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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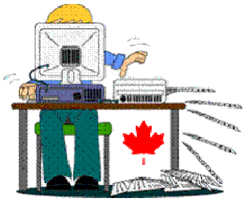

Compiled & Annotated by Barry R. Ashpole

"Never at ease" – Scroll down to Specialist Publications and 'Family carers within integrated palliative care: A multinational, mixed method study' (p.5), in *BMC Palliative Care*.

Canada

Ontario is courting a home-care fiasco

ONTARIO | *The Globe & Mail* (Toronto) – 1 March 2018 – Back in October, in a routine news release about home care funding, the Ontario provincial government made a passing reference to the creation of a new agency. Soon after, CBC journalist Mike Crawley obtained internal documents that revealed details of the new institution: Personal Support Services Ontario (PSSO) is going to recruit, train and employ personal support workers and provide care to a select group of home care clients. The agencies that provide home care were gobsmacked, and now they've taken legal action to prevent the government from following through on PSSO. In documents filed in court, a coalition of 11 not-for-profit and for-profit home care providers who, between them, provide 95% of home care services in the province, allege that the move "will have dire consequences for patients and their families, for service providers and their employees and for the home care and health care systems at large." At first blush, this looks like businesses protecting their turf. But the possibility that this could actually worsen patient care is worrisome. (The allegations in the lawsuit are unproven and the government has yet to file a legal response.) Ontario spends about $2.5-billion a year on publicly funded home care, providing care to about 700,000 patients. Most of them receive short-term services... A small and growing number of patients with complex chronic illnesses receive home care for years... https://goo.gl/6ZvFNk

Specialist Publications

'A case study exploring the implications of one Alberta rural community's experience with planning their own hospice care' (p.10), in *Journal of Rural & Community Development.*

N.B. Reports on Ontario's proposed Personal Support Services Ontario noted in the 13 November 2017 issue of Media Watch (#538, p.2).

Cont. next page

Noted in Media Watch 13 November 2017 (#538, p.2):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 8 November 2017 – **'The evolving role of the personal support worker in home care in Ontario, Canada.'** A review of home-care service user charts indicate that normally personal support workers (PSWs) provide personal and supportive care commensurate with their training. However, in approximately one quarter of care plans reviewed, PSWs also completed more complex care activities transferred to them by regulated health professionals. Although there is potential for the expansion of home-care services through increased utilisation of PSWs, healthcare leadership must ensure that the right provider is being utilised at the right time and in the right place to ensure safe and effective quality care. **Abstract:** https://goo.gl/hhUVbq

U.S.A.

Never too late to operate? Surgery near end of life is common, costly

KAISER HEALTH NEWS | Online – 28 February 2018 – Nearly 1 in 3 Medicare patients undergo an operation in the year before they die, even though the evidence shows that many are more likely to be harmed than to benefit from it. The practice is driven by financial incentives that reward doctors for doing procedures, as well as a medical culture in which patients and doctors are reluctant to talk about how surgical interventions should be prescribed more judiciously, said Dr. Rita Redberg... "We have a culture that believes in very aggressive care," said Redberg, who at the University of California-San Francisco specializes in heart disease in women. "We are often not considering the chance of benefit and chance of harm, and how that changes when you get older. We also fail to have conversations about what patients value most." While surgery is typically lifesaving for younger people, operating on frail, older patients rarely helps them live longer or returns the quality of life they once enjoyed... The cost of these surgeries – typically paid for by Medicare, the government health insurance program for people over 65 – involve more than money, said Dr. Amber Barnato, a professor at the Dartmouth Institute for Health Policy & Clinical Practice. Older patients who undergo surgery within a year of death spent 50% more time in the hospital than others, and nearly twice as many days in intensive care. https://goo.gl/9UoxyB

Specialist Publications

'Aggressive care and palliative care' (p.5), in *American Journal of Critical Care.*

'End-of-life care for unauthorized immigrants in the U.S.' (p.10), in *Journal of Pain & Symptom Management.*

'Can we talk about it now? Recognizing the optimal time to initiate end-of-life care discussions with older Chinese Americans and their families' (p.11), in *Journal of Transcultural Nursing.*

'Physician-assisted suicide and Midwest social workers: Where do they stand?' (p.14), in *Journal of Social Work in End-of-Life & Palliative Care.*

'Lawful physician-hastened death: American Academy of Neurology position statement' (p.14), in *Neurology.*

Noted in Media Watch 2 May 2016 (#460, p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 April 2016 – **'Surgeons' perspectives on avoiding non-beneficial treatments in seriously ill older patients with surgical emergencies: A qualitative study.'** Little is known about how surgeons formulate treatment decisions to avoid non-beneficial surgery, or engage in preoperative conversations about end-of-life care. Surgeons [i.e., study participants] reported performing operations they knew would not benefit the patient to give the family time to come to terms with the patient's demise. They identified multiple factors that undermine adequate communication and lead to non-beneficial surgery. **Abstract:** http://goo.gl/kNrt2N

Alabama House passes Alex Hoover bills for terminally ill students

ALABAMA | Al.com (Birmingham) – 26 February 2018 – Legislation affecting end-of-life (EoL) medical care for terminally ill children and how that care would apply to children at school won overwhelming approval in the Alabama House of Representatives. The legislation is named after Alex Hoover of Athens, who died last year after striving to attend East Limestone High School with a terminal heart ailment. Alex's mother, Rene Collins, advocated for the legislation as a way to help terminally ill children like Alex attend school with medical orders that they would not receive certain life-sustaining medical interventions. Republican Representative April Weaver ... sponsored the two bills... Weaver's first bill would create a task force that would help the Department of Public Health develop a form for a palliative and EoL care order for minors. Parents of a terminally ill child could work with their doctors to write the EoL care orders. Weaver's second bill calls for development of palliative and EoL individual health plans for terminally ill children in school. It would create a task force that would advise the state Board of Education on the development of those individual health plans. https://goo.gl/grCJkt

> **N.B.** Additional articles regarding the Alex Hoover case noted in the 21 August 2017 issue of Media Watch (#526, p.3).
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> Noted in Media Watch 5 September 2016 (#478, p.17):
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> - *PEDIATRIC CLINICS OF NORTH AMERICA*, 2016;63(5):899-911. **'Integrating pediatric palliative care into the school and community.'** The needs of children with complex chronic conditions exist both in a health care context and in the community where children interact with peers, including school, places of worship, sports, activities and organizations. Partnerships between pediatric palliative care professionals and teachers, coaches, spiritual leaders, activity directors, and others, may lead to greater health and well-being. Children near the end of life or those with out-of-hospital do-not-resuscitate orders may also find palliation in their community. **Abstract:** http://goo.gl/wpZI26

Failing to tell patients that nothing will help may only make them suffer more

THE WASHINGTON POST | Online – 26 February 2018 – Why is it so hard to tell chronically ill patients that further treatment is futile – that it might erode their quality of life without making a difference in their life expectancy? Surgeons do it indirectly when they declare a patient "inoperable," a determination of futility that people generally accept, maybe because the harm of ineffective surgery is so obvious that it can't be avoided. But a physician dealing with patients who have advanced chronic diseases doesn't have such clear-cut negative certainties to rely on, especially when patients make such broad inquiries as "Doctor, isn't there anything else that you can do – that might possibly help?" In many cases the answer is, technically, "yes," when practically speaking it is "no, not really." Such treatment will give the impression that something is being done, but it will not have curative or even significant results that simultaneously improves quality while prolonging life. The most widely recognized example of futile treatment that makes this distinction is tube feeding a brain-dead patient. https://goo.gl/3ta1GG

Opioid limits hit hospice, cancer patients

OREGON | *The Bulletin* (Bend) – 24 February 2018 – New strategies to rein in the overprescribing and misuse of opioid pain medications have almost universally excluded patients with end-of-life or cancer pain from those limits. But doctors treating such patients are increasingly reporting challenges getting medications for patients who truly need them. St. Charles Bend has experienced sporadic shortages of intravenous morphine and intravenous hydromorphone ... over the past year. The supply of morphine and Dilaudid has been affected by the hurricane that hit Puerto Rico in September as well as the flooding in Texas that shut down production facilities several weeks earlier. Additionally, concerns about the oversupply of opioids prompted federal officials to limit manufacturing in 2017 and 2018. That may have left little excess capacity to overcome the unexpected production shutdowns. https://goo.gl/7nZUnC

> **N.B.** Additional articles on the consequences of stricter controls on opioid use in the U.S., in the context of hospice and palliative care, noted in the 19 and 12 February 2018 issues of Media Watch (#551, p.4, and #550, p.4, respectively).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | Sky-Hi News (Grand County) – 2 March 2018 – **'69 Coloradoans seek assisted suicide in first year of program.'** Colorado voters approved an Access to Medical Aid in Dying proposition in 2016 which allows eligible terminally ill individuals with a prognosis of six months or less to live the option to request and self-administer life ending medication. The act also authorizes physicians to prescribe the medical aid-in-dying medication, and creates criminal penalties for tampering or coercing someone to request the medication. In 2017, 69 patients received prescriptions for the medication... Of those 69 individuals, the Colorado Department of Public Health & the Environment (CDPHE) received reports that the medication had actually been dispensed to 50 individuals. CDPHE received death certificates for 56 patients through vital records registration, though not all of the deceased patients were necessarily dispensed the medication, bringing up some interesting nuances of the law. The Colorado End-of-Life Options Act does not authorize CDPHE to follow up with physicians who prescribe the medication, patients or their families to obtain information about the use of the medication. The act also requires by law that the cause of death assigned on a patient's death certificate be the underlying terminal illness. In other words, the state doesn't know exactly how many people took the medication, only that 50 individuals could have. https://goo.gl/vxWT8V

International

End-of-life care in Australia

National palliative care standards

AUSTRALIA | Palliative Care Australia – 27 February 2018 – The association has published the fifth edition of the 'National Palliative Care Standards' and also the 'Palliative Care Service Development Guidelines,' the first revision of the two documents since 2005. They are designed to complement the work being undertaken by the Commonwealth of Australia (i.e., the federal government) to update the National Palliative Care Strategy, due to be released later in 2018. **Download/view at:** https://goo.gl/iGbEmF and https://goo.gl/yxqdDW, respectively.

Specialist Publications

'Facilitation of an end-of-life care programme into practice within U.K. nursing care homes: A mixed-methods study' (p.8), in *International of Nursing Studies.*

'The Liverpool Care Pathway for the Dying Patient: A critical analysis of its rise, demise and legacy in England' (p.13), in *Wellcome Open Research.*

N.B. National Palliative Care Strategy 2010, Department of Health, Government of Australia. **Download/ view at:** https://goo.gl/b3hKvn

Irish prison chiefs denied dying Midlands inmate a hospital transfer

IRELAND | *The Times* – 26 February 2018 – The prison watchdog has called for terminally ill prisoners to be released to die in a more appropriate setting. Helen Casey, acting inspector of prisons, said that the issue should be treated as a priority and that new laws should be brought in if necessary. The recommendations follow her report into the case of a 68-year-old terminally ill patient who was refused release for almost three weeks after a doctor asked for him to be moved to a specialist unit. In her report, Ms. Casey argued a prison environment was not suitable for someone requiring palliative care. Before his death on 16 May, the inmate in the Midlands Prison in Portlaoise was refused full temporary release twice by the Irish Prison Service. https://goo.gl/9EGDX5

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OFFICE OF THE INSPECTOR OF PRISONS

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 February 2018) can be downloaded/view at Palliative Care Network-e: https://goo.gl/YLckx6

Specialist Publications

Aggressive care and palliative care

AMERICAN JOURNAL OF CRITICAL CARE, 2018;27(2):84-86. Differentiating palliative care (PC) from end-of-life (EoL) care is important ... because failing to distinguish between the two may lead clinicians to overlook ongoing PC needs during critical illness. PC can be provided concurrently with aggressive care; it need not be initiated only at the EoL. PC can contribute to symptom management at every stage of serious illness, and it is not restricted to those who have a poor or terminal prognosis. It can and should be provided "for all ICU patients, from the time of admission, regardless of prognosis." It may be of particular importance for ICU patients who are receiving aggressive treatments that induce or exacerbate problematic symptoms; PC may mitigate these effects. Three models of PC have emerged: an integrated model, where the ICU team provides PC as a part of the ICU clinical care; an interdisciplinary specialty, where a PC consultant or team is responsible for directing PC; and a blended model. There are many examples of successful programs, and many resources are available to institute "PC bundles." The model and processes that work best for an individual unit will depend on institutional culture, resources, and PC skills. Ideally, every member of the interdisciplinary team should be involved in PC and have PC competencies. **Full text:** https://goo.gl/ZFWqhr

Related

- *POSTGRADUATE MEDICAL JOURNAL* | Online – 24 February 2018 – **'Futility and appropriateness: Challenging words, important concepts.'** The factors that drive non-beneficial treatments include personal biases, patient-related pressures and institutional imperatives. Breaking loose from the perceived necessity to deliver non-beneficial treatment is a major challenge. Curative intent should give way to appropriateness such that curative and palliative interventions are valued equally. Goals of treatment should be shaped by illness trajectory, the risk of harms as well as potential benefits and patient preferences. This strategy should be reflected in professional training and the design of acute services. **Abstract:** https://goo.gl/3H5S51

"Never at ease" – Family carers within integrated palliative care: A multinational, mixed method study

BMC PALLIATIVE CARE | Online – 1 March 2018 – Family carers manage a wide range of responsibilities in the lives and care of patients receiving palliative care. They fulfil multiple roles and perform activities within different settings. This has immediate consequences on family carers' every-day lives. According to literature, family carers in PC are both part of the formal and informal care network, but also persons in need of support. Family carers looking after patients with cancer, chronic obstructive pulmonary disease or chronic heart failure were recruited at 22 palliative care initiatives (IPC-i) in Belgium, Germany, Hungary, The Netherlands and the U.K. On average, data showed moderate burden, but the qualitative findings indicated that this burden might be underrated. There is some evidence that IPC-i with well-developed professional care networks and communication systems relieved family carers' burden by direct and indirect interventions; e.g., provision of night shift nurses or psychological support. Needs of family carers were similar in all participating countries. However, in all countries IPC-i mostly offered one-off events for family carers, lacking systematic or institutionalised support structures. The authors recommend recognizing family carers as part of the "unit of care" and partner in caregiving, to improve their knowledge about, and access to, and the support available. **Full text:** https://goo.gl/JzZpUo

Related

- *PALLIATIVE MEDICINE* | Online – 28 February 2018 – **'Who cares for the carers at hospital discharge at the end of life?'** Enabling successful discharge of palliative care patients to home and prevention of readmissions is a key issue for health services. To date, the focus of interventions to achieve this outcome has been on patients. This study shifts the focus ... of discharge planning to include whether and in what way the support needs of carers might be assessed and addressed during the transition to home care. It offers a new direction for intervention development for hospital discharge to improve support for carers over the transition to home and prevent breakdown of care at home which is often a cause of readmission of patients to hospital. **Full text:** https://goo.gl/GxLrzV

Use of health services in the last year of life and cause of death in people with intellectual disability: A retrospective matched cohort study

BMJ OPEN | Online – 25 February 2018 – A review of the research literature into the health of people with intellectual disability in comparison to the general population highlighted a cascade of disparities. The disparities are to some extent expected due to the serious and complex comorbid conditions that can co-occur with intellectual disability. However, many problems with access to healthcare have been documented, such as a lack of uptake of health-promoting activities and preventative care, inadequate healthcare in the community and problems with access to hospital care. These can in turn lead to exacerbation of conditions, particularly those that are ambulatory care sensitive, for which the institution of effective management and treatment could prevent the need for emergency presentation or hospital admission and contribute to a reduction in premature mortality in this population. **Full text:** https://goo.gl/bJYSLH

> **N.B.** Articles on palliative and end-of-life care for people living with intellectual disabilities noted in the 1 January 2018 issue of Media Watch (#544, pp.21-22).

Ethical decision-making climate in the ICU: Theoretical framework and validation of a self-assessment tool

BMJ QUALITY & SAFETY | Online – 23 February 2018 – Literature depicts differences in ethical decision-making (EDM) between countries and intensive care units (ICU). Of 3,610 nurses and 1,137 physicians providing ICU bedside care [in 13 European countries and the U.S.], 2,275 (63.1%) and 717 (62.9%) participated respectively [in this study]. Statistical analyses revealed that a shortened 32-item version of the Ethical Decision-Making Climate Questionnaire (EDMCQ) scale provides a factorial valid measurement of seven facets of the extent to which clinicians perceive an EDM climate: self-reflective and empowering leadership by physicians; practice and culture of open interdisciplinary reflection; culture of not avoiding end-of-life (EoL) decisions; culture of mutual respect within the interdisciplinary team; active involvement of nurses in EoL care and decision-making; active decision-making by physicians; and, practice and culture of ethical awareness. The 32-item version of the EDMCQ might enrich the EDM climate measurement, clinicians' behaviour and the performance of healthcare organisations. This instrument offers opportunities to develop tailored ICU team interventions. **Abstract:** https://goo.gl/HCBtW1

Noted in Media Watch 5 February 2018 (#549, p.14):

- *MONASH BIOETHICS REVIEW* | Online – 8 January 2018 – '**Expensive care? Resource-based thresholds for potentially inappropriate treatment in intensive care.**' While professional guidelines confirm that physicians are not always obliged to provide requested treatment, determining when treatment would be inappropriate is extremely challenging. One potential reason for refusing to provide a desired and potentially beneficial treatment is because (within the setting of limited resources) this would harm other patients. **Full text:** https://goo.gl/7fuApS

Noted in Media Watch 2 October 2017 (#532, p.8):

- *CRITICAL CARE MEDICINE* | Online – 21 September 2017 – **'Emotional impact of end-of-life decisions on professional relationships in the ICU: An obstacle to collegiality?'** This study suggests nurses' feelings toward their patients and physicians' feelings toward their patients' families influence the decisions they make. Although these emotional dimensions allow nurses and physicians to act in a manner that is consistent with their professional ethics, the professionals themselves seem to have a poor understanding of these dimensions and often overlook them... **Abstract:** https://goo.gl/k1N6JA

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.

Emerging methodologies in pediatric palliative care research: Six case studies

CHILDREN | Online – 26 February 2018 – Given the broad focus of pediatric palliative care (PPC) on the physical, emotional, and spiritual needs of children with potentially life-limiting illnesses and their families, PPC research requires creative methodological approaches. The authors describe issues encountered in their own areas of research and the novel methods they have identified to target them. Specifically, they discuss potential approaches to: assessing symptoms among non-verbal children, evaluating medical interventions, identifying and treating problems related to polypharmacy, addressing missing data in longitudinal studies, evaluating longer-term efficacy of PPC interventions, and monitoring for inequities in PPC service delivery. **Full text:** https://goo.gl/tg3egJ

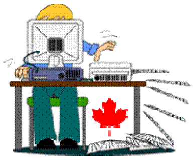
Related

- *HEALTH COMMUNICATION* | Online – 27 February 2018 – **'A time to live and a time to die: Heterotopian spatialities and temporalities in a pediatric palliative care team.'** The authors report on a long-term ethnographic study of a pediatric palliative care team (PPCT). Using the concepts of spatiality and temporality, Deleuze's concepts of smooth and striated spaces, Innis's concepts of space and time biases, Foucault's concept of heterotopian space – places with multiple layers of meaning, and, a related concept of heterokairoi – moments in time with multiple possibilities – they consider how the PPCT constructs and reconstructs meaning in the midst of chaos, ethical dilemmas, and heartbreaking choices. **Abstract:** https://goo.gl/sU2EHj

The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia

DEMENTIA, 2018;17(2):252-257. The Challenge Project has improved access to appropriate palliative, end-of-life care and other services for people with dementia and their families, with many now being referred earlier in their disease trajectory. It has led to self-reported improvements in the knowledge, confidence and care skills of family carers and acts as an important source of emotional and respite support for patients and families. In turn, it seems that the service has also enabled more patients to be cared for at home. By providing comprehensive training and education, and acting as a valued point of contact and advice, the Project has positively influenced the knowledge and practice of some local health and social care professionals, leading to earlier referrals, improved understandings, communication practices and more collaborative ways of working when caring for patients and families with dementia. This was a small-scale evaluation with associated limitations. The absence of baseline data on care planning made it difficult to determine the influence of the project on such outcomes, while the low numbers of survey responses limit the generalisability of results. Further research is needed to more rigorously assess the effectiveness and value of this service model in relation to: referral rates, place of care; uptake of care planning; patient and carer quality of life; the knowledge, confidence and skills of families and health and social care professionals and associated healthcare costs and savings. **Full text:** https://goo.gl/pS5DBJ

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in the 19 & 26 February 2018 issues of Media Watch (#551, pp.15-16 and #552, p.12, respectively).



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: http://goo.gl/5CHoAG

Facilitation of an end-of-life care programme into practice within U.K. nursing care homes: A mixed-methods study

INTERNATIONAL OF NURSING STUDIES | Online – 24 February 2018 – The predicted demographic changes internationally have implications for the nature of care older people receive and place of care as they age. Healthcare policy now promotes the implementation of end-of-life care (EoLC) interventions to improve care delivery within different settings. The Gold Standards Framework in Care Homes (GSFCH) programme is one EoLC initiative recommended by the English Department of Health. Only a small number of care homes that start the programme complete it, which raises questions about the implementation process. Three facilitation approaches were provided to nursing home staff [i.e., study participants] when implementing the GSFCH programme: "fitting it in" facilitation; "as requested" facilitation; and "being present" facilitation. "Being present" facilitation most effectively enabled the completion of the programme, through to accreditation. However, it was not sufficient to just be present. Without mastery and commitment, from all participants, including the external facilitator, learning and initiation of change failed to occur. Implementation of the programme required an external facilitator who could mediate multi-layered learning at an individual, organisational and appreciative system level. The cost savings in the study outweighed the cost of providing a "being present" approach to facilitation. **Abstract:** https://goo.gl/cJAj8A

Noted in Media Watch 26 February 2018 (#552, p.16):

- *JOURNAL OF RESEARCH IN NURSING* | Online – 15 February 2018 – **'Family perceptions of care at the end of life in U.K. nursing care homes.'** Over a fifth of the population of developed countries die in care homes. While studies are emerging on the outcomes of care in the last few weeks of life, few report on the experience as perceived by the family members. Qualitative responses from family members [i.e., participants in this study] highlighted some excellent care, although issues in relation to medical input, professional teamwork, last days of life, and spiritual care remain problematic. **Abstract (w. list of references):** https://goo.gl/jcZJY3

Recommendations from the Salzburg Global Seminar on rethinking care toward the end of life

INTERNATIONAL JOURNAL FOR QUALITY IN HEALTH CARE | Online – 2 March 2018 – In December 2016, 66 health leaders from 14 countries convened at the Salzburg Global Seminar (SGS) to engage in cross-cultural and collaborative discussions centered on 'Rethinking Care Toward the End of Life.' Conversations focused on global perspectives on death and dying, challenges experienced by researchers, physicians, patients and family caregivers. Featured sessions focused on critical issues of end-of-life care (EoLC) led by key stakeholders, physicians, researchers, and other global leaders in palliative care (PC). Sessions spanned across several critical themes including: patient/family/caregiver engagement, integrating health and community-based social care, eliciting and honoring patient preferences, building an evidence base for PC, learning from system failures, and delivering EoLC in low-resource countries. Sessions were followed by intensive collaborative discussions which helped formulate key recommendations for rethinking and ultimately advancing EoLC. Prominent lessons learned from SGS include learning from low-resource countries, development of evidence-based quality measures, implementing changes in training and education, and respecting the personal agency of patients and their families. This authors outline key aspects of EoLC that warrant explicit improvement through specific action from key stakeholders. **Abstract:** https://goo.gl/vgtemf

Noted in Media Watch 26 February 2018 (#552, p.8):

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2018;68(668):116-117. **'Population-based, person-centred end-of-life care: Time for a rethink.'** The way we care for people in the last chapter of their lives has been said to be a litmus test for our society. Lifespan now outstrips health span and, with increasing complexity, symptom burden, and rising mortality, the context of end-of-life care (EoLC) is changing and broadening. It is time for a new approach – a reframed, inclusive, big-picture population-based approach to EoLC to meet the challenges of the 21st century. **Introductory paragraph:** https://goo.gl/QkE6zE

The trade-offs when focusing on the mortality benefit

JAMA INTERNAL MEDICINE | Online – 26 February 2018 – There is growing evidence that patients have varying priorities at the end of their life. Some want to focus on maximizing their quality of life, whereas others focus on living longer. Current clinical practice prioritizes the latter. For example, most cardiac device trials use overall survival as the primary outcome, instead of quality-adjusted life years. What is left unsaid is that these mortality benefits often come at a cost: discomfort, loss of mobility, polypharmacy with its attendant adverse effects, procedural complications, device failure, or loss of functional status. **First page preview:** https://goo.gl/1KqCWo

Family caregivers' preparations for death: A qualitative analysis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 February 2018 – Many family caregivers are not prepared for the death of their family member or friend. Palliative care (PC) services tend to emphasise the patients' preparation for death rather than caregivers' preparation for, or living after, death. Caregivers' perspectives on anticipating and preparing for death are under-researched, despite preparation being associated with better bereavement outcomes. Sixteen family caregivers of people in receipt of PC participated in semi-structured, face-to-face interviews. Analysis yielded two overarching themes: 1) Here and now centred on the caregivers' focus on the multidimensional and all-consuming nature of caregiving for someone who is near death; and, 2) Negotiating the here/after described the tension the caregivers faced in vacillating between focusing on the care during the illness trajectory (here) and worries and plans for the future (after). The caregivers described the complexities of trying to prepare while feeling overwhelmed with demands of caregiving throughout an unpredictable illness trajectory. The caregivers in the present study were cognitively prepared, some were behaviourally prepared, but emotional preparedness was challenging. Services should not assume that all family caregivers are well-prepared for the death. Caregivers would likely benefit from the assessment and promotion of their death preparedness. **Abstract:** https://goo.gl/7dtGUx

Community perspectives of end-of-life preparedness

DEATH STUDIES | Online – 2 March 2018 –While death is a universal human experience, the process of planning for death can be difficult and may be avoided altogether. To understand community perspectives of end-of-life preparedness, the authors undertook a multi-method study exploring the experiences of 25 community members and 10 stakeholders engaged in end-of-life (EoL) planning. In addition, card sorting activities and focused discussions with 97 older adults were undertaken to highlight perspectives and needs. Overall, the participants perceived many benefits to being EoL prepared, however, few community members had engaged in formal planning. Key barriers include concerns about the accessibility and accuracy of information, discomfort when engaging in EoL conversations, and perceptions about the cost associated with engaging in formal legal or financial preparations. Areas for further research include the need for studies that capture the cultural dimensions of EoL planning and explores the implementation and evaluation of community-based interventions to improve preparedness. **Abstract:** https://goo.gl/kmRWWt

Noted in Media Watch 27 June 2016 (#468, p.12):

- *THE GERONTOLOGIST* | Online – 23 June 2016 – '**Preparedness for death: How caregivers of elders with dementia define and perceive its value.**' Only one third of caregivers interviewed were prepared for the death, and the majority who were prepared were enrolled in hospice. Five primary themes revealed ways that caregivers define various domains of preparedness: 1) Accepting reality; 2) Knowing death is near; 3) Getting your "house in order"; 4) Saying "what you need to say"; and, 5) Giving "permission" to die. **Abstract:** http://goo.gl/9wtJZe

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Noted in Media Watch 8 December 2014 (#387, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 December 2014 – '**Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents.**' Preparedness for death as a predictor of post-bereavement adjustment has not been studied prospectively. Little is known about pre-death factors associated with feeling prepared prior to the death of a loved one. CGs Family caregivers who reported feeling more prepared for the death experienced lower levels of complicated grief post-bereavement. **Full text:** https://goo.gl/b8tcwH

Noted in Media Watch 5 January 2009 (#78, p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMEN*T, 2009;37(1):3-12. '**Preparing family caregivers for death and bereavement.**' Life experiences such as the duration of caregiving/illness, advance care planning, previous experiences with caregiving or death, and medical sophistication all impacted preparedness, or the degree to which a caregiver is ready for the death and bereavement. Regardless of life experiences, however, all caregivers reported medical, practical, psychosocial, and religious/spiritual uncertainty. **Full text:** https://goo.gl/jFbMPD

End-of-life care for unauthorized immigrants in the U.S.

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 February 2018 – The notion of patients' rights is based on the Universal Declaration of Human Rights, which recognizes inherent human dignity and the equal and unalienable rights of all members of the human family to be universally protected irrespective of race, color, gender, language, religion, political or other opinion, national or social origin, property, birth, or other status. These fundamental human rights become particularly important to seriously ill patients as they are vulnerable due to the limitations imposed by their illness(es). **Abstract:** https://goo.gl/KwuA8E

N.B. Additional articles on unauthorized/undocumented immigrants in the U.S., in the context of palliative and end-of-life care, noted in the 18 December 2017 issue of Media Watch (#543, p.3).

End-of-life care in Canada

A case study exploring the implications of one Alberta rural community's experience with planning their own hospice care

JOURNAL OF RURAL & COMMUNITY DEVELOPMENT, 2018;13(1):1-12. There are major implications for rural health care when citizens are organizing themselves to plan and address their own community health care needs. This article describes how one community in rural Alberta, Canada, worked to plan for their rapidly increasing hospice care needs. Specifically, it explores the factors that both helped and hindered them as they grew from a handful of citizens to a highly organized incorporated organization over a period of several years. The results reinforce that communities are not simply "engaged" in such work but are actually leading the way in the planning, and delivering of social and health supports and services. Their story emphasizes the significant lack and neglect of needed healthcare in rural communities and shows, once again, how rural communities continue to do more with less by building on their own resources and capacities. This study advances understanding about how hospice care, a major health care service in high demand, is being provided by community members as a result of governments downloading health service planning onto the shoulders of local communities in the name of "community engagement." **Full text:** https://goo.gl/3aURCH

N.B. Postings on the Rural Ontario Institute website offer a perspective on end-of-life care in remote and rural communities: 1) 'End-of-life Care in Rural Communities' https://goo.gl/P4e4rn; and, 2) 'Survey: Urban vs. Rural Palliative Medicine' https://goo.gl/i5KcPZ. The latter was conducted in 2015 by the Canadian Medical Association.

Can we talk about it now? Recognizing the optimal time to initiate end-of-life care discussions with older Chinese Americans and their families

JOURNAL OF TRANSCULTURAL NURSING | Online – 24 February 2018 – Older Chinese Americans often defer end-of-life care (EoLC) discussions. Researchers sought to explore how to engage older Chinese Americans and their families in EoLC discussions and to understand the optimal timing to initiate such discussions. Interviews were conducted with community-dwelling older Chinese Americans, adult children, and clinicians. Older Chinese Americans and their families would discuss EoLC when introduced at "optimal times," which included after-triggering events (e.g., death of loved ones, fall accidents), changes in health status, or advanced age. Adult children are not expected to initiate EoLC discussions with their parents. Thus, culturally congruent health care that could better engage Chinese Americans in such discussions would be optimized by having clinicians proactively assess their patients' readiness and initiate such discussion at optimal times. **Abstract (w. list of references):** https://goo.gl/ZEJ74o

Creating a sense of security in palliative home care: Interviews with public health nurses

NURSING & PALLIATIVE CARE | Online – 2 March 2018 – The results [of this study] showed that it was important that the public health nurse (PHN) respected that they were a guest in the patient's home, where the patient decides. This is in line with previous research, which found that the PHN should have an understanding of what the home symbolises for the patient. In order to practice nursing at home, the PHN was required to accept the patient's lifestyle, culture and the way they have it at home. The PHN described the importance for creating a sense of security of the patient being able to decide where to be cared for at the end-of-life stage. It is consistent with research that the patient's autonomy should be respected at home, since there may be time to sit down in the patient's safe environment and thus increase the understanding of the patient. Care in the patient's home should be based on a caring science theory that the patient is at the centre of care and is an expert on herself. The daily life of the patient is important when care is given at home and must be taken seriously by the staff. Care becomes more personal when it occurs at home and more on the patient's terms, such that the PHN has to have increased consideration for patient self-determination and must support the patient's decision if the patient wants to be cared for in a hospital. The authors' experience is that relatives often experience the situation at home as insecure, which causes some patients to be cared for in hospital. It is important to be aware of this. **Full text:** https://goo.gl/kd6BA5

Not just things: The roles of objects at the end of life

SOCIOLOGY OF HEALTH & ILLNESS | Online – 26 February 2018 – While the study of objects in care contexts is an emerging research field, it is largely overlooked in end-of-life (EoL) care. Open individual interviews were conducted with 25 family members recruited from palliative in-patient and homecare units, as well as residential care facilities. The authors conceptualise the roles of objects as relating to temporality, transformations of the everyday, and care. Through analysis we offer two main insights, the first relating to interdependency between objects and people, and the second to the recognition of objects as simultaneously flexible and stable in this interdependent relationship. The capacity and challenge of objects as part of EoL care lies in their ability to encompass various viewpoints and relationships simultaneously. **Full text:** https://goo.gl/8BUhdU

Related

- *SANTE PUBLIQUE*, 2018;29(6):851-859. **'Palliative patients in home care: Care pathways and clinical features.'** The great majority of French people express their desire to receive palliative care (PC) at home. 817 patients receiving PC at home in the [Ile-de-France region in 2014] were included in the study. They were older, more often referred to hospital at home by a primary care physician, had shorter lengths of stay and more often died at home compared to patients without PC. PC patients mainly presented cancer and received frequent technical nursing care. The oldest patients more often presented neurodegenerative diseases, were less often transferred to hospital, and more often died at home compared to younger patients. **Full text (French language version):** https://goo.gl/rAhGkv

  N.B. English language version (full text): https://goo.gl/8NN2wj

Assessment of the wish to hasten death in patients with advanced cancer: A comparison of two different approaches

PSYCHO-ONCOLOGY | Online – 28 February 2018 – The Desire for Death Rating Scale (DDRS) and the short form of the Schedule of Attitudes toward Hastened Death (SAHD-5) are different approaches to assessing the wish to hasten death (WTHD). Both have clinical threshold scores for identifying individuals with a meaningfully elevated WTHD. However, the agreement between the two measures, and patient opinions about assessment of the WTHD, are unknown. The WTHD was assessed in 107 patients with advanced cancer using both the DDRS and SAHD-5. Patients were subsequently asked their opinion about this assessment. Correlation between scores on the SAHD-5 and the DDRS was moderate. The SAHD-5 identified 13 patients at risk of the WTHD, and the DDRS identified 6 patients with a moderate-high WTHD. Concordance between the DDRS and SAHD-5 in identifying individuals with an elevated WTHD was poor when using recommended cut-off scores..., but could be improved by using different thresholds. Only 4 patients regarded the assessment questions as bothersome, and 90.6% considered it important that healthcare professionals inquire about the WTHD. **Abstract:** https://goo.gl/R6yF4L

> **N.B.** Additional articles on the desire/wish to hasten death noted in the 9 October 2017 issue of Media Watch (#533, p.10).

The Catholic tradition on the due use of medical remedies: The Charlie Gard case

THEOLOGICAL STUDIES | Online – 23 February 2018 – The widely publicized British case of Charlie Gard became an international cause *célèbre* when the treating physicians petitioned the British courts to prevent the parents from taking their dying child to America where a physician held out promise of an unproven experimental therapy. The case became more sensationalized when the press reported that Pope Francis had intervened in the case against the position of the Vatican's Academy for Life on the appropriate response to a patient with a lethal genetic disorder for which there was no known treatment. A review of the centuries-long teaching of Catholic moral theology on care of the dying demonstrates that the pastoral concern of Pope Francis for the grieving parents did not signal a change in church teaching on the care of the dying patient or reveal a disagreement between Pope Francis and the Academy for Life's position on the appropriate care of Charlie Gard. **Abstract:** https://goo.gl/HyHQM8

Noted in Media Watch 1 January 2018 (#544, p.25):

- *MEDICAL LAW REVIEW* | Online – 15 December 2017 – **'Who knows best (interests)? The case for Charlie Gard.'** When baby Charlie Gard was diagnosed with a rare mitochondrial disease, his parents located a Professor of Neurology in the U.S. willing to provide nucleoside therapy which offered a theoretical chance of improvement and successfully raised £1.3 million through crowd funding. The decision that unproven therapy was contrary to Charlie Gard's best interests and that life-sustaining treatment should be withdrawn was devastating for his parents and difficult for their supporters to comprehend. **Abstract:** https://goo.gl/m5eFvN

> **N.B.** Additional articles/reports on the Charlie Gard case noted in the 13 November 2017 issue of Media Watch (#538, p.8).

Terminal illness and tourism: A review of current literature and directions for future research

TOURISM RECREATION RESEARCH | Online – 28 February 2018 – This research note explores the contributions of scholarly research into terminal illness and tourism. Through a review of previous health tourism research, the authors found very limited extant literature on tourism and life-threatening and terminal illness. Specific areas where research direction is needed include a reconceptualisation of health tourism to include notions of ill-health and its implications for the tourism industry; greater understanding of the lived experiences of travellers with life-threatening or terminal illness; and, consideration of the notion of care and the needs of those providing palliative care during travel. **Abstract:** https://goo.gl/iuxmf2

The Liverpool Care Pathway for the Dying Patient: A critical analysis of its rise, demise and legacy in England

WELLCOME OPEN RESEARCH | Online – Accessed 27 February 2018 – The Liverpool Care Pathway for the Dying Patient ("the LCP") was an integrated care pathway (ICP) recommended by successive governments in England & Wales to improve end-of-life care (EoLC), using insights from hospice and palliative care (PC). It was discontinued in 2014 following mounting criticism and a national review. The ensuing debate among clinicians polarised between "blaming" of the LCP and regret at its removal. The authors aimed to address three questions: 1) Why and how did the LCP come to prominence as a vehicle of policy and practice; 2) What factors contributed to its demise; and, 3) What immediate implications and lessons resulted from its withdrawal? The rapidity of transfer and translation of the LCP reflected uncritical enthusiasm for ICPs in the early 2000s. The subsequent LCP "scandal" demonstrated the power of social media in creating knowledge, as well as conflicting perceptions about end-of-life interventions. While the LCP had some weaknesses in its formulation and implementation, it became the bearer of responsibility for all aspects of National Health Service (NHS) EoLC. This was beyond its original remit. It exposed fault lines in the NHS, provided a platform for debates about the "evidence" required to underpin innovations in PC and became a conduit of discord about "good" or "bad" practice in care of the dying. It also fostered a previously unseen critique of assumptions within PC. In contrast to most observers of the LCP story who refer to the dangers of scaling up clinical interventions without an evidence base, the authors call for greater assessment of the wider risks and more careful consideration of the unintended consequences that might result from the roll out of new end-of-life interventions. **Full text:** https://goo.gl/yLSnYf

Establishing end-of-life boards for palliative care of patients with advanced diseases

WIENER KLINISCHE WOCHENSCHRIFT (Central European Journal of Medicine) | Online – 23 February 2018 – Interdisciplinary tumor board decisions improve the quality of oncological therapies, while no such boards exist for end-of-life (EoL) decisions. The aim of this study was to assess the willingness of hemato-oncological and palliative care (PC) professionals to develop and participate in EoL boards ... to establish an interdisciplinary and comprehensive care for the remaining lifetime of patients suffering from advanced incurable diseases. Staff from the interdisciplinary teams of all hemato-oncological and PC wards in Vienna were invited to anonymously participate in an online survey. 91% respondents reported a need to establish an EoL board; 63% expressed their willingness to actively participate; and, 25% were indecisive. 50% voted for an EoL board in the presence of the patients, and 36% voted for an EoL board in the absence of the patients. 64% stated that the development of an EoL board would be worthwhile, while 28% did not see enough resources available at their institutions. 61% voted for a centrally available EoL decision, and 31% supported an in-house-based documentation. 94% voted for the availability of an information folder about EoL care. **Full text:** https://goo.gl/1c8ttV

Voluntary stopping eating and drinking: A position paper of the Austrian Palliative Society

WIENER MEDIZINISCHE WOCHENSCHRIFT | Online – 27 February 2018 – In some cases terminally ill patients fear of prolonged dying and suffering can manifest itself in the voluntary refusal of food and fluids, aiming to accelerate the dying process. This represents a considerable area of conflict, because of the ethical responsibility to not aid a person's death, but also to respect a patients autonomy. There is a clear separation between an assisted suicide and following a patient's wishes. Not to accept the voluntary refusal of FVNF [i.e., the voluntary renunciation of food and fluid] would have to be considered as forced treatment of patients while they are capable of self-determination. Several symptoms associated with or caused by voluntary refusal of food and fluids do require palliative care. It is important to be aware that caring for dying patients refusing food and fluids and accepting their choice is not synonymous with assisted suicide. Rather is it part of medical and nursing care for patients during their dying-process. An interprofessional working group of the Austrian Palliative Society intends to shed light on the legal, ethical, medical and nursing related aspects concerning this subject of growing public and professional interest. **Abstract (w. list of references):** https://goo.gl/xoEx8j

> **N.B.** German language article. Selected articles on voluntarily stopping eating and drinking noted in the 29 January 2018 issue of Media Watch (#548, pp.11-12).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 1 March 2018 – **'Physician-assisted suicide and [U.S.] Midwest social workers: Where do they stand?'** Sixty-two social workers from Minnesota, Iowa, and Wisconsin completed an anonymous online survey. The results indicated that over one-half of the participants supported physician-assisted suicide (PAS) legislation... While there was a range of perceived preparedness for implementation, a majority felt moderately to very prepared. Professional and personal values as well as professional experience influenced their perceived preparedness. Few social workers had accurate awareness of PAS legislation in their state or had attended workshops/events for further education or as a policy advocate. To practice competently and advocate at all levels of practice, hospice and palliative care at end-of-life social workers' need to understand their own attitudes and values toward PAS and pursue additional education around this ethical issue. **Abstract:** https://goo.gl/v6wEKd

- *NEUROLOGY* | Online – 27 February 2018 – **'Lawful physician-hastened death: American Academy of Neurology position statement.'** In consideration of the Ethics, Law & Humanities Committee recommendations, the American Academy of Neurology (AAN) Board of Directors carefully deliberated this important issue, taking into account the evolving legal environment, all aspects of the ethical debate, the reported values of AAN members, and expectations of their adult patients dying of neurologic illness. Accordingly, the AAN has decided to retire its 1998 position on 'Assisted suicide, euthanasia, and the neurologist' and to leave the decision of whether to practice or not to practice lawful physician-hastened death (LPHD) to the conscientious judgment of its members acting on behalf of their patients. The Ethics, Law & Humanities Committee and the AAN make no attempt to influence an individual member's conscience in consideration of participation or non-participation in LPHD. Although the AAN endorses the belief that LPHD decision-making is ideally made within a well-established patient/doctor relationship, it places no obligation on its members to identify another physician willing to participate should their conscience preclude them from participation. The AAN remains opposed to member participation in euthanasia... **Full text:** https://goo.gl/b37aZo

- *RELIGIONS* | Online – 27 February 2018 – **'Religiosity and the wish of older adults for physician-assisted suicide.'** The goal of this study was to ascertain if religiosity could be a predicting factor of older adults' wish for physician-assisted suicide (PAS). A sample of 216 men and women over 60 years answered the following question: "Would you disagree or agree with assisted suicide for yourself if you were very sick and would die in the near future?" They also completed questionnaires on religiosity, ageism and death anxiety. A regression analysis showed that religiosity explained a significant proportion of the variance in the wish for PAS. Religiosity seems to reduce the likelihood that older adults would ask for PAS if they had a terminal illness, while ageism and death anxiety seemed to have the opposite effect. Health professionals and legislators must be aware that psychosocial and spiritual variables have an important influence on the wish for PAS. **Full text:** https://goo.gl/fpXBFK

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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Cont.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
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.

Worth Repeating

In defence of the "tick-box approach": Why end-of-life care is no exception

BRITISH JOURNAL OF GENERAL PRACTICE, 2016;66(647):290-291. The need for better training in palliative care is undeniable, and initiatives such as the General Medical Council's recently launched educational campaign around end-of-life care (EoLC) are extremely welcome.[1] However, improved training does not negate the need for accessible real-time guidance for practising clinicians. Examples such as the North of England Cancer Network's excellent 'Palliative and End-of-Life Care Guidelines for Cancer and Non-Cancer Patients' demonstrate that concise and specific, yet broad-reaching advice applicable to patients of varying diagnoses is indeed possible.[2] Documents such as these have the capacity to empower junior clinicians to give excellent care and indeed the Royal College of Physicians audit found that virtually all trusts had guidance on prescribing for the commonest end-of-life symptoms.[3] However a national discourse which is actively distancing itself from specific advice risks driving these useful resources further into the closet. Conversely, this sort of guidance needs to be given greater prominence, arguably by direct incorporation into clinical documentation, and to be standardised nationally to give consistent, quick access for junior doctors who move frequently between places of work: a set-up which begins to look rather similar to the former Liverpool Care Pathway (LCP). The LCP has gone, and nothing is gained in continuing to lament its passing. However, if it is true that it wasn't really broken in the first place, then trying to fix its perceived problems is likely to cause more harm than good. Rather than causing any recently documented improvements, the removal of protocols and tick-boxes from EoLC may have impeded even greater progress, where high standards can spread even to where expert support is sparse. [Noted in the 30 May 2016 issue of Media Watch (#464, pp.9-10)] **Full text:** http://goo.gl/MV5ext

Talking about death is not outrageous – reducing it to a tick box exercise is

BRITISH MEDICAL JOURNAL | Online – 29 August 2014 – Tick-box forms always insist on binary answers. But life is complicated and messy, and being ill, alone, or scared can make us vulnerable. Talking about death is not a bad thing to do, but when health professionals are driven by a policy designed to save money rather than serve patients, we hardly deserve our patients' trust. This is all part of the government's belief that the work of general practice – which has always included appropriately timed and careful talk of what we want to happen at the end of life – can be splintered off into disparate tasks and forms. Those services can then be contracted out to the cheapest short term provider. Why aren't we furious that our professional and vocational lives are being run on non-evidence based policy? [Noted in the 8 September 206 issue of Media Watch (#375, p.7)] **Full text:** http://goo.gl/SPMDWf

Cont.

1. ‘End-of-Life Care – Support, Work, Learn Together,’ General Medical Council, 2016. **Download/view:** http://goo.gl/1zNZEi

2. ‘Palliative and End-of-Life Care Guidelines for Cancer and Non-Cancer Patients,’ National Health Service North of England Cancer Network, 2012. **Download/view at:** http://goo.gl/PN35hi

3. ‘End of Life Care Audit – Dying in Hospital National Report for England 2016,’ Royal College of Physicians, May 2016. [Noted in the 9 May 2016 issue of Media Watch (#461, p.6)] **Download/view at:** https://goo.gl/x2qSih

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/C7qLhA

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

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ

[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’; see also ‘Media Watch: Behind the Scenes’ at https://goo.gl/6vdk9v]

Asia

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

[Scroll down to ‘Resource Collection’ and ‘Media Watch Barry Ashpole]

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

[Scroll down to ‘Are you aware of Media Watch?’]

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

[Scroll down to ‘Additional Resources’]

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/jjCHez

[January/February 2018 issue (Scroll down to ‘Paediatric palliative care; the patient’s voice’]

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

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

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