# Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Effecting change: Scroll down to <u>Specialist Publications</u> and 'Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: A retrospective case-note audit' (p.12), in *Journal of Adolescent & Young Adult Oncology*.

# Canada

# Inadequate home care for Ottawa-area families with sick children, study finds

ONTARIO | CBC News (Ottawa) – 3 August 2017 – Taking care of a sick child not only takes up a family's time, but it would also cost the healthcare system more than half a billion dollars in the Ottawa area alone, if the government had to pay personal support workers to do the job parents are currently doing. Families spend 15.7million hours per year caring for their children with both acute, chronic and complex health issues, a first-of-its-kind study in Ontario by the Champlain Local Health Integration Network has found. The number of children and youth in the Ottawa area is set to grow by 30% in the next two decades. Despite this, the region currently receives 20% fewer home care services compared to the provincial average, according to the report. https://goo.gl/3ygEXm

# **Specialist Publications**

'Validation of quality indicators for end-of-life communication: Results of a multicentre survey' (p.9), in *Canadian Medical Association Journal.* 

### Palliative patients wanting to die at home face new and costly drug dispensing fees

MANITOBA | CTV News (Winnipeg) – 1 August 2017 – George Shallcross, 73, lives with Parkinson's disease and has chosen to die at home. Shallcross' wife, Susan, said under the province's palliative program all of the costs of his medication are covered, including dispensing fees. Starting 18 August, the province is introducing a cap on dispensing fees for drugs. It means pharmacies can charge the province no more than \$60 for liquid drugs that require mixing in sterile conditions. Shallcross takes 25 doses of liquid medication a day. His pharmacy said the changes will cost him about \$900 a month. A government spokesperson said Manitoba has the highest average dispensing fees by a provincial drug program in Canada and is the only province without a cap on the fees. The spokesperson also said exceptions could be made for some patients. <a href="https://goo.gl/a9eiQT">https://goo.gl/a9eiQT</a>

# <u>U.S.A.</u>

# Senate passes "right to try" bill to help terminally ill patients get experimental drugs

THE WASHINGTON POST | Online - 3 August 2017 - The Senate passed by unanimous consent a measure designed to make it easier for terminally ill patients to get access to experimental treatments without oversight from the Food & Drug Administration (FDA). The "right-to-try" legislation has been championed by the libertarian Goldwater Institute, which has worked to pass similar legislation in 37 states. The federal version, now headed to the House, would bar the government from blocking patients from getting access to medications that have undergone only preliminary testing in humans. Patients first would have to try all other available treatments and be ineligible for clinical trials. The bill would provide drug companies some legal protection if a treatment results in harm. But critics say the legislation is unnecessary. Alison Bateman-House, an assistant professor of medical ethics at New York University Langone Medical Center, called the bill "inherently deceptive" because it simply says patients can ask drug companies for the treatments. Companies often are reluctant to provide unapproved products for a variety of reasons, and the FDA has an efficient system to handle requests for experimental drugs, she said. https://goo.gl/bdbNLX

### **Specialist Publications**

'Toward improving quality of end-of-life care: Encoding clinical guidelines and standing orders using the Omaha system' (p.15), in *Worldviews* on Evidence-Based Nursing.

### Related

- MARYLAND | Hub (John Hopkins University) 1 August 2017 'Guidelines needed to help terminally ill patients gain access to trial drugs, Johns Hopkins expert says.' For those diagnosed with a terminal illness survival could depend on gaining access to new or experimental drugs in clinical trials – and far from approval for public use. Access to these drugs is difficult, but not impossible to get. A recent study by a Johns Hopkins University expert on the legal aspects of health care proposes a solution.<sup>1</sup> https://goo.gl/4GcaaM
  - 'The expanded access cure: A twenty-first century framework for companies,' *Journal of Business Ethics*, published online 5 May 2017. <u>https://goo.gl/Sb3PCT</u>

Noted in Media Watch 3 April 2017, #506 (p.4):

THE WASHINGTON POST | Online – 26 March 2017 – 'Are right-to-try laws a last hope for dying patients – or a false hope?' Thirty-three states have passed such laws, which ostensibly allow patients to take experimental medicines outside of clinical trials and without Federal Drug Administration (FDA) oversight as long as the therapies have undergone preliminary safety testing. And now, for the first time, federal legislation is gaining traction. But the increased momentum is raising alarms, with opponents saying that such laws largely offer false hope. <a href="https://goo.gl/SzY1UK">https://goo.gl/SzY1UK</a>

**N.B.** Additional articles on "right-to-try" laws are noted in the 6 March 2017 issue of Media Watch (#502, p.6).



# Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.

## Many still sidestep end-of-life care planning, study finds

*KAISER HEALTH NEWS* | Online – 1 August 2017 – Even though advance directives (ADs) have been promoted for nearly 50 years, only about a third of U.S. adults have them, according to a recent study.<sup>1</sup> People with chronic illnesses were only slightly more likely than healthy individuals to document their wishes. Researchers reviewed 150 studies published from 2011 to 2016 that reported on the proportion of adults who completed ADs, focusing on living wills and health care power-of-attorney documents. Of nearly 800,000 people on whom the studies reported, 36.7% completed some kind of AD. Of those, 29.3% completed living wills, 33.4% health care proxies, and 32.2% were "undefined," meaning the type of AD wasn't specified or combined the two. People older than 65 were significantly more likely to complete any type of AD than younger ones, 45.6% vs. 31.6%. But the difference between people who were healthy and those who were sick was much smaller, 32.7% compared with 38.2%. The Medicare program began reimbursing physicians in January 2016 for counseling beneficiaries about advance care planning. https://goo.gl/MZaMLZ

 'Approximately one in three U.S. adults completes any type of advance directive for end-of-life care,' Health Affairs, 2017;36(7):1244-1251. <u>https://goo.gl/wZHzmG</u>

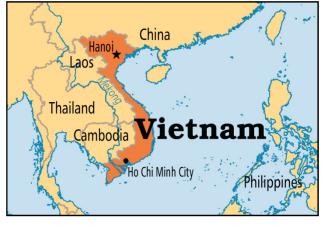
**N.B.** The focus of this issue of *Health Affairs* is on advance illness and end-of-life care. [Noted in Media Watch 10 July 2017, #520 (p.10)] Journal contents page: <u>https://goo.gl/jebK3j</u>

# International

#### End-of-life care in Vietnam

### More people to benefit from palliative care

VIETNAM | Vietnam News Agency (Hanoi) – 4 August 2017 – Health experts and doctors met in Hanoi to discuss the updated and amended guiding document on palliative care (PC). In 2006, the Department of Medical Examination & Treatment, under the Ministry of Health, issued guidance on PC for cancer and AIDS patients. The updated document expands the subjects of the specialised medical and nursing care to all people with lifelimiting illnesses. It says the therapy begins when diseases are detected and continues throughout the treatment process. It encourages building multi-component groups, which include medical staff, families, social workers and volunteers, to care for patients. PC can take place at hospitals,



at home and within the community. <u>https://goo.gl/6REBXc</u>

Noted in Media Watch 23 November 2015, #437 (p.6):

- VIETNAM | Viêt Nam News (Hanoi) 18 November 2015 'Palliative care eases burden on healthcare system.' In Vietnam, about 150,000 diagnoses of cancer occur annually with 70% of them in the last stage. The Ministry of Health tried to encourage the practice by issuing guidelines for cancer and AIDS patients in 2006, but so far only 13 hospitals have palliative care wards or have implemented programmes. Viet Nam ranks 58th on end-of-life care...<sup>1</sup> <u>https://goo.gl/ieUttA</u>
  - 1. '2015 Quality of Death Index,' Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch 2 November 2015, #434 (p.15)] <u>https://goo.gl/xzAJhr</u>

#### End-of-life care in Australia

#### Significant unmet need for palliative services in residential care despite cost-effectiveness

AUSTRALIA (New South Wales) | Australian Ageing Agenda (Glebe) - 2 August 2017 - Palliative and end-of-life (EoL) care in residential facilities improves residents' quality of life and saves public money through reduced use of ambulance and hospital services, but take up remains low, new economic analysis shows.<sup>1</sup> The research ... looked at palliative care's impact in seven areas including residential aged care, home-based care and hospitals. It found that palliative care (PC) in all settings had positive outcomes for Australians while also reducing healthcare costs, but that greater investment was needed to realise the care preferences of people approaching EoL. Despite its costeffectiveness, there is "significant unmet need" for PC in residential aged care, where about a third of permanent residents die each year usually in their facility or following transfer to hospital. Of the 55,600 permanent residents who died in aged care in 2014-2015, over 87% had been in care for more than three months and over half had stayed in care for more than two years... Only 4% of residents in aged care in 2014-2015 were assessed as requiring PC according to their Aged Care Funding Instrument appraisal. https://goo.gl/JKcwdA

#### Specialist Publications

'Improving specialist palliative care in residential care for older people: A checklist to guide practice' (p.8), in *BMJ Supportive & Palliative Care*.

'Admissions to inpatient care facilities in the last year of life of community-dwelling older people in Europe' (p.8), in *European Journal of Public Health.* 

 'The Economic Value of Palliative Care & End-of-Life Care,' National Centre for Social & Economic Modelling, University of Canberra, July 2017. <u>https://goo.gl/w4DXDa</u>

# "Surprise question" sees thousands wrongly told they will die under faulty National Health Service system

U.K. (England) | The Daily Telegraph (London) -2 August 2017 - Tens of thousands of patients are being prematurely warned they could be about to die because of a defective diagnostic method used across the National Health Service. Experts have said families and loved ones are being needlessly worried after new research showed the tool over-predicted the chances of death more often than not.<sup>1</sup> The so-called "surprise question" encourages doctors to ask themselves "Would you be surprised if this patient were to die in the next few months, weeks, days?" A wide scale analysis by University College London found that more than half of those predicted to die within a specific time lived longer than expected.<sup>1</sup> It means that care for those patients is being moved onto a end-of-life footing earlier than necessary. The research revealed that the unreliability of the question, which forms one of several diagnostic criteria,

means other patients who really are about to die and need palliative care are not receiving it. https://goo.gl/ckpPcR

#### An apparent contradiction?

The author's of the study concluded: "This review has highlighted the wide degree of accuracy reported for the "surprise question" (SQ) as a prognostic tool." The authors add that further work, however, is required to understand the processes by which clinicians arrive at their prognostic estimates, to refine the accuracy of the SQ, and to compare its performance against other more sophisticated prognostic tools, particularly in populations where a higher proportion of deaths occur. Additional articles on the "surprise question" for predicting death in seriously ill patients are noted in the 10 April 2017 issue of Media Watch (#507, pp.10-11). **BRA** 

1. 'How accurate is the "surprise question" at identifying patients at the end of life? A systematic review and meta-analysis,' *BMC Medicine*, published online 2 August 2017. <u>https://goo.gl/mjCEGM</u>

#### End-of-life care in the U.K.

### More than 100,000 terminally ill patients denied hospice care

U.K. (England & Wales) | Sky News – 2 August 2017 – One in four terminally ill people who need expert end-of-life care are not receiving it because of funding pressures, the hospice movement has told Sky News. Hospice UK said as many as 118,000 people in the U.K. with terminal or life-limiting conditions are not able to access palliative care (PC) from its members. Britain's 200 hospices treat around 200,000 people every year but, with an ageing population, demand for their services is growing. Hospices offer PC to improve the quality of life of those dying, as well as emotional and psychological support to families facing bereavement. On average, hospices most of which are charities, receive just one-third of their funding from the National Health Service (NHS) and rely on donations, shops, bequests and investments for the rest. Hospice UK said two-thirds of hospices had their NHS funding cut or frozen last year. It argues that with more certain funding it could treat many more people, significantly easing the pressure on NHS hospitals. Around 500,000 people die in England & Wales every year, half of them in hospitals despite many of them having no clinical need to be there. <a href="https://goo.gl/APzkXG">https://goo.gl/APzkXG</a>

## Scotland in top 10 countries for palliative care

U.K. (Scotland) | The Scotsman (Edinburgh) - 2 August 2017 - Scotland is in the top ten countries in Europe for levels of palliative care (PC), although a new study has said there remains "room for improvement."1 For the first time, academics at Glasgow University compared the level of end-of-life care provided in Scotland with that in the rest of Europe, including elsewhere in the U.K. There are 23 specialist PC inpatient units in Scotland, containing a total of 349 beds. In addition, there are 27 specialist PC hospital support teams and 38 specialist PC home care teams. Relative to other European Union countries, Scotland ranked seventh for provision of specialist PC inpatient units and hospital support teams, and fifth for home care teams. Statistics for Scotland had only been included with U.K. data before, but the Scottish Atlas of Palliative Care, published in 2016,<sup>2</sup> meant more detailed information was available. https://goo.gl/6xxSuT

#### Palliative care team axed in health care review

U.K. (Scotland) | *The Courier* (Dundee) – 4 august 2017 – The dedicated workforce providing palliative and end-of-life care in the community, based at the £4 million Cornhill Macmillan Centre in Perth, are being replaced by district nurses. It follows a review of care across the Perth and Kinross patch, although bosses at the Perth and Kinross Health Care Social Care Partnership – an organisation led by National Health Service Tayside and council chiefs – has insisted it is not a cost-saving measure. Three members of the Marie Curie Fast Track service were based at the centre, part of the Perth Royal Infirmary site, offering help and support to terminally ill patients. https://goo.gl/LWfoAN

- 1. 'The level of provision of specialist palliative care services in Scotland: An international benchmarking study,' *BMJ Supportive & Palliative Care*, published online 2 August 2017. <u>https://goo.gl/JD4Yr3</u>
- 'Scottish Atlas of Palliative Care,' End-of-Life Studies Group, University of Glasgow, September 2016. [Noted in Media Watch 26 September 2016, #481 (p.4)] <u>https://goo.gl/Sf3DCy</u>

Noted in Media Watch 3 July 2017, #519 (p.6):

U.K. (Scotland) | The Scotsman (Edinburgh) – 26 June 2017 – 'Scotland lagging behind in delivery of end-of-life care.' Scotland is fairing worse than similar sized countries when it comes to delivering end-of-life care (EoLC) with around a third of people in hospital on any given day likely to die within one year. Experts from Denmark, New Zealand and Scotland met in Glasgow to discuss the correlation between hospital admissions and the likelihood of death. In all three countries studies have revealed that the number of people who would benefit from palliative and EoLC but do not necessarily receive it is higher than previously thought. <a href="https://goo.gl/Tt6oEC">https://goo.gl/Tt6oEC</a>

Noted in Media Watch 27 February 2017, #501 (p.4):

 U.K. (Scotland) | *The Scotsman* (Edinburgh) – 24 February 2017 – 'Thousands of Scots miss out on end-of-life palliative care.' Experts estimate about 11,000 people in Scotland could have benefited from palliative care at the end of their lives, but did not receive it. Charities Marie Curie, Sue Ryder and Hospice UK are calling for an Anticipatory Care Plan which patients complete with their GP, recording their explicit wishes, to be added as a new indicator for reviewing end-of-life care. <u>https://goo.gl/5EEX2l</u>

**N.B.** Selected articles, reports, etc., on end-of-life care in Scotland are noted in 12 December 2016 issue of Media Watch (#491, p.5).

#### Latin America lacks palliative care plan for the terminally ill

VENEZUELA | Latin American Herald Tribune (Caracas) – 1 August 2017 – The inclusion of palliative care (PC) for the terminally ill – also known as comfort care – is a big unresolved issue in Latin American healthcare systems, Felicia Marie Knaul, director of the University of Miami Institute for the Advanced Study of the Americas, told EFE News Agency in an interview. "If we're able to work on the prevention of illnesses and the access to treatment, we can also work on providing PC" that eases patients' physical, psychological, social and spiritual suffering, said Knaul, who has dedicated the last three years to study-ing that problem. The Harvard graduate with a PhD in economics has just delivered the final manuscript of a world report on the subject that *The Lancet* will publish in October... https://goo.gl/QsVFSb

Noted in Media Watch 15 May 2017, #512 (p.8):

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 May 2017 – 'The development of palliative care in Argentina: A mapping study using Latin American Association for Palliative Care indicators.' The Latin American Association for Palliative Care developed 10 indicators to monitor the development of palliative care. The indicators have been applied across Latin American countries, but have not been used internally. The application of the indicators at the province level led to the identification of inequalities in the development and distribution of services across the country. https://goo.gl/Yqs9Ta

**N.B.** See 'Atlas de Cuidados Paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012. Available in Spanish, Portuguese & English. [Noted in Media Watch 7 January 2013, #287 (p.8)] <u>https://goo.gl/jh1mAZ</u>

#### Lessons from Britain's compassionate cities

SINGAPORE | *The Straits Times* (Singapore) – 31 July 2017 – In the small town of Todmorden in West Yorkshire, Britain, volunteers take people on graveyard tours. Neighbourhood florists run workshops to get people talking about end-of-life issues, using the life cycle of flowers as inspiration. And funeral brass bands offer music as part of a community-initiated festival to start conversations around death and be-reavement. In East London, St Joseph's Hospice runs a Compassionate Neighbours social movement that matches volunteers with people living with a long-term or terminal illness. Its 200 volunteers are trained in areas such as relationship analysis, active listening and self-care. The volunteers are matched to people who live nearby and have similar interests. Severn Hospice in Shropshire adopted a similar programme and there has been a significant reduction in the use of unscheduled healthcare services by people receiving volunteer support. Emergency services were freed up to tend to more complicated medical cases. These are examples of "compassionate communities" in Britain. <a href="https://goo.gl/4CkPNt">https://goo.gl/4CkPNt</a>

Noted in Media Watch 10 July 2017, #520 (p.7):

 BMC PALLIATIVE CARE | Online – 3 July 2017 – 'Piloting a compassionate community approach to early palliative care.' A compassionate community approach to palliative care provides important rationale for building community-based hospice volunteer capacity. In this project, the authors piloted one such capacity-building model in which volunteers and a nurse partnered to provide navigation support beginning in the early palliative phase for adults living in community. <a href="https://goo.gl/2vvZe6">https://goo.gl/2vvZe6</a>

**N.B.** Additional articles on the concept of "compassion communities," particularly in the context of end-oflife care, are noted in this issue of Media Watch.

# Charlie Gard: On reflection

### Restoring balance to "best interests" disputes in children

BRITISH MEDICAL JOURNAL | Online – 2 August 2017 – Commentators, politicians, and some supporters of the [Gard] family attacked the hospital, the doctors, and the health system. Overseas medical and scientific experts, politicians, and religious leaders ventured opinions and offered treatment, apparently without knowledge of the full clinical circumstances. On the other side, the hospital and health professionals involved didn't feel able to defend themselves in public out of concern for the confidentiality of the child and family and to protect staff of the hospital. Independent experts have been reluctant to comment because of the lack of important medical details. <a href="https://goo.gl/G7QvQV">https://goo.gl/G7QvQV</a>

#### Plight of Charlie Gard hijacked by campaigners

U.K. (England) | *The Mail* (Barrow-in-Furness, Cumbria) – 2 August 2017 – The life and – last week – death of Charlie Gard has been a tragic saga of human suffering. It has also been a most unedifying example of how social mediadriven campaigns so often degenerate into divisive, emotive virtue-signalling of the very worst kind. While little Charlie and his parents suffered unimaginable agonies, the child's life and the legal battle into which it was dragged became public property, with ignorant people on both sides of the Atlantic taking it upon themselves to claim possession of this child's plight. <u>https://goo.gl/ZN8PtG</u>

#### Charlie Gard highlights "series of issues" for PR pros and clients, says Charted Institute of Public Relations

U.K. | *PRWeek* – 1 August 2017 – Institute president-elect Sarah Hall responded to an article in *The Times* which raised concerns about freelance journalist Alison Smith-Squire, who allegedly acted as spokeswoman for Charlie Gard's parents while also selling stories about them via her business Featureworld. Asked whether this constituted a conflict of interest, Smith-Squire told *PRWeek*: "The Gard family contacted Featureworld, a long-standing news agency, to help publicise their case and subsequent media interest. As with all interviewees, the arrangements must remain confidential." <u>https://goo.gl/idjuCN</u>

#### How would a Charlie Gard story unfold in Malta?

MALTA | *The Malta Independent* (St. Julian's) – 31 July 2017 – At its heart, the case pitted the right of parents to decide what is best for their children against the authorities' responsibility to uphold the rights of people who cannot speak for themselves. Under British law, children have rights independent of their parents, and it is usual for courts to intervene when parents and doctors disagree on the treatment of a child. Minister of Health Chris Feame explained that in the unlikely case where there is disagreement between parents and medical professionals the court's advice is sought. <a href="https://goo.gl/gNnVel">https://goo.gl/gNnVel</a>.

#### Tribunal could have spared Charlie Gard's parents "false hope"

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 31 July 2017 – Charlie Gard's parents may have been spared months of "false hope" and legal wrangling if tribunals were used instead of courts, specialists have suggested. Expert panels deciding similar cases could help "avoid the worst features of enormous public discussion and the enormous length and expense", Oxford University physician Dominic Wilkinson told the Press Association. Professor Wilkinson, who focuses on newborn intensive care, added: "They could make decisions that wouldn't be subject to multiple levels of appeal. Time was clearly a very important factor here. <a href="https://goo.gl/xMpcvf">https://goo.gl/xMpcvf</a>

### Ten cases like Charlie Gard's heard in English courts this year

U.K. (England) | *The Guardian* (London) – 29 July 2017 – The news comes as concern grows over the manner in which such cases are dealt with in the wake of the traumatic final days of Charlie Gard... Last year approximately 18 such cases were considered by judges sitting in England. The figures, confirmed by Cadcass, the independent body that represents children in family court cases, highlight the fact that most cases involving disputed medical treatment are dealt with out of the public eye with a guardian appointed to represent the child's best interests, independent of what the parents may want. <a href="https://goo.gl/B1XrMh">https://goo.gl/B1XrMh</a>

# Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | The Herald Sun (Melbourne) 4 August 2017 '116 Victorian patients refuse lifesaving treatment.' Four Victorians a week are taking legal action to prevent doctors giving them lifesaving treatment, with the number expected to multiply next year when new regulations make refusing care easier. As the Victorian parliament prepares to debate voluntary euthanasia laws in coming months ... 116 patients have already used legally binding certificates to ban hospitals prolonging their lives this year; however, the measures stop short of assisting them to die. Refusal of Treatment Certificates must be completed by a patient while they are deemed competent and can only cover a specific condition from which they are already suffering. <a href="https://goo.gl/QsVbgp">https://goo.gl/QsVbgp</a>
- NEW ZEALAND | New Zealand Herald (Auckland) 2 August 2017 'Major inquiry on voluntary euthanasia does not recommend law change.' Parliament's largest-ever inquiry into voluntary euthanasia has not recommended that government make it legal. The two-year inquiry heard from 22,000 submitters, including 1,000 of them in person. There were concerns expressed about palliative care in New Zealand, in particular its availability and funding. <u>https://goo.gl/Dy2t5G</u>

# **Specialist Publications**

## Integrating palliative care into neurology services: What do the professionals say?

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 August 2017 – The authors present survey results describing the current levels of collaboration between neurology and palliative care (PC) services and exploring the views of professionals towards a new short-term integrated palliative care (SIPC) service. 33 neurology and 26 PC professionals responded. Collaborations between the two specialties were reported as being "good/excellent" by 36% of neurology and by 58% of PC professionals. However, nearly half (45%) of neurology compared with only 12% of PC professionals rated current levels as being "poor/none." Both professional groups felt that the new SIPC service would influence future collaborations for the better. However, they identified a number of barriers for the new SIPC service such as resources and clinician awareness. <a href="https://goo.gl/UxpJfY">https://goo.gl/UxpJfY</a>

**N.B.** Additional articles on palliative care for patients living with a neurological disease are noted in the 24 July 2017 issue of Media Watch (#522, p.14).

# Improving specialist palliative care in residential care for older people: A checklist to guide practice

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 August 2017 – The palliative care (PC) needs round checklist is presented, alongside rich description of how needs rounds are conducted. Extracts from interviews with needs rounds participants illustrate the choice of items within the checklist and their importance in supporting the evolution towards efficient and effective high-quality specialist PC input to the care of older people living in residential care. The checklist can be used to support the integration of specialist PC into residential care to drive up quality care, provide staff with focused case-based education, maximise planning, and reduce symptom burden for people at end of life. <a href="https://goo.gl/vQ6PXV">https://goo.gl/vQ6PXV</a>

### Related

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 28 July 2017 – 'Admissions to inpatient care facilities in the last year of life of community-dwelling older people in Europe.' Although healthcare policies increasingly stress the importance that people reside at home as long as possible, admissions to inpatient care facilities [e.g., hospital, nursing home or hospice] in the last year of life are relatively common across all countries. The authors' found a striking variation concerning the proportion of admissions across countries which cannot only be explained by patient needs. It suggests that such admissions are at least partly driven by system-level or cultural factors. <a href="https://goo.gl/h2FRA2">https://goo.gl/h2FRA2</a>

Cont.

 HONG KONG MEDICAL JOURNAL | Online – 4 August 2017 – 'End-of-life services for older people in residential care homes in Hong Kong.' In 2015, the Hospital Authority started the 'Enhance community geriatric assessment team support to end-of-life (EoL) patients in residential care homes for the elderly' programme. In September 2015, the Hospital Authority guideline on life-sustaining treatment for terminally ill people was updated. The possible establishment of enduring powers of attorney for health care decision-making and enhancement of careful (comfort) hand feeding are new developments in the coming years. <a href="https://goo.gl/ZQEsLi">https://goo.gl/ZQEsLi</a>

## A qualitative inquiry into the barriers and facilitators to achieving home death

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 July 2017 – Thirty-three interviews were conducted [with end-of-life care experts] compromising of a mixture of face-to-face and tele interviews. The experts included healthcare professionals working in the community, hospital and policy/academic settings. Three overarching themes, further divided into a total of 12 sub-themes were identified. The three themes were "managing people," "education" and "planning." The "managing people" theme included subthemes of patient preferences and family influences; the "education" theme encompassed knowledge and training, perceptions of death and communication, and the "planning" theme contained seven sub-themes including "coordination," "resources" and "cost." Multiple barriers and facilitators to achieving death at home were identified in this study. Of particular significance was the identification of the fear and stigma associated with death among doctors, patients and their families serving as a barrier to home death, not previously identified in the literature. Additionally, the importance of social networks and resource provision were highlighted as key in influencing patient death at home. <a href="https://goo.gl/ZSos87">https://goo.gl/ZSos87</a>

Noted in Media Watch 19 June 2017, #517 (p.12):

PALLIATIVE MEDICINE | Online – 12 June 2017 – 'Barriers and facilitators influencing death at home: A meta-ethnography.' Significant variation exists in the proportion of home deaths achieved internationally, with many countries unable to meet the wishes of a large number of patients. This review builds on previous literature investigating factors influencing home death, synthesising qualitative research to supplement evidence that quantitative research in this field may have been unable to reach. <a href="https://goo.gl/jtyzjm">https://goo.gl/jtyzjm</a>

Noted in Media Watch 29 May 2017, #514 (p.8):

JOURNAL OF PAIN MANAGEMENT, 2017;10(1):107-115. 'Barriers to home death for Canadian cancer patients: A literature review.' A comprehensive literature search was performed across several databases to locate relevant studies. Barriers were defined as amendable determinants which may be changed with appropriate resources and policies. Four major barriers were identified: 1) Inadequacy of support services; 2) Insufficiency of family caregivers; 3) Inadequacy of home locations and sizes; and, 4) Discontinuity of care by family physicians. <a href="https://goo.gl/o6DIM7">https://goo.gl/o6DIM7</a>

#### End-of-life care in Canada

### Validation of quality indicators for end-of-life communication: Results of a multicentre survey

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(30):e980-e989. The lack of validated quality indicators is a major barrier to improving end-of-life (EoL) communication and decision-making. The authors sought to show the feasibility of – and provide initial validation for – a set of quality indicators related to EoL communication and decision-making. They administered a questionnaire to patients and their family members in 12 hospitals and asked them about advance care planning and goals-of-care discussions. At all sites, both overall quality indicators and individual domain scores were low and there was wide variability around the point estimates. <a href="https://goo.gl/uAYSgk">https://goo.gl/uAYSgk</a>

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#### Related

- CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(30):e978-e979. 'Measuring quality of end-of-life communication and decision-making: Do we have this right?' Access to this article requires a subscription to the journal. <u>https://goo.gl/taCcvm</u>
- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 3 August 2017 'A systematic review
  of end-of-life care communication skills training for generalist palliative care providers: Research quality and reporting guidance.' Despite a proliferation of end-of-life communication skills
  training interventions in the literature, evidence is limited by poor reporting and weak methodology. The
  authors' present a CONSORT statement supplement to improve future reporting and encourage more
  rigorous testing. <a href="https://goo.gl/99Gu6i">https://goo.gl/99Gu6i</a>
- PATIENT EDUCATION & COUNSELING, 2017;100(5):909-918. 'From theory to practice: Measuring end-of-life communication quality using multiple goals theory.' The authors analyzed 17 conversations in which 68 participants played a game that prompted discussion in response to openended questions about end-of-life (EoL) issues. Their coding scheme provides a theory-based measure of EoL conversation quality that is superior to other methods of measuring communication quality. <u>https://goo.gl/dV5mx7</u>

# Trending longitudinal agreement between parent and child perceptions of quality of life for pediatric palliative care patients

*CHILDREN* | Online – 1 August 2017 – Pediatric palliative care (PC) studies often rely on proxy-reported instead of direct child-reported quality of life (QoL) metrics. This study revealed overall consistency between parent- and child-reported QoL across a number of wellness domains. Physical health was noted to be in closest agreement. At the time of initial PC consult, children collectively scored their social QoL higher than parental perception of the child's social QoL; whereas, emotional and cognitive QoL domains were scored lower by children than by the parental report. At the one year survey time point, the physical, emotional, and social domains trended toward more positive patient perception than proxy perception with congruence between QoL scores for the cognitive domain. Findings reveal the importance of eliciting a child report in addition to a parent report when measuring and longitudinally trending perceptions on QoL. https://goo.gl/E5XkcC

### Related

- JOURNAL OF PALLIATIVE MEDICINE | Online 2 August 2017 'Providing pediatric palliative care education using problem-based learning.' The Institute of Medicine and the American Academy of Pediatrics has called for improvement in education and training of pediatricians in pediatric palliative care (PPC). Given the shortage of PPC physicians and the immediate need for PPC medical education, this study reports the outcomes of a problem-based learning module facilitated by academic general and subspecialty pediatric faculty (non-PPC specialists) to third year medical students. <a href="https://goo.gl/RngcZA">https://goo.gl/RngcZA</a>
- PALLIATIVE & SUPPORTIVE CARE | Online 31 January 2017 'Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals.' There are sparse scientific data on the domains of quality of life (QoL) and no measurement strategies are available. In this study, the authors identified seven domains of QoL: 1) "Physical comfort"; 2 "Alleviation of psychological suffering"; 3) "Fun and the present moment"; 4) "Sense of control"; 5) "Feeling valued and appreciated"; 6) "Feeling that life goes on"; and, 7) "Meaningful social relationships." https://goo.gl/x9NK4F
- PUBLIC HEALTH | Online 28 July 2017 'Pediatric palliative care initiative in Cambodia.' Cancer care with curative intent remains difficult to manage in many resource-limited settings such as Cambodia. Cambodia has a small workforce with limited financial and health-care resources resulting in delayed diagnoses and availability of limited therapeutic tools. Palliative care (PC) becomes the primary form of care in most cases. Although PC is becoming an integral part of medical care in developed countries, this concept remains poorly understood and utilized in developing countries. Angkor Hospital for Children serves a relatively large pediatric population in northern Cambodia. <u>https://goo.gl/STWypG</u>

## Clinicians' perspectives on the duty of candour: Implications for medical ethics education

*CLINICAL ETHICS* | Online – 3 August 2017 – Truth-telling is an integral part of medical practice in many parts of the world. However, recent public inquiries, including the Francis Inquiry reveal that a duty of candour in practise are at times compromised.<sup>1</sup> Consequently, the duty of candour became a statutory requirement in England. Eleven clinical educators were interviewed; three general practitioners, six physicians, and two surgeons. Thematic analysis identified three key themes; 1) Reaction to legislation; 2) Barriers to implementation; and, 3) Areas of the medical curriculum that can be further developed to better prepare future doctors. Currently, the legislation is not reaching all frontline staff; there remains a lack of appropriate training and teaching on the legislation that responds to the perceived challenges to implementing candour. These challenges include tensions in the clinical workplace and concerns about the patient's best interests conflicting with requirements of the legislation. Both undergraduate and postgraduate curricula need to integrate teaching on the implications of the legislation and take a practice based approach in doing so. <u>https://goo.gl/9hPxVW</u>

1. 'Report of the Mid-Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch 11 February 2013, #292 (p.5). <u>https://goo.gl/mYV9Jc</u>

### How long a life is enough life?

THE HASTINGS CENTER REPORT, 2017;47(4):16-18. Humans have long been troubled by the prospect of old age and its culmination in death. Whether to rebel against or accept this fate have been wrestled with down through the centuries. But new medical technologies and the growing science of aging have sided with rebellion. We know that aging can be pushed back and improved in its quality. That progress is well under way, but now intensified by many scientists and Silicon Valley entrepreneurs. In 2016, Mark Zuckerberg and Priscilla Chan pledged three billion dollars toward eventually "preventing, curing or managing all diseases." And some visionaries have made the elimination of death or its indefinite postponement a goal. To put those aspirations in a broader context, it is helpful to keep in mind where population growth and aging trends stand. Apart from any success in the explicit efforts to increase longevity, there will be a steady increase in the number of elderly worldwide – and a much higher percentage of the elderly as part of the overall population. Most of the largest changes will be in developing countries. They will be overburdened by the death of the elderly from expensive chronic diseases – already a vexing problem for affluent countries. https://goo.gl/aorTcD

### Prognostic variables and scores identifying the end of life in COPD: A systematic review

*INTERNATIONAL JOURNAL OF COPD*, 2017;12:2239-2256. A total of 5,276 abstracts were screened, leading to 516 full-text reviews, and 10 met the inclusion criteria. No multivariable indices were developed with the specific aim of predicting all-cause mortality in stable COPD within 12 months. Only nine indices were identified from four studies, which had been validated for this time period. Tools developed using expert knowledge were also identified. A number of variables contributing to the prediction of all-cause mortality in COPD were identified. However, there are very few studies that are designed to assess, or report, the prediction of mortality at or less than 12 months. The quality of evidence remains low, such that no single variable or multivariable score can currently be recommended. <a href="https://goo.gl/BDsQEi">https://goo.gl/BDsQEi</a>

Noted in Media Watch 12 June 2017, #516 (p.6):

 CLINICAL MEDICINE | Online – 1 June 2017 – "High-risk" patients with chronic obstructive pulmonary disease have a poor prognosis and need to be able to access palliative care services." The prognosis for this group is poor, with almost half dying within a year, yet only 37% [of the patient group studied] had accessed palliative care services. <u>https://goo.gl/MZfRNc</u>

**N.B.** To access full text of the *International Journal of COPD* article click on pdf icon. Additional articles on palliative care and patients living with chronic obstructive pulmonary disease are noted in the 2 January 2017 issue of Media Watch (#493, p.9).

# Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: A retrospective case-note audit

JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY | Online – 2 August 2017 – Adolescents and young adults (AYA) with cancer are a cohort requiring specialized healthcare models to address unique cognitive and physical challenges. Advance care planning (ACP) discussions likely warrant ageappropriate adaptation, yet, there is little Australian research data available to inform best practice for this group. The results of this study indicate that end-of-life care preferences for this unique cohort may differ from those of the adult population and need to be captured and understood. An ACP document incorporating a discussion regarding goals of care, preferred location of care, preference for place of death, and consent to future intervention, including cardiopulmonary resuscitation and prompts for review, could assist in pursuing this objective. <a href="https://goo.gl/M42De4">https://goo.gl/M42De4</a>

Noted in Media Watch 30 January 2017, #497 (p.8):

 CANCER NURSING | Online – 20 January 2017 – 'Refinement of a conceptual model for adolescent readiness to engage in end-of-life discussions.' Understanding the dynamic process of readiness for engaging in end-of-life preparedness provides clinician insight for guiding discussions that facilitate shared decision making and promote quality of life for adolescents and their families. <u>https://goo.gl/mm4k4z</u>

# Research priorities in subspecialty palliative care: Policy initiatives

JOURNAL OF PALLIATIVE MEDICINE, 2017;20(8):813-820. Palliative care (PC) demonstrably improves quality of life for the seriously ill in a manner that averts preventable health crises and their associated costs. Because of these outcomes, PC is now broadening its reach beyond hospitals, and hospice care for those near death, to patients and their families living in the community with chronic multi-morbidities that have uncertain or long expected survival. In this article, the authors address research needed to enable policies supportive of PC access and quality, including changes in regulatory, accreditation, financing, and training approaches in the purview of policy makers. <a href="https://goo.gl/oWRi3w">https://goo.gl/oWRi3w</a>

Noted in Media Watch 5 December 2016, #490 (p.8):

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(6):290-293. 'Does current U.K. research address priorities in palliative and end-of-life care?' Published in 2015, the Palliative & End-of-Life Care Priority Setting Partnership (PeolcPSP) report is being used to guide research funding. This project highlights that research spending in palliative and end-of-life care (P&EoLC) remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in P&EoLC. The number one PeolcPSP priority – how to provide palliative care out of hours – is one of the questions most in need of further research investment. Of the 83 questions, 19 are not addressed by any directly related research funding active in 2014.

**N.B.** Access to the journal requires a subscription. Contents page for the November/December 2016 issue: <u>https://goo.gl/gGVJCP</u>



# Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <a href="http://goo.gl/5CHoAG">http://goo.gl/5CHoAG</a>

## A proposed framework of supportive and palliative care for people with high grade glioma

*NEURO-ONCOLOGY* | Online – 27 July 2017 – Patients with high-grade malignant glioma (HGG) have significant supportive and palliative care (PC) needs yet few tailored guidelines exist to inform practice. This study sought to develop a HGG framework of supportive and PC informed by patient, family and health care professional reported needs. Key principles guiding framework development [identified in this study] were that care: 1) Aligns with patient/family caregiver needs according to illness transition points; 2) Involves continuous monitoring of patient/family caregiver needs; 3) Be proactive in response to anticipated concerns; 4) Includes routine bereavement support; and, 5) Involves appropriate partnership with patients/families. Framework components and resulting activities designed to address unmet needs were enacted at illness transition points and included: coordination, repeated assessment, staged information provision according to the illness transition, proactive responses and referral systems, and specific regular enquiry of patient's and family caregivers' concerns. <u>https://goo.gl/ZRZ2xJ</u>

Noted in Media Watch 12 June 2017, #516 (p.11):

THE LANCET ONCOLOGY, 2017;18(6):e330-e340. 'European Association for Neuro-Oncology guidelines for palliative care in adults with glioma.' A multidisciplinary task force undertook a systematic review of the available scientific literature to formulate the best possible evidence-based recommendations for adult patients with glioma, with the aim to reduce symptom burden and improve the quality of life of patients and their caregivers, particularly in the end-of-life phase. <a href="https://goo.gl/A8efeV">https://goo.gl/A8efeV</a>

Noted in Media Watch 28 July 2014, #368 (p.8):

 JOURNAL OF NEURO-ONCOLOGY | Online – 20 July 2014 – 'End-of-life care in high-grade glioma patients in three European countries: A comparative study.' In The Netherlands, Austria and the U.K., respectively, patients most often died at home (60%), in a hospital (41%) or hospice (41%). Advance directives were present in 46% of Dutch, 36% of British and 6% of Austrian patients. Fifty-three percent of patients experienced good quality of care, irrespective of country. <a href="https://goo.gl/nkNTGk">https://goo.gl/nkNTGk</a>

### Benefits of, and barriers to, family-witnessed resuscitation in practice

*NURSING STANDARDS*, 2017:31(49):47-51. Family-witnessed resuscitation is not common practice in healthcare settings, despite its well-documented benefits. Lack of implementation arises because of fear and anxiety among healthcare practitioners about the potential negative consequences for the patient, the family and themselves. However, research has suggested that addressing these concerns could positively affect practice and increase the number of cases of family-witnessed resuscitation. <u>goo.gl/6b7c9j</u>

Noted in Media Watch 3 July 2017, #519 (p.8):

TRENDS IN ANAESTHESIA & CRITICAL CARE | Online – 23 June 2017 – 'Family presence during resuscitation: A concise narrative review.' Studies have shown that nursing staff are more supportive of family presence during resuscitation (FPDR) than physicians are. Physicians, who do not often support FPDR, believe that FPDR may interfere with resuscitation, may induce psychological trauma, or be the object of legal repercussions. Currently, several international organizations have published statements and guidelines supporting FPDR. Studies investigating FPDR contain various methodological flaws meaning it is difficult to make any definite conclusions. <a href="https://goo.gl/mEzDkp">https://goo.gl/mEzDkp</a>

**N.B.** Additional articles on family presence during cardiopulmonary resuscitation are noted in the 1 May 2017 issue of Media Watch (#510, p.8).

#### Related

JOURNAL OF PALLIATIVE MEDICINE | Online – 31 July 2017 – 'Wanted and unwanted care: The double-edged sword of partial do-not-resuscitate orders.' The interpretation of do-not-resuscitate orders (DNRs) may vary in non-arrest situations. To reduce ambiguity, many hospitals allow patients to elect partial DNRs. The authors investigated the effect of partial DNRs on physicians' willingness to perform cardiopulmonary resuscitation (CPR) and non-arrest procedures. The findings of this study suggest an ongoing need to develop better means of incorporating patients' goals of care into orders that more faithfully guide care for both non-arrest and arrest situations. <u>https://goo.gl/3fFBBu</u>

# Indian Council of Medical Research issues draft consensus document on definitions of terms used in limitation of treatment and providing palliative care at end of life

PHARMABIZ.COM | Online - 2 August 2017 -The Indian Council of Medical Research's initiative holds significance as there has been a considerable evolution of terminology pertaining to this area of healthcare over the past three decades. One fundamental barrier to proper end-oflife care (EoLC) in India is the lack of clarity on several terms that are often mistaken for euthanasia. So, these terms relating to treatment limitation and EoLC need to be brought up-to-date to facilitate discussion, preparation of guidelines and framing of laws. The purpose of this document is very relevant as in most of the hospitals in India, patients are subjected to painful inappropriate life sustaining interventions, while in U.S. and in Europe withdrawal of inappropriate life-sustaining interventions preceded death in up to 90% of deaths in intensive care units. In India, it has been reported from very few centres, where withdrawal of inappropriate lifesustaining interventions preceded death in 22-49% of deaths. Anticipatory directives and advance care planning are non-existent and patients are not referred to palliative care for symptom management and EoLC. Family and caregivers of the deceased patients feel that the patients at end of life have poorly controlled symptoms and distress. Health related communication is incompletely delivered and most hospitals do not have trained healthcare providers equipped to provide EoLC. <u>https://goo.gl/ek8BxK</u>

# INDIAN JOURNAL OF MEDICAL ETHICS

A recent issue of the *Indian Journal of Medical Ethics,* noted in the 8 February 2016 issue of Media Watch (#448, p.14), includes several articles that offer insight into the complexities of end-of-life care in India from an ethical, legal and medical perspective. Contents page (scroll down to 'Theme: Healing & Dying with Dignity'): <u>https://goo.gl/XKpm86</u>

# End-of-life care for immigrants in Germany. An epidemiological appraisal of Berlin

*PLOS ONE* | Online – 1 August 2017 – Immigrants are underrepresented in the hospice and palliative care (PC) institutions of Berlin. Despite this, a need for services exists as immigrants on average make use of care younger than non-immigrants. In this regard, the Turkish immigrants in particular are hardly found, despite being the largest immigrant population in Germany. The results of this study should prompt research on Turkish immigrants, in regards to barriers to access. In the comparison of the kinds of institutions, one sees a decline between the PC wards and the outpatient hospice services, in which immigrants hardly access. Apparently, the PC wards appear to be a smaller hurdle for utilization, which could give them the character of a "door opener" to HPC for immigrants. The high uptake of the only intercultural hospice service in Berlin shows the acceptance of this form of care by immigrants. The data presented in this study should also give rise to an urgency of action, for it shows a non-existent, or non-demonstrable, "healthy immigrant effect" of the first generation of work immigrants represent, is a key role in the efforts to provide adequate and fair access to end-of-life care for all people in Berlin. https://goo.gl/UoBav7

Noted in Media Watch 26 June 2017, #518 (p.13):

ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE | Online – 14 June 2017 – 'Considering diversity in nursing and palliative care – the example of migrants.' Currently, one fifth of the population in Germany is considered to be of immigrant origin. Healthcare needs of immigrants are often not sufficiently taken into account by healthcare institutions. This may result in many barriers encountered by immigrants in the healthcare system, which may affect the utilization and quality of care. These barriers are particularly pronounced in nursing and palliative care. <a href="https://goo.gl/odVvvu">https://goo.gl/odVvvu</a>

N.B. German language article.



Media Watch: Behind the Scenes http://goo.gl/XDjHxz

#### End-of-life care in the U.S.

# Toward improving quality of end-of-life care: Encoding clinical guidelines and standing orders using the Omaha system

*WORLDVIEWS ON EVIDENCE-BASED NURSING* | Online – 29 July 2017 – A growing body of research has led to the creation of several evidence-based clinical guidelines for end-of-life care (EoLC). As evidence for the effectiveness of timely EoLC swells, so does the increased need for efficient information exchange between disciplines and across the care continuum. Four evidence-based clinical guidelines and one current set of hospice standing orders were encoded using the Omaha System Problem Classification Scheme and Intervention Scheme, as well as Systematized Nomenclature of Medicine-Clinical Terms. The resulting EoLC guideline consists of 153 interventions that may enable patients and their surrogates, clinicians, and ancillary providers to communicate interventions in a universally comprehensible way. <a href="https://goo.gl/X8Wjtv">https://goo.gl/X8Wjtv</a>

### Assisted (or facilitated) death

Representative sample of recent journal articles:

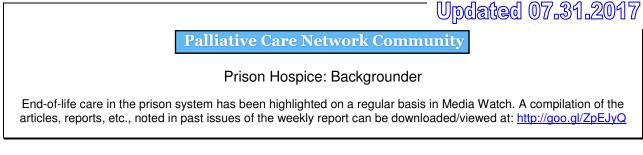
• AMA JOURNAL OF ETHICS, 2017;19(8):802-814. 'Should euthanasia be considered iatrogenic?' Euthanasia could be viewed as iatrogenic insofar as it results in an outcome (death) that some might consider inherently negative. However, this perspective fails to acknowledge that death, the outcome of euthanasia, is not an inadvertent or preventable complication but rather the goal of the medical intervention. Conversely, the refusal to engage in the practice of euthanasia might be conceived as iatrogenic insofar as it might inadvertently prolong patient suffering. <u>https://goo.gl/BhsyVZ</u>

# Worth Repeating

### "This is our last stop"

### Negotiating end-of-life transitions in assisted living

JOURNAL OF AGING STUDIES, 2014;(30):1-13. Assisted living (AL) increasingly is becoming a site of end-of-life care (EoLC) and a place where people die. AL residents are moving in older and sicker and with more complex care needs, yet AL remains largely a non-medical care setting that subscribes to a social rather than a medical model of care. The authors present a model for how EoLC transitions are negotiated in AL that depicts the range of multilevel intersecting factors that shape end-of-life (EoL) processes and events in AL. Facilities studied developed an EoL presence, which varied across and within settings depending on multiple influences, including, notably, the dying trajectories and care arrangements of residents at EoL, the prevalence of death and dying in a facility, and the attitudes and responses of individuals and facilities toward EoL processes and events, including how deaths were communicated and formally acknowledged and the impact of death and dying on the residents and staff. Findings indicate, in the majority of cases, EoLC must be supported by collaborative arrangements of care partners and that hospice care is a critical component. [Noted in Media Watch 7 April 2014, #352 (p.10)] https://goo.gl/a3hzYj



# 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, research and teaching tool.

### **Distribution**

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4. Access to a complete article, in some cases, may require a subscription or one-time charge.

5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

**6.** Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

#### Something Missed or Overlooked?

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

# Media Watch: Online

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/nZMuK7

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK COMMUNITY: <a href="http://goo.gl/8JyLmE">http://goo.gl/8JyLmE</a>

PALLIMED: <u>http://goo.gl/7mrgMQ</u> [Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/IXO4mD

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <u>https://goo.gl/JL3j3C</u>

#### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <u>https://goo.gl/BLgxy2</u> [Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <u>https://goo.gl/wGi7BD</u> [Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/IOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: <u>https://goo.gl/ds5wYC</u> [Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Cont.

### Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://goo.gl/o7kN3W</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1I9K

U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

# **Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8l



Barry R. Ashpole Guelph, Ontario CANADA <sup>6</sup>phone: 519.837.8936 e-mail: <u>barryashpole@bell.net</u>