

## 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

The illness experience: Scroll down to [Specialist Publications](#) and 'Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis' (p.7), in *Advances in Nursing Science*.

## Canada

### Emergency aid workers save lives – but can they make death more comfortable, too?

ONTARIO | TVO Ontario – 8 December 2016 – Emergency responders have always had to confront death at natural disaster sites and in warzones, yet palliative care (PC) has never been a priority for aid groups operating in such places. Their first priority is to save lives: no widely adopted guidelines exist to help them address the reality of death. A new Canadian research project may change this. 'Aid When There Is Nothing Else to Offer,' a study co-led by a pair of bioethicists at McMaster and McGill universities, hopes to identify gaps in PC delivery during emergencies, establish good practices, and identify training needs. "The core focus is to provide the best care for patients," lead investigator Lisa Schwartz says, "even when health providers recognize that there's little more they can do to save a patient's life." PC can be a tough sell to health workers trained primarily to respond to emergencies, says Kevin Bezanon, a researcher participating in the study, which will be published next year. During disease outbreaks, natural disasters, and armed conflicts, scarce resources and increased health-care needs place overwhelming demands on already-burdened systems. Where health workers are poorly trained or lack the resources to provide PC, dying patients suffer. <https://goo.gl/lojYL3>

Noted in Media Watch 7 March 2016, #452 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 March 2016 – '**Near-death and other transpersonal experiences occurring during catastrophic events.**' The authors describe examples of near-death and other transpersonal experiences occurring during catastrophic events like floods, wars, bombings, and death camps. To date, researchers have limited their investigations of these transpersonal events to those occurring to seriously ill patients in hospitals, those dying from terminal illnesses... <http://goo.gl/fONh7S>

Noted in Media Watch 17 August 2009, #110 (p.7):

- *BIOSECURITY & BIOTERRORISM: BIODEFENSE STRATEGY, PRACTICE & SCIENCE*, 2009;7(2): 199-210. '**Palliative care considerations in mass casualty events with scarce resources.**' This article introduces the topic of palliative care (PC) during a mass casualty event and reviews the findings for a [U.S.] federally funded guide that examined PC issues associated with providing medical care under circumstances where resources are scarce. The authors focus on the role of PC in the support of individuals not expected to survive and offer recommendations of specific actions for a coordinated disaster response plan. <https://goo.gl/TuJl6f>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | The Canadian Press – 7 December 2016 – ‘**Ontario legislation updates regulations for medically assisted death.**’ The Medical Assistance In Dying Statute includes a series of amendments to several pieces of legislation to provide more clarity on the issue for patients, families, doctors and other health-care providers. The changes align Ontario regulations with federal legislation passed last June that guides how medical assistance in dying can be provided, and outlines the criteria for patient eligibility such as having an incurable medical condition. <https://goo.gl/Z0soL6>

**N.B.** The Medical Assistance in Dying Statute Law Amendment Act Background: <https://goo.gl/Tjvhzn>

### Specialist Publications

‘**Medically assisted death in Canada – unsettled (and unsettling?) law**’ (p.16), in *Journal of The Canadian Health Libraries Association*.

## U.S.A.

### Life expectancy in U.S. declines slightly, and researchers are puzzled

*THE NEW YORK TIMES* | Online – 8 December 2016 – American life expectancy is in decline for the first time since 1993, when HIV-related deaths were at their peak. But this time, researchers can’t identify a single problem driving the drop, and are instead pointing to a number of factors, from heart disease to suicides, that have caused a greater number of deaths. A study on mortality rates released ... by the National Center for Health Statistics showed that Americans could expect to live for 78.8 years in 2015, a decrease of 0.1 from the year before.<sup>1</sup> The overall death rate increased 1.2% – that’s about 86,212 more deaths than those recorded in 2014. <https://goo.gl/q0bnwv>

1. ‘Mortality in the U.S., 2015,’ Centers for Disease Control & Prevention, National Center for Health Statistics December 2016. <https://goo.gl/cCRBRy>

### Doctors slow to have end-of-life conversations

OHIO | *The Chicago Tribune* – 6 December 2016 – When the concept of paying doctors to help patients plan for end-of-life care first came up as part of health reform, opponents thumped it as a step toward “death panels” and “pulling the plug on grandma.” Advance care planning was scuttled then, but seven years later, it has been rather quietly incorporated into services reimbursable by Medicare. Patients now can seek guidance from their physicians and other health care professionals about what they want and don’t want in terms of life-sustaining or life-prolonging care and have it included in their medical records. But codifying what many describe as a sea change in thinking may have come about too quietly. The Centers for Medicare & Medicaid Services ... can’t say how many physicians have billed for these conversations since the provision took effect 1 January, but a poll released in April showed only about 14% of doctors who regularly treat patients over 65 have submitted such bills to Medicare.<sup>1</sup> <https://goo.gl/Oex1vu>

### Specialist Publications

‘**Improving hospice referral: Application of regret-based decision modeling at end-of-life care**’ (p.8), in *Blood*.

1. ‘Conversation Stopper: What’s preventing physicians from talking with patients about end of life and advance care planning?’ John A. Hartford Foundation, California Health Care Foundation & Cambia Health Foundation, April 2016. [Noted in Media Watch 18 April 2016, #458 (p.3)] <http://goo.gl/NTzOpZ>

## Alone and aging: Creating a safety net for isolated seniors

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 2 December 2016 – Phyllis Krantzman represents a universe that's come to be known among geriatric specialists as "elder orphans" – seniors with no relatives to help them deal with physical and mental health challenges. Their rising numbers prompted the American Geriatrics Society this week to unveil guidelines for a segment of these older adults who can no longer make their own medical decisions and have no designated surrogates.<sup>1</sup> The non-profit dubbed them "unbefriended" and called for a national effort to help prevent a surge among incapacitated seniors who don't have a decision maker and face a health crisis. Single seniors have always existed, but demographic and social changes have slowly transformed aging America. In 1900, average life expectancy was 47. Now, the combination of increased longevity, the large and graying baby boom generation, the decline in marriage, the rise in divorce, increased childlessness and family mobility has upended the traditional caregiving support system. <https://goo.gl/Nlv5yG>

### Specialist Publications

**'How effective are volunteers at supporting people in their last year of life? A pragmatic randomised wait-list trial in palliative care'** (p.8), in *BMC Medicine*.

1. 'Making medical treatment decisions for unbefriended older adults,' *Journal of the American Geriatric Society*, published online 22 November 2016. [Noted in *Medias Watch* 28 November 2016, #489 (p.11)] <https://goo.gl/68dZQy>

Noted in *Media Watch* 28 September 2015, #429 (p.5):

- *THE NEW YORK TIMES* | Online – 25 September 2015 – '**Near the end, it's best to be "befriended."**' The unconscious man in his 90s was brought to emergency. The staff couldn't find any relatives to make medical decisions on his behalf. He had outlived all his family. Nobody could find an advance directive, either. The hospital's ethics committee had to guide the medical team to decisions about continuing life support. Experts describe patients like this as "unbefriended." <https://goo.gl/qRikeu>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBN NEWS | Online – 6 December 2016 – '**Evangelicals in the minority when it comes to assisted suicide views.**' A new survey finds most Americans think assisted suicide is morally acceptable.<sup>1</sup> However, most Evangelical Christians say the practice is wrong. Survey respondents were asked to either agree or disagree with the following statement: "When a person is facing a painful terminal disease, it is morally acceptable to ask for a physician's aid in taking his or her own life." Two-thirds of all the respondents agreed. This included Americans of all age groups. Even the majority of people of faith such as Catholics and Protestants and those who attended religious services only occasionally, such as less than once a month, agreed with the statement. However, Evangelical Christians were reversed in their opinions. Two-thirds disagreed with the statement. The majority of people who attended religious services more frequently than once a month disagreed as did the majority of African-American respondents. <https://goo.gl/IP80xa>

1. 'Most Americans say assisted suicide is morally acceptable,' LifeWay Research, December 2016. <https://goo.gl/YAZ3Jl>



### 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.

## International

### End-of-life care in Australia

#### **End-of-life care among six human service areas flagged for reform**

AUSTRALIA | *Australian Ageing Agenda* – 7 December 2016 – People would have a greater say over where and when they receive end-of-life care (EOLC) through increased competition in the delivery of services under proposals being considered by the Productivity Commission.<sup>1</sup> Access to high quality EOLC varies within and between jurisdictions while indigenous Australians, those from culturally and linguistically diverse backgrounds and people with illnesses other than cancer, are particularly underserved, according to a new report from the commission. The commission identified six priority areas – social housing, public hospitals, public dental, services in remote Indigenous communities, EOLC and government-commissioned family and community services – that it said were best suited to deliver improved outcomes in a more competitive environment. With 26 services in scope of the inquiry, residential and home aged care services did not make the priority list but were among those which the commission said could benefit from this type of reform. For those nearing end of life, the commission said preferences could be better satisfied and outcomes improved if people were provided with more choice about the timing and setting of EOLC. <https://goo.gl/cqi6AT>

#### Specialist Publications

**‘Romanian National Association for Palliative Care: Quality assurance for palliative care in Romani’** (p.10), in *European Journal of Palliative Care*.

**‘The role of “accompagnement” in the end-of-life debate in France: From solidarity to autonomy’** (p.15), in *Theoretical Medicine & Bioethics*.

1. ‘Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform,’ Productivity Commission, December 2016. <https://goo.gl/qjHKrH>

#### 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.

**Campaigners warn of health and social care “crisis”**

U.K. (Scotland) | *The Herald* (Glasgow) – 6 December 2016 – A new report by a coalition of organisations has made a series of recommendations for improving the delivery of health and social care for people living with a terminal illness and their carers.<sup>1</sup> Too many people are missing out on specialist end-of-life care and co-ordinated, creative solutions are needed to tackle the challenge of an ageing population amid increasing pressure on public funds. The report said: “We are concerned that these many challenges cannot be met now, or in the future, solely by finding more money for more statutory services. Scotland faces a crisis in caring for older and dying people.” Of the 57,500 people who die in Scotland each year, 80% would benefit from some form of palliative care, but 25% of those will not receive the necessary services. In 2015, a total of 276 people died while waiting for their social care packages to start while others waited over a year. The report also identifies a “postcode lottery” for personal care charging for those under 65 who have a condition not seen as terminally-ill. Among the recommendations is a call for social care packages to start immediately when they are needed and be adaptable to changes, as well as for improved sharing of patient information between health and social care teams. <https://goo.gl/9EJdEg>

1. ‘Dying to Care: A report into social care at the end of life,’ published jointly by Marie Curie, the Association of Palliative Care Social Workers, Hospice UK, and Motor Neurone Disease Scotland, December 2016. <https://goo.gl/ZyQQhV>

**Selected reports on end-of-life care in Scotland**

‘Scottish Atlas of Palliative Care,’ End-of-Life Studies Group, University of Glasgow, September 2016. [Noted in Media Watch 26 September 2016, #481 (p.4)] <https://goo.gl/Sf3DCy>

‘Dying Doesn’t Work 9-5,’ Sue Ryder Scotland, August 2016. [Noted in Media Watch 5 September 2016, #478 (p.6)] <http://goo.gl/lq7wch>

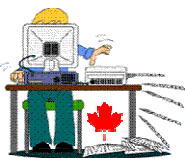
‘Why do older people get less palliative care than younger people,’ *European Journal of Palliative Care*, 2016;23(3):132-137. [Noted in Media Watch 6 June 2016, #465 (p.12)] <http://goo.gl/XfHTo0>

‘Palliative and End-of-Life Care in Scotland: The rationale for a public health approach,’ Scottish Public Health Network, March 2016. [Noted in Media Watch 7 March 2016, #452 (p.6)] <http://goo.gl/FeVDfk>

‘Strategic Framework for Action on Palliative & End-of-Life Care,’ Scottish Government, December 2015. [Noted in Media Watch 21 December 2015, #441 (p.8)] <http://goo.gl/CKePjU>

‘Children in Scotland Requiring Palliative Care,’ Managed Service Network for Children & Young People, with Cancer and Children’s Hospice Association Scotland, October 2015. [Noted in Media Watch 9 November 2015, #435 (p.6)] <http://goo.gl/K5wC16>

‘International Comparisons in Palliative Care Provision: What can the indicators tell us?’ Health & Sport Committee, Scottish Parliament, September 2015. [Noted in Media Watch 21 September 2015, #428 (p.6)] <http://goo.gl/KhqtqU>



**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>

## Doctors caring for dying patients need more support, British Medical Association says



U.K. | *The Guardian* – 5 December 2016 – The British Medical Association (BMA) has called for more support for doctors caring for dying patients after a survey found fewer than one in five physicians feel they get sufficient assistance.<sup>1</sup> The poll highlighted the deep-seated effect treating patients at the end of their life has on doctors, with 93.9% saying it has an emotional impact on them. Dr. Zoe Greaves, the BMA's medical ethics committee deputy chair, said: "Although doctors are professionally trained to deal with death, the emotional toll from caring for patients at the end of their life should not be underestimated. Doctors will always remember their 'first death' and for many there are those more difficult cases that always stay with you." She said the BMA wanted to see the use of support services become normal practice, with staff encouraged to access them early "before their health is adversely affected." More

than a third (37.2%) of the 457 doctors who responded to the online poll said they cared for dying patients frequently or all the time. A similar proportion (34.6%) said they occasionally cared for people at the end of their life, with 28.2% saying they never did. Only 14.7% said they had accessed formal or informal support networks, either locally or nationally. <https://goo.gl/26oq2y>

### Specialist Publications

**'End-of-life care for infants, children and young people with life limiting conditions: Summary of National Institute for Health & Care Excellence guidance'** (pp.12,13), in *British Medical Journal*.

**'Going for gold: The Gold Standards Framework programme and accreditation in primary care'** (p.9), in *End of Life Journal*.

1. 'BMA Quarterly Survey: Current views from across the medical profession,' (see pp.7-11), British Medical Association, December 2016. <https://goo.gl/Pi3Dtd>

Noted in Media Watch 11 July 2016, #470 (p.10):

- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 6 July 2016 – **'Providing end-of-life care in general practice: Findings of a national GP questionnaire survey.'** Four interdependent themes emerged: 1) Continuity of care – which can be difficult to achieve because of resource concerns including time, staff numbers, increasing primary care workload, and lack of funding; 2) Patient and family factors – with challenges including early identification of palliative care (PC) needs and recognition of the end of life, opportunity for care planning discussions, and provision of support for families; 3) Medical management – including effective symptom-control and access to specialist PC services; and, 4) Expertise and training – the need for training and professional development was recognised to enhance knowledge, skills, and attitudes towards end-of-life care. <http://goo.gl/HOaBWN>

### Elder care in England

#### **Revealed: Millions paid to social care companies amid crisis in standards**

U.K. (England) | *The Guardian* – 3 December 2016 – An investigation into the five biggest firms providing homecare services in the U.K. has found millions of pounds has been paid to some owners amid a crisis in standards of care. An analysis of published reports from the Care Quality Commission, the care regulator for England, reveals that of the 192 domiciliary care services run by major companies, and inspected over the last two years, 80 were found to "require improvement," with eight found to be "inadequate" and placed into special measures. In services rated inadequate, people were found to be unwashed, unfed, unable to get out of bed, and left at risk of harm. In some cases, medicine was not given on time or safely and services were described as unsafe and short-staffed. Yet, in the past five years, an analysis of care records and company accounts by Corporate Watch reveals evidence of £36 million being paid to owners, with a further £34 million in liabilities being stacked up in company accounts.<sup>1</sup> <https://goo.gl/4bYu3b>

1. 'The Home Care Business,' Corporate Watch, December 2016. <https://goo.gl/NNFrvl>

Cont.

## Related

- U.K. (England) | *The Daily Telegraph* – 6 December 2016 – ‘**11,000 care home residents at risk of starving and going thirsty.**’ New figures show that since last year, 312 homes have been found to be in breach of basic standards to ensure vulnerable residents are not left hungry or dehydrated. Figures revealed in a parliamentary answer suggest that more than 11,500 residents are living in care homes, which are breaching standards on nutrition and hydration. <https://goo.gl/P7qf6m>
- U.K. (England) | BBC News – 5 December 2016 – ‘**London care home closure rate nearing “crisis levels.”**’ Five hundred care homes have closed in the capital in the past decade, the Care Quality Commission said. The BBC has found that one in four care homes is at risk of going out of business by 2020. <https://goo.gl/n3cCHd>
- U.K. (England) | *The Daily Telegraph* – 5 December 2016 – ‘**Care home fees soar by one quarter as quality plummets, report finds.**’ On average, fees for care homes rose by 23% in one year. In many places there is little relationship between the cost and quality of care; many affluent areas charged more, without providing better services. <https://goo.gl/KeWrWf>
- U.K. (England) | *The Sunday Times* – 4 December 2016 – ‘**Alert as care home giants face cash crunch.**’ The Department of Health has ordered the sector watchdog to monitor the finances of the leading care home companies “to warn local authorities of any insolvencies where services could stop.” <https://goo.gl/kl3SER>

### A practice development initiative supporting care home staff deliver high quality end-of-life care

Care homes provide care for a fifth of the U.K. population who die each year. Most homes are privately owned and not part of the National Health Service, which exposes staff to a lack of skills/knowledge in relation to end-of-life care.

**Source:** *International Journal of Palliative Nursing*, 1 November 2016. <https://goo.gl/VbtWX4>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SOUTH AFRICA | Reuters (Johannesburg) – 6 December 2016 – ‘**South Africa’s appeals court overturns ruling allowing “assisted dying.”**’ South Africa’s Supreme Court of Appeals (SCA) ... overturned a ruling by a lower court granting a terminally ill patient the right to die ... thereby upholding South Africa’s laws forbidding assisted suicide. In a groundbreaking ruling in 2015, South Africa’s High Court had granted a terminally ill man, Robin Stransham-Ford, the right to die with dignity by way of euthanasia. Stransham-Ford, who was suffering from cancer, died just hours before the High Court ruling was delivered. The government appealed against the ruling, saying it had far-reaching implications on its interpretation and possible abuse by others in the absence of a legislative framework that regulates assisted suicide. <https://goo.gl/cq7Qoz>

## [Specialist Publications](#)

### Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis

*ADVANCES IN NURSING SCIENCE* | Online – 6 December 2016 – A palliative approach involves adapting and integrating principles and values from palliative care into the care of persons who have life-limiting conditions throughout their illness trajectories. The aim of this research was to determine what approaches to nursing care delivery support the integration of a palliative approach in hospital, residential, and home care settings. The findings substantiate the importance of embedding the values and tenets of a palliative approach into nursing care delivery, the roles that nurses have in working with interdisciplinary teams to integrate a palliative approach, and the need for practice supports to facilitate that embedding and integration. <https://goo.gl/ALhGWp>

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

### **Improving hospice referral: Application of regret-based decision modeling at end-of-life care**

*BLOOD* | Online – Accessed 6 December 2016 – The authors report the application of a regret-based model built to facilitate referral to hospice while helping patients clarify their preferences related to how they wish to spend the remaining days of their lives. To their knowledge, this is the first formal study in which helping patient clarify their preferences enabled them to make actual choices with high level of satisfaction. The regret model was well received by study participants] and its recommendations were largely accepted. People suffering from a terminal disease who are initially inclined to choose hospice and do not regret such a choice will select hospice care with high level of certainty. <https://goo.gl/sl8aEM>

### **How effective are volunteers at supporting people in their last year of life? A pragmatic randomised wait-list trial in palliative care**

*BMC MEDICINE* | Online – 9 December 2016 – Clinicians can confidently refer to volunteer services at the end of life (EOL). More hours or increased frequency of contact with a volunteer has a statistically significant effect on the rate of decline of physical quality of life... Other measured outcomes of the volunteer provided support showed no statistically significant benefit over usual care, although a trend in favour of the intervention can be seen. This is the first trial of volunteer provided support in the last year of life and provides an emergent answer to questions of whether volunteer support should be used at the EOL... <https://goo.gl/PVqxHTT>

**N.B.** Additional articles on hospice and palliative care volunteers are noted in Media Watch 28 November 2016, #489 (p.8) and 25 July 2016, #476 (pp.5-6,11).

### **The need for an effective process to resolve conflicts over medical futility: A case study and analysis**

*CRITICAL CARE NURSE*, 2016;36(6):13-23. Procedural approaches to medical futility cases provide all parties involved with a process-driven framework for resolving these disputes. Medical paternalism or the belief in the absolute rightness of the medical model will not serve to resolve these disputes. Although medical futility is first determined by medicine, in order for the determination to meet legal criteria, it must be subject to review. The hope is that through a review process that meets legal criteria, the issue can be resolved without the need for court proceedings. If resolution cannot be obtained through this process, surrogates still have the right to seek court intervention. This issue is of relevance and importance in critical care nursing because of the role and position of critical care nurses, who have direct contact with patients and patients' families, the potential for moral distress in cases of possibly futile treatment, and the expanding roles of nurses, including critical care nurses and advanced practice nurses, in management and policy development. <https://goo.gl/O6qftU>

### **Developing the Senses Framework to support relationship-centred care for people with advanced dementia until the end of life in care homes**

*DEMENTIA* | Online – 6 December 2016 – People with advanced dementia living in care homes can experience social death before their physical death. Social death occurs when a person is no longer recognised as being an active agent within their relationships. A shift is required in how we perceive people with advanced dementia so that the ways they continue to be active in their relationships are noticed. Paying attention to embodied and inter-embodied selfhood broadens the scope and opportunities for relationships with people with advanced dementia, acting as a counter to social death. This has the potential to improve the quality of care, including end-of-life care, of people with advanced dementia in care homes. This study examined the role of embodied and inter-embodied selfhood within care-giving/care-receiving relationships in a specialist dementia care home. <https://goo.gl/nPn8LX>

**N.B.** Additional articles on end-of-life care for people living with dementia are noted in Media Watch 5 December 2016, #490 (p.7), 1 August 2016, #473 (p.11), and 4 July 2016, #469 (pp.15-16).



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

### **Going for gold: The Gold Standards Framework programme and accreditation in primary care**

*END OF LIFE JOURNAL* | Online – 9 December 2016 – Primary care teams are pivotal in caring for patients in the final year of life, enabling more to live well and die where they choose. They face increasing pressures from an ageing population, rising mortality, and limited resources. Therefore, proactive approaches are required to support people nearing the end of life. The Gold Standards Framework (GSF) Quality Improvement Programmes have been influential in end-of-life care (EOLC) since 2000. The first 10 general practitioner (GP) practices completing the updated 'GSF Gold' Programme and associated Accreditation are demonstrating enhanced EOLC including earlier identification of patients, more advance care planning discussions, and improved outcomes for more patients. Use of this proactive approach demonstrates what is possible to achieve in general practices. Progress to date is encouraging, with evidence of significant change, exemplifying a possible model for 21st century primary care to meet the needs of those nearing the end of life. <https://goo.gl/61tEoP>

### **The ethics of unilateral implantable cardioverter defibrillators and cardiac resynchronization therapy with defibrillator deactivation: Patient perspectives**

*EUROPACE* | Online – 2 December 2016 – Decisions about deactivation of implantable cardioverter defibrillators (ICDs) are complicated. Unilateral do-not-resuscitate (DNR) orders (against patient/family wishes) have been ethically justified in cases of medical futility ... [and] ... may be seen as a logical extension of a unilateral DNR order. However, the ethical implications ... have not been explored. Only 15% of [survey] respondents had thought about device deactivation if they were to develop a serious illness from which they were not expected to recover. A majority (53%) had advance directives, but only one mentioned what to do with the device. However, a majority (78%) did not consider deactivation of an ICD shocking function against patients' wishes to be ethical or moral. Few patients [i.e., survey respondents] consider device deactivation at end of life, although a large majority believes that unilateral deactivation is not ethical/moral, even in the setting of medical futility. Advance care planning for these patients should address device deactivation. <https://goo.gl/5d4cVs>

#### **Related**

- *CRITICAL CARE NURSE*, 2016;36(6):24-31. '**Planning for deactivation of implantable cardioverter defibrillators at the end of life in patients with heart failure.**' Based on this author's literature review, recommendations for discussing and implementing implantable cardioverter defibrillators (ICD) deactivation are offered. Health care organizations should have clear policies addressing ICD deactivation to provide for seamless integration of palliative care services throughout the course of heart failure. <https://goo.gl/Ks0BLH>

Noted in Media Watch, 27 June 2016, #468 (p.7):

- *HEART, LUNG & CIRCULATION*, 2016;25(8):814-819. '**Cardiac implantable electronic devices and end-of-life care: An Australian perspective.**' This article focuses on the subset of patients who may request, or be appropriate for, device deactivation and discuss the issues surrounding end-of-life decisions, along with the ethical and legal implications of device deactivation. <http://goo.gl/yyFHHE>

**N.B.** Additional articles on implantable cardioverter-defibrillators in the context of end-of-life care are noted in Media Watch 1 February 2016, #447 (p.11).

## Romanian National Association for Palliative Care: Quality assurance for palliative care in Romani

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(6):278-280. Since 1992, new palliative care (PC) services have been set up in both the public and private healthcare systems. The current legal framework and the funding mechanisms have been gradually encouraging the emergence of new PC services, particularly as inpatient units. Home-based PC services are still isolated private initiatives, and their funding through the health insurances system is low, despite the fact that 70% of people die at home in Romania and most of them wish to be looked after in their home environment at the end of life. The map of specialised PC services, as illustrated in the last service directory published in 2014 by National Association of Palliative Care [ANIP], shows 79 services delivered by 47 providers – 20 in the public healthcare system, 23 non-governmental charitable organisations, and 4 for-profit services. It has been estimated that more than 150,000 people annually need PC in Romania, using an international estimation methodology based on epidemiological criteria. Comparing the estimated needs for PC services for oncological and non-oncological patients to the actual services available, Romania had 7.9% needs coverage in 2015. The distribution of services was rather inconsistent, with 19 counties out of 41 still having no PC providers. The slow and random development of services is due to

the fact that PC has only recently been included in the national healthcare strategy, with an ambitious strategic objective of reaching 60% coverage of the overall needs for PC by 2020.



Access to this article requires a subscription. Journal contents page for the November/December issue: <https://goo.gl/qGVJCP>

## Trauma-informed hospice and palliative care

*THE GERONTOLOGIST* | Online – 7 December 2016 – This review highlights the need to integrate trauma-informed practices into hospice and palliative care (PC). The pervasiveness of psychological trauma exposure has been established in the general population and among the elderly adults. Moreover, there is emerging evidence for multiple additional opportunities for exposure to psychological trauma at or near the end of life (EOL). For example, many people experience intensive medical interventions prior to their admission to hospice and/or PC, and there is increasing recognition that these interventions may be traumatic. These and related opportunities for trauma exposure may combine synergistically at the EOL, particularly in the presence of pain, anxiety, delirium, dementia, or ordinary old age. This, in turn, can negatively affect patient mental health, well-being, behavior, and reported experience of pain. <https://goo.gl/CtFIAQ>

### Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 6 December 2016 – ‘**Finding peace in clinical settings: A narrative review of concept and practice.**’ The purpose of this review was to investigate and review the concept of “peace” and the role it plays in the spiritual well-being and care of people with a chronic or terminal illness. The authors examined the importance of peace in palliative care as a measure of acceptance and in chronic illness settings as a predictor of improved survival. They also explored the dimensions of peace and their relationships with spiritual well-being and examined how the constructs of peace are assessed both within valid spiritual well-being measures and as individual items related solely to peace. Finally, the authors examined therapies aimed at promoting peace and emotional well-being in palliative and chronic illness settings. <https://goo.gl/rPCGZf>

## “Just let me go”: End-of-life planning among Ojibwe elders

*THE GERONTOLOGIST* | Online – 7 December 2016 – Although advance care planning (ACP) is designed to promote person-centered end-of-life care (EOLC), the principles underpinning it are at odds with the values and norms of many American Indian/Alaska Native (AI/AN) communities, contributing to low rates of ACP among AI/AN elders. The purpose of this study was to explore the apparent tension between Western approaches to EOLC, including its emphasis on ACP, and the expectations and wishes of one community of AI elders, in hopes of informing more culturally appropriate approaches to planning for EOLC. Despite seeing little need for ACP, the elders were generally open to discussing the care they would want at end of life (EOL). Many were readily able to describe their wishes for a peaceful death and had already developed funeral and burial or cremation plans. Although establishing one’s individual legacy was not a salient EOL concern for the elders, several found meaning in describing their contributions to preserving their families, the community, and their cultural lifeways. <https://goo.gl/ablSCD>

Noted in Media Watch 14 November 2016, #487 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2016 – ‘**Palliative care for American Indians and Alaska Natives: A review of the literature.**’ Common themes included the importance of culturally appropriate communication, multiple barriers to treatment, and less frequent use of advance directives than other populations. Heterogeneity of study types, population, and small sample sizes makes it hard to draw broad conclusions regarding the best way to care for American Indians and Alaska Natives. <https://goo.gl/DTw0oW>

## Understanding what people intend: Is it possible from written advance directives?

*JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 30 November 2016 – The study by Clemency *et al* ... underlines important challenges to understanding and honoring Physician Orders for Life-Sustaining Treatment (POLST) documents – the MOLST (Medical Orders for Life-Sustaining Treatment) form is New York’s endorsed version – in the emergency setting.<sup>1</sup> The issues they raise highlight the limitations of written advance directives in general and POLST documents in particular. <https://goo.gl/UqBpfg>

1. ‘Decisions by default: Incomplete and contradictory MOLST in emergency care,’ *Journal of the American Medical Directors Association*, published online 27 September 2016. [Noted in Media Watch 3 October 2016, #482 (p.14)]. <https://goo.gl/2Ew9LH>

Noted in Media Watch 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – ‘**Toward evidence-based end-of-life care.**’ More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. <http://goo.gl/9gFs4X>

## Dying with Carolyn: Using simulation to improve communication skills of unregulated care providers working in long-term care

*JOURNAL OF APPLIED GERONTOLOGY*, 2016;35(12):1259-1278. This article examines the development, implementation, and evaluation of a pilot project utilizing high-fidelity simulation (HFS) to improve frontline staff members’ confidence and skills to communicate about death and dying in long-term care homes. The target group was unregulated care providers who provide palliative care for residents and their families. Results supported the effectiveness of HFS as an educational tool for unregulated health care providers. <https://goo.gl/MxVpVO>

## Advance care discussions with young people affected by life-limiting neuromuscular diseases: A systematic literature review and narrative synthesis

*NEUROMUSCULAR DISORDERS* | Online – 21 November 2016 – End-of-life care (EOLC) policy in the U.K. advocates open discussions between health professionals and patients as the end of life approaches. Despite well documented understanding of the progression of life-limiting neuromuscular diseases, the majority of patients affected by such conditions die without a formal end-of-life plan in place. The authors performed a review to investigate conversations regarding EOLC between healthcare professionals and younger adult patients with life-limiting neuromuscular diseases. The search strategy included terms that focused on death and dying along with other factors that could impact length of life. The review found a very limited body of literature regarding EOLC conversations between young people affected by neuromuscular diseases and health professionals. The views and preferences of patients themselves have not been investigated. There is a shared reluctance of patients, family carers and healthcare professionals to initiate EOLC discussions. There are many factors that need to be investigated further in order to develop a consensus that would allow

healthcare professionals to engage patients in EOLC conversations allowing them to face the end of their lives with appropriate plans in place. <https://goo.gl/P2wv90>

### Palliative care practice in neurocritical care

*SEMINARS IN NEUROLOGY*, 2016;36(06):631-641. 'The authors discuss the ongoing debate regarding what model of palliative care (PC) delivery is optimal, focus on the process of shared decision making during goals-of-care discussions, and briefly comment on transitions from intensive care to comfort care. Regardless of an institution's model of PC practice, every neurocritical care clinician should possess core competencies necessary to provide basic, integrative PC for neurocritically ill patients. Given the high proportion of neurocritically ill patients who lack decision-making capacity, communication skills that enable clinicians to facilitate shared decision making with patients' surrogates are of particular relevance, especially when the limitation of life support is in the discussion. <https://goo.gl/a5gTif>

### Related

- *BRITISH MEDICAL JOURNAL* | Online – 8 December 2016 – 'End-of-life care for infants, children and young people with life limiting conditions: Summary of National Institute for Health & Care Excellence guidance.' Children and young people can have a wide range of life-limiting conditions and may sometimes live with such conditions for many years. This guideline recommends that end-of-life care (EOLC) be managed as a long term process that begins at the time of diagnosis of a life-limiting condition and entails planning for the future. Sometimes it may begin before the child's birth. It is part of the overall care of the child or young person and runs in parallel with other active treatments for the underlying condition itself. This guideline was commissioned with the aim to standardise EOLC for infants, children, and young people living with a life-limiting condition, and thus promote equity and consistency. Important themes are to involve children and young people and their parents or carers in decisions about their care, facilitate their care in their preferred location (most likely home), and plan for day and night care. This article summarises the most recent guidance from the recent National Institute for Health & Care Excellence (NICE) on the planning and management of end of life care in infants, children, and young people. <https://goo.gl/nyUO4n>

**N.B.** 'End-of-life care for infants, children and young people with life-limiting conditions: Planning and management,' National Institute for Health & Care Excellence, December 2016. <https://goo.gl/8GLw37>

**See next page** for a visual summary of the NICE recommendations for end-of-life care for children and young people, including likely needs of young person and their family, professional involvement required, and advance care planning



## Hospital doctors' understanding of use and withdrawal of the Liverpool Care Pathway: A qualitative study of practice-based experiences during times of change

*PALLIATIVE MEDICINE* | Online – 8 December 2016 – The Liverpool Care Pathway (LCP) was used in U.K. hospitals (late 1990s to July 2014) in an attempt to generate hospice-style high-quality end-of-life care (EOLC) in acute settings. Despite being widely established, there was limited research or contextual evidence regarding this approach or its impact. Growing criticism from the public, media, politicians and healthcare professionals culminated with a critical independent review (July 2013) and subsequent withdrawal of the LCP.<sup>1</sup> This research explores experiences of doctors using the LCP, prior to and during its withdrawal, to better understand short-fallings and inform future initiatives in hospital EOLC. Seven themes shaped doctors' experiences of using the LCP: 1) Changing perceptions according to length of clinical practice;; 2) Individual interpretation and application of the LCP; 3) Limitations arising from setting, speciality and basic EOLC competence; 4) Understanding and acceptance of medical uncertainty at the end-of-life;; 5) Centrality of communication and fear of discussing dying; 6) External challenges, including a culture to cure, role modelling and the media; and, 7) Desire for reassurance in EOLC decisions. Future initiatives in hospital EOLC must address doctors' fears, (in)ability to tolerate medical uncertainty, communication skills, and understanding of the dying phase, in order to provide optimum care in the last days of life. <https://goo.gl/bzP06l>

1. 'Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://goo.gl/ujDKOT>

## **Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important**

*PALLIATIVE MEDICINE* | Online – 8 December 2016 – Despite most expected deaths occurring in hospital, optimal end-of-life care (EOLC) is not available for all in this setting. Of 1,922 articles, 16 met the inclusion criteria providing patient and family data for analysis. Synthesis yielded 7 patient and 10 family themes including 6 common themes: 1) Expert care; 2) Effective communication and shared decision-making; 3) Respectful and compassionate care; 4) Adequate environment for care; 5) Family involvement; and, 6) Financial affairs. Maintenance of sense of self was the additional patient theme, while the four additional family themes were: 1) Maintenance of patient safety; 2) Preparation for death; 3) Care extending to the family after patient death; and; 4) Enabling patient choice at the end of life. Consumer narratives help to provide a clearer direction as to what is important for hospital EOLC. Systems are needed to enable optimal EOLC, in accordance with consumer priorities, and embedded into routine hospital care. <https://goo.gl/30Egk6>

### **The death rattle in intensive care: An expression of agony at the end of life?**

*REVUE INTERNATIONALE DE SOINS PALLIATIFS*, 2016;31(3):135-141. Do terminal secretions (death rattle) indicate discomfort or agony in the dying patient? This question is still under discussion in published material as well as among the experts. Studies agree that, on the whole, family and friends find it disturbing. As far as nursing staff working with dying patients are concerned, they too are negatively affected by the rattle. Death in intensive care is distinctive inasmuch as it occurs after a decision to discontinue a therapy and is organized by the nursing staff. In this context, the extubation procedure can turn out to be traumatic and needs to be fully understood by the family. The medical staff must be prepared to live these difficult moments themselves and at the same time to give support to the family. An update of the Cochrane Review concluded that any intervention, be it pharmacological or not, would be no better than a *placebo* in treating the sound of a death rattle.<sup>1</sup> The fact remains that a dying person's respiratory symptoms are often distressing for the family and nursing staff. It therefore seems important that all those involved with the patient be prepared for extubation as part of the end-of-life procedure and for the related symptoms. This gives rise to an ethical dilemma of imposing a treatment on the patient to relieve the family's and/or the medical staff's discomfort. <https://goo.gl/hK8Z8N>

1. 'Interventions to treat noisy breathing, or "death rattle": The unpleasant, gurgling breathing occurring in many patients who are about to die,' *Cochrane Database of Systematic Reviews*, published online 23 January 2008. <https://goo.gl/H1B7Mw>

**N.B.** French language article.

Noted in Media Watch 19 July 2010, #158 (p.10, under 'Worth Repeating'):

- *PALLIATIVE MEDICINE*, 2008;22(2):173-176. '**Death rattle: Its impact on staff and volunteers in palliative care.**' Most participants [in this study] expressed negative feelings about hearing the sound of death rattle and felt that relatives were also distressed by it. Medical and nursing participants reported diverse views on why they intervene. Some acknowledged the influence of their own emotional response to the sound. Others felt that intervention was part of their professional role or that the existence of a therapeutic option made it necessary to intervene. Doctors and nurses need to consider why, when and how they intervene and the consequences of that intervention. <https://goo.gl/KMjO83>

Noted in Media Watch 11 August 2008, #57 (p.9, under 'Worth Repeating'):

- U.S. | *The New York Times* – 7 August 2005 – '**Will we ever arrive at the good death?**' The death rattle is what's so unnerving. People who sit beside someone who is close to death, someone in a stage the experts call "active dying," might hear a sound that's not quite a snore, not quite a gurgle, not quite a rasp. It doesn't hurt; it probably isn't something the dying person is even aware of. But it sounds terrible. "Once the so-called death rattle starts," says Charles G. Meys, a hospice nurse, "that's usually an indication that the person is not coming back." The sound, made with each intake of breath, is merely air moving across phlegm. <https://goo.gl/6e1fS5>

## **A skill used in palliative care: Cross-disciplinary challenge**

*REVUE INTERNATIONALE DE SOINS PALLIATIFS*, 2016;31(3):127-134. PhD research has been carried out, with a practice-based approach, among 15 experienced and recognized palliative care professionals in Quebec [Canada]. It has enabled a model to emerge of a practised skill characterized by cross-disciplinary, transmittable, subject-centred knowledge. The particularity of this skill is that its practice has brought to light an ethical and spiritual dynamic. This calls for the reconsideration of the place occupied by these two aspects of a care professional's skills in the academic *corpa* of these future practitioners as well as in the existential support offered to these people. <https://goo.gl/t2wr8c>

## **Caring at home until death: Enabled determination**

*SUPPORTIVE CARE IN CANCER* | Online – 6 December 2016 – Clarifying caregiving goals and supporting the factors that enable caregiver determination appear to be critical in enhancing the likelihood of a desired home death. [In this study] four themes captured the experience of caring at home until death: 1) Context of providing care; 2) Supportive antecedents to providing care; 3) Determination to provide care at home; and, 4) Enabled determination. Factors that enabled determination ... included initiation of formal palliative care, asking for and receiving help, augmented care, relief or respite, and making the healthcare system work for the ill person. <https://goo.gl/9Pkt3Q>

## **The role of “accompagnement” in the end-of-life debate in France: From solidarity to autonomy**

*THEORETICAL MEDICINE & BIOETHICS* | Online – 3 December 2016 – This article traces the way autonomy has become a recognised value in health care in France. In a country that based its social fundamentals on the very idea of solidarity for many years, autonomy has long been considered a foreign “Anglo-American principle.” Taking the example of the end-of-life (EOL) debate, the article shows, however, how the use of the French term “accompagnement” allowed autonomy to be redefined and to be associated with the concept of solidarity. Exploring the arguments used over the past 25 years in professional guidelines, parliamentary reports, ethics committee reports, and legal texts, the authors describe the shift that took place in public and legal discourses on EOL care. The analysis demonstrates how the scope of autonomy has been limited by other social values, such as the protection of the dying person, in order to become an accepted social value in its own right. The example of the French EOL debate shows that depending on how the concept of autonomy is adapted and applied in a specific context, it can be compatible with the idea of solidarity. Such compatibility has been challenged previously in the international bioethics debate. By demonstrating the possibility of combining autonomy and solidarity, this article makes an important contribution to the international bioethics debate and to the dialogue between countries that are often perceived as significantly different. <https://goo.gl/Z93134>

## **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- *BUNDESGESUNDHEITSBLATT – GESUNDHEITSFORSCHUNG – GESUNDHEITSSCHUTZ* (Federal Health Gazette – Health Research – Health Protection) | Online – 28 November 2016 – ‘**Attitudes and experiences regarding physician assisted suicide: A survey among members of the German Association for Palliative Medicine.**’ More than 90% [of survey respondents] agreed that “wishes for physician-assisted suicide (PAS) may be ambivalent” and “are rather a wish to end an unbearable situation.” Of the 833 participating physicians, 56% refused participating in PAS and 74.2% had been asked to perform PAS. PAS was actually performed by 3%. Of all participating members, 56% approved of a legal ban of organizations offering assisted suicide. More than 60% of all professions agreed that PAS is not a part of palliative care. <https://goo.gl/mTXbmG>

**N.B.** German language article.

Cont.

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 8 December 2016 – ‘**Four reasons why assisted dying should not be offered for depression.**’ Recently, several authors have argued that assisted dying may be ethically appropriate when requested by a person who suffers from serious depression unresponsive to treatment. The authors present four arguments to the contrary. First, the arguments made by proponents of assisted dying rely on notions of “treatment-resistant depression” that are problematic. Second, an individual patient suffering from depression may not be justified in believing that chances of recovery are minimal. Third, the therapeutic significance of hope must be acknowledged; when mental healthcare opens up the door to admitting hopelessness, there is a danger of a self-fulfilling prophecy. Finally, proponents of assisted dying in mental healthcare overlook the dangers posed to mental-health services by the institutionalization of assisted dying. <https://goo.gl/olpUVI>
- *JOURNAL OF THE CANADIAN HEALTH LIBRARIES ASSOCIATION*, 2016;37(3):118-120. ‘**Medically assisted death in Canada – unsettled (and unsettling?) law.**’ This paper explores several controversial and unresolved provisions of the new statute that health librarians may have to assist their patrons in researching. The former provisions are requiring that the patient’s death be reasonably foreseeable, differentiating between the recorded cause and manner of death, and allowing someone other than the patient to sign the medically assisted death request form. The identified unresolved terms relate to the law’s application to mature minors and to psychological disorders, and allowing assisted-dying provisions in personal directives. <https://goo.gl/SMYb7G>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/WAbX4S>

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/5d1I9K>

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



### Closing the Gap Between Knowledge & Technology

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

<http://goo.gl/OTpc8I>



## Worth Repeating

### **Reining in patient and individual choice**

*JOURNAL OF MEDICAL ETHICS*, 2014;40(5):291-292. Patient choice, we might think, is the popular version of the ideas of informed consent and the principle of respect for autonomy and intimately connected to the politics of liberal individualism. There are various accounts to be given for why patient choice, in all its forms, has dominated thinking in bioethics and popular culture. All of them [the author suggests] will make reference to the decline of paternalism. The bad old days of “doctor knows best” are gone and were replaced by the primacy of patient choice and informed consent. The response to the dominance of the principle of patient choice has been slow in building, but it has come in a number of ways. Two articles in this issue of the *Journal of Medical Ethics* show just how far this response has come and the degree to which the pendulum is swinging back in the other direction.<sup>1,2</sup> [Noted in Media Watch 5 May 2014, #356 (p.8)] <https://goo.gl/d0IW34>

1. ‘Forced to be free? Increasing patient autonomy by constraining it.’ <https://goo.gl/RByguo>
2. ‘Against autonomy: Justifying coercive paternalism.’ <https://goo.gl/xDdC0C>

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