spend fewer days in the hospital in their last six months and receive more days of hospice care than elders in all but one other state. http://www.sltrib.com/sltrib/news/51608042-78/care-hospice-patientshospitals.html.csp?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+StatelineorgRss-Utah+(Stateline.org+RSS+-+Utah)

N.B. The U.S.A. was rated 9th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | KBND News (Bend) – 12 April 2011 – **'Proposed suicide kit ban.'** The [proposed] law would make it illegal to sell or transfer anything with the intent that it helps someone commit suicide. Health care professionals would be exempted to comply with the state's assisted suicide law. http://www.kbnd.com/page.php?page_id=60248&article_id=7157

International

Hospice advice line receives 6,000 calls in first nine months

U.K. | Carehome.co.uk – 18 April 2011 – St. Elizabeth Hospice in set up the OneCall phone line in summer 2010, allowing care workers, members of the public and medical professionals in East Suffolk to get advice direct from senior registered nurses. An average of 660 calls have been received each month. http://www.carehome.co.uk/news/article.cfm/id/1552471/hospice-advice-line-receives-6000-calls-in-first-nine-months

Portugal makes progress in palliative care

PORTUGAL NEWS | Online report – 16 April 2011 – Thousands of professional healthcare workers will soon begin training in palliative care, with the aim of creating four 'home care' teams to operate within the Oporto, Planalto, Mirandês and Mértola regions. The step forward follows a protocol signed between the Health Ministry and the Calouste Gulbenkian Foundation [a charitable organization], and is being applauded by private associations who have been pushing for progress in palliative care. http://www.theportugalnews.com/cgi-bin/article.pl?id=1108-14

N.B. Portugal was rated 31st in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Pay funeral costs in return for organs: Study

SWEDEN | *The Local* – 14 April 2011 – Swedish county health authorities should be allowed to pay for funerals in return for the relatives allowing the donation of the deceased's organs, Swedish researchers have argued in a new study. The researchers ... argue that the provision of 30,000 ($4,800) – 45,000 kronor to pay for funeral costs would help to increase the supply of organs in Sweden. They also argue that the sum is too small to encourage greed and the money would be reserved exclusively for funeral expenses or donations to charity. "There is really no moral argument against this model," said one of the researchers Gustav Tinghög. *The Local* reported in late March that some 30 Swedes had travelled abroad since the 1980s to have transplants using organs bought from impoverished people in foreign countries. One of the Swedes who bought an organ explained that he had tired of waiting in line for an operation and had instead travelled to Pakistan to buy a kidney. Organ trade is prohibited under Swedish law. http://www.thelocal.se/33194/20110414/

Hospice care extended to patients in general hospital wards

TAIWAN | Focus Taiwan News Channel (Taipei) – 14 April 2011 – Terminally-ill patients unable to enter the hospice because of a lack of space can now apply for subsidized bedside hospice service, a trial program launched by the Bureau of National Health Insurance. Previous regulations stated that subsidized palliative care for patients who are dying could only be given to those admitted into registered hospice wards. But now, bed numbers have fallen far short of the current demand. The bureau said it only has 629 registered hospice beds at its 43 hospitals. http://focustaiwan.tw/ShowNews/WebNews_Detail.aspx?Type=aLIV&ID=201104140009

N.B. Taiwan was rated 14th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Paediatric palliative care

Report highlights lack of respite care

IRELAND | Raidió Teilifís Éireann (Dublin) – 13 April 2011 – Respite care is not available to all families of a child with a life-limiting condition, such as cancer, in 11 counties, a new report has found.[1] Limited access to respite care currently depends on factors such as the child's age, diagnosis, prognosis and where they live... The report ... says the need for respite services in the home and out of home for children with life-limiting conditions will increase in the years ahead. The report adds that a budget of over €10m a year is needed to provide the necessary services. Nationally, there are 1,400 children living with a life-limiting condition and most are usually cared for at home. Around 350 deaths occur each year and usually in the first year of life. The report says that a well structured respite service would reduce hospital admissions and allow parents to also spend time with their other children. http://www.rte.ie/news/2011/0413/hospice.html

1. *Respite Services for Children with Life-Limiting Conditions and their Families.* Children's Sunshine Home and the Irish Hospice Foundation.http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=644&Itemid=11

Specialist Publications

Of particular interest:

'Teenagers' and parents' views on a short-break service for children with life-limiting conditions: A qualitative study' (p.11), published in *Palliative Medicine.*

From Media Watch dated 11 April 2011:

- IRELAND | *Irish Health* – 5 April 2011 – **'1st consultant in child palliative care.'** Dr. Mary Devins appointment is one of a number of measures outlined by the Department of Health & Children in the national policy on palliative care for children.[1] http://www.irishhealth.com/article.html?id=18943

1. *Palliative Care for Children with Life-Limiting Conditions in Ireland – A National Policy*, March 2010. http://www.dohc.ie/publications/pdf/palliative_care_en.pdf?direct=1

N.B. Ireland was rated 4th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.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. http://www.pcn-e.com/community/

Hospitals told to use morphine as pain-killer for cancer patients

INDIA | *Indian Express* (New Delhi) – 6 April 2011 – Waking up to the need for morphine in pain management of terminally ill cancer patients, the Union Ministry of Health & Family Welfare has decided to promote the use of the drug. For the first time, the Ministry has sent instructions to all regional cancer centres, asking them to take steps "for popularising the use of morphine for medical purposes." http://www.indianexpress.com/news/hospitals-told-to-use-morphine-as-painkiller-for-cancer-patients/772364/1

- UNITED NATIONS OFFICE ON DRUGS & CRIME (South Asia) | Online interview – 7 April 2011 – **'India: The principle of balance to make opioids accessible for palliative care.'** Dr. M. R. Rajagopal, Chairman, Pallium India, shares his thoughts on increasing the availability of opioid analgesics for patients in India. http://www.unodc.org/southasia/en/frontpage/2011/april/interview-m-r-rajagopal-access-to-opioids-for-palliative-care.html

  N.B. India was rated the lowest of the forty countries surveyed in terms of the availability of morphine and morphine equivalents in *The Quality of Death: Ranking End of-life-Care Across the World* (p.28), commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Guardian* – 16 April – 2011 – **'Who is to judge which lives are worth living?'** [The novelist and Alzheimer's sufferer Terry] Pratchett says: "Everybody possessed of a debilitating and incurable illness should be allowed to pick the hour of their death." Clearly, with him, the dignity of choice is paramount. However, while one has enormous sympathy for Pratchett suffering such a vile disease, the fact remains that he is a rich, powerful man and it is highly unlikely that his wishes would be ignored. With respect, euthanasia laws are not in place to protect people such as him. http://www.guardian.co.uk/commentisfree/2011/apr/17/barbara-ellen-assisted-death
- SWITZERLAND | *Daily Mail* (U.K.) – 14 April 2011 – A Swiss region is poised to give old people in state-subsidised care homes the right to die via assisted suicide if that is their wish. The assisted suicide organisation Exit, which already helps terminally ill patients in a number of nursing homes, forced a poll on the issue in Vaud – a Swiss first – back in 2009 and garnered the required number of signatures to make it law. http://www.dailymail.co.uk/news/article-1376883/Assisted-suicide-set-legalised-Swiss-old-peoples-homes.html?ito=feeds-newsxml

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.hpcconnection.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/search/?tag=Media+Watch

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

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

A discourse of silence: Professional carers reasoning about death and dying in nursing homes

AGEING & SOCIETY, 2011;31(4):529-544. The aim of this study was to explore the discourse of death and dying in nursing homes from the perspective and understanding of the staff. The findings show that the discourse had three characteristics: a) dying was silent and silenced; b) emotions were pushed into the background; and, c) attentiveness to death arose after the moment of the elderly person's death. The structure of the discourse was characterised by a movement between two positions, avoiding and confronting death, the main focus being on avoidance. The articulation and practices of silence highlight a need to regard dying as a process that requires attention. One way to ensure appropriate attention could be to instil the philosophy of palliative care in nursing homes, including training and support for the staff in their work. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8235355&fulltextType=RA&fileId=S0144686X10000905

Of related interest

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 15 April 2011 – **'Staff perceptions of end-of-life care in aged residential care: A New Zealand perspective.'** Respondents [i.e., participants in this survey] indicated a relatively high level of confidence regarding their care of the dying, including aspects of communication, teamwork and use of documentation. However, this was often contradicted by their written responses. Six themes [were] identified: the naturalness of dying; the character of care; care relationships; emotional response; knowledge; and the organizational environment. http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0471

Improving care at the end of life

ARCHIVES OF INTERNAL MEDICINE | Online article – 11 April 2011 – It is widely assumed that more medical care (i.e., more tests and procedures) results in better outcomes and that adequately treating pain and other symptoms brings death closer, but there is mounting evidence to suggest otherwise. In addition to the risk of harm that is inherent in all tests and procedures and the discomfort associated with much end-of-life care, new evidence suggests that treating patients' pain and other symptoms is associated with improvements in physical status and may even lengthen survival. In fact, at Mt. Sinai School of Medicine, New York, New York, an elderly man with hematemesis who was treated with "comfort measures" fared better than a woman with end-stage renal disease who was treated aggressively. Over the next 5 months, the woman was admitted twice to revise her fistula, once for urosepsis, once for hyperkalemia, and finally, for a high-grade small bowel obstruction. After resection of ischemic bowel, she developed overwhelming sepsis and multiorgan failure. One day before her death, the surgical and intensive care unit team communicated her poor prognosis to the family, and she was given a do-not-resuscitate order and weaned from the ventilator. After transfusion, the elderly man was back to baseline and was discharged the following day. http://archinte.ama-assn.org/cgi/content/full/archinternmed.2011.132

A national comparison of the outcomes of consultation teams vs. inpatient units

ARCHIVES OF INTERNAL MEDICINE, 2011; 171(7):649-655. It is not known whether palliative care is best provided by consultative teams or in dedicated units. [In the findings of this survey] families of patients who received a palliative care consultation were more likely than those who received usual care to report that the patient's care in the last month of life had been "excellent." However, families of patients who received care in a palliative care unit were even more likely to report excellent care. Care received in palliative care units may offer more improvements in care than those achieved with palliative care consultations. http://archinte.ama-assn.org/cgi/content/abstract/171/7/649

Trends in place of death

Study of recent and future trends in place of death in Belgium using death certificate data: A shift from hospitals to care homes

BMC PUBLIC HEALTH | Online article – 13 April 2011 – Hospital deaths decreased from 55.1% to 51.7% and care home deaths rose from 18.3% to 22.6%. The percentage of home deaths remained stable. The odds of dying in a care home versus hospital increased steadily. This increase could be attributed to the replacement of residential beds by skilled nursing beds. Continuation of these trends would result in the more than doubling of deaths in care homes and a decrease in deaths at home and in hospital by 2040. Additional end-of-life care resources in care homes largely explain the decrease in hospital deaths. Care homes will become the main locus of end-of-life care in the future. Governments should provide sufficient skilled nursing resources in care homes to fulfil the end-of-life care preferences and needs of patients. http://www.biomedcentral.com/content/pdf/1471-2458-11-228.pdf

> **N.B.** Belgium was rated 5th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

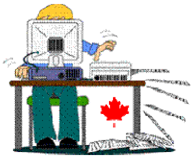
Multidisciplinary palliative care in unborn and newborn babies

BRITISH MEDICAL JOURNAL | Online article – 12 April 2011 – In September 2010 the ... [journal] ... published an article about palliative care and achieving a good death in the 21st century.[1] However, the article did not comment on palliative care in the fetus and the newborn. Spontaneous and induced pregnancy losses are common. Evidence shows that parents undergo a grief reaction and require support and counselling in the long term. The management of such situations has an enduring effect on the psychological and emotional wellbeing of parents and the wider family. Family centred care has become a crucial part of care of neonates. If the overall prognosis for the baby is in doubt, palliative care is considered and discussed with parents in the prenatal or early neonatal period. http://www.bmj.com/content/342/bmj.d1808.extract

1. The *British Medical Journal* published a series of online articles on different aspects of palliative care (noted in Media Watch dated 20 September 2010).

From Media Watch dated 1 February 2010:

- MEDSCAPE | Online article – 29 January 2010 – **'Dealing with death in the neonatal intensive care unit.'** Palliative care has come a long way in recent years. Nowhere is this more true than in the neonatal intensive care unit (NICU), where the very idea of death is incongruent with the reason for the unit's existence. http://www.medscape.com/viewarticle/715963



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

GP guidance drawn up for end-of-life care

GP (U.K.) | Online report – 12 April 2011 – GPs involved with end-of-life care can now access detailed guidance on best practice to ensure the necessary actions are conducted safely and respectfully. The advice highlights issues faced by GPs and other health professionals when an adult patient dies. It was created by the National Health Service National End of Life Care Programme with contributions from the Royal College of General Practitioners and other medical organisations. The guidance covers advice on honouring the wishes of the deceased person and their family or carers. It includes respecting people's wishes for organ and tissue donation, and ensuring the health and safety of everyone who comes into contact with the deceased patient's body. It also covers issues about documentation so that GPs can be confident that correct certification procedures have been followed. http://www.gponline.com/News/article/1064864/gp-guidance-drawn-end-of-life-care/

Watching death

CANADIAN FAMILY PHYSICIAN, 2011;57(4): 457. I probably see death most weeks, but last week I watched it as if for the first time. Usually I am too hurried to take the time to watch death closely. Either I am trying hard to stop it or am too busy to wait for it. Or sometimes the strong emotions I feel from family and friends at the bedside draw my attention to them and away from the dying patient. But last week the family was stoic. Everything that could reasonably be done had been done. While I was in the midst of discussing with the family whether to send the patient back to the nursing home for palliation or to keep him in the emergency department, the monitor suddenly showed the heart rate slow from 120 beats per minute to 70 then to 50. There was no point in running off to do something else, as I was sure the end would come within minutes.http://www.cfp.ca/content/57/4/457.full.pdf+html

End-of-life Care for people with intellectual disabilities: Paid carer perspectives

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES, 2011;24(3):199-207. Participants [in this study] wanted to provide palliative care and felt the experience enriched practice. However, they were inadequately prepared to meet need and this often led to staff stress. A number of issues appeared to heighten stress: situations when end-of-life care decision making was challenging, when staff felt 'pushed out' by relatives and when staff did not have sufficient support or time to provide care or mourn the loss of service users. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00605.x/abstract

Of related interest:

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES*, 2011;24(3):199-198. **'The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia.'** Specialist palliative care staff recognized that person-centred care delivered in intellectual disability services was consistent with palliative approaches, but staff in intellectual disability services did not consider advanced dementia care as 'palliative care.' http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00592.x/abstract

Double effect: A useful rule that alone cannot justify hastening death

JOURNAL OF MEDICAL ETHICS | Online article – 8 April 2011 – The rule of double effect is regularly invoked in ethical discussions about palliative sedation, terminal extubation and other clinical acts that may be viewed as hastening death for imminently dying patients. Unfortunately, the literature tends to employ this useful principle in a fashion suggesting that it offers the final word on the moral acceptability of such medical procedures. In fact, the rule cannot be applied appropriately without invoking moral theories that are not explicit in the rule itself. Much of the rich moral conversation germane to the rule has been reflected in arguments about physician-assisted suicide and voluntary active euthanasia, but the rule itself has limited relevance to these debates, and requires its own moral justifications when applied to other practices that might hasten death. http://jme.bmj.com/content/early/2011/04/08/jme.2010.041160.abstract

Cont.

Of related interest:

- *CLINICAL RESEARCH & BIOETHICS*, 2011;2(2):1000102e. **'Quality palliative care or physician-assisted death: A comment on the French perspective of end-of-life care in neurological disorders.'** Conflating physician-assisted death with palliative care is a growing concern in medicine. Palliative care is symptom-management medical care without actively shortening the end-of-life trajectory of a terminal illness. Physician-assisted death intentionally shortens the dying process to bring about preplanned death as the means of relieving suffering. Physician-assisted death may be conflated with palliative care where this practice is illegal, e.g., France. http://www.omicsonline.org/2155-9627/2155-9627-2-102e.pdf

- *EUROPEAN JOURNAL OF HEALTH LAW*, 2011;18(2):149-162. **'The way assisted suicide is legalised: Balancing a medical framework against a demedicalised model.'** In three European countries and three American states ... it is permitted by law for one person to assist in the suicide of another person. When comparing the legislations of these countries/states, it becomes apparent that The Netherlands, Luxemburg, Oregon, Washington and Montana have chosen a medical approach ... whereas the Swiss legal framework for assisted suicide is clearly a non-medical one... http://www.ingentaconnect.com/content/mnp/ejhl/2011/00000018/00000002/art00003

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online article – 8 April 2011 – **'Palliative treatment alternatives and euthanasia consultations: A qualitative interview study.'** There is much debate about euthanasia within the context of palliative care. The six criteria of careful practice for lawful euthanasia in The Netherlands aim to safeguard the euthanasia practice against abuse and a disregard of palliative treatment alternatives. Two different roles of a euthanasia consultant were identified [in this study]: a limited one, restricted to the evaluation of the criteria for careful practice, and a broad one, extended to actively providing advice about palliative care. http://www.jpsmjournal.com/article/S0885-3924(11)00017-0/abstract

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.

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Something Missed or Overlooked?

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

Patients' perspectives of the substitute decision maker: Who makes better decisions?

JOURNAL OF MEDICAL ETHICS | Online article – 8 April 2011 – Substitute decision making on behalf of incapable patients is based on the ethical principle of 'respect for autonomy.' Results of this [cross sectional] study show that the people we usually consult for decisions concerning patient treatment are significantly different from the patients' preferred substitute decision makers. http://jme.bmj.com/content/early/2011/04/08/jme.2010.040691.abstract

Teenagers' and parents' views on a short-break service for children with life-limiting conditions: A qualitative study

PALLIATIVE MEDICINE | Online article – 7 April 2011 – Few opportunities exist outside the home for children and teenagers with life-limiting conditions to have a break in a setting specifically designed and adequately staffed and resourced to meet their complex clinical, practical and emotional needs; until recently provision focused primarily on providing respite for parents/carers. Based on policy recommendations, a short-break service was established with the aim of working in partnership with families and voluntary and statutory agencies... This qualitative study used interviews and focus groups to determine teenagers' and parents' views of the service. Three themes emerged: accessibility and communication; needs and boundaries; and shaping the service. http://pmj.sagepub.com/content/early/2011/04/07/0269216311401947.abstract

The Case of Eluana Englaro

Quality of reporting on the vegetative state in Italian newspapers

PLoS ONE | Online article – 12 April 2011 – Medical reporting was judged as complete if three core vegetative state [VS] characteristics were described: patient unawareness of self and the environment, preserved wakefulness, and spontaneous respiration. The authors retrieved 2,099 articles, and 967 were dedicated to VS. Of these, 853 (88.2%) were non-medical and mainly focused on describing the political, legal, and ethical aspects of VS. Of the 114 (11.8%) medical articles, 53 (5.5%) discussed other medical problems such as death by dehydration, artificial nutrition, neuroimaging, brain death, or uterine hemorrhage, and 61 (6.3%) described VS. Of these 61, only 18 (1.9%) reported all three core characteristics and were judged complete.http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0018706;jsessionid=906DF44247EF4082F1F1ADA88E987846.ambra02

Brain-damaged woman could become first person to have food and water tubes withdrawn while she is still 'conscious'

U.K. | *Daily Mail* – 15 April 2011 – A brain-damaged woman in a 'minimally conscious state' is the subject of a 'unique' case where a judge must decide if life-sustaining treatment should be withdrawn. The application for withdrawal of artificial nutrition and hydration has been made by the mother of the 53-year-old. During preliminary proceedings at the Court of Protection ... in preparation for a full hearing of the case in July, Mr. Justice Baker described it as a 'unique' case which raised 'very important issues of principle.' http://www.dailymail.co.uk/news/article-1377161/Judge-decide-conscious-woman-life-support-machine-switched-off.html

From Media Watch dated 14 June 2010:

- *JOURNAL OF MEDICAL ETHICS*, 2010;36(6):333-335. **'Eluana Englaro, chronicle of a death foretold: Ethical considerations on the recent right-to-die case in Italy.'** This paper ... gives a chronicle of Eluana's last months until her death on 9 February 2009, and discusses the right-to-die controversy in Italy. http://jme.bmj.com/content/36/6/333.abstract

Being me and being us in a family living close to death at home

QUALITATIVE HEALTH RESEARCH, 2011;21(5):683-695. The authors used interpretive description to describe how everyday life close to death was experienced and dealt with in families with one member who had a life-threatening illness. They found two patterns, namely, "being me in a family living close to death" and "being us in a family living close to death." "Being me" meant that every individual in the family had to deal with the impending death, regardless of whether or not he or she was the person with the life-threatening illness. This was linked to ways of promoting the individual's self-image, or "me-ness." This pattern was present at the same time as the pattern of "being us," or in other words, being a family, and dealing with impending death and a new "we-ness" as a group. "Striving for the optimal way of living close to death" was the core theme. http://qhr.sagepub.com/content/21/5/683.abstract

Worth Repeating

Expressions of grief

My mother's body: A story of grieving, remembering and touch

CANADIAN CREATIVE ARTS IN HEALTH TRAINING & EDUCATION JOURNAL, 2009;1(7):29-35. My daughter, not yet six years old, was teaching me how to grieve. In fact, it was my daughter who had led me back to Newfoundland to be at my mother's side before she died. Caught in the vortex of trying to balance work demands and family responsibilities, I thought that I could wait until my mother died and then travel to Newfoundland for the funeral. I had, I told myself, already grieved my mother's absence from my life as Alzheimer's consumed more and more of her. But when I told my daughter that (her) Grandma was going to die soon, she immediately said, "We have to go and say 'Good-bye.'" http://www.cmclean.com/archives/CCAHTE-Journal-7-Yallop.html

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