EthxWeb Search Results

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Document 1
White, Douglas B; Pope, Thaddeus M
The courts, futility, and the ends of medicine.
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Document 2
Edwards, Craig
"Respect for other selves"
Kennedy Institute of Ethics Journal 2011 December; 21(4): 349-378
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Document 3
Spence, Des
Advance advance directives.
BMJ (Clinical research ed.) 2011 November 2; 343: d7074
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Document 4
White, Douglas B; Arnold, Robert M
The evolution of advance directives.
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Nesdale, Tess
Dying with dignity.
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Document 6
Ritchie, Lorraine
Planning end-of-life care.
A qualitative investigation of selecting surrogate decision-makers.

**Abstract:** Empirical studies of surrogate decision-making tend to assume that surrogates should make only a 'substituted judgement'--that is, judge what the patient would want if they were mentally competent.

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Accuracy of a decision aid for advance care planning: simulated end-of-life decision making.

**Abstract:** Advance directives have been criticized for failing to help physicians make decisions consistent with patients' wishes. This pilot study sought to determine if an interactive, computer-based decision aid that generates an advance directive can help physicians accurately translate patients' wishes into treatment decisions.

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Advance care directives: realities and challenges in Central California.

**Abstract:** To discover where patients with advance directives (ADs) obtain them and to learn what patients' understanding is of how ADs function.

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Exemplary cases in clinical ethics: commentary on the case of Mr. A.

**Abstract:** A commentary on a case of a man who is left a "high quad" (ventilator dependant as well as quadriplegic) after an accident discusses the following: The right of patients who sustain catastrophic injuries to choose to discontinue life-sustaining treatment, The role of capacity assessment in treatment decisions and in ethics consultations, The role of advance directives (ADs) for such patients if they lack capacity, Whether a do-not-resuscitate or do-not-attempt-resuscitation order should be seen as "a medical order" or an advance directive, Some hints about what might be intended when a patient refers to the criterion of having a "meaningful life."
Document 12
Ludwick, Ruth; Baughman, Kristin
Editorial: Advancing the advance care planning process.
International journal of older people nursing 2011 Sep; 6(3): 163-4
Georgetown users check Georgetown Journal Finder for access to full text

Document 13
Jeong, Sarah Yeun-Sim; Higgins, Isabel; McMillan, Margaret
Experiences with advance care planning: nurses' perspective.
International journal of older people nursing 2011 Sep; 6(3): 165-75
Abstract: The aim of this paper is to report the findings of a case study that explored the phenomenon of advanced care planning and advance care directives in residential care settings in Australia. In particular, this paper focuses on the experiences of Registered Nurses with advanced care planning and advance care directives.
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Document 14
Jeong, Sarah Yeun-Sim; Higgins, Isabel; McMillan, Margaret
Experiences with advance care planning: older people and family members' perspective.
International journal of older people nursing 2011 Sep; 6(3): 176-86
Abstract: The aim of this study is to report the findings of a case study that explored the phenomenon of advance care planning and advanced care directives in residential care settings in Australia. In particular, this study focuses on the experiences of residents' and family members'.
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Document 15
Antolín, Albert; Míro, Oscar; Sánchez, Miquel
[Comments on living wills]. = Comentarios acerca del documento de voluntades anticipadas.
Atencion primaria / Sociedad Española de Medicina de Familia y Comunitaria 2011 Sep; 43(9): 503-4; author reply 504
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Document 16
Silvester, William; Detering, Karen
Advance directives, perioperative care and end-of-life planning.
Abstract: It is ethically and legally important, when providing care to our patients, to respect their autonomy and dignity, to act in their best interests and avoid doing harm. Advance care planning is essential to achieving this by giving patients the opportunity to tell us what they would want us to do if they became seriously unwell and could no longer communicate their wishes. Whereas earlier attempts at advance care planning focussed on the completion of forms, the more recent, successful focus has been on the patient-centered discussion, involving family, appointment of substitute decision makers and identification of what the patient would see as an acceptable outcome from any proposed treatment. Advance care planning is successful in caring for the elderly, including in the perioperative setting. There is an increasing focus on improving end-of-life care, including the prevention of suffering, making earlier and wiser end-of-life decisions about the appropriateness of treatment and improving communication with patients and families. New awareness of the poor outcomes from cardiopulmonary resuscitation (CPR) is catalysing reassessment of the appropriateness of this intervention.
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Document 17
Weber, Martina
Pflege Zeitschrift 2011 Sep; 64(9): 560-2
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Document 18
Knott, Cameron I; Psirides, Alex J; Young, Paul J; Sim, Dalice
A retrospective cohort study of the effect of medical emergency teams on documentation of advance care directives.
Abstract: To describe the longitudinal changes in documentation of advance care directives (ACDs), including limitation of medical therapy (LMT) and not-for-resuscitation (NFR) directives among patients reviewed by a medical emergency team (MET).
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Document 19
Durbin, Christine R
When a family questions a living will.
The Nurse practitioner 2011 Aug; 36(8): 9-10
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Document 20
Randall, Fiona
Advance care planning: ethical and clinical implications for hospital medicine.
Abstract: Advance care planning takes place 'in advance of' anticipated loss of capacity with the aim of informing the best interests judgments required when capacity is later lost. It is an ethically and clinically distinct subset of general care planning.
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Document 21
Garand, Linda; Dew, Mary Amanda; Lingler, Jennifer H; DeKosky, Steven T
Incidence and predictors of advance care planning among persons with cognitive impairment.
Abstract: Persons with mild cognitive impairment (MCI) and Alzheimer disease (AD) are at heightened risk for future decisional incapacity. We sought to characterize advance care planning (ACP) rates over time in individuals who had no advance directives (living will or durable power of attorney) in place when they initially presented for a cognitive evaluation.
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Document 22
Su Hyun Kim,
Factors influencing preferences of Korean people toward advance directives.
Nursing ethics 2011 Jul; 18(4): 505-13
Abstract: Although Korean society has begun to seek a way of utilizing advance directives, there is not much known about the factors influencing the average Korean person's preference toward advance directives. The purpose of this study was to examine factors, in addition to demographic variables, influencing preferences regarding advance directives. These include: to what extent people's awareness of advance directives, preferences of extending their life at the end of life, experience of illness and medical care, and family functioning independently influence the preferences toward advance directives. The participants were 382 community-dwelling Korean people. The data analysis was performed using hierarchical multiple logistic regression analysis. The findings showed that a majority of Korean people had a positive preference on advance directives and the factors influencing their preferences for advance directives were the preferences against the use of life-sustaining treatment at the end of life, a good self-rated health status, and an unsatisfactory family functioning.

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**Document 23**
Thomasson, Joseph; Petros, Tommy; Lorenzo-Rivero, Shauna; Moore, Richard A; Stanley, J Daniel
*Quality of documented consent for the de-escalation of care on a general and trauma surgery service.*
The American surgeon 2011 Jul; 77(7): 883-7

Abstract: Postoperative and posttrauma mortality in the acute care setting often occurs after a decision for de-escalation of care. It is important that the quality of consent for de-escalation of care is maintained to ensure patient autonomy. This retrospective review aims to determine the quality of the consent process for care de-escalation in patients on a trauma and general surgery service who sustained in-hospital mortality. One hundred thirty-three patients (99 trauma) were identified who died in 1 year. Of these patient deaths, 80 (60%) involved de-escalation of care. In three (3%) cases, there were no documented discussions for de-escalation consent. Of the remaining cases, documentation was considered optimal 21 per cent of the time. Only nine (11%) patients were able to participate in a discussion of their end-of-life care. The other 23 patients who were initially competent lost their ability to participate in discussions after a debilitating event. In this study, the majority of patients who died on a surgical service underwent a de-escalation of care. The documentation quality was suboptimal in most cases. Earlier and more thorough discussion of the patient's end-of-life wishes may improve the de-escalation of care consent process.

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**Document 24**
Miracle, Vickie A
*Advanced directives.*

**Document 25**
Bond, Catherine Jane; Lowton, Karen
Age and ageing 2011 Jul; 40(4): 450-6

Abstract: An anticipatory decision document records a person's wishes regarding medical treatment at a time when they have capacity to make choices, to be enacted when this capacity is lost. In England and Wales an advance decision to refuse treatment (ADRT, or advance decision), a legally binding document, is currently rarely used. A disparity is suggested to exist between physicians' support for anticipatory decisions in principle and their lack of impact on decision-making in practice.

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**Document 26**
Dunn, Andrew; Litrivis, Evgenia
*Aligning patient preferences and patient care at the end of life.*
Journal of general internal medicine 2011 Jul; 26(7): 681-2

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Document 27
Weaver, Susan
**POLST [Physician Orders for Life-Sustaining Treatment] is coming to New Jersey.**
New Jersey nurse 2011 Jul; 41(3): 7
Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 28
**Too much to ask?**
The Hastings Center report 2011 Jul-Aug; 41(4): 15
Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 29
Lammers, Stephen E
**Case study. Too much to ask? Commentary.**
The Hastings Center report 2011 Jul-Aug; 41(4): 16
Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 30
Smith, Lauren B; Lyndale, Patricia J
**Case study. Too much to ask? Commentary.**
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Document 31
Albers, Gwenda; Pasman, H Roeline W; Rurup, Mette L; de Vet, Henrica C W; Onwuteaka-Philipsen, Bregje D
**Analysis of the construct of dignity and content validity of the patient dignity inventory.**
Health and quality of life outcomes 2011 June 19; 9: 45
**Abstract:** Maintaining dignity, the quality of being worthy of esteem or respect, is considered as a goal of palliative care. The aim of this study was to analyse the construct of personal dignity and to assess the content validity of the Patient Dignity Inventory (PDI) in people with an advance directive in the Netherlands.
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Document 32
Vyshka, Gentian; Kruja, Jera
**Inapplicability of advance directives in a paternalistic setting: the case of a post-communist health system.**
BMC medical ethics 2011 June 15; 12: 12
**Abstract:** The Albanian medical system and Albanian health legislation have adopted a paternalistic position with regard to individual decision making. This reflects the practices of a not-so-remote past when state-run facilities and a totalitarian philosophy of medical care were politically imposed. Because of this history, advance directives concerning treatment refusal and do-not-resuscitate decisions are still extremely uncommon in Albania. Medical teams cannot abstain from intervening even when the patient explicitly and repeatedly solicits therapeutic abstinence. The Albanian law on health care has no provisions regarding limits or withdrawal of treatment. This restricts the individual's healthcare choices.
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Document 33
Katsetos, Antonios D; Mirarchi, Ferdinando L
A living will misinterpreted as a DNR order: confusion compromises patient care.
Abstract: Advance directives are becoming ever more commonplace in the United States. Correct interpretation of living wills and do-not-resuscitate (DNR) orders is essential if patient safety and autonomy are to be preserved.

Document 34
Muramoto, Osamu
Socially and temporally extended end-of-life decision-making process for dementia patients.
Abstract: There are two contrasting views on the decision-making for life-sustaining treatment in advanced stages of dementia when the patient is deemed incompetent. One is to respect the patient's precedent autonomy by adhering to advance directives or using the substituted judgement standard. The other is to use the best-interests standard, particularly if the current judgement on what is best for the incapacitated patient contradicts the instructions from the patient's precedent autonomy. In this paper, I argue that the protracted clinical course of dementia over many years requires the extended perspective of a progressive decision-making process-extended in both social space and time. The ongoing debate between these two competing views has missed this perspective by focussing on an exclusive disjunction between the competent former self and the incompetent current self. Drawing on theories of situated cognition in cognitive science, I will show that the cognition of a demented patient can be viewed as extended and embodied by her supportive social environment. As the disease progresses, the content of the mind of a demented person becomes partially constituted by such external resources along with her diminishing intrinsic mind. With this understanding, medical decision-making for a demented patient can be construed as a temporally and socially extended practice. A collective decision-making body consisting of the patient, her family and surrogates, and the clinician, should make progressive decisions as a whole over years of the disease course. Finally, I will provide a practical example of how this proposal can be applied in clinical practice.

Document 35
Robinson, Carole A
Advance care planning: revising our ethical approach.
The Canadian journal of nursing research = Revue canadienne de recherche en sciences infirmières 2011 Jun; 43(2): 18-37
Abstract: This qualitative study explored the applicability and usefulness of a promising advance care planning (ACP) intervention and examined the ACP process. Nine dyads (patients newly diagnosed with advanced lung cancer and a family member) participated in the ACP intervention, with evaluative interviews at 3 and 6 months after the intervention. All interviews were recorded, transcribed verbatim, and analyzed using constant comparison. The process was found not to be one of preparing a substitute decision-maker to speak for oneself and direct health care at a time when one is incapacitated; rather, the families engaged in a deeply relational process where meaning, values, and preferences were negotiated in conversation. ACP is theoretically rooted in a traditional notion of patient autonomy that is not aligned with the relational process that unfolded in this study. An approach that embraces relational autonomy is more congruent and provides a stronger foundation for meeting the needs of families.

Document 36
Fried, Terri R; Redding, Colleen A; Robbins, Mark L; O'Leary, John R; Iannone, Lynne
Agreement between older persons and their surrogate decision-makers regarding participation in advance care planning.
Abstract: To examine agreement between older persons and their surrogates regarding participation in advance care planning (ACP).
Document 37

**Advanced directives for euthanasia in dementia: how do they affect resident care in Dutch nursing homes?**

Experiences of physicians and relatives.


**Abstract:** To gain insight into how advance directives for euthanasia affect resident care in Dutch nursing homes.

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Document 38

**Palliative medicine consultation for preparedness planning in patients receiving left ventricular assist devices as destination therapy.**


**Abstract:** To assess the benefit of proactive palliative medicine consultation for delineation of goals of care and quality-of-life preferences before implantation of left ventricular assist devices as destination therapy (DT).

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Document 39

**The visitor: People have a right to live--and a right to die.**

EMS world 2011 Jun; 40(6): 20

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Document 40

**The near-death patient: a dying man's orders restrict his treatment--but what about during transport?**

EMS world 2011 Jun; 40(6): 24-6

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Document 41

**Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand.**


**Abstract:** In New Zealand an advance directive can be either an oral statement or a written document. Such directives give individuals the opportunity to make choices about future medical treatment in the event they are cognitively impaired or otherwise unable to make their preferences known. All consumers of health care have the right to make an advance directive in accordance with the common law. When we consider New Zealand’s rapidly ageing population, the fact that more people now live with and die of chronic rather than acute conditions, the importance given to respecting autonomous decision-making, increasing numbers of individuals who require long-term residential care, and financial pressures in the allocation of medical resources, there would seem to be a number of compelling reasons to encourage individuals to write or verbalize an advance directive. Indeed the promotion of advance directives is encouraged. However, caution should be exercised in promoting advance directives to older people, especially in light of several factors: ageist attitudes and stereotypes towards them, challenges in the primary healthcare setting, and the way in which advance directives are currently focused and formulated. This paper considers some of the specific challenges that need to be addressed if the promotion of advance directives are to improve outcomes of patient treatment and care near the end of life.
**Document 42**

Franco Tovar, B; da Silva Gama, Z A; Saturno Hernández, P J

[**Advanced knowledge of patient preferences for end-of-life care in national health service hospitals of the Murcia Region.** = Conocimiento de las preferencias de los pacientes terminales en los hospitales públicos de la Región de Murcia.]

Revista de calidad asistencial : órgano de la Sociedad Española de Calidad Asistencial 2011 May-Jun; 26(3): 152-60

**Abstract:** Provision of unwanted end-of-life care is an adverse event that can be avoided and is regulated by law. One of the Safe Practices recommended by the National Quality Forum (NQF) is “Ensure that patient preferences regarding end-of-life care are known”. Our objective is to assess compliance with this recommendation, and the associated socio-professional factors, in the National Health Service hospitals in the Murcia Region (Spain).

**Document 43**

Hertogh, Cees M P M

**The misleading simplicity of advance directives.**

International psychogeriatrics / IPA 2011 May; 23(4): 511-5

**Document 44**

Habal, Marlena V; Micevski, Vaska; Greenwood, Sarah; Delgado, Diego H; Ross, Heather J

**How aware of advanced care directives are heart failure patients, and are they using them?**

The Canadian journal of cardiology 2011 May-Jun; 27(3): 376-81

**Abstract:** The increasing prevalence of heart failure and its unpredictable trajectory highlight the need for patients to make their end-of-life care wishes known using advanced care directives (ACDs). The paucity of literature addressing heart failure patients’ decision-making processes and knowledge of ACDs underscores the need for investigation. The purposes of this study were to (1) determine patients’ awareness, comprehension, and utilization of ACDs and (2) determine their knowledge of the process of cardiopulmonary resuscitation and their current resuscitation preference.

**Document 45**

Antolín, Albert; Sánchez, Miquel; Miró, Oscar

[**Advance directives: long way to go to achieve full autonomy of the patient.** = Documentos de voluntades anticipadas: mucho camino por recorrer para alcanzar una autonomía plena del paciente.

Medicina clínica 2011 Apr 9; 136(9): 409-10

**Document 46**

Turillazzi, Emanuela; Fineschi, Vittorio

**Advance directives in therapeutic intervention: a review of the Italian bioethical and juridical debate.**

Medicine, science, and the law 2011 Apr; 51(2): 76-80

**Abstract:** The authors present a review of the Italian bioethical and juridical debate about advance directives. The relevant points of difference between desistence from therapy and euthanasia and of the definition of the concept of therapy are also examined. The Italian Senate has passed a bill in which the value of advance health-care directives is affirmed. However, it is also affirmed that in conditions of emergency or when the subject's life is at immediate risk, the advance health-care directives should not be applied and artificial nutrition and hydration cannot be included in advance directives. In fact, these
practices are thought to be of vital support and physiologically aimed at alleviating suffering until the end of life. Therefore, they cannot be the object of advance health-care directives. It is the authors' view that it is not at all desirable to trust legislative choices about a subject which continually varies in relation to scientific and clinical knowledge, options and alternatives. The physician is rather asked for a behaviour inspired by the value of the dignity and autonomy of the persons involved, by the respect of wishes previously expressed or, in any case, objectively proved.

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Document 47
Rüddel, H; Zenz, M

[Validation of an advance directive]. = Validierung einer Patientenverfügung.
Der Anaesthesist 2011 Apr; 60(4): 325-33

Abstract: German Legislation has defined the legal significance of advance directives (AD). Nevertheless, many precast ADs are of limited help in clinical decision making. Empirical results are rare and controversial. The SUPPORT study showed that precast ADs had a tendency to being ignored. Value-based AD proved to be of help in the interpretation of patients' wills by physicians. We therefore investigated whether a value-based AD that can be individualized with the help of a check-box-system is a valid instrument of communicating the patient's preferences. This is the first validation of an AD.

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Document 48
Halpern, Neil A; Pastores, Stephen M; Chou, Joanne F; Chawla, Sanjay; Thaler, Howard T

Advance directives in an oncologic intensive care unit: a contemporary analysis of their frequency, type, and impact.

Abstract: Our objective was to provide a contemporary analysis of the prevalence, types, and impact of advance health care directives in critically ill cancer patients.

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Document 49
Ting, Fion H; Mok, Esther

Advance directives and life-sustaining treatment: attitudes of Hong Kong Chinese elders with chronic disease.
Hong Kong medical journal = Xianggang yi xue za zhi / Hong Kong Academy of Medicine 2011 Apr; 17(2): 105-11

Abstract: To examine the attitudes of Hong Kong Chinese elders with chronic disease with regard to advance directives and life-sustaining treatment.

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Document 50
Bravo, Gina; Dubois, Marie-France; Cohen, Carole; Wildeman, Sheila; Graham, Janice; Painter, Karen; Bellemare, Suzanne

Are Canadians providing advance directives about health care and research participation in the event of decisional incapacity?

Abstract: Advance planning for health care and research participation has been promoted as a mechanism to retain some control over one's life, and ease substitute decision making, in the event of decisional incapacity. Limited data are available on Canadians' current advance planning activities. We conducted a postal survey to estimate the frequency with which Canadians communicate their preferences about health care and research should they become incapacitated.

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Hérisson, Brigitte

[Let’s apply the Leonetti’s law at every care setting]. = Faisons vivre la loi Leonetti dans tous les lieux de soins.
Soins; la revue de référence infirmière 2011 Apr(754): 1

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Swetz, Keith M; Kuczewski, Mark G; Mueller, Paul S

Surrogate decision-making and the need for advance care planning: issues raised by the Al Barnes case.
Minnesota medicine 2011 Apr; 94(4): 43-6

Abstract: Decisions regarding health care are increasingly difficult to make, especially as patients live longer and with more medical comorbidities. The case of Al Barnes, a man with advanced dementia who recently died in a Minnesota hospital despite months of aggressive care, illustrates the frequently encountered challenges that go along with making decisions about medical care for patients who lack the ability to do so themselves. These challenges can lead surrogates to opt for treatments that are efficacious but may be burdensome and inconsistent with the values, goals, or preferences the patient previously expressed either orally or in a written advance directive. In this article, we describe approaches that may help those who must make decisions for patients who cannot do so themselves and the merits and limitations of advance care planning.

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Golden, Adam G; Tewary, Sweta; Qadri, Syeda; Zaw, Khin; Ruiz, Jorge G; Roos, Bernard A

The positive attitudes and perceptions of care managers about advance directives.

Abstract: In a previous intervention, we found that reminders from care managers failed to increase the number of their homebound older adult clients with advance directives. Thus, in the current study, we looked at the perceptions and attitudes of care managers about the need to discuss advance directives with their clients. Ninety-five care managers serving community-based nursing home-eligible older adults completed an 18-question survey, which found that care managers overwhelmingly believe it is important to address advance directives. Only 3.2% reported that discussing advance directives is time consuming. No attitudinal barriers were identified. Given their positive attitudes about advance directives, care managers need educational interventions that will provide the knowledge and skills to interact effectively with clients who are resistant to addressing end-of-life issues.

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Yang, Chia-Ling; Chiu, Tai-Yuan; Hsiung, Yi-Fang Yvonne; Hu, Wen-Yu

Which factors have the greatest influence on bereaved families’ willingness to execute advance directives in Taiwan?
Cancer nursing 2011 Mar-Apr; 34(2): 98-106

Abstract: Preferences for end-of-life care and attitudes toward executing advance directives (ADs) vary depending on ethical and cultural influences. In traditional Asian family-centered decision making, the family makes important medical decisions. Few studies have examined willingness of Taiwanese to execute ADs.

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Mooiman, Sara M

Older adults’ preferences for independent or delegated end-of-life medical decision making.
Journal of aging and health 2011 Feb; 23(1): 135-57

Abstract: This study assesses the proportions of participants who prefer independent or delegated medical decision making at the end of life and examines the relationships of personal beliefs, affiliative beliefs, and end-of-life planning behaviors to decision-making preference.

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Wiese, C H R; Bartels, U E; Ruppert, D B; Graf, B M; Hanekop, G G

Prehospital emergency physicians' experiences with advance directives in Germany: a questionnaire-based multicenter study.

Minerva anestesiologica 2011 Feb; 77(2): 172-9

Abstract: Palliative medical emergencies and end-of-life decisions resulting from the exacerbation of cancer account for approximately 3% of all out-of-hospital emergency applications in Germany. Therefore, prehospital emergency physicians (EP) may be confronted with advance directives and ethical and end-of-life decisions. The purpose of the study was to identify EPs' knowledge about ethical and end-of-life decisions and their legal education and experiences concerning advance directives.

Chu, Leung-Wing; Luk, James K H; Hui, Elsie; Chiu, Patrick K C; Chan, Cherry S Y; Kwan, Fiona; Kwok, Timothy; Lee, Diana; Woo, Jean

Advance directive and end-of-life care preferences among Chinese nursing home residents in Hong Kong.

Journal of the American Medical Directors Association 2011 Feb; 12(2): 143-52

Abstract: The objectives of the present study were to describe the knowledge and preferences of Hong Kong Chinese older adults regarding advance directives and end-of-life care decisions, and to investigate the predictors of preferences for advance directive and community end-of-life care in nursing homes.

Swetz, Keith M; Mueller, Paul S; Ottenberg, Abigale L; Dib, Chadi; Freeman, Monica R; Sulmasy, Daniel P

The use of advance directives among patients with left ventricular assist devices.


Abstract: Patients who undergo implantation of left ventricular assist devices (LVADs) often have improved quality of life, but may eventually succumb to their heart failure and/or sustain LVAD-related complications. In end-of-life situations, decisions must be made about when to deactivate LVAD support. Previous studies have demonstrated that end-of-life planning, particularly with the use of advance directives (ADs), can clarify patients' end-of-life preferences when they are unable to speak for themselves. However, many patients do not have ADs, and among patients who do, the ADs may lack useful information on how to guide care surrogates and clinicians regarding patients' preferences on life-sustaining treatments. The authors retrospectively reviewed the charts of 68 patients with advanced heart failure (56 men [82%]; mean [standard deviation] age, 59.0 ± 12.2 years) who underwent LVAD implantation between March 2003 and January 2009. The indication for the LVAD was destination therapy in 36 (53%) patients and bridge to heart transplant in 32 (47%) patients. Overall, 32 (47%) patients had ADs of varying types; 25 (78%) ADs were completed before LVAD implantation. Although life-sustaining treatments (eg, tube feeding, cardiopulmonary resuscitation, mechanical ventilation, and hemodialysis) were mentioned, none explicitly mentioned the LVAD or withdrawal of LVAD support at the end of life. We hypothesize that if instructions regarding LVAD management in ADs are explicit, surrogate and clinician distress may decrease, and ethical dilemmas may be avoided.

Bell, Howard

Personalized medicine.

Minnesota medicine 2011 Feb; 94(2): 22-7

Abstract: Patients who undergo implantation of left ventricular assist devices (LVADs) often have improved quality of life, but may eventually succumb to their heart failure and/or sustain LVAD-related complications. In end-of-life situations, decisions must be made about when to deactivate LVAD support. Previous studies have demonstrated that end-of-life planning, particularly with the use of advance directives (ADs), can clarify patients' end-of-life preferences when they are unable to speak for themselves. However, many patients do not have ADs, and among patients who do, the ADs may lack useful information on how to guide care surrogates and clinicians regarding patients' preferences on life-sustaining treatments. The authors retrospectively reviewed the charts of 68 patients with advanced heart failure (56 men [82%]; mean [standard deviation] age, 59.0 ± 12.2 years) who underwent LVAD implantation between March 2003 and January 2009. The indication for the LVAD was destination therapy in 36 (53%) patients and bridge to heart transplant in 32 (47%) patients. Overall, 32 (47%) patients had ADs of varying types; 25 (78%) ADs were completed before LVAD implantation. Although life-sustaining treatments (eg, tube feeding, cardiopulmonary resuscitation, mechanical ventilation, and hemodialysis) were mentioned, none explicitly mentioned the LVAD or withdrawal of LVAD support at the end of life. We hypothesize that if instructions regarding LVAD management in ADs are explicit, surrogate and clinician distress may decrease, and ethical dilemmas may be avoided.
Document 60

Halaas, Gwen Wagstrom

The best care.
Minnesota medicine 2011 Feb; 94(2): 30-2

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Document 61

Price, Lynn J

We need to talk.
Minnesota medicine 2011 Feb; 94(2): 56

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Document 62

Ahmed, Kamran; Daniels, Nazi; Aswad, Azhar; Ng, Nicola; Cohen, Victoria

An audit of resuscitation status decisions in an older adult psychiatric unit.
International journal of geriatric psychiatry 2011 Feb; 26(2): 214-6

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Document 63

Wilkinson, Dominic James

A life worth giving? The threshold for permissible withdrawal of life support from disabled newborn infants.

Abstract: When is it permissible to allow a newborn infant to die on the basis of their future quality of life? The prevailing official view is that treatment may be withdrawn only if the burdens in an infant's future life outweigh the benefits. In this paper I outline and defend an alternative view. On the Threshold View, treatment may be withdrawn from infants if their future well-being is below a threshold that is close to, but above the zero-point of well-being. I present four arguments in favor of the Threshold View, and identify and respond to several counter-arguments. I conclude that it is justifiable in some circumstances for parents and doctors to decide to allow an infant to die even though the infant's life would be worth living. The Threshold View provides a justification for treatment decisions that is more consistent, more robust, and potentially more practical than the standard view.

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Document 64

Chen, Yen-Chang; Chen, Yen-Yuan

A moderate zero line approach: opposing thresholds beyond the zero line.

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 65

Castillo, Lesley S; Williams, Brie A; Hooper, Sarah M; Sabatino, Charles P; Weithom, Lois A; Sudore, Rebecca L

Lost in translation: the unintended consequences of advance directive law on clinical care.
Annals of internal medicine 2011 Jan 18; 154(2): 121-8

Abstract: Advance directive law may compromise the clinical effectiveness of advance directives.

Georgetown users check [Georgetown Journal Finder](#) for access to full text
Document 66
Vogel, Lauren

*Advance directives: obstacles in preparing for the worst.*

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 67
Campbell, Ellen; Newton, Shawn

*Planning for final exit.*
CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne 2011 Jan 11; 183(1): 84

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 68
Thomson Reuters/West

Issue brief (Health Policy Tracking Service) 2011 Jan 3: 1-37

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 69
Bomba, Patricia A; Morrissey, Mary Beth; Leven, David C

*Key role of social work in effective communication and conflict resolution process: Medical Orders for Life-Sustaining Treatment (MOLST) Program in New York and shared medical decision making at the end of life.*

**Abstract:** In this article, the authors review the development of the Medical Orders for Life-Sustaining Treatment (MOLST) Program and recent landmark legislation in New York State in the context of advance care planning and shared medical decision making at the end of life. Social workers are central health care professionals in working with patients, families, practitioners, health care agents, and surrogates in the health systems and in the communication and conflict resolution process that is integral to health care decision making. The critical importance of ethics and end-of-life training and education for social workers is also addressed. Data from a pilot study evaluating interdisciplinary ethics training on legal and ethical content in communication and conflict resolution skills in health care decision making are reported. Recommendations are made for research on education and training of social workers, and investigation of the role and influence of systems in shaping social work involvement in end-of-life and palliative care.

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Document 70
Bullock, Karen

*The influence of culture on end-of-life decision making.*

**Abstract:** In their research, scholars have documented racial and ethnic differences in end-of-life care preferences, which have translated into cultural barriers. However, few studies have explained the racial differences. In the present study, focus groups with semi-structured follow-up interviews were utilized to elicit explanations for variance in decision making in a sample of Black and White community-dwelling residents. Participants identified specific cultural beliefs, values, and communication patterns that can be used to promote cultural competency among practitioners who provide care at end of life.

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[Ethical conflicts over verbal statements regarding last wishes]. = Conflictos éticos ante la manifestación verbal de las últimas voluntades.

**Abstract:** Within our socio-professional framework, there are few occasions in which there is sincere communication between health care teams and patients and their families that allows questions to be raised about decisions made during the process of an illness i.e., whether an intervention, or its omission in certain cases, would be accepted. Decisions regarding representation or living wills are merely an extension of the inclusion of the patients' moral autonomy in clinical decision making. Nevertheless, the best way to make patients' rights effective is not by focussing on these documents, but rather by achieving the development of integral processes that promote patient participation and decision making. On the basis of a discussion in which a number of ethical conflicts that concern patients' last wishes are intertwined, we present the following clinical case that allows reflection on the most effective kind of intervention, the nature of its duration and intensity and the way health care professionals must be faithful to patients' and families' desires and expressions in these cases.

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**Document 72**

Sharman, Stefanie J

**Current negative mood encourages changes in end-of-life treatment decisions and is associated with false memories.**


**Abstract:** To investigate the effects of mood on people's end-of-life treatment decisions and their false memories of those decisions, participants took part in two sessions. At Time 1, participants were experimentally induced into positive or negative moods. They decided whether they would want to receive or refuse treatments in a range of hypothetical medical scenarios, such as tube feeding while in a coma. Four weeks later, at Time 2, participants were induced into the same or the opposite mood and made these decisions a second time. They also recalled their previous decisions. Participants in negative moods at Time 2 changed more of their current decisions and falsely remembered more of their previous decisions than participants in positive moods. These findings suggest that people's current moods influence whether they change their treatment decisions; current decisions in turn bias recall of past decisions.

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**Document 73**

Navarro Bravo, Beatriz; Sánchez García, Margarita; Andrés Pretel, Fernando; Juárez Casalengua, Inés; Cerdá Díaz, Rosario; Párraga Martínez, Ignacio; Jiménez Redondo, José Ramón; López-Torres Hidalgo, Jesús D

[Living will declarations: Qualitative study of the elderly and primary care general practitioners]. = Declaración de voluntades anticipadas: estudio cualitativo en personas mayores y médicos de Atención Primaria.

Atención primaria / Sociedad Española de Medicina de Familia y Comunitaria 2011 Jan; 43(1): 11-7

**Abstract:** First, to assess knowledge and attitudes of people aged 65 and over to the Advance Directives Document (ADD) and know the role that, in their opinion, a family doctor should play in the early planning of death. Second, to assess the level of knowledge and attitude of primary care physicians to that document, as well as to know the role played by these professionals.

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**Document 74**

Kostorz, P

[The medical treatment of patients who are incapable of giving consent to a medical measure in the focus of the new law of living will in °° 1901a and 1901b BGB]. = Die ärztliche Behandlung einwilligungsunfähiger Patienten im Licht des neuen Patientenverfügungsrechts nach °° 1901a und 1901b BGB.

Gesundheitswesen (Bundesverband der Ärzte des Öffentlichen Gesundheitsdienstes (Germany)) 2011 Jan; 73(1): 13-9

**Abstract:** With the new law of living will which came into force on September 1 (st) 2009 the legislator has ended a long-lasting discussion about the erection, the range and the putting into action of living wills. This essay describes the new regulations in the German Civil Code (BGB) and discusses which aspects need to be taken into consideration at the
treatment of patients being (un)able to consent to a medical measure.

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Document 75

Cai, Xueya; Cram, Peter; Li, Yue

Origination of medical advance directives among nursing home residents with and without serious mental illness.

Abstract: Nursing home residents with serious mental illness need a high level of general medical and end-of-life services. This study tested whether persons with serious mental illness are as likely as other nursing home residents to make informed choices about treatments through medical advance care plans.

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Document 76

Jones, Adrienne L; Moss, Abigail J; Harris-Kojetin, Lauren D

Use of advance directives in long-term care populations.
NCHS data brief 2011 Jan(54): 1-8

Abstract: An advance directive (AD) allows a patient to communicate health care preferences in the event that he or she is no longer able to make these decisions. Many view advance care planning (ACP) as a process that includes discussing values and goals of care among the patient, family, and physician, and determining or executing treatment directives as a way to help ensure that wishes about end-of-life care are honored. Ideally, ADs are part of the ACP process. Twenty years ago, Congress passed the Patient Self-Determination Act (PSDA) requiring most health care facilities to inform adult patients about their rights to execute an AD. Research indicates that the preference for having an AD can be influenced by individual attitudes, cultural beliefs, health conditions, and trust in health care professionals. This report presents the latest national data on ADs in three long-term care populations: those receiving home health care or hospice care and those residing in nursing homes.

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Document 77

Samsi, Kritika; Manthorpe, Jill

'I live for today': a qualitative study investigating older people's attitudes to advance planning.
Health & social care in the community 2011 Jan; 19(1): 52-9

Abstract: This article reports investigation of prevalent understandings and systems of beliefs that underpin older people's attitudes towards making plans for their future. The Mental Capacity Act 2005 (MCA) enables adults with capacity to make plans and decisions in advance, to arrange proxy decision-making and provides safeguards for those who might lose the capacity to make decisions for themselves in the future. This study explored the attitudes of a diverse sample of 37 self-declared well older people living in the community in England about their views on drawing up statements of wishes and documenting their decision-making preferences. The study was conducted in early 2009. Findings revealed that most individuals had a personal tendency or preference towards planning, guided by personality, beliefs, living situation and the relevancy of planning to their situation. Financial plans and funeral arrangements were most commonly drawn up with an absence of health and social care plans, which participants tended to postpone considering. Housing and residential care were important for all. Overall, few participants had heard of the MCA and most were unsure where to turn for support. Participants appreciated support when discussing these issues; some turned to family, while others felt professionals were a more appropriate source of advice. The family doctor was cited as trustworthy and a potential place to begin inquiries. Conceptualising onset of certain debilitating conditions also encouraged participants to think about planning for them. This study has implications for public education campaigns and health-related information that could potentially impact on many older people who are interested in making plans but are unaware that legal safeguards and practical support are available to aid this.

Georgetown users check Georgetown Journal Finder for access to full text

Document 78

Mitchell, Jennifer K
POLST complement advance directives to better honor patients' preferences for end-of-life care.
ONS connect 2011 Jan; 26(1): 19
Georgetown users check Georgetown Journal Finder for access to full text

Dimick, Chris
Sorting out advance directives.
Journal of AHIMA / American Health Information Management Association 2011 Jan; 82(1): 26-30; quiz 31
Abstract: Important differences exist in advance directives. Only some grant access to another person's medical records, and that can change with time.
Georgetown users check Georgetown Journal Finder for access to full text

Walter, Jennifer K; Goold, Susan Dorr
Case study. Conjectural mixed motives. Commentary.
The Hastings Center report 2011 Jan-Feb; 41(1): 12
Georgetown users check Georgetown Journal Finder for access to full text

Jones, Adrienne; Moss, Abigail J.; and Harris-Kojetin, Lauren D.
National Center for Health Statistics (U.S.)
USE OF ADVANCE DIRECTIVES IN LONG-TERM CARE POPULATIONS
http://www.cdc.gov/nchs/data/databriefs/db54.pdf (link may be outdated)

Thomas, Keri and Lobo, Ben, eds.
ADVANCE CARE PLANNING IN END OF LIFE CARE
Call number: R726.2.A37 2011

Bachl, Margrit
[Final words]. = Worte zum Schluss.
Krankenpflege. Soins infirmiers 2011; 104(10): 5
Georgetown users check Georgetown Journal Finder for access to full text

Näf, Ernst
Krankenpflege. Soins infirmiers 2011; 104(10): 10-3, 48-51, 72-5
Document 85

Näf, Ernst

[Patient wills: better legal anchorage]. = Patientenverfügungen: Rechtlich besser verankert.
Krankenpflege. Soins infirmiers 2011; 104(10): 13-4

Document 86

Taillens, Françoise

[Informed choices]. = Des choix éclairés.
Krankenpflege. Soins infirmiers 2011; 104(10): 43

Document 87

Bagnaschi, Pia

[Respect for autonomy]. = Il rispetto dell'autonomia.
Krankenpflege. Soins infirmiers 2011; 104(10): 69

Document 88

Hajizadeh, Negin; Crothers, Kristina; Braithwaite, R Scott

A theoretical decision model to help inform advance directive discussions for patients with COPD.
BMC medical informatics and decision making 2010 December 20; 10: 75

Abstract: Advance directives (AD) may promote preference-concordant care yet are absent in many patients with Chronic Obstructive Pulmonary Disease (COPD). In order to begin to inform AD discussions between clinicians and COPD patients, we constructed a decision tree to estimate the impact of alternative AD decisions on both quality and quantity of life (quality adjusted life years, QALYs).

Document 89

Glauser, Wendy

Australian physician advises advance planning for final exit.
CMAJ : Canadian Medical Association journal = journal de l'Association medicale canadienne 2010 Dec 14; 182(18): E815-6

Document 90

Mallia, Pierre

Clinical intervention in aging: ethicolegal issues in assessing risk and benefit.
Clinical interventions in aging 2010 December 2; 5: 373-80

Abstract: The ethical dimension of treating the elderly, including risk-benefit analysis, focuses mainly on quality of life and end-of-life issues. These include arguments on advance directives and the concept of extraordinary treatments. This paper looks more closely at the philosophical approach to aging in order to address questions on the direction of research and issues such as longevity and social construction of the aging process. It is the way society moves to understand the value-
laden choices on aging that directs the goals of treatment and research. Whilst these vary culturally, one has to reckon with a postmodern view of aging which may, in turn, reflect on the course of action of future care and research in aging. The paper canvasses how, in reality, four principles act as guidelines for moral discourse, and discusses how changing values in society decide this course of action.

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**Document 91**

Beth Karver, Sloan; Berger, Jessalyn

The importance of discussing living wills with patients with heart failure.

Revista española de cardiología 2010 Dec; 63(12): 1396-8

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**Document 92**

Antolín, Albert; Sánchez, Miquel; Llorens, Pere; Martín Sánchez, Francisco Javier; González-Armengol, Juan Jorge; Ituño, Juan P; Carbajosa, José F; Fernández-Cañadas, José M; González del Castillo, Juan; Miró, Óscar

[Knowledge about disease course and living wills among patients with heart failure]. = Conocimiento de la enfermedad y del testamento vital en pacientes con insuficiencia cardiaca.

Revista española de cardiología 2010 Dec; 63(12): 1410-8

**Abstract:** To determine the level of knowledge about possible disease outcomes and living wills among patients with heart failure (HF) treated in an emergency department and to evaluate their willingness to draw up a living will.

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**Document 93**

Cohen, Marya J; McCannon, Jessica B; Edgman-Levitan, Susan; Kormos, William A

Exploring attitudes toward advance care directives in two diverse settings.

Journal of palliative medicine 2010 Dec; 13(12): 1427-32

**Abstract:** Advance care directives (ACD) are not used equally by different ethnic groups in the United States. Theories regarding this difference include lack of access to health care, mistrust of the health care system, absence of surrogate decision makers, and universal lack of knowledge on this topic. Few studies have investigated attitudes toward advance care planning for future end-of-life decision-making in the Latino and Cambodian communities.

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**Document 94**

Willmott, Lindy; White, Ben; Mathews, Ben

Law, autonomy and advance directives.

Journal of law and medicine 2010 Dec; 18(2): 366-89

**Abstract:** The principle of autonomy underpins legal regulation of advance directives that refuse life-sustaining medical treatment. The primacy of autonomy in this domain is recognised expressly in the case law, through judicial pronouncement, and implicitly in most Australian jurisdictions, through enactment into statute of the right to make an advance directive. This article seeks to justify autonomy as an appropriate principle for regulating advance directives and relies on three arguments: the necessity of autonomy in a liberal democracy; the primacy of autonomy in medical ethics discourse; and the uncontested importance of autonomy in the law on contemporaneous refusal of medical treatment. This article also responds to key criticisms that autonomy is not an appropriate organising principle to underpin legal regulation of advance directives.

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**Document 95**

Wiesing, U; Jox, R J; Hessler, H-J; Borasio, G D

Georgetown users check Georgetown Journal Finder for access to full text
A new law on advance directives in Germany.

Journal of medical ethics 2010 Dec; 36(12): 779-83

Abstract: This article presents the new German law on advance directives from 1 September 2009. The history of the parliamentary process of this law is described, the present regulations are explained, their relevance for medical practice discussed and shortcomings are identified. Finally, the new law is compared with other regulations in the international context. Previously established legal practice in Germany has now become largely confirmed by the new law: An advanced directive must be respected in any decision concerning medical treatment, regardless of the stage of the illness. It can be informally revoked at any time, even with limited decision-making capacity. Nobody may be obliged to issue a directive in any way. Advance directives do not need notarisation or routine updating after certain time intervals. Provided that the patient, who is no longer mentally competent, has issued a lasting power of attorney (Bevollmächtiger), or provided that the patient has been appointed a healthcare proxy by the courts (Betreuer), this authorized surrogate must assert the patient's will. The role of the guardianship court is clarified: it only needs to be involved in cases of disagreement as to the patient's will. The new German law thus combines more legal certainty with a liberal emphasis on patient autonomy and flexible, adaptable regulations.

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What constitutes a 'good death'?

Castledine, George


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Practical use of advance directives.

Keay, Timothy J

Maryland medicine: MM: a publication of MEDCHI, the Maryland State Medical Society 2010 Winter; 11(1): 11-2

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Who will speak for me?

Nay, Patricia Tomsko; Vaughan, William

Maryland medicine: MM: a publication of MEDCHI, the Maryland State Medical Society 2010 Winter; 11(1): 18-20

Georgetown users check Georgetown Journal Finder for access to full text

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Nebot, Cristina; Ortega, Blas; Mira, José Joaquin; Ortiz, Lidia

Gaceta sanitaria / S.E.S.P.A.S 2010 Nov-Dec; 24(6): 437-45

Abstract: To describe the profile of persons who exercise their right to draw up a living will, to analyze physicians' knowledge of living wills and attitudes toward them, and to compare the regulations pertaining to this right in the distinct autonomous regions of Spain.

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Leisner, W G

Gaceta sanitaria / S.E.S.P.A.S 2010 Nov-Dec; 24(6): 437-45
Abstract: Since September 1st 2009, the Living Will Declaration is regulated by law as held in §1901 a-c BGB. It does not need a certain format except for being in the written form. This must be distinguished from the right to choose a certain treatment according to the medical attendant and his intention to agree to or forbid a certain treatment. The Living Will Declaration binds the physician to certain clearly specified procedures that the patient has agreed to and is valid independently from the nature of the patient's illness or its stage because the basic right for self-determination (Art. 2 Abs. 2 GG) includes the right to die. As the physician is committed to observe the patient's will, he will have to face legal consequences in terms of liability and criminal law if he disregards the Living Will Declaration.

Document 101
Becker, Matthias; Jaspers, Birgit; King, Claudius; Radbruch, Lukas; Voltz, Raymond; Nauck, Friedemann
Did you seek assistance for writing your advance directive? A qualitative study.
Abstract: the completion of an advanced directive is paired with a high degree of self-responsibility of the signatory. It requires anticipation of probably complex medical situations. In the literature, the family physician is often seen as the most important person for advice when writing an advance directive. But little is known about whether or not patients want to involve medical advisors and to what extent physicians are willing to give advice. The aim of this study was to analyse whether or not individuals approached advisors for the completion of their advance directive, whom they chose and which reasons were given for seeking or foregoing assistance.

Document 102
Schulte-Wissermann, Hermann
[Manners of dying]. = Wege zum Sterben.
Kinderkrankenschwester : Organ der Sektion Kinderkrankenpflege / Deutsche Gesellschaft für Sozialpädiatrie und Deutsche Gesellschaft für Kinderheilkunde 2010 Nov; 29(11): 446

Document 103
Schell, Werner
[Patient advanced directives are binding and justify by unequivocal declaration also discontinuation of treatment]. = Patientenverfügungen sind verbindlich und rechtfertigen bei eindeutiger Willensbekundung auch einen Behandlungsabbruch.
Kinderkrankenschwester : Organ der Sektion Kinderkrankenpflege / Deutsche Gesellschaft für Sozialpädiatrie und Deutsche Gesellschaft für Kinderheilkunde 2010 Nov; 29(11): 460-1

Document 104
Fung, Ada W T; Lam, Linda C W; Lui, Victor W C
Could hypothetical scenarios enhance understanding on decision for life-sustaining treatment in non-demented Chinese older persons?
Aging & mental health 2010 Nov; 14(8): 994-9
Abstract: With increasing longevity, there is an increasing need for medical professionals to face situations in which explanation for decision on life-sustaining treatment (LST) would be required.
Document 105

Vadász, Gábor

[End-of-life decisions: Proposal for a more transparent terminology and some thoughts on the legal framework of medical treatment]. = Az életvégi orvosi döntések?!, közöttük az eutanáziáról. (Javaslat egy áttekinthető terminológiára és gondolatok az orvoslás jogi szabályozásáról).

Orvosi hetilap 2010 Oct 24; 151(43): 1769-75

Abstract: Indication of euthanasia is only one of several medical decisions at the end of life. Precise definition of this topic related to the clinical events happening around the sick-bed is not complete in the legal and medical literature. The present review attempts to classify the different end of life events with the aim of clarifying which of these do not belong to the concept of passive euthanasia. Euthanasia is not a legal category. The everyday expressions of active and passive euthanasia are simplifications, which cover actions of different purposes. Use of these in medical and legal literature can be confusing and misleading. We differentiate decisions at the end of life on basis of their purpose. Based on the definition and category of the Hungarian Doctors’ Chamber, euthanasia is the act or the lack of action in order to mercifully shorten or end the life of a suffering fellow-man to help him. Concepts of active, passive and forced euthanasia are defined. The terms of indirect and intermediate euthanasia are not used in order to avoid misunderstanding. Help and participation of non-professionals in the implementation cannot be completely excluded from the concept of euthanasia, and we believe euthanasia is not merely related to doctors. We outline those medical decisions at the end of life which do not belong to the category of passive euthanasia, namely: withdrawal of ineffective and life sustaining treatments, letting go of the patient, contra-indication of therapy escalation, use of palliative therapy, pain-relieving treatment, compromise medicine, consideration of reanimation and choosing cost-effective therapy. We touch upon the subject of the living will, why it cannot be applied, and its relation to active and passive euthanasia. With reference to the legal regulation of life saving and life sustaining treatment, we deal with the expected spirit of medical legislation.

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Document 106

Schaden, Eva; Herczeg, Petra; Hacker, Stefan; Schopper, Andrea; Krenn, Claus G

The role of advance directives in end-of-life decisions in Austria: survey of intensive care physicians.

BMC medical ethics 2010 October 21; 11: 19

Abstract: Currently, intensive care medicine strives to define a generally accepted way of dealing with end-of-life decisions, therapy limitation and therapy discontinuation. In 2006 a new advance directive legislation was enacted in Austria. Patients may now document their personal views regarding extension of treatment. The aim of this survey was to explore Austrian intensive care physicians’ experiences with and their acceptance of the new advance directive legislation two years after enactment (2008).

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Document 107

Hensby, Paul S

Palliative care beyond cancer. Death plans reduce death taboo.

BMJ (Clinical research ed.) 2010 October 19; 341: c5800

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Document 108

Emanuel, Linda; Scandrett, Karen Glasser

Decisions at the end of life: have we come of age?

BMC medicine 2010 October 8; 8: 57

Abstract: Decision making is a complex process and it is particularly challenging to make decisions with, or for, patients who are near the end of their life. Some of those challenges will not be resolved - due to our human inability to foresee the future precisely and the human proclivity to change stated preferences when faced with reality. Other challenges of the decision-making process are manageable. This commentary offers a set of approaches which may lead to progress in this field. One clearly desirable approach can and should be used more often than it is: the routine inclusion of discussions about the goals of care and documentation with all patients who have a poor prognosis. The match between a patient's goals and the care received should be the gold standard for quality palliative care. Planning for future situations is necessary but hard.
In order to achieve efficient elicitation and documentation of advance care planning, research is needed on each individual’s thresholds for transitioning from curative to palliative intent and on the trajectory of changed preferences when illness occurs. Another clearly desirable approach is the documentation and use of community preferences, so that proxies making decisions without guidance from the patient can at least know what the majority of people considering similar situations chose to do. Part of the challenge of achieving ‘quality dying’ may have to do with the still current (mainly Western) tendency to a death-denying culture and the inability of dying people to enter into the dying role. Awareness of the tasks of the dying role and the provision of time and space for those tasks during the delivery of medical care is essential. Medicine needs to continue to enhance the existential maturity of our profession, our patients and the cultures in which we practice. This state of mind should provide for decisions made with a more settled acceptance of mortality and with more awareness of the necessary connection to our survivors and next generation that mortality creates. Specific interventions, such as Dignity Therapy and advance care planning, may aid this state of mind.

Sherwen, Eleanor

**Advance care planning ensures patient choice on place of death.**

*Nursing times* 2010 Oct 12-18; 106(40): 8

Clark, Melissa A; Boehmer, Ulrike; Rogers, Michelle L; Sullivan, Mairead

**Planning for future care needs: experiences of unmarried heterosexual and sexual minority women.**

*Women & health* 2010 Oct; 50(7): 599­617

**Abstract:** This study examined the experiences of legally unmarried, middle-aged and older sexual minority (e.g., lesbian, bisexual) and heterosexual women in planning for future care needs and long-term assistance. A total of 215 women (90 sexual minority women and 125 heterosexual women) 41-78 years of age completed a survey about long-term care planning strategies, including: (1) executing a will; (2) naming a health care proxy; (3) purchasing long-term care insurance; and (4) discussing potential living arrangements with at least one family member. Overall, 18.5% of women reported completing zero of the strategies, and 3.4% reported completing all four. Over half (59%) had completed at least two strategies. Women were most likely to have executed a will (68%) and named a health care proxy (61%). Both sexual minority women and heterosexual women were most likely to have talked to a family member of choice, rather than a biological family member about living with them if they were unable to care for themselves. Currently, serving as a health care proxy was an important correlate for having made long-term care plans and was particularly important for sexual minority women. Women who are not in traditional marriage relationships tend to adopt long-term care planning strategies that legally clarify and establish the nature of their important relationships.

Kapur, Navneet; Clements, Caroline; Bateman, Nick; Foëx, Bernard; Mackway-Jones, Kevin; Huxtable, Richard; Gunnell, David; Hawton, Keith

**Advance directives and suicidal behaviour.**

*BMJ (Clinical research ed.)* 2010 September 7; 341: c4557

Durbin, Christine R; Fish, Anne F; Bachman, Jean A; Smith, Katharine V

**Systematic review of educational interventions for improving advance directive completion.**

*Journal of nursing scholarship*: an official publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau 2010 Sep 1; 42(3): 234-41

**Abstract:** To systematically analyze evidence about the outcome and percent of newly completed ADs, focusing on the effectiveness of (a) types of educational interventions versus controls and (b) one educational intervention over another.
Illinois. Health care power of attorney.
Mental and physical disability law reporter 2010 Sep-Oct; 34(5): 812

Antolín, A; Ambrós, A; Mangirón, P; Alves, D; Sánchez, M; Miró, O
[Grade of knowledge about the advance directive document by the chronic patient who comes to the emergency department]. = Grado de conocimiento del documento de voluntades anticipadas por el enfermo crónico que acude a urgencias.
Revista clínica española 2010 Sep; 210(8): 379-88

Stein, Gary L; Kerwin, Jeanne
Disability perspectives on health care planning and decision-making.
Journal of palliative medicine 2010 Sep; 13(9): 1059-64

Newport, Kristina Braine; Patel, Shejal; Lyckholm, Laurie; Bobb, Barton; Coyne, Patrick; Smith, Thomas J
The "PSOST": Providers' Signout for Scope of Treatment.
Journal of palliative medicine 2010 Sep; 13(9): 1055-8
Factors influencing older adults to complete advance directives.

Abstract: The purpose of this study was to determine the factors which influence advance directive (AD) completion among older adults.

Knowledge and attitudes of primary care professionals on the "living will" document. = Conocimientos y actitudes de los profesionales de los equipos de atención primaria sobre el documento de voluntades anticipadas.

Abstract: To assess the current state of knowledge and attitudes on the advance directives (living wills) document of professionals working in primary.

Prognosis and resuscitation status of critically ill patients with lung cancer admitted to the intensive care unit.

Abstract: The aims of the study were to assess the intensive care unit (ICU) outcome for critically ill patients with lung cancer to determine the risk factors for mortality and to examine the resuscitation status on admission and during their ICU course. Data was collected from May 1999 to March 2009 for patients with lung cancer admitted to the ICU. During the study period, 51 patients with lung cancer were admitted to our ICU The ICU and hospital mortality rates were 49 and 60%, respectively. The majority of patients were full resuscitation on admission to ICU The resuscitation status was changed in 56% of patients during the ICU course. It is suggested that end-of-life decisions should be addressed earlier in these patients' illnesses.
Redefining the "planning" in advance care planning: preparing for end-of-life decision making.

**Abstract:** The traditional objective of advance care planning has been to have patients make treatment decisions in advance so that clinicians can attempt to provide care consistent with their goals. The authors contend that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions. They provide practical steps for clinicians to help patients and surrogate decision makers achieve this objective in the outpatient setting. Preparation for in-the-moment decision making shifts the focus from having patients make premature decisions based on incomplete information to preparing them and their surrogates for the types of decisions and conflicts they may encounter when they do have to make in-the-moment decisions. Advance directives, although important, are just one piece of information to be used at the time of decision making.

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Sharing summary care records. What about advance directives?

**Abstract:**

Advance directives (ADs) are legal documents that express an individual's wishes regarding medical treatment in the event of losing capacity to make decisions. Relevant and applicable ADs are legally binding, even when refusal of the specified treatment will lead to the patient's death; but health professionals are required under the Mental Capacity Act to consider a number of factors in deciding whether a patient's AD should be followed. The decision for the health professional is not always clear-cut. For example, what happens when Alzheimer's changes an individual's personality so much that they seem to be a different person: does their previous decision still stand? This article examines the criteria to be considered in such a case, and highlights the wider principles to be followed in making any decision on whether to follow an individual's instruction to refuse treatment.

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Imagine my surprise: a controversial advance directive scenario.

**Abstract:**

Advance directives (ADs) are legal documents that express an individual's wishes regarding medical treatment in the event of losing capacity to make decisions. Relevant and applicable ADs are legally binding, even when refusal of the specified treatment will lead to the patient's death; but health professionals are required under the Mental Capacity Act to consider a number of factors in deciding whether a patient's AD should be followed. The decision for the health professional is not always clear-cut. For example, what happens when Alzheimer's changes an individual's personality so much that they seem to be a different person: does their previous decision still stand? This article examines the criteria to be considered in such a case, and highlights the wider principles to be followed in making any decision on whether to follow an individual's instruction to refuse treatment.

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What influences individuals to engage in advance care planning?

**Abstract:**

Advance care planning (ACP) is an underutilized process that involves thinking about what kind of life-prolonging medical care one would want should the need arise, identifying a spokesperson, and then communicating these wishes.

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[A pilot study on the perspectives of hemodialysis room nurses on promoting advance directives].

Hsieh, Ling-Yu; Lin, Shu-Ying

Abstract: Previous studies have shown that patients with end-stage renal disease experience a lower than optimal quality of dying and achieve a lower rate of advance directives (ADs) completion. Patients are frequently unaware of their option to withdraw from dialysis and also believe their physicians would oppose such a decision. Where there are inherent difficulties for medical staff in discussing end-of-life (EOL) issues with patients, patients on dialysis often develop a trusting, almost familial relationship with their nurses, who play a vital role in assisting patient and family to make EOL care decisions.

Lau, Bonnie; Kirkpatrick, James N; Merchant, Raina M; Perman, Sarah M; Abella, Benjamin S; Gaiskei, David F; Becker, Lance B; Chiames, Chris; Reitsma, Angelique M

Experiences of sudden cardiac arrest survivors regarding prognostication and advance care planning.

Abstract: We sought to better understand SCA survivors’ beliefs about complex issues that arise in the immediate post-arrest period and explore advance care planning. Specifically, we wished to explore four themes: (1) patient and family perception of medical providers’ prognostication in the immediate post-arrest phase; (2) patient definitions of death; (3) use of advance directives (ADs); and (4) perceptions of health and organ donation.

Tobler, Laura

Planning for end-of-life care.

Abstract: A recent inquest in South Wales heard of the tragic case of a husband who killed himself and his wife through carbon monoxide poisoning because he could not bear to see her continued suffering. His wife had spent two years in a persistent vegetative state and attempts to obtain a court order allowing the withholding of her artificial nutrition and hydration had been subject to lengthy delays. This article discusses how this case highlights the importance of making preparations for possible future incapacity by creating an advance decision refusing treatment and a health and welfare power of attorney under the Mental Capacity Act 2005. These provisions will ensure that the wishes of the patient are respected without the need to go to court and so avoid delay.

Griffith, Richard; Tengnah, Cassam

Preparing for future incapacity.

Abstract: A recent inquest in South Wales heard of the tragic case of a husband who killed himself and his wife through carbon monoxide poisoning because he could not bear to see her continued suffering. His wife had spent two years in a persistent vegetative state and attempts to obtain a court order allowing the withholding of her artificial nutrition and hydration had been subject to lengthy delays. This article discusses how this case highlights the importance of making preparations for possible future incapacity by creating an advance decision refusing treatment and a health and welfare power of attorney under the Mental Capacity Act 2005. These provisions will ensure that the wishes of the patient are respected without the need to go to court and so avoid delay.

Bradley, Ciaran T; Brasel, Karen J; Schwarze, Margaret L

Physician attitudes regarding advance directives for high-risk surgical patients: a qualitative analysis.

Abstract: Advance directive (AD) use is uncommon in surgical patients, yet the exact reasons for this are unknown. Our aim was to identify and describe beliefs held by surgeons regarding ADs. A qualitative exploration of physicians’ opinions of ADs for surgical patients was designed. This methodology is preferred to quantitative techniques, which are subject to bias when an issue’s underlying themes are unknown.
Document 132
Bradley, Ciaran T; Brasel, Karen J; Schwarze, Margaret L
**Physician attitudes regarding advance directives for high-risk surgical patients: a qualitative analysis.**
Surgery 2010 Aug; 148(2): 209-16
**Abstract:** Advance directive (AD) use is uncommon in surgical patients, yet the exact reasons for this are unknown. Our aim was to identify and describe beliefs held by surgeons regarding ADs. A qualitative exploration of physicians’ opinions of ADs for surgical patients was designed. This methodology is preferred to quantitative techniques, which are subject to bias when an issue’s underlying themes are unknown.

Document 133
Song, J; Ratner, E R; Wall, M M; Bartels, D M; Ulvestad, N; Petroskas, D; West, M; Weber-Main, A M; Grengs, L; Gelberg, L
**Summaries for patients. End-of-Life Planning intervention and the Completion of Advance Directives in homeless persons.**
Annals of internal medicine 2010 Jul 20; 153(2): I-38

Document 134
Song, John; Ratner, Edward R; Wall, Melanie M; Bartels, Dianne M; Ulvestad, Nancy; Petroskas, Dawn; West, Melissa; Weber-Main, Anne Marie; Grengs, Leah; Gelberg, Lillian
**Effect of an End-of-Life Planning Intervention on the completion of advance directives in homeless persons: a randomized trial.**
Annals of internal medicine 2010 Jul 20; 153(2): 76-84
**Abstract:** Few interventions have focused on improving end-of-life care for underserved populations, such as homeless persons.

Document 135
Song, J; Ratner, E R; Wall, M M; Bartels, D M; Ulvestad, N; Petroskas, D; West, M; Weber-Main, A M; Grengs, L; Gelberg, L
**Summaries for patients. End-of-Life Planning intervention and the Completion of Advance Directives in homeless persons.**
Annals of internal medicine 2010 Jul 20; 153(2): I-38

Document 136
Song, John; Ratner, Edward R; Wall, Melanie M; Bartels, Dianne M; Ulvestad, Nancy; Petroskas, Dawn; West, Melissa; Weber-Main, Anne Marie; Grengs, Leah; Gelberg, Lillian
**Effect of an End-of-Life Planning Intervention on the completion of advance directives in homeless persons: a randomized trial.**
Annals of internal medicine 2010 Jul 20; 153(2): 76-84
**Abstract:** Few interventions have focused on improving end-of-life care for underserved populations, such as homeless persons.
Document 137
Kierzek, Gerald; Rac, Valeria; Pourriat, Jean-Louis
*Advance directives and surrogate decision making before death.*

Document 138
Henrikson, Charles A
*Advance directives and surrogate decision making before death.*

Document 139
Tamayo-Velázquez, María-Isabel; Simón-Lorda, Pablo; Villegas-Portero, Román; Higueras-Callejón, Camila; García-Gutiérrez, José-Francisco; Martínez-Pecino, Flora; Barrio-Cantalejo, Inés-Maria
*Interventions to promote the use of advance directives: an overview of systematic reviews.*
Patient education and counseling 2010 Jul; 80(1): 10-20

*Abstract:* To identify, appraise and synthesise the results of systematic reviews of the literature (SRLs) that examines the effectiveness of interventions to increase advance directive (AD) completion rate.

Document 140
Yung, Victoria Y; Walling, Anne M; Min, Lillian; Wenger, Neil S; Ganz, David A
*Documentation of advance care planning for community-dwelling elders.*
Journal of palliative medicine 2010 Jul; 13(7): 861-7

*Abstract:* Advance planning for end-of-life care has gained acceptance, but actual end-of-life care is often incongruent with patients’ previously stated goals. We assessed the flow of advance care planning information from patients to medical records in a community sample of older adults to better understand why advance care planning is not more successful.

Document 141
Hickman, Susan E; Nelson, Christine A; Perrin, Nancy A; Moss, Alvin H; Hammes, Bernard J; Tolle, Susan W
*A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program.*
The Journal of the American Geriatrics Society 2010 Jul; 58(7): 1241-8

*Abstract:* OBJECTIVES: To evaluate the relationship between two methods to communicate treatment preferences (Physician Orders for Life-Sustaining Treatment (POLST) program vs traditional practices) and documentation of life-sustaining treatment orders, symptom assessment and management, and use of life-sustaining treatments. DESIGN: Retrospective observational cohort study conducted between June 2006 and April 2007. SETTING: A stratified, random sample of 90 Medicaid-eligible nursing facilities in Oregon, Wisconsin, and West Virginia. PARTICIPANTS: One thousand seven hundred eleven living and deceased nursing facility residents aged 65 and older with a minimum 60-day stay. MEASUREMENTS: Life-sustaining treatment orders; pain, shortness of breath, and related treatments over a 7-day period; and use of life-sustaining treatments over a 60-day period. RESULTS: Residents with POLST forms were more likely to have orders about life-sustaining treatment preferences beyond cardiopulmonary resuscitation than residents without (98.0% vs 16.1%, P<.001). There were no differences between residents with and without POLST forms in symptom assessment or management. Residents with POLST forms indicating orders for comfort measures only were less likely to receive medical interventions (e.g., hospitalization) than residents with POLST full treatment orders (P=.004), residents with traditional do-
not-resuscitate orders (P<.001), or residents with traditional full code orders (P<.001). CONCLUSION: Residents with POLST forms were more likely to have treatment preferences documented as medical orders than those who did not, but there were no differences in symptom management or assessment. POLST orders restricting medical interventions were associated with less use of life-sustaining treatments. Findings suggest that the POLST program offers significant advantages over traditional methods to communicate preferences about life-sustaining treatments.

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Document 142
Hammes, Bernard J; Rooney, Brenda L; Gundrum, Jacob D
A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem.
Abstract: OBJECTIVES: To determine whether outcomes have changed over time for a managed, systematic approach to advance care planning (ACP). DESIGN: Retrospective comparison of medical record and death certificate data of adults who died over a 7-month period in 2007/08 with those of adults who died over an 11-month period in 1995/96. SETTING: All healthcare organizations in La Crosse County, Wisconsin. PARTICIPANTS: Five hundred forty adults who died in 1995/96 and 400 adults who died in 2007/08. INTERVENTION: A systematic ACP approach, Respecting Choices, collaboratively implemented in 1993 and continuously improved in subsequent years. MEASUREMENTS: Demographic and cause-of-death data were collected from death certificates. Type and content of any advance directive (AD), existence and content of Physician Orders for Life-Sustaining Treatment, and medical treatment provided at the location of death in the last 30 days of life were abstracted from the medical record. RESULTS: The recent data show a significantly greater prevalence of ADs (90% vs 85%, P=.02) and of availability of these directives in the medical record at the time of death (99.4% vs 95.2%, P<.001) than the data collected over 10 years ago. The new data suggest that quality efforts have improved the prevalence, clarity, and specificity of ADs. CONCLUSION: A system for ACP can be managed in a geographic region so that, at the time of death, almost all adults have an advance care plan that is specific and available and treatment is consistent with their plan.

Document 143
Allmark, Peter; Cobb, Mark; Liddle, B Jane; Tod, Angela Mary
Is the doctrine of double effect irrelevant in end-of-life decision making?
Nursing philosophy : an international journal for healthcare professionals 2010 Jul; 11(3): 170-7
Abstract: In this paper, we consider three arguments for the irrelevance of the doctrine of double effect in end-of-life decision making. The third argument is our own and, to that extent, we seek to defend it. The first argument is that end-of-life decisions do not in fact shorten lives and that therefore there is no need for the doctrine in justification of these decisions. We reject this argument; some end-of-life decisions clearly shorten lives. The second is that the doctrine of double effect is not recognized in UK law (and similar jurisdictions); therefore, clinicians cannot use it as the basis for justification of their decisions. Against this we suggest that while the doctrine might have dubious legal grounds, it could be of relevance in some ways, e.g. in marking the boundary between acceptable and unacceptable practice in relation to the clinician's duty to relieve pain and suffering. The third is that the doctrine is irrelevant because it requires there to be a bad effect that needs justification. This is not the case in end-of-life care for patients diagnosed as dying. Here, bringing about a satisfactory dying process for a patient is a good effect, not a bad one. What matters is that patients die without pain and suffering. This marks a crucial departure from the double-effect doctrine; if the patient's death is not a bad effect then the doctrine is clearly irrelevant. A diagnosis of dying allows clinicians to focus on good dying and not to worry about whether their intervention affects the time of death. For a patient diagnosed as dying, time of death is rarely important. In our conclusion we suggest that acceptance of our argument might be problematic for opponents of physician-assisted death. We suggest one way in which these opponents might argue for a distinction between such practice and palliative care; this relies on the double-effect doctrine's distinction between foresight and intention.

Document 144
Mayo Clinic women's healthsource 2010 Jul; 14(7): 4-5
Appel, Jacob

**When any answer is a good answer: a mandated-choice model for advance directives.**


Shah, Tara; Shah, Binay K

**Do-not-hospitalize order: is it absolute?**


Gillick, Muriel R

**The challenge of applying advance directives in hospital practice.**


Abstract: Critically ill elderly patients facing crucial decisions about their future medical treatment routinely come under the care of hospital physicians who may have no previous relationship with them or their families. The majority of patients for whom this sort of decision must be made are unable to participate in decision making because of dementia, delirium, or both. They are desperately ill, often with a new medical problem with which they have had little time to come to terms. Hospital physicians must rely on advance directives—either a living will, health care proxy, or both—to make decisions. Translating advance directives into practice is a challenging and complex process that is best approached carefully and systematically.

Pollack, Keshia M; Morhaim, Dan; Williams, Michael A

**The public's perspectives on advance directives: implications for state legislative and regulatory policy.**

Health policy (Amsterdam, Netherlands) 2010 Jun; 96(1): 57-63

Abstract: OBJECTIVES: Determine the prevalence of advance directives (ADs) in Maryland and identify the barriers and enablers to their adoption, in order to guide the formulation of state legislative policy. METHODS: Cross-sectional survey administered over the telephone to a representative age-stratified random sample of 1195 Maryland adults. RESULTS: Approximately 34% (n=401) of Maryland adults reported having an AD. Older adults (65+ years) were more likely than younger adults (18-64 years) to have ADs (p<0.001); the proportional difference between those with and without ADs diminished as age increased. Two times as many Whites than Blacks reported having ADs (43-23%; p<0.001). Of those who had an AD, the primary motivations for creating one was a personal medical condition or a diagnosis to one's self or a family/friend (41%). Those without ADs identified lack of familiarity with them (27%), being too young or healthy to need one (14%), or uncertainty of the process for adopting one (11%) as reasons for not having one. CONCLUSIONS: Barriers to AD adoption appear amenable to policy interventions. Policies that seek to increase access and ensure ease of enrollment, combined with a targeted public health advocacy campaign, may help increase the prevalence of ADs.
care of hospital physicians who may have no previous relationship with them or their families. The majority of patients for whom this sort of decision must be made are unable to participate in decision making because of dementia, delirium, or both. They are desperately ill, often with a new medical problem with which they have had little time to come to terms. Hospital physicians must rely on advance directives—either a living will, health care proxy, or both—to make decisions. Translating advance directives into practice is a challenging and complex process that is best approached carefully and systematically.

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were more likely than non-white respondents to report that the patient had a written advance directive (OR = 4.2, p = 0.001). CPR; OR = 3.9; p = 0.002), or mechanical ventilation (OR = 2.7; p = 0.02) than non-white respondents. White respondents report having ACP discussions with the patient about: feeding tubes (OR = 4.7; p = 0.001), cardiopulmonary resuscitation (OR = 2.1, p = 0.03), and less likely to have dementia (OR = 0.43, p = 0.001). White respondents were more likely to have cancer (odds ratio [OR] = 2.3, p = 0.02), die at home (OR = 3.3, p = 0.006), have a length of stay in hospice greater than 7 days (OR = 2.1, p = 0.03), and less likely to have dementia (OR = 0.43, p = 0.001). White respondents were more likely to report having ACP discussions with the patient about: feeding tubes (OR = 4.7; p = 0.001), cardiopulmonary resuscitation (CPR; OR = 3.9; p = 0.002), or mechanical ventilation (OR = 2.7; p = 0.02) than non-white respondents. White respondents were more likely than non-white respondents to report that the patient had a written advance directive (OR = 4.2, p = 0.001).
DISCUSSION: These data indicate that some patients are not actively involved in the decision to enroll in hospice and that others, often physicians and family members, are making these decisions for the patient collaboratively. These data support the need for early education and interventions that assist patients and families in discussing ACP preferences and the need for greater understanding of how involved patients want to be with the decision to enroll in hospice.

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**Document 157**

Winter, Laraine; Parks, Susan M; Diamond, James J

*Ask a different question, get a different answer: why living wills are poor guides to care preferences at the end of life.*

Journal of palliative medicine 2010 May; 13(5): 567-72

**Abstract:** CONTEXT: Living wills have a poor record of directing care at the end of life, as a copious literature attests. Some speculation centers on the questionable correspondence between the scenario described in living wills versus the real-life circumstances that typically arise at the end of life. OBJECTIVE: To assess the strength of association between responses to a standard living will question and preferences for treatments in six end-of-life scenarios. DESIGN: Cross-sectional. SETTING: Telephone interviews. PARTICIPANTS: Two hundred two community-dwelling men and women 70 years of age or older in the greater Philadelphia area. MAIN OUTCOME MEASURES: Strength of preferences for four life-sustaining treatments in each of six poor-health scenarios. RESULTS: Associations between responses to the standard living will question and preferences for treatment (means across the four) in six specific scenarios were statistically significant but modest in size, accounting for 23% of variance at most. The association for the worse-case scenario (severe stroke with coma) was significantly stronger than for any other association. CONCLUSIONS: The modest correspondence between living will responses and wishes for life-sustaining treatment in specific scenarios helps to elucidate the living will's poor performance. Presentation of more realistic end-of-life scenarios should improve the living will's ability to guide care, as well as preparing patients and families better for the end of life.

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**Document 158**

Fins, Joseph J; Schiff, Nicholas D

*In the blink of the mind's eye.*


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**Document 159**

Picton, Claire

*Dealing with the trauma of death.*


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**Document 160**

Arauzo, Vanessa; Trenado, Josep; Busqueta, Gloria; Quintana, Salvador

*Grado de conocimiento sobre la ley de voluntades anticipadas entre los familiares de los pacientes ingresados en un servicio de medicina intensiva.*

Medicina clinica 2010 Apr 10; 134(10): 448-51

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**Document 161**

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Kettl, Paul
A piece of my mind. One vote for death panels.
JAMA: The Journal of the American Medical Association 2010 April 7; 303(13): 1234-1235

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http://jama.ama-assn.org (link may be outdated)

* Document 162
Silveira, Maria J.; Kim, Scott Y.H.; Langa, Kenneth M.
Advance directives and outcomes of surrogate decision making before death.
New England Journal of Medicine 2010 April 1; 362(13): 1211-1218

Abstract: BACKGROUND: Recent discussions about health care reform have raised questions regarding the value of advance directives. METHODS: We used data from survey proxies in the Health and Retirement Study involving adults 60 years of age or older who had died between 2000 and 2006 to determine the prevalence of the need for decision making and lost decision-making capacity and to test the association between preferences documented in advance directives and outcomes of surrogate decision making. RESULTS: Of 3746 subjects, 42.5% required decision making, of whom 70.3% lacked decision-making capacity and 67.6% of those subjects, in turn, had advance directives. Subjects who had living wills were more likely to want limited care (92.7%) or comfort care (96.2%) than all care possible (1.9%); 83.2% of subjects who requested limited care and 97.1% of subjects who requested comfort care received care consistent with their preferences. Among the 10 subjects who requested all care possible, only 5 received it; however, subjects who requested all care possible were far more likely to receive aggressive care as compared with those who did not request it (adjusted odds ratio, 22.62; 95% confidence interval [CI], 4.45 to 115.00). Subjects with living wills were less likely to receive all care possible (adjusted odds ratio, 0.33; 95% CI, 0.19 to 0.56) than were subjects without living wills. Subjects who had assigned a durable power of attorney for health care were less likely to die in a hospital (adjusted odds ratio, 0.72; 95% CI, 0.55 to 0.93) or receive all care possible (adjusted odds ratio, 0.54; 95% CI, 0.34 to 0.86) than were subjects who had not assigned a durable power of attorney for health care. CONCLUSIONS: Between 2000 and 2006, many elderly Americans needed decision making near the end of life at a time when most lacked the capacity to make decisions. Patients who had prepared advance directives received care that was strongly associated with their preferences. These findings support the continued use of advance directives.

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http://content.nejm.org/content/vol362/issue13/ (link may be outdated)

* Document 163
Gillick, Muriel R.
Reversing the code status of advance directives? [editorial]
New England Journal of Medicine 2010 April 1; 362(13): 1239-1240

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http://content.nejm.org/content/vol362/issue13/ (link may be outdated)

* Document 164
Weissman, David E; Quill, Timothy E; Arnold, Robert M
Helping surrogates make decisions #226.
Journal of palliative medicine 2010 Apr; 13(4): 461-2

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* Document 165
Mueller, Paul S; Litin, Scott C; Hook, C Christopher; Creagan, Edward T; Cha, Stephen S; Beckman, Thomas J
A novel advance directives course provides a transformative learning experience for medical students.
Teaching and learning in medicine 2010 Apr; 22(2): 137-41

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http://content.nejm.org/content/vol362/issue13/ (link may be outdated)
**Abstract:** Inadequate physician training may be a barrier to physician-patient discussions of advance directives (ADs).

Inadequate physician training may be a barrier to physician-patient discussions of advance directives (ADs).

**Preferences of elderly cancer patients in their advance directives.**

Critical reviews in oncology/hematology 2010 Apr; 74(1): 61-5

**Abstract:** Efforts to improve the quality of end-of-life decision-making have emphasized the principle of individual autonomy to better ensure that patients receive care consistent with their preferences. Advance directives (ADs) can be vehicles for in-depth and ongoing discussions among health care professionals, patients, and families. The aim of our study was to identify preferences and values expressed in ADs of 50 elderly patients with cancer. Main concerns of the patients were resuscitation and introduction of artificial nutrition. Very few patients had unrealistic expectation. Preferences about patient's symptom management were quite different from one to another. Content of ADs not only involved life-sustaining technology, but also psychosocial items and religious beliefs and values. All patients designated at least one surrogate. In conclusion, ADs should not be considered simply as another questionnaire, but more as a process to improve communication.

*Document 166*

Pautex, Sophie; Notaridis, Grigoris; D?ram?, Laurence; Zulian, Gilbert B

**It's not optional. [editorial]**


**Too soon to give up: re-examining the value of advance directives.**

American Journal of Bioethics 2010 April; 10(4): 3-22

**A dead proposal: Levi and Green on advance directives.**


**Abstract:** It's not optional. [editorial]

**Abstract:** Too soon to give up: re-examining the value of advance directives.

**Abstract:** A dead proposal: Levi and Green on advance directives.
Document 170
Gastmans, Chris; Denier, Yvonne
What if patients with dementia use decision aids to make an advance euthanasia request?
Georgetown users check Georgetown Journal Finder for access to full text
http://www.bioethics.net/journal/issues.php (link may be outdated)

Document 171
Barnard, David
Living with doubt.
Georgetown users check Georgetown Journal Finder for access to full text
http://www.bioethics.net/journal/issues.php (link may be outdated)

Document 172
Barfield, Raymond C.; Brandon, Debra; Thompson, Julie; Harris, Nichol; Schmidt, Michael; Docherty, Sharron
Mind the child: using interactive technology to improve child involvement in decision making about life-limiting illness.
Georgetown users check Georgetown Journal Finder for access to full text
http://www.bioethics.net/journal/issues.php (link may be outdated)

Document 173
Aultman, Julie M.
Ethics of translation: MOLST and electronic advance directives.
American Journal of Bioethics 2010 April; 10(4): 30-32
Georgetown users check Georgetown Journal Finder for access to full text
http://www.bioethics.net/journal/issues.php (link may be outdated)

Document 174
Berger, Jeffrey T.
What about process? Limitations in advance directives, care planning, and noncapacitated decision making.
American Journal of Bioethics 2010 April; 10(4): 33-34
Georgetown users check Georgetown Journal Finder for access to full text
http://www.bioethics.net/journal/issues.php (link may be outdated)

Document 175
Shalowitz, David I.; Silveira, Maria J.
Building a better advance directive: next steps.
American Journal of Bioethics 2010 April; 10(4): 34-36
Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on Advance Directives.

Abstract: ADs are documents in which one can state one's preferences concerning end-of-life care, aimed at making someone's wishes known in situations where he/she is not able to do so in another manner. There is still a lot unclear about ADs. We designed a study aimed at investigating the whole process from the formulating of an AD to its actual use at the end of life.

Examining the root cause of surrogate conflicts in the intensive care unit and general wards.

Abstract: This study is an analysis of surrogate-focused ethics consultations in the Intensive Care Unit (ICU) and the general wards (Ward) of a large community hospital in Northern California. We identified the major themes of surrogate-focused ethics consultations to better understand the root cause of surrogate conflicts, and identified the similarities and differences between surrogate-based conflicts in the two settings. Consults requested because the surrogate had desires that conflicted with the physician's medical opinion of 'best interest', or cases involving surrogates not upholding a patient's known values reflected the root cause of the majority of surrogate conflicts (72.7% ICU, 83.3% Ward).

Dignity for patients at the end of their lives.

Advance directives in the clinical ethics context: an African perspective

Advance directives from a cross-cultural perspective [editorial]
Advance commitment: an alternative approach to the family veto problem in organ procurement.

Advance commitment: an alternative approach to the family veto problem in organ procurement.

Abstract: This article tackles the current deficit in the supply of cadaveric organs by addressing the family veto in organ donation. The authors believe that the family veto matters—ethically as well as practically—and that policies that completely disregard the views of the family in this decision are likely to be counterproductive. Instead, this paper proposes to engage directly with the most important reasons why families often object to the removal of the organs of a loved one who has signed up to the donor registry—notably a failure to understand fully and deliberate on the information and a reluctance to deal with this sort of decision at an emotionally distressing time. To accommodate these concerns it is proposed to separate radically the process of information, deliberation and agreement about the harvesting of a potential donor's organs from the event of death and bereavement through a scheme of advance commitment. This paper briefly sets out the proposal and discusses in some detail its design as well as what is believed to be the main advantages compared with the leading alternatives.

Dying tax free: the modern advance directive and patients' financial values.

Abstract: Advance directives are often used to help patients articulate their end-of-life treatment preferences and guide proxy decision makers in making health care decisions when patients cannot. This case study and commentary puts forth a situation in which a palliative care consultation team encountered a patient with an advance directive that instructed her proxy decision maker to consider estate tax implications when making end-of-life decisions. Following presentation of the case, the authors focus on two ethical issues: 1) the appropriateness of considering patients' financial goals and values in medical decision making and 2) whether certain kinds of patient values should be considered more or less relevant than others as reasons for expressed treatment preferences. Clinicians are encouraged to accept a wide range of patient values as relevant to the clinical decision-making process and to balance the influence of those values with more traditional notions of clinical harm and benefit.

An important step in the promotion of patients' self-determination.

Council of Europe. Recommendation CM/Rec(2009)11 of the Committee of Ministers to member states on principles continuing powers of attorney and advance directives for incapacity.

Attitudes of patients with malignancies towards completion of advance directives.

Abstract: AIM: The purpose of advance directives (AD) is to preserve the patient's autonomy at the end of his/her life. In a
cohort study, we investigated attitudes towards AD in hospitalized patients with malignant disease. MATERIALS AND METHODS: All patients were informed about the basic features of AD in a standardized manner by a single independent physician. One hundred and eight (39 women, 69 men; mean age 56.6 +/- 14.9 years) of 140 invited patients completed the study. MAIN RESULTS: Five percent of patients (5/108) already had an AD; 85% (92/108) did not wish to issue an AD. "Full confidence in physicians" (22%) and "not important for me at the moment" (15%) were the most frequently stated reasons for not issuing an AD. Only 10% (11/108) of patients decided to complete an AD. Their decision was not related to a specific diagnosis or a number of socio-demographic variables that were studied. Patients who decided in favor of an AD had significantly higher Hospital Anxiety and Depression Scale (HADS-D) score than those who decided against it (HADS-D, 8.3 +/- 5.0 vs. 5.8 +/- 4.1, p = 0.035). The patients' HADS depression score was negatively associated with their Karnofsky index (r = -0.232, p = 0.017). CONCLUSIONS: Our data reveal a scarce demand for AD in our population of hospitalized cancer patients. Patients who wanted to issue an AD had a high HADS-D, which is associated with a low performance status.

Guevin, Benedict M.
Revising secular advance directives
Ethics and Medics 2010 March; 35(3): 3-4

Akhtar, Jamshed
Living wills in health care: a way of empowering individuals

Murphy, Jennifer; Fayanju, Oluwadamilola; Brown, Douglas; Kodner, Ira J.
Withdrawal of care in a potentially curable patient.
Surgery 2010 March; 147(3): 441-445

Torke, Alexia M.; Moloney, Rachael; Siegler, Mark; Abalos, Anna; Alexander, G. Caleb
Physicians' views on the importance of patient preferences in surrogate decision-making.
Journal of the American Geriatrics Society 2010 March; 58(3): 533-538

Abstract: OBJECTIVES: To explore the degree to which physicians report reliance on patient preferences when making medical decisions for hospitalized patients lacking decisional capacity. DESIGN: Cross-sectional survey. SETTING: One academic and two community hospitals in a single metropolitan area. PARTICIPANTS: Two hundred eighty-one physicians who recently cared for hospitalized adults. MEASUREMENTS: A self-administered survey addressing physicians' beliefs about ethical principles guiding surrogate decision-making and physicians' recent decision-making experiences. RESULTS: Overall, 72.6% of physicians identified a standard related to patient preferences as the most important ethical standard for surrogate decision-making (61.2% identified advanced directives and 11.4% substituted judgment). Of the 73.3% of physicians who reported recently making a surrogate decision, 81.8% reported that patient preferences were highly important in decision-making, although only 29.4% reported that patient preference was the most important factor in the decision. Physicians were significantly more likely to base decisions on patient preferences when the patient was in the intensive care unit (odds ratio (OR)=2.92, 95% confidence interval (CI)=1.15-7.45) and less likely when the patient was older (OR=0.76 for each decade of age, 95% CI=0.58-0.99). The presence of a living will, prior discussions with the patient, and the physicians' beliefs about ethical guidelines did not significantly predict the physicians' reliance on patient preferences. CONCLUSION:
Although a majority of physicians identified patient preferences as the most important general ethical guideline for surrogate decision-making, they relied on a variety of factors when making treatment decisions for a patient lacking decisional capacity.

**Document 190**

Biller-Andorno, Nikola; Brauer, Susanne

*Advance directives from a cross-cultural perspective.*

Bioethics 2010 March; 24(3): ii-iv

**Document 191**

Beširevié, Violeta


Bioethics 2010 March; 24(3): 105-112

**Abstract:** This article explores universal normative bases that could help to shape a workable legal construct that would facilitate a global use of advance directives. Although I believe that advance directives are of universal character, my primary aim in approaching this issue is to remain realistic. I will make three claims. First, I will argue that the principles of autonomy, dignity and informed consent, embodied in the Oviedo Convention and the UNESCO Declaration on Bioethics and Human Rights, could arguably be regarded as universal bases for the global use of advance directives. Second, I will demonstrate that, despite the apparent consensus of ethical authorities in support of their global use, it is unlikely, for the time being, that such consensus could lead to unqualified legal recognition of advance directives, because of different understandings of the nature of the international rules, meanings of autonomy and dignity which are context-specific and culture-specific, and existing imperfections that make advance directives either unworkable or hardly applicable in practice. The third claim suggests that the fact that the concept of the advance directive is not universally shared does not mean that it should not become so, but never as the only option in managing incompetent patients. A way to proceed is to prioritize work on developing higher standards in managing incompetent patients and on progressing towards the realization of universal human rights in the sphere of bioethics, by advocating a universal, legally binding international convention that would outlaw human rights violations in end-of-life decision-making.

**Document 192**

Kim, Soyoon; Hahm, Ki-Hyun; Park, Hyoung Wook; Kang, Hyun Hee; Sohn, Myongsei

*A Korean perspective on developing a global policy for advance directives.*

Bioethics 2010 March; 24(3): 113-117

**Abstract:** Despite the wide and daunting array of cross-cultural obstacles that the formulation of a global policy on advance directives will clearly pose, the need is equally evident. Specifically, the expansion of medical services driven by medical tourism, just to name one important example, makes this issue urgently relevant. While ensuring consistency across national borders, a global policy will have the additional and perhaps even more important effect of increasing the use of advance directives in clinical settings and enhancing their effectiveness within each country, regardless of where that country's state of the law currently stands. One cross-cultural issue that may represent a major obstacle in formulating, let alone applying, a global policy is whether patient autonomy as the underlying principle for the use of advance directives is a universal norm or a construct of western traditions that must be reconciled with alternative value systems that may place lesser significance on individual choice. A global policy, at a minimum, must emphasize respect for patient autonomy, provision of medical information, limits to the obligations for physicians, and portability. And though the development of a global policy will be no easy task, active engagement in close collaboration with the World Health Organization can make it possible.

**Document 193**

van Wijmen, Matthijs P.S.; Rurup, Mette L.; Pasman, H. Roeline W.; Kaspers, Pam J.; Onwuteaka-Philipsen, Bregje D.

Bioethics 2010 March; 24(3): 118-126

Abstract: RESEARCH OBJECTIVE: This study focuses on ADs in the Netherlands and introduces a cross-cultural perspective by comparing it with other countries. METHODS: A questionnaire was sent to a panel comprising 1621 people representative of the Dutch population. The response was 86%. RESULTS: 95% of the respondents didn't have an AD, and 24% of these were not familiar with the idea of drawing up an AD. Most of those familiar with ADs knew about the Advanced Euthanasia Directive (AED, 64%). Both low education and the presence of a religious conviction that plays an important role in one's life increase the chance of not wanting to draw up an AD. Also not having experienced a request for euthanasia from someone else, and the inconceivability of asking for euthanasia yourself, increase the chance of not wanting to draw up an AD. DISCUSSION: This study shows that the subjects of palliative care and end-of-life-decision-making were very much dominated by the issue of euthanasia in the Netherlands. The AED was the best known AD; and factors that can be linked to euthanasia play an important role in whether or not people choose to draw up an AD. This differentiates the Netherlands from other countries and, when it comes to ADs, the global differences between countries and cultures are still so large that the highest possible goals, at this moment in time, are observing and possibly learning from other cultural settings.

Guzen, Tolga; Sert, Gurkan

Advance directives in Turkey's cultural context: examining the potential benefits for the implementation of patient rights.

Bioethics 2010 March; 24(3): 127-133

Abstract: Advance directives are not a part of the healthcare service in Turkey. This may be related with the fact that paternalism is common among the healthcare professionals in the country, and patients are not yet integrated in the decision-making process adequately. However, starting from the enactment of the Regulation of Patient Rights in 1998, this situation started to change. While the paternalist tradition still appears to be strong in Turkey, the Ministry of Health has been taking concrete measures in the recent years to ensure that patient rights are implemented in healthcare practice. Therefore, Turkey now seems to be in a transitional period where a move towards a more patient-autonomy centred approach is being supported by the regulatory authorities, as well as the academic circles and the public at large. In the light of this background, this paper aims to examine the potential benefits of advance directives, particularly with regard to their possible effect in the clinical decision-making process of Turkey's context. It will be argued that advance directives, if correctly understood and implemented in the right settings, may be beneficial, particularly for improving communication between patients and healthcare professionals and for implementing of the right to refuse treatment.

Shalev, Carmel

Reclaiming the patient's voice and spirit in dying: an insight from Israel.

Bioethics 2010 March; 24(3): 134-144

Abstract: In the latter half of the 20th century, Western medicine moved death from the home to the hospital. As a result, the process of dying seems to have lost its spiritual dimension, and become a matter of prolonging material life by means of medical technology. The novel quandaries that arose led in turn to medico-legal regulation. This paper describes the recent regulation of dying in Israel under its Dying Patient Law, 2005. The Law recognizes advance directives in principle, but limits their effect and form through complex medico-legal artifices. It reflects a culture that places high value on both scientific medicine and the sanctity of life as such, and illustrates a medical culture that pitches battle against death. At the same time, the Law constructs the will of the individual in a medico-legal language that is alien to the lay person. The paper suggests an alternative approach to advance care planning that is patient-centred and addresses the psycho-social needs of the individual in terms of her relational autonomy. From this perspective, advance care planning becomes an opportunity to extract the patient from the medical context and allow her to speak about her approaching death with close ones in her own terms of reference. To this end, there is a need for facilitation of an intimate encounter where patients can speak about their concerns with their loved ones. The paper also presents a methodological approach of attentive listening, which can be applied across diverse cultures and circumstances.
Pascalev, Assya; Vidalis, Takis

'Vague Oviedo': autonomy, culture and the case of previously competent patients.
Bioethics 2010 March; 24(3): 145-152

Abstract: The paper examines the ethical and legal challenges of making decisions for previously competent patients and the role of advance directives and legal representatives in light of the Oviedo Convention. The paper identifies gaps in the Convention that result in conflicting instructions in cases of a disagreement between the expressed prior wishes of a patient, and the legal representative. The authors also examine the legal and moral status of informally expressed prior wishes of patients unable to consent. The authors argue that positivist legal reasoning is insufficient for a consistent interpretation of the relevant provisions of the Convention and argue that ethical argumentation is needed to provide guidance in such cases. Based on the ethical arguments, the authors propose a way of reconciling the apparent inconsistencies in the Oviedo Convention. They advance a culturally sensitive approach to the application of the Convention at the national level. This approach understands autonomy as a broader, relational consent and emphasizes the social and cultural embeddedness of the individual. Based on their approach, the authors argue that there exists a moral obligation to respect the prior wishes of the patient even in countries without advance directives. Yet it should be left to the national legislations to determine the extent of this obligation and its concrete forms.

Schwarze, Margaret L.; Bradley, Ciaran T.; Brasel, Karen J.

Surgical "buy-in": the contractual relationship between surgeons and patients that influences decisions regarding life-supporting therapy.
Critical Care Medicine 2010 March; 38(3): 843-848

Abstract: OBJECTIVE: There is a general consensus by intensivists and nonsurgical providers that surgeons hesitate to withdraw life-sustaining therapy on their operative patients despite a patient's or surrogate's request to do so. The objective of this study was to examine the culture and practice of surgeons to assess attitudes and concerns regarding advance directives for their patients who have high-risk surgical procedures. DESIGN: A qualitative investigation using one-on-one, in-person interviews with open-ended questions about the use of advance directives during perioperative planning. Consensus coding was performed using a grounded theory approach. Data accrual continued until theoretical saturation was achieved. Modeling identified themes and trends, ensuring maximal fit and faithful data representation. SETTING: Surgical practices in Madison and Milwaukee, WI. SUBJECTS: Physicians involved in the performance of high-risk surgical procedures.

INTERVENTIONS: None. MEASUREMENTS AND MAIN RESULTS: We describe the concept of surgical "buy-in," a complex process by which surgeons negotiate with patients a commitment to postoperative care before undertaking high-risk surgical procedures. Surgeons describe seeking a commitment from the patient to abide by prescribed postoperative care, "This is a package deal, this is what this operation entails," or a specific number of postoperative days, "I will contract with them and say, 'look, if we are going to do this, I am going to need 30 days to get you through this operation.'" "Buy-in" is grounded in a surgeon's strong sense of responsibility for surgical outcomes and can lead to surgeon unwillingness to operate or surgeon reticence to withdraw life-sustaining therapy postoperatively. If negotiations regarding life-sustaining interventions result in treatment limitation, a surgeon may shift responsibility for unanticipated outcomes to the patient.

CONCLUSIONS: A complicated relationship exists between the surgeon and patient that begins in the preoperative setting. It reflects a bidirectional contract that is assumed by the surgeon with distinct implications and consequences for surgeon behavior and patient care.

Manthous, Constantine

Denounce demagoguery on directives!
Critical Care Medicine 2010 March; 38(3): 1014-1015; author reply 1015-1016

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Advance directives in dementia: issues of validity and effectiveness.
International Psychogeriatrics / IPA 2010 March; 22(2): 201-208

Abstract: BACKGROUND: Although advance directives may seem useful instruments in decision-making regarding incompetent patients, their validity in cases of dementia has been a much debated subject and little is known about their effectiveness in practice. This paper assesses the contribution of advance directives to decision-making in the care of people with dementia, with a special focus on non-treatment directives and directives for euthanasia. METHODS: The relevant problems from the ethical debate on advance directives in cases of dementia are summarized and we discuss how these relate to what is known from empirical research on the validity and effectiveness of advance directives in the clinical practice of dementia care. RESULTS: The ethical debate focuses essentially on how to respond to the current wishes of a patient with dementia if these contradict the patient's wishes contained in an advance directive. The (very limited) empirical data show that the main factors in medical decision-making in such cases is not the patient's perspective but the medical judgment of the physician and the influence of relatives. Insight into the experiences and wishes of people with dementia regarding advance directives is totally lacking in empirical research. CONCLUSIONS: Ethics and actual practice are two "different worlds" when it comes to approaching advance directives in cases of dementia. It is clear, however, that the use of advance directives in practice remains problematic, above all in cases of advance euthanasia directives, but to a lesser extent also when non-treatment directives are involved. Although generally considered valid, their effectiveness seems marginal. Further empirical research into the (potential) value of advance directives in dementia care is recommended.

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The essentials of Advance Care Planning for end-of-life care for older people.

Abstract: AIMs AND OBJECTIVES: The aim of the study was to investigate the phenomenon of Advance Care Planning and the use of Advance Care Directives in residential aged care facilities in Australia. The objectives were to: investigate the implementation process of Advance Care Planning and the use of Advance Care Directives; investigate the outcomes of Advance Care Planning and experiences of people involved in Advance Care Planning and Advance Care Directives, including residents, families and nursing staff. BACKGROUND: Benefits of Advance Care Planning for older residents are considerable given their degenerative health-breakdown and minimal chance of recovery. To date, the use of Advance Care Planning and Advance Care Directives is limited and models of service delivery and processes are needed to enhance best practice with Advance Care Planning and positive outcomes for older Australians. DESIGN: Case study. METHODS: The study conducted using multiple sources of evidence to enrich understanding of the phenomenon of Advance Care Planning. The researcher engaged in data collection over six months involving participant observation, field notes, semi-structured interviews and document analysis. The findings contribute to the limited knowledge of options currently available to older adults and their families in their decision-making about end-of-life care options. PERMISSION TO CONDUCT THE STUDY: Prior to commencement of the data collection, ethics clearances from the University of Newcastle and the regional Area Health Service were achieved. Permission to access the residential aged care facilities to undertake the study was obtained from the relevant residential aged care facility ethics committees or designated authorities. The researcher undertook several strategies to ensure all the ethical principles were considered and adhered to while conducting the project. RESULTS: The research identified the components and factors involved in the Advance Care Planning process and in attaining desired outcomes. The conceptual framework developed elaborates how Advance Care Planning should be implemented and what may constitute successful implementation of Advance Care Planning in residential aged care facilities. The four main elements (input, throughput, output, feedback), and 20 sub-elements were requisites for nurses to initiate and implement the Advance Care Planning. CONCLUSION: The essential components for end-of-life care are identified in the implementation processes of Advance Care Planning in residential aged care facilities. The study contributes to greater awareness of the processes needed for 'dying well' and highlights the need to explore experiences of 'successful dying' and the way nurses contribute to these events. RELEVANCE TO CLINICAL PRACTICE: The case study identified four determinative requisites for successful implementation of Advance Care Planning in aged care facilities: the expert nurse, discussion, education and involvement of a multidisciplinary team. Nurses should take these factors into account and use person-centred approach in formalised processes to encourage participation in plans for end-of-life care.

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[Medical and medical ethical basis of precautionary options] = Medizinische und medizinethische Grundlagen der Vorsorgemöglichkeiten.
Der Anaesthesist 2010 February; 59(2): 118-125

Abstract: The main activities of anesthesiologists in addition to the operation theatre are intensive and emergency treatment...
as well as pain and palliative care. Discussions and decisions about strategies and enforcement of therapy are indispensable in all areas. Acknowledgment of the patients' wishes and protection of patient autonomy are very important in the context of medical fiduciary duty. Determination of the aim of therapy and the patient's prognosis are of special importance. Against the background of the current amendments of patient advance directives different possibilities, such as advance directive and emergency forms in different areas of anesthesiology will be discussed.
Understanding Iowa's out-of-hospital DNR law—its benefits and its limitations.
Iowa medicine : journal of the Iowa Medical Society 2010 Jan-Feb; 100(1): 10-1
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Document 208
Cosmacini, Giorgio
TESTAMENTO BIOLOGICO: IDEE ED ESPERIENZE PER UNA MORTE GIUSTA

Document 209
ECRI
THE PATIENT SELF-DETERMINATION ACT

Document 210
Lienert, Tania; Cartwright, C.; and Beck, K.
Aged Services Learning and Research Centre
THE EXPERIENCES OF GAY, LESBIAN, AND TRANSGENDER PEOPLE AROUND END-OF-LIFE CARE: SCOPING STUDY REPORT
[Coffs Harbour], New South Wales: Southern Cross University, ASLaRC, [2010]. 67 p.
Call number: citation only

Document 211
Fitzpatrick, Jeanne and Fitzpatrick, Eileen M.
A BETTER WAY OF DYING: HOW TO MAKE THE BEST CHOICES AT THE END OF LIFE
Call number: R726.2 .F58 2010

Document 212
Mason, Christina M; Caufield, Carolyn R; Kishinevsky, Lily
Sweeping changes to New York's powers of attorney.
Care management journals : Journal of case management ; The journal of long term home health care 2010; 11(4): 220-6
Georgetown users check Georgetown Journal Finder for access to full text

Document 213
Rurup, Mette L; Pasman, H R W Roeline; Onwuteaka-Philipsen, Bregje D
[Advance euthanasia directives rarely carried out with dementia Qualitative study of physicians and patients and patients] = Euthanasieverklaringen bij dementie. Kwalitatief onderzoek onder artsen en patiënten.
Nederlands tijdschrift voor geneeskunde 2010 154(16): A1273
Abstract: OBJECTIVE: To study how advance euthanasia directives (AEDs) in dementia are viewed in practice in the Netherlands. DESIGN: Qualitative study. METHOD: In-depth interviews on nine patients with the patients themselves and/or partners and their physicians. The patients were included from a cohort of people with an AED. All interviews were done in 2006. Cases were included with different diagnoses and at different stages of dementia. RESULTS: Interviewed patients and their relatives had very high expectations of the feasibility of the AED. Interviewed physicians often thought of AEDs as aids in starting up a dialogue about medical decisions at the end of life, but they did not always do this in practice. Most physicians were open to adhering to AEDs in exceptional cases, on condition that the patient obviously suffered, and that
communication with the patient to some extent was possible. In this study two cases were found in which adhering to the AED was seriously considered. In one case, fear of legal consequences was the only reason the physician had not adhered to the AED, while it seemed all the requirements of due care could be met. Euthanasia was not carried out in the other patient either. Several physicians mentioned the need for more detailed practical guidelines for the use of AEDs for dementia. CONCLUSION: Patients had too high expectations of AEDs. It seemed that in exceptional cases the requirements for due care for euthanasia can be met in patients with dementia with an AED. It seems advisable that more detailed practical guidelines for the use of AEDs in cases of dementia be drawn up, as a first step to more clarity for patients and physicians.

Mueller, Luke A.; Reid, Kevin I.; Mueller, Paul S.
Readability of state-sponsored advance directive forms in the United States: a cross sectional study.
BMC Medical Ethics 2010; 11: 6
Abstract: BACKGROUND: State governments provide preprinted advance directive forms to the general public. However, many adults in the United States (US) lack the skills necessary to read and comprehend health care-related materials. In this study, we sought to determine the readability of state government-sponsored advance directive forms. METHODS: A cross sectional study design was used. The readability of advance directive forms available online from all 50 US states and the District of Columbia was determined using 6 validated readability scales. RESULTS: Overall, 62 advance directive forms were obtained. For 47 states, forms were available by way of government-sponsored Web sites. The average (SD) readability (with the Flesch-Kincaid score) of all forms was grade level 11.9 (2.6). Similar results were obtained with the other readability scales. No form had a readability score at the 5th grade level or lower, the level recommended by the National Work Group on Literacy and Health. The readability of the forms exceeded this level by an average of 6.9 grade levels (95% confidence interval, 6.3-7.6; P < .001). Only 5 of the forms had a readability score at 8th grade level or lower, the average reading skill level of US adults. The readability of the forms exceeded this level by an average of 3.9 grade levels (95% confidence interval, 3.3-4.6; P < .001). CONCLUSIONS: The readability of US state government-sponsored advance directive forms exceeds the readability level recommended by the National Work Group on Literacy and Health and the average reading skill level of most US adults. Such forms may inhibit advance care planning and therefore patient autonomy.

Wilson, Bruce
Doing death better.
The American heart hospital journal 2009 Winter; 7(2): E104-5

Ito, Hiroaki; Nakajima, Takashi; Itai, Koichiro; Ito, Michiya; Imai, Takashi
[On a principle of advance directives]
Gan to kagaku ryoho. Cancer & chemothepary 2009 Dec ; 36 Suppl 1(): 66-8
Abstract: We explored a principle of advance directives. Advanced directives are a tool to help execute a broader concept of advance care planning, which is included in advance life planning. Advance directives should be formed by consent with inter- and multi-disciplinary care teams on the basis of patient's intension, passing process such as medical treatment, patient care and mental supports. The contents can update according to patient's health condition and environment. A definition of advance directives is, "oral or written statement in which people declare their treatment preferences in the event that they lose decision-making capacity". Under the present conditions in Japan, we show two problems that the process which reaches to the consent formation is neglected, and the document preparation is excessively considered. Advance directives are of two principle types: instructional directives and proxy consent. There are advantages and disadvantages to each type, and people often used a combination of both types. We conclude an interpretation process of instructional directive with proxy (key person), which assumes the patient's intention, is important for advance directives.
Document 217
Yates, Ferdinand D.,(Nick), Jr.
Clinical ethics case consultation: "When should the family challenge the patient's medical directives?"
Georgetown users check Georgetown Journal Finder for access to full text

Document 218
Manippo, Kelli M.; DePriest, Jack L.
Patients don't consider end-stage medical conditions the same as being permanently unconscious when they fill out a living will.
Georgetown users check Georgetown Journal Finder for access to full text

Document 219
Pope, Thaddeus Mason
Legal briefing: advance care planning.
Georgetown users check Georgetown Journal Finder for access to full text

Document 220
Bonner, Stephen; Tremlett, Michael; Bell, Dominic
Are advance directives legally binding or simply the starting point for discussion on patients' best interests? [debate]
British Medical Journal 2009 November 28; 339(7732): 1230-1234
Georgetown users check Georgetown Journal Finder for access to full text

http://www.bmj.com (link may be outdated)

Document 221
Sudore, Rebecca L.
Can we agree to disagree? [a piece of my mind]
Georgetown users check Georgetown Journal Finder for access to full text

http://jama.ama-assn.org/content/vol302/issue15/. (link may be outdated)

Document 222
Bezzina, Andrew J
Prevalence of advance care directives in aged care facilities of the Northern Illawarra.
Abstract: To assess the prevalence of advance care directives in the residential aged care facilities within the catchment for a single ED and to assess the systems in place for development of those advance care directives with focus on documentation and communication.
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Alfonso, Heather

**The importance of living wills and advance directives.**

**Abstract:** Living wills and advance directives are important components of patients' medical records, which all too often do not indicate the appropriate palliative care measures the patient desires. A review of the current literature indicates that approximately 85% to 95% of the population does not have adequate advance directives or palliative care measures written in their medical record. Furthermore, these orders may not follow the patient when he or she is transferred to other facilities for intermittent care. Unwanted tracheal intubations can be both costly to the facility and distressing to the patient and family members. By instituting a change in policy, organizations can ensure that patients' wishes for end-of-life care are met appropriately. In addition, nurses should advocate for a centralized database at the political level.

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Townsend, Liz

**Suicidal British woman allowed to die**
National Right to Life News 2009 October; 36(10): 6

Georgetown users check [Georgetown Journal Finder](http://www.chausa.org/Pub/MainNav/News/HCEthics/) for access to full text

Shepherd, Lois

**Asking too much: autonomy and responsibility at the end of life**
Journal of Contemporary Health Law and Policy 2009 Fall; 26(1): 72-81

Georgetown users check [Georgetown Journal Finder](http://www.nrclc.org/news) for access to full text

Miller, Ronald B.

**Physician orders to supplement advance directives: rescuing patient autonomy.**
Journal of Clinical Ethics 2009 Fall; 20(3): 212-219

**Abstract:** To adapt Churchill's comment on democracy, "No one pretends that [POLSTs are] perfect..." but physicians' orders about life-sustaining treatments are a very important supplement to advance directives, especially for patients who are extremely or terminally ill, and most particularly for patients who require emergency treatment by first responders or by physicians who do not know them as persons. The standardized orders of limited options, however, are no substitute for a detailed treatment directive of a patient with a known illness, with predictable trajectories and complications. And, in this latter circumstance, a thoroughly informed proxy may also assist physicians in selecting appropriate treatment for patients who have lost decisional capacity and/or the ability to express it. I believe all patients should have an advance directive, preferably a combined proxy-treatment directive, and preferably one that has been thoroughly discussed with the attending physician and with the proxy, successor proxies, and preferably relatives and friends. Nurses, social workers, and chaplains may be very helpful to the patient in thinking through his or her preferences, especially if the severity of illness and the
limited efficacy of interventions are such that the patient would wish to omit life-sustaining treatment or to discontinue it after a time-limited trial. Finally, because POLST is new or yet to be initiated in many areas of the country, it behooves all physicians to become knowledgeable of POLST and to initiate discussion of it with colleagues, patients, patients’ proxies, and with relatives of patients. Even more recent is the combined advance directive/physician's orders to permit natural dying, actionable immediately for patients suffering severely and irremediably, but actionable at a future time if the patient progresses to advanced stages of dementia or other devastating brain disorders. In order to encourage physicians to initiate advance care planning with their patients, this quote from a patient shortly before his death from prostatic cancer might prove helpful: "Not every patient can be saved, but his illness can be eased by the way that the doctor responds to him. In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and everything to gain by letting the sick man into his heart. If he does, they can share--as few others can--the wonder, terror, and exultation of being on the edge of being"
**Document 232**
Gillett, Grant

*Whose best interests? Advance directives and clinical discretion.*
Journal of law and medicine 2009 May; 16(5): 751-8

**Abstract:** A patient's advance directive (AD), confronts a clinician with a quasi-legal document of uncertain status in different jurisdictions and therefore a challenge to her or his clinical acumen and skill. The permutations of factors that need to be taken into account in the resulting clinical decision can be quite confusing. The uncertainties that arise in relation to the provision or otherwise of various forms of invasive and possibly risky clinical treatment can be very disconcerting in that the clinician may be aware of the need to account for the appropriateness of judgments about life-saving treatment and not just the clinical competence that was exhibited. The clinician needs to be clear about the relationships between the duty of care, reasonable medical practice, consent, and what would be considered a substantial benefit or unacceptable risk to the patient. This column outlines a decision structure that treats reasonable practice and the patient's wishes as combining to determine whether or not clinical interventions should proceed.

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**Document 233**
Bogdanoski, Tony

*Psychiatric advance directives: the new frontier in mental health law reform in Australia?*
Journal of law and medicine 2009 May; 16(5): 891-904

**Abstract:** The legal recognition of psychiatric advance directives is arguably at the forefront of human rights-based mental health law reform in Australia. However, academic discourse in Australia has largely neglected this important development. On the one hand, proponents of psychiatric advance directives believe that such instruments further the rights and autonomy of the mentally ill by allowing consumers of mental health services the right to participate in their own health care when they are competent to make health care decisions. On the other hand, opponents believe that they are undesirable and unworkable in practice and that giving mentally ill persons a right to consent to, or refuse, mental health treatment before the onset of any psychiatric illness does not actually promote or protect the best interests of the mentally ill since future decisions cannot be made about potentially unforeseen circumstances. This article argues that the time has come to consider using psychiatric advance directives in the mental health arena and for amending legislation to be introduced to give them a legal basis.

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**Document 234**
Rondeau, Dawn Felch; Schmidt, Terri A.

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among the three outcomes. Canadian region of residence, female gender, and more years of education predicted having
thought about preferences; region of residence, female gender, and lack of cognitive impairment predicted discussion of
preferences; and region of residence and not being married predicted whether formal documents were in place. Ontario
residents were most likely to have thought about, discussed, and formalized their preferences, whereas Atlantic residents
were least likely to. Finally, having thought about preferences was associated with discussion, and having thought about and
having discussed preferences were each associated with formalization of preferences. These findings are in keeping with the
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Abstract: OBJECTIVES: To analyse and compare the surveys on German doctors and judges on end of life decision making regarding their attitudes on the advance directive and on the dying process. DESIGN: The respondents were to indicate their agreement or disagreement to eight statements on the advance directive and to specify their personal view on the beginning of the dying process. PARTICIPANTS: 727 doctors (anaesthetists or intensive-care physicians, internal specialists and general practitioners) in three federal states and 469 judges dealing with guardianship matters all over Germany. MAIN MEASUREMENTS: Comparisons of means, analyses of variance, pivot tables (chi(2) test) and factor analyses (varimax with Kaiser normalisation). RESULTS: Three attitude groups on advance directive were disclosed by the analysis: the decision model, which emphasises the binding character of a situational advance directive; the deliberation model, which puts more emphasis on the communicative aspect; and the delegation model, which regards the advance directive as a legal instrument. The answers regarding the beginning of the dying process were broadly distributed, but no marked difference was observed between the responding professions. The dying process was assumed by most participants to begin with a life expectancy of only a few days. CONCLUSIONS: A high degree of valuation for advance directive was seen in both German doctors and judges; most agreed to the binding character of the situational directive. Regarding the different individual concepts of the dying process, a cross-professional discourse on the contents of this term seems to be overdue.

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proxy. A majority in all groups believed that advance directives may influence the course of treatment (79-85%), yet half of those surveyed in all groups fear that patients could be pressurised into writing an advance directive, and 38-65% thought that relatives could abuse such documents. CONCLUSIONS: Only a minority of the participants had written an advance directive and knew about the possibility of authorizing a health care proxy. Deteriorating health was associated with increasing willingness to make a directive. Despite a majority belief that advance directives may influence treatment at the end of life, other factors limit their employment, such as fear of abuse.

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**Would they follow what has been laid down? Cancer patients' and healthy controls' views on adherence to advance directives compared to medical staff**

Medicine, Health Care and Philosophy: A European Journal 2005; 8(3): 297-305

**Abstract:** Advance directives are propagated as instruments to maintain patients' autonomy in case they can no longer decide for themselves. It has been never been examined whether patients' and healthy persons themselves are inclined to adhere to these documents. Patients' and healthy persons' views on whether instructions laid down in advance directives should be followed because that is (or is not) "the right thing to do", not because one is legally obliged to do so, were studied and compared with that of medical staff. METHOD: Vignette study presenting five cases. Cancer patients, healthy persons, nursing staff and physicians (n = 100 in each group) were interviewed. An adherence score was calculated (maximum value 5). The adherence score is found to be low in all groups, yet lowest in patients (1.55; standard deviation 1.13) and healthy controls (1.60; 1.37). The scores are significantly different between nursing staff on the one hand and patients and healthy controls on the other (p < 0.005 and p < 0.05, respectively), and between doctors and patients (p < 0.05). Interviewees who want these documents to be followed tend to live alone and to have already written an advance directive. CONCLUSIONS: Cancer patients and healthy persons widely disregard instructions laid down in advance directives and consider them less binding than physicians and nursing staff do. Only a minority tends to adhere more to advance directives. To improve decision-making at the end of life when patients are no longer able to decide for themselves alternative concepts, such as advanced care planning, should be considered.

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**Do pregnant women have (living) will?**


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