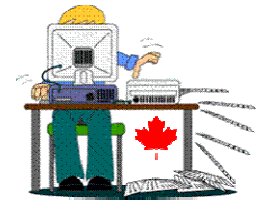


## Media Watch...

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

Meeting unmet needs: Scroll down to **Specialist Publications** and 'Under-resourced and under-developed family-centred care within palliative medicine' (p.9), in *Palliative Medicine*.

## Canada

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Montreal Gazette* – 23 February 2017 – '**Quebec opens door to expanding end-of-life law to Alzheimer's disease.**' A consensus is emerging among Quebec parliamentarians to launch a public debate on the appropriateness of legalizing medically assisted suicide for persons unable to give informed consent, such as patients suffering from Alzheimer's disease. The Quebec law on end-of-life care stipulates an eligible person who is considered in agony and suffering from an incurable disease must be clear-sighted and must give his or her consent to obtain medical assistance to shorten his or her life. Thus, people suffering from various forms of dementia, including Alzheimer's disease, are excluded. <https://goo.gl/mdAth1>

### Specialist Publications

'Engaging with patients who desire death: Interpretation, presence, and constraint' (p.10), in *Canadian Oncology Nursing Journal*.

## U.S.A.

### Doctor takes death education to high school classrooms

CALIFORNIA | National Public Radio – 25 February 2017 – Obviously, in our line of work, we value people who can lead difficult conversations. And one of the most difficult has to be talking about death. But that's become Dr. Jessica Zitter's life work. She's a clinical and palliative care specialist at Highland Hospital in Oakland, California. Working in intensive care, Dr. Zitter was often confronted with the sick and dying, and she began to notice that when patients died, everybody involved – family, friends, the patients themselves – were often woefully unprepared. So Dr. Zitter decided to try to open up the conversation about death and dying to make it easier to talk about. She's written about her experiences in the ICU for *The New York Times* and *The Atlantic*, and now she's taking the subject into high school classrooms. Last month, she made her first presentation about death to a group of ninth-graders in Oakland, and she's been invited back. <https://goo.gl/496EbZ>

Cont.

## Selected articles on including the topic of dying and death into the school curriculum

- U.S. (Hawaii) | KITV 4 News (Honolulu) – 10 February 2015 – **‘Iolani School offers hospice course to students.’** As a teacher, Bob Kane began pondering ways he could use the subjects of death and terminal illness to boost the self-esteem of his students. He devised a year-long hospice course where students could be trained in caring for those facing life-limiting illnesses. [Noted in Media Watch 23 February 2015, #398 (p.4)] <http://goo.gl/gSVu3K>
- U.S. (Minnesota) | *International Falls Daily Journal* – 29 October 2011 – **‘The journey from life to death: Students participate in end-of-life simulation.’** After learning about hospice in the community, Rainy River Community College students were given 12 pieces of paper on which they wrote the names of three important people in their lives, three prized possessions, three favorite activities and three attributes about themselves of which they were most proud. After being told they had a life-threatening illness with six months to live, they were given thirty seconds to rip up three pieces of paper, signifying things they had to give up. Later, one-by-one, they had torn up all their papers except two. The exercise is intended to show students when your life is ending, you can’t always control what you lose first. [Noted in Media Watch 31 October 2011, #225 (p.3)] <http://goo.gl/cr7w5K>
- THE NETHERLANDS | TheAge.com.au – 14 February 2007 – **‘Lesson in life and death: Pupils build dying teacher’s coffin.’** Eri van den Biggelaar has just a few weeks to live after being diagnosed with an aggressive form of cervical cancer. She asked the woodwork teacher, a friend, to build a coffin for her. “Why don’t you let the children make it?” he replied. Now pupils ... have been helping with the finishing touches. “Life and death belong together,” van den Biggelaar said. “The children realised that when I explained it to them. I didn’t want to be morbid about it; I wanted them to help me. None of the children considered it creepy ... and nobody felt traumatised. Parents of the children involved all gave their consent. [Noted in Media Watch 8 August 2011, #213 (p.9, under ‘Worth Repeating’)] <http://goo.gl/6R3T11>

## End-of-life registry helps patients die at home

WEST VIRGINIA | West Virginia Public Broadcasting (Charleston) – 21 February 2017 – Most Americans say they want to die at home. But without the right paperwork, many end up living out their final days in institutions or hospitals. The West Virginia e-Directive Registry is trying to change that. The registry includes advanced directives, living wills, medical orders and do not resuscitate cards. These documents help medical providers understand West Virginians’ end-of-life wishes, including where participants want to die and what kind of treatment they want in their last days of life. In 2016, nearly half those who participated in the registry died at home compared to 36% state-wide... The issue is also an economic one. The average cost per patient per day in a hospital step-down unit is almost \$8,000 compared to \$180 a day for in-home hospice care... More than 4,000 registry participants died in 2016, which saved \$45 million on health care charges at the end of life. <https://goo.gl/9CzoTw>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ARIZONA | *The Arizona Republic* (Phoenix) – 22 February 2017 – **‘Will Arizona let doctors ignore dying wishes of your loved ones?’** Senate Bill 1439 ... would protect from discrimination a health-care provider that refuses to participate in any service or provide any item that results in the death of an individual. It would apply to individuals, such as doctors or nurses, and entire medical facilities. The bill now moves to the House after a 17-13 party-line vote... Center for Arizona Policy President Cathi Herrod said during a prior hearing on the bill that it would allow healthcare providers to decide what action they feel violates their religious beliefs. That lack of specificity has raised concerns that doctors or nurses may refuse to carry out an individual’s end-of-life instructions, which could include not performing life-saving CPR or not inserting a breathing tube, ceasing food or water, or increasing some medications. <https://goo.gl/iTja9R>

Cont.

- KAISER HEALTH NEWS | Online – 21 February 2017 – **‘Docs in Northwest tweak aid-in-dying drugs to prevent prolonged deaths.’** Two years after an abrupt price hike for a lethal drug used by terminally ill patients to end their lives, doctors in the Northwest are once again rethinking aid-in-dying medications – this time because they’re taking too long to work. The concerned physicians say they’ve come up with yet another alternative to Seconal, the powerful sedative that was the drug of choice under Death with Dignity laws until prices charged by a Canadian company doubled to more than \$3,000 per dose. It’s the third drug mixture recommended by the doctors whose medication protocols help guide decisions for prescribers in the six U.S. states where aid-in-dying is allowed. The first Seconal alternative turned out to be too harsh, burning patients’ mouths and throats, causing some to scream in pain. The second drug mix, used 67 times, has led to deaths that stretched out hours in some patients – and up to 31 hours in one case. <https://goo.gl/7kcU8N>

## International

### End-of-life care in Australia

**The solution to cutting the cost of aged care is as simple as offering a cup of tea, palliative care expert Dr. Julian Abel said**

AUSTRALIA (Australian Capital Territory) | *The Canberra Times* – 26 February 2017 – There is a promising solution to solve the burden of an ageing population on the Australian health system, and it’s as simple as offering someone a cup of tea. The “compassionate communities” approach, which started in Australia, is being touted as a success by U.K. palliative care expert Dr. Julian Abel who visited the national capital this week as part of a lecture tour. The initiative aims to foster stronger, healthier communities. While there have been plenty of similar prototypes in the past, this new model is the most promising yet. And the proof, Dr. Abel said, is in the pudding. In his hometown in south-west England, the model has reduced hospital emergency admissions by 30% across the population as a whole.<sup>1</sup> If implemented across the U.K. it could see a five to six per cent reduction in total health care cost, he said. The burden of ageing on the healthcare system is evident in the number of days “nursing home-type patients” occupied beds in Canberra Hospital. This rose 25% in the past financial year to more than 10,000 – a figure double that recorded just four years ago. <https://goo.gl/yzaKkF>

1. ‘Palliative care reimagined: A needed shift,’ *BMJ Supportive & Palliative Care*, published online 31 January 2016. [Noted in Media Watch 8 February 2016, #448 (p.7)] <http://goo.gl/XlxCkm>

### Specialist Publications

**‘Clinicians’ perspectives on advance care planning for patients with chronic kidney disease in Australia: An interview study’** (p.5), in *American Journal of Kidney Diseases*.

**‘Beyond cultural stereotyping: Views on end-of-life decision making among religious and secular persons in the U.S., Germany, and Israel’** (p.6), in *BMC Medical Ethics*.

**‘Factors associated with the decision-making process in palliative sedation therapy. The experience of an Italian hospice struggling with balancing various individual autonomies’** (p.6), in *Cogent Medicine*.

**‘Exploring the challenges of implementing palliative care in China’** (p.6), in *European Journal of Palliative Care*.

**‘A shorter average length of stay in a U.K. hospice – how is this happening?’** (p.7), in *European Journal of Palliative Care*.

**‘Developing a model for pharmaceutical palliative care in rural areas: Experience from Scotland’** (p.10), in *Pharmacy*.

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Noted in Media Watch 13 February 2017, #499 (p.3):

- AUSTRALIA | *Australian Ageing Agenda* – 10 February 2017 – ‘**Aged care providers central to community-led palliative care: Expert.**’ The “compassionate communities” movement aims to promote and integrate social approaches to dying, death and bereavement by building community capacity around end-of-life care and support. Not only does the model provide for more inclusive and person-centered palliative care, the experience in Europe has shown it also reduces unnecessary and costly hospital treatment. <https://goo.gl/Dc1YWY>

Noted in Media Watch 30 January 2017, #497 (p.12):

- UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE | Online – Accessed 28 January 2017 – ‘**Compassionate communities and their role in end-of-life care.**’ Given the need for support throughout all aspects of end-of-life care (EoLC), an emerging paradigm shift shows compassionate communities as a new standard for placing responsibility back in the community and promoting respectful and compassionate care. Development of Compassionate Communities promotes quality EoLC designed to meet the individualized needs of the dying as well as their caregivers. <https://goo.gl/rqQDj>

### **Thousands of Scots miss out on end-of-life palliative care**

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 24 February 2017 – Experts estimate that about 11,000 people in Scotland could have benefited from palliative care (PC) 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. The organisations said that measuring how many people had completed the plan provides evidence that people’s choices were adhered to and there was a greater likelihood of them having a “good death.” The Scottish Government has recently committed to ensuring that by 2021 everyone who needs PC should be provided with it. <https://goo.gl/5EEX2l>

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

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

#### **Dying patients forced to spend last days in hospital amid funding wrangles**

U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Telegraph* – 22 February 2017 – Elderly people are dying while hospitals and councils wrangle over who should take care of them, a survey of nurses shows. The research found that more than nine in 10 nurses had witnessed cases where dying patients remained needlessly in hospital because of delays agreeing funding to pay for their care. Studies suggest that nine in 10 people would prefer to die in their own home or in a hospice. But the poll of almost 1,000 nurses found 94% were aware of cases where delays in funding and community provision of care meant dying patients were forced to remain in hospital. Two in three of nurses polled by charity Marie Curie and *Nursing Standard* magazine said they did not have enough time to give dying patients high-quality care. <https://goo.gl/jpqj6U>

**N.B.** Download *Nursing Standard*/Marie Curie survey at <https://goo.gl/mxV7W7>.

#### **Related**

- U.K. (England) | *The Nuneaton Times* – 22 February 2017 – ‘**George Eliot Hospital’s cancer death figures reveal “lack of beds.”**’ A lack of hospice beds in the borough is one of the reasons why more people with terminal cancer are passing away at Nuneaton’s hospital compared to anywhere else in the country. The George Eliot Hospital has the highest number of people suffering from cancer dying on its wards compared to hospitals across the nation. <https://goo.gl/euddfc>

## Neath Port Talbot Council first in Wales to support terminally ill employees

U.K. (Wales) | *Business News Wales* – 21 February 2017 – Neath Port Talbot Council has become the first organisation in Wales to formally sign a voluntary charter which aims to secure the rights of workers diagnosed with a terminal illness. Led by the Trade Union Congress the ‘Dying to Work’ campaign is asking organisations to sign a charter which sets out an agreed process to support, protect and guide employees who have been given a terminal diagnosis. The charter recognises that terminal illness requires support and understanding and not additional and avoidable stress and worry. It also aims to give terminally ill workers security over the support they will receive following their diagnosis and recognises that safe and reasonable work can help maintain dignity, offer a valuable distraction and can be therapeutic in itself. Under the Charter employees will have the security of work, peace of mind and the right to choose the best course of action for themselves and their families which helps them through a challenging period with dignity and without undue financial loss. Supporting the campaign also aims to ensure that all employees battling terminal illness have adequate employment protection and have their death in service benefits protected for the loved ones they leave behind. <https://goo.gl/hRVEWz>

Noted in Media Watch 22 August 2016, #476 (p.6):

- U.K. (England | LocalGov – 18 August 2016 – ‘**First county to back Dying to Work campaign.**’ Nottinghamshire has become the first county council to sign up to a new charter helping employees with terminal illnesses stay in their job. The Trade Union Council’s Dying to Work Voluntary Charter gives employees a “protected period” in which they can not be dismissed from their role as a result of their terminal illness. <http://goo.gl/Y2Nlvu>

**N.B.** Additional articles on job protection for people living with a terminal illness are noted in Media Watch 28 March 2016, #455 (p.5).

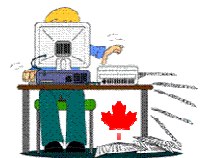
## Specialist Publications

### **Clinicians’ perspectives on advance care planning for patients with chronic kidney disease in Australia: An interview study**

*AMERICAN JOURNAL OF KIDNEY DISEASES* | Online – 16 February 2017 – Five major themes were identified: 1) Facilitating informed decision making (avoiding preconceptions, conveying complete truths, focusing on supportive care, and synchronizing with evolving priorities); 2) Negotiating moral boundaries (contending with medical futility and respecting patient vs family autonomy); 3) Navigating vulnerable conversations (jeopardizing the therapeutic relationship, compromising professional confidence, emotionally invested, and enriching experiences); 4) Professional disempowerment (unsupportive culture, doubting logistical feasibility, and making uncertain judgments); and, 5) Clarifying responsibilities (governing facilitation, managing tensions, and transforming multidisciplinary relationships). The tensions among themes reflect that advance care planning (ACP) is paradoxically rewarding for clinicians because ACP empowers patients yet can expose personal and professional vulnerabilities. Clinicians believe that a more collaborative approach is needed, with increased efforts to identify the evolving and individualized needs and goals of patients with chronic kidney disease. <https://goo.gl/C77KzR>

### 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>



## **Beyond cultural stereotyping: Views on end-of-life decision making among religious and secular persons in the U.S., Germany, and Israel**

*BMC MEDICAL ETHICS* | Online – 17 February 2017 – End-of-life decision making constitutes a major challenge for bioethical deliberation and political governance in modern democracies. On the one hand, it touches upon fundamental convictions about life, death, and the human condition. On the other, it is deeply rooted in religious traditions and historical experiences and thus shows great socio-cultural diversity. The bioethical discussion of such cultural issues oscillates between liberal individualism and cultural stereotyping. This paper confronts the bioethical expert discourse with public moral attitudes. As group discussions indicate, there are no clear-cut positions anchored in “nationality,” “culture,” or “religion.” Instead, attitudes are personally decided on as part of a negotiated context representing the political, social and existential situatedness of the individual. Therefore, more complex theoretical and practical approaches to cultural diversity have to be developed. <https://goo.gl/yA1eHj>

## **Factors associated with the decision-making process in palliative sedation therapy. The experience of an Italian hospice struggling with balancing various individual autonomies**

*COGENT MEDICINE* | Online – 13 February 2017 – The authors aimed to evaluate how the practice of palliative sedation therapy (PST) in a hospice setting has changed in a given period of clinical activity and which psychosocial factors have influenced it. They considered the prevalence of PST and the prevalence of some factors associated with the decision-making process in PST (e.g., awareness of death, impairment of cognitive function, discussion of sedation with physicians, etc.). Despite a downward trend in patients without awareness of death, the interlocutor of the decision-making process is always the caregiver... Furthermore, the probability that conscious sedation preceded deep sedation was significantly reduced when the principal interlocutor in the decision-making process was the caregiver. The weight of the decision-making of the patient seems to be relative to an awareness of the death process and the families' responsibility is a relevant aspect in advanced care planning. <https://goo.gl/KMWe3B>

**N.B.** English language article.

Noted in Media Watch 2 January 2017, #493 (p.19):

- *MINERVA ANESTESIOLOGICA* | Online – 22 December 2016 – ‘**Palliative sedation: The position statement of the Italian National Committee for Bioethics.**’ In January 2016 the Italian National Bioethics Committee published a position statement, ‘Deep and continuous palliative sedation in the imminence of death,’ related to the use of sedation and analgesia for relief from pain and psychological distress in dying patients. The Committee points out the clinical and ethical appropriateness of palliative sedation as a therapeutic procedure. <https://goo.gl/NLynP4>

## **Exploring the challenges of implementing palliative care in China**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(1):12-17. Uneven allocation of health resources, medical and cultural attitudes, and social and political factors make the speedier development of palliative care (PC) services in China highly challenging. PC in China is still in its infancy, which provides opportunities for developing innovative models of PC, obtaining policy and financial support, deepening global collaborations and promoting PC as an independent discipline. Professional training and more high-quality research in PC are needed in China. There is still a long way to go in China in promoting and furthering the implementation of PC for every patient and family in need. The first steps, perhaps, should be in staff training and raising public awareness of PC, death and dying.



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Noted in Media Watch 20 February 2017, #500 (p.6):

- CHINA | Sixth Tone (Shanghai) – 16 February 2017 – ‘**China issues first end-of-life care standards.**’ Thirty years after China’s first hospice center opened its doors in Beijing, the country’s top health authority has finally released a set of standards for palliative care. China’s end-of-life health care is desperately under resourced. In a country where 7 million people die each year, there are just 2,103 hospices and 289 nursing homes for dedicated palliative services. <https://goo.gl/iGyO7m>

### Reflections on ethical issues in palliative care for patients with heart failure



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(1):18-22. Advanced heart failure is a life-limiting condition and, although prognostic uncertainty is a concern, discussion of end-of-life issues should be integrated early in disease management, particularly because advances in heart failure treatment during the last three decades have led to further ethical issues. The European Association for Palliative Care Taskforce undertook a review, presented here, to consider the complex ethical issues in the palliative care (PC) of people with advanced heart failure, incorporating a multidisciplinary perspective and including cardiologists, PC experts and ethicists from various European countries.

### Psychological ideas in palliative care: Attachment theory



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(1):24-27. There is growing recognition in the palliative care (PC) community of the emotional and psychological needs of patients – and their carers – as they reach the end of life. But not every patient needs, wants or has access to formal contact with a psychologist. What’s more, all members of a multidisciplinary team are likely to experience the impact of psychological matters on their daily practice with patients and colleagues, whether or not their role is to explicitly address those. This series of articles aims to summarise some of the “big ideas” in psychology and translate them into practical advice to promote psychologically informed practice for those providing PC, whether as doctor, nurse, allied health professional or in any other clinical or nonclinical role.

### A shorter average length of stay in a U.K. hospice – how is this happening?



*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(1):33-35. The average length of stay (ALOS) at Willow Wood (6.6 days) is half that of U.K. hospices (13.7 days) nationally due to the influence of the Hospice Transfer Project between Willow Wood and Tameside General Hospital. Patients are accurately identified as dying at an early point in their hospital admissions and are transferred to the hospice appropriately. Admissions from the medical assessment unit have the shortest ALOS. Acutely unwell patients admitted from the acute hospital setting undergo rapid deterioration and their likely eventual death leads to a higher death rate compared to hospices nationally. While some may question the benefit of transferring a dying patient to a hospice for a few hours, the families of the bereaved have described the value of those precious moments to them and the patient.

### What do we know about older former carers? Key issues and themes

*HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 22 February 2017 – Despite a significant growth in the number older former family carers, they remain largely invisible in carer-related research and literature. To begin to address this deficit, a four-stage literature review was conducted to identify existing knowledge about older former carers. The findings yielded five themes: 1) The concept of “older former carer”; 2) The legacies of caring; 3) Influences on the legacies of caring; 4) Conceptualising post-caring; and, 5) Support services for older former carers. Critical analysis of these findings suggests that existing evidence has a number of strengths. It highlights the terminological and conceptual confusion in the field, identifies the profound financial and health-related legacies older former carers’ experience, the factors which shape these legacies, and some of the complexities of bereavement older former carers face. The support needs of older former carers are also illuminated. However, the field is characterised by key weaknesses. The evidence base is fragmented and uneven. <https://goo.gl/8ippTp>

## **Family presence during resuscitation: Extending ethical norms from paediatrics to adults**

*JOURNAL OF MEDICAL ETHICS* | Online – 23 February 2017 – Many families of patients hold the view that it is their right to be present during a loved one's resuscitation, while the majority of patients also express the comfort and support they would feel by having them there. Currently, family presence is more commonly accepted in paediatric cardiopulmonary resuscitation (CPR) than adult CPR. Even though many guidelines are in favour of this practice and recognise potential benefits, healthcare professionals are hesitant to support adult family presence to the extent that paediatric family presence is supported. However, in this paper, the authors suggest that the ethical case to justify family presence during paediatric resuscitation is weaker than the justification of family presence during adult resuscitation. They go on to support this claim using three main arguments that people use in clinical ethics to justify family presence during resuscitation. These include scarcity of evidence documenting disruption, psychological benefits to family members following the incident and respect for patient autonomy. <https://goo.gl/N6Drzp>

**N.B.** Selected articles on relatives' presence during cardiopulmonary resuscitation are noted in Media Watch 13 June 2016, #466 (p.12).

## **Palliative care for patients with Parkinson's disease: An interdisciplinary review and next step model**

*JOURNAL OF PARKINSONISM & RESTLESS LEGS SYNDROME* | Online – 20 February 2017 – The complex and extensive patient and caregiver needs warrant a dedicated clinic to provide the necessary interdisciplinary care. In contrast to a typical model where the neurology clinician refers the patient to various ancillary treatment groups resulting in multiple separate clinic visits, the interdisciplinary model supports direct communication between the different disciplines during the clinic visit, allowing for a more coordinated response that takes into account multiple perspectives. Such an interdisciplinary model has been utilized in neurologic disorders with complex end-stage disease needs, such as amyotrophic lateral sclerosis with notable improvement in quality of life and survival. The Oregon Health & Science University Parkinson Center and Movement Disorders Clinic has developed an interdisciplinary clinic called Next Step composed of neurology clinicians, a physical therapist, a speech pathologist, a social worker, and a nursing coordinator. The clinic focuses on palliative care issues, including complex late stage motor symptoms, non-motor symptoms, and quality of life goals of both the patient and caregiver(s). This article describes the Next Step clinic structure and processes, while reviewing the literature and incorporating clinical expertise from the perspective of each discipline. <https://goo.gl/ZjCMJm>

**N.B.** Click on [Download Article \[PDF\]](#) to access complete text. Additional articles on palliative care for people living with Parkinson's disease are noted in past issues of Media Watch, e.g., 28 November 2016, #489 (p.6); and, 11 April 2016, #457 (p.12).

## **Understanding the impact of a new public health approach to end-of-life care: A qualitative study of a community led intervention**

*THE LANCET* | Online – 23 February 2017 – Social isolation is recognised for its substantial impact on mortality, ranking above many established public health threats. The end of life (EoL) can compound this problem; with escalating acute care costs due to poor social support and rising numbers of deaths, new solutions are needed. Examples of peers providing social support exist within EoL care, but have not been well characterised. The authors aimed to understand the impacts and facilitative processes of a home visiting intervention. Data included 21 in-depth interviews, 19 episodes of participant observation, and 19 documents. Three central impacts emerged. Participants stated that peer-support filled a gap in social support that neither professionals nor family could meet. Participants described becoming socially connected and linked this connection to increased wellbeing. Volunteers viewed themselves and those they visited as peers, despite differences in age or diagnosis. This view explained how compassion could

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be expressed, instead of a more detached form of empathy. A key facilitative process was the development of a relationship based on mutuality rather than passivity and dependence. On this basis, the relationship could be reconstructed outside the professional domain and could develop a depth and sustainability beyond the formal intervention. This study highlights the role of social networks in promoting well-being at the EoL. For sustainable changes to occur, relationships must be reciprocal rather than passive. These findings have important implications for how social care interventions are structured at the EoL. Peer support networks are a sustainable and appropriate care model, and this study provides evidence of their utility and sheds light on the fundamental components of compassionate care. <https://goo.gl/DDalwa>

#### Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 23 February 2017 – ‘**Home palliative care works: But how? A meta-ethnography of the experiences of patients and family caregivers.**’ This review showed that home palliative care (PC) increases the sense of security of patients and caregivers facing life-threatening diseases with PC needs at home. Professionals taking care of these populations should be aware of their security-enabling role, by providing competent care and being present. Home PC teams should be widely available and empowered with the resources to be competent (i.e., providing effective symptom control and skilful communication) and present (offering 24/7 availability and home visits). <https://goo.gl/ihMTgH>

#### Under-resourced and under-developed family-centred care within palliative medicine

*PALLIATIVE MEDICINE*, 2017;31(3):195-196. The most difficult challenge in further developing the practice of palliative care (PC) is the effective delivery of family-centred care. New models that target family support to those with unmet family needs will help to address this gap. Where PC training programmes conduct communication skills training, a module on “running a family meeting” needs to be part of the core curriculum. Research needs to better define the skills needed to facilitate safety in conducting meetings with difficult families in PC. What place do circular questions have to reveal family dynamics? How are challenging families better engaged in psychosocial care programmes? More trials of family interventions need to confirm the optimal timing, dose of intervention and model of therapy to optimise family functioning. The evidence base is emerging about how to achieve this clinical work; its translation with op-

timal staffing will enhance outcomes through further dissemination – implementation research in the future. Beyond information provision and education for the family, research needs to define effective models that lead to the routinisation of family-centred care for those with more complex needs. <https://goo.gl/2yh4bs>

## PALLIATIVE MEDICINE

The focus of the current issue is on family needs when a parent is dying and on models of family-centred care. Contents page: <https://goo.gl/9Umc3L>

#### Related

- *PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 20 February 2017 – ‘**Barriers to access to palliative care.**’ Despite significant advances in understanding the benefits of early integration of palliative care (PC) with disease management, many people living with a chronic life-threatening illness either do not receive any PC service or receive services only in the last phase of their illness. The author explores some of the reasons for failure to provide PC services and recommends strategies to overcome these barriers, emphasizing the importance of describing PC accurately. The author provides language to help health care professionals of all disciplines explain what PC has to offer and ensure wider access to PC, early in the course of their illness. <https://goo.gl/u1euQh>

## Developing a model for pharmaceutical palliative care in rural areas: Experience from Scotland

*PHARMACY* | Online – 16 February 2017 – This paper describes the experience of developing a model to deliver pharmaceutical palliative care (PC) in rural Scotland via the MacMillan Rural Palliative Care Pharmacist Practitioner (MRPP) project. The focus of the service was better integration of the MRPP into different care settings and professional teams, and to develop educational resources for the wider multidisciplinary team including care home and social care staff on medicine related issues in PC. A variety of integration activities are reported with advice on how to achieve this. Similarly, many resources were developed, including bespoke training on pharmaceutical matters for care home staff. The experience allowed for a 3-step service and sustainability model for community pharmacy PC services to be developed. Moving through the steps, the key roles and responsibilities of the MRPP gradually shift towards the local community pharmacist(s), with the MRPP starting from a locality-based hands-on role to a wider supportive facilitating role for local champions. <https://goo.gl/H8uVaR>

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN ONCOLOGY NURSING JOURNAL*, 2017;27(1):56-64. **‘Engaging with patients who desire death: Interpretation, presence, and constraint.’** Canadian end-of-life care (EoLC) is changing. Given recent legislative changes concerning assisted death (euthanasia and assisted suicide), it is vital to examine the perspectives of nurses regarding their care of patients who want to die. This qualitative descriptive study reports findings from interviews with 11 oncology nurses about their experiences of engaging with patients who desire death. Findings provide important insights about how oncology nurses interpret patients’ desire-for-death and enact therapeutic presence with these patients. Findings further speak to contextual forces that constrain therapeutic engagement. Interviews were conducted before laws changed in Canada, generating insights that are relevant now more than ever, as increasing numbers of patients will contemplate and receive assisted death in the new landscape of Canadian EoLC. <https://goo.gl/sQrjAh>
- *VERBUM ET ECCLESIA*, 2017;38(1). **‘Euthanasia in South Africa: Philosophical and theological considerations.’** The issue of euthanasia has arisen from time to time, but the question of whether it should be legalised was not seriously considered until it recently attracted attention because of a particular case, that of Cape Town advocate Robin Stransham-Ford. Although euthanasia is still illegal (this is because the Stransham-Ford ruling is confined to this particular case only) ... the Court granted leave to appeal its April 2015 judgement regarding euthanasia in the application lodged by Stransham-Ford. In considering the contentious nature of the issue of euthanasia, this article adopts a multidisciplinary approach which includes historical, legal, theological, philosophical, theoretical and analytic frameworks, discussing euthanasia from philosophical and theological perspectives, in particular. The authors conclude by recommending that the subject of applied ethics, which helps to educate citizens about contemporary moral problems such as euthanasia, be introduced at school level. <https://goo.gl/VVHv53>



### 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.12.



### Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.

<http://goo.gl/OTpc8I>

## Worth Repeating

### Discovering the truth beyond the truth

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 December 2014 – Truth within the field of medicine has gained relevance because of its fundamental relationship to the principle of patient autonomy. In order to fully participate in their medical care, patients must be told the truth – even in the most difficult of situations. Palliative care emphasizes patient autonomy and a patient-centered approach, and it is precisely among patients with chronic, life-threatening, or terminal illnesses that truth plays a particularly crucial role. For these patients, finding out the truth about their disease forces them to confront existential fears. As physicians, we must understand that truth, similar to the complexity of pain, is multi-dimensional. In this article, the authors discuss the truth from three linguistic perspectives: the Latin *veritas*, the Greek *aletheia*, and the Hebrew *emeth*. *Veritas* conveys an understanding of truth focused on facts and reality. *Aletheia* reveals truth as a process. And, *emeth* shows that truth is experienced in truthful encounters with others. In everyday clinical practice, truth is typically equated with the facts. However, this limited understanding of the truth does not account for the uniqueness of each patient. Although two patients may receive the same diagnosis (or facts) each will be affected by this truth in a very individual way. To help patients apprehend the truth, physicians are called to engage in a delicate back-and-forth of multiple difficult conversations in which each patient is accepted as a unique individual. [Noted in Media Watch 29 December 2014, #390 (p.9)] <https://goo.gl/HtUNoN>

### 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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### 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.

## [Media Watch: Online](#)

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/o9wzNe>

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

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

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

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

### **Canada**

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

### **Europe**

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

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