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UNIT 1 END-OF-LIFE DECISION MAKING 1

Issue 1. Does Depression Make End-of-Life Decisions Untrustworthy? 2

YES: Benjamin Brody, from “Who Has Capacity?” *The New England Journal of Medicine* (July 16, 2009) 6

NO: National Ethics Committee of the Veterans Health Administration, from *Ten Myths About Decision-Making Capacity*, www.ethics.va.gov/docs/necrpts/NEC_Report_20020201_Ten_Myths_about_DMC.pdf (September 2002) 9

Benjamin Brody, a psychiatry resident physician, offers a discussion of cases he was called to evaluate for decisional capacity because of concerns about depression impairing decisional capacity. He demonstrates that each case must be uniquely approached and that in some cases depression can impair decisions related to end-of-life care. The National Ethics Committee of the Veterans Health Administration warns against using a single diagnosis as a criterion for the lack of decisional capacity. Instead they provide guidelines on what persons should be able to understand about their specific treatment in order to have decisional capacity.

Issue 2. Do Advance Directives Improve Care for Those Unable to Make Decisions? 24

YES: Maria J. Silveira, Scott Y. H. Kim, and Kenneth M. Langa, from “Advance Directives and Outcomes of Surrogate Decision Making Before Death,” *The New England Journal of Medicine* (2010) 28

NO: Cees M. P. M. Hertogh, from “The Misleading Simplicity of Advance Directives,” *International Psychogeriatrics* (2011) 38

University of Michigan physicians Silveira, Kim, and Langa found that if older adults had advance directives, the end-of-life care that they received was strongly associated with their previously stated preferences. In their study, about 25 percent of older adults were decisionally incapacitated at the end of life and required a surrogate decision-maker. The study found that those who had advance directives (AD) received care that was

consistent with their previously expressed preferences. Professor of geriatric ethics in the Netherlands C. M. P. M. Hertogh argues that despite their history in enabling “prospective autonomy,” many problems emerge for ADs. These include low frequency, low compliance, low adherence, changing preferences, unstable health, and a “disability paradox” that people change their minds as their health changes. To resolve potential conflicts between prior values of a competent person and best interests of one later incapacitated, he suggests patients shift instead to an ongoing dialogue between doctor and patient.

UNIT 2 CAREGIVER END-OF-LIFE DECISION MAKING 53

Issue 3. Do Dying Persons Without Advocates Get a Different Quality of Care? 54

YES: Elizabeth Barnett Pathak, Michele L. Casper, Jean Paul Tanner, Steven Reader, and Beverly Ward, from “A Multilevel Analysis of Absence of Transport to a Hospital Before Premature Cardiac Death,” *Preventing Chronic Disease* (vol. 7, no. 3, 2010) 58

NO: Linda S. Wasserman, from “Respectful Death: A Model for End-of-Life Care,” *Clinical Journal of Oncology Nursing* (vol. 12, no. 4, 2008) 65

Elizabeth Barnett Pathak, Jean Paul Tanner, Steven Reader, and Beverly Ward, of the University of South Florida, and Michele L. Casper, from the Centers for Disease Control and Prevention, found that people who are unmarried and live alone are vulnerable to dying from cardiac events without medical aid or a witness. Linda Wasserman, an advance practice nurse proposes a “respectful death” model of care that would be used as an approach to all patients, regardless of whether they have an advocate. The model includes identifying a caregiver for dying patients, with or without advocates.

Issue 4. Compassion Fatigue: Does Burnout Occur in All Caregivers of Dying Patients? 79

YES: Nancy Jo Bush, from “Compassion Fatigue: Are You at Risk?” *Oncology Nursing Forum* (vol. 36, no. 1, 2009) 83

NO: Dorothy J. Dunn, from “The Intentionality of Compassion Energy,” *Holistic Nursing Practice* (vol. 23, no. 4, 2009) 95

Nancy Jo Bush, an assistant professor at the University of California, identifies the phenomenon of compassion fatigue in nurses. She discusses caregivers at risk for emotional exhaustion related to their work. Dorothy Dunn of Florida Atlantic University describes compassion energy as the converse of compassion fatigue. She believes that nurses and other caregivers can grow and thrive if they understand how to prevent burnout by self-generating vigor as compassion energy.

UNIT 3 TREATMENT REQUESTS AND DECISIONS: PAIN AND FUTILITY 111

Issue 5. Does a Dying Person with Severe Pain Have a Right to Effective Pain Management? 112

YES: Kathryn L. Tucker, from “Medico-Legal Case Report and Commentary: Inadequate Pain Management in the Context of Terminal Cancer. The Case of Lester Tomlinson,” *Pain Medicine* (vol. 5, no. 2, 2004) 116

NO: Rodney Syme, from “Necessity to Palliate Pain and Suffering as a Defence to Medical Homicide,” *Journal of Law & Medicine* (vol. 17, no. 3, 2009) 127

Kathryn L. Tucker, the Director of Legal Affairs for the Compassion and Choices in Seattle, discusses the case of Lester Tomlinson, an 85-year-old patient dying of cancer whose family was successful in reaching an agreement after a lawsuit against the hospital and health providers for inadequate pain treatment. Brushwood (2004) and Johnson (2004) qualify Tucker’s claims. Rodney Syme argues that it is surprising that under current laws more physicians are not prosecuted for homicide when delivering high doses of pain medications at the end of life. He identifies a need for a defense for medical homicide based on the necessity to relieve pain.

Issue 6. Should Pain Be Alleviated if It Hastens Death? 148

YES: Richard A. Mularski, Kathleen Puntillo, Basil Varkey, Brian L. Erstad, Mary Jo Grap, Hugh C. Gilbert et al., from “Pain Management Within the Palliative and End-of-Life Care Experience in the ICU,” *CHEST* (vol. 135, no. 5, 2009), doi:10.1378/chest.08-2328 151

NO: Charles L. Sprung, Didier Ledoux, Hans-Henrik Bulow, Anne Lippert, Elisabet Wennberg, Mario Baras et al., from “Relieving Suffering or Intentionally Hastening Death: Where Do You Draw the Line?” *Critical Care Medicine* (vol. 36, no. 1, 2008) 163

Richard A. Mularski, a physician from the Center for Health Research at Kaiser Permanente Northwest, and colleagues from around the country discuss palliative care and end-of-life care in the intensive care unit. They identify that the intent of pain medications in this setting is the relief of pain and suffering, even if the possibility exists that these treatments will hasten death. Charles L. Sprung, MD, JD, a physician, lawyer, and professor at Haddasah University Hospital, in Jerusalem, writes with colleagues from around the world about their concerns with treatments and medications in the ICU that actively shorten the dying process. They raise concerns about the lack of distinction between alleviating suffering and active euthanasia and that inappropriately large doses of pain medications may be given to hasten death “in the guise” of relieving pain and suffering.

Issue 7. Does Too Much Treatment Result in an Inhumane Dying? 174

YES: Shannon Brownlee, from "Afterward," In *Overtreated: Way Too Much Medicine Is Making Us Sicker and Poorer* (New York, NY: Bloomsbury, pp. 305–312, 2008) 178

NO: Amanda Bennett and Charles Babcock, from "Lessons of a \$618,616 Death," *BusinessWeek* (no. 4170, 2010) 184

In the Afterword of her book, medical journalist Shannon Brownlee offers a poignant story of an elderly man with an implanted small battery-powered electrical impulse generator to correct an irregular heartbeat (called an implanted cardiac defibrillator or ICD). She raises serious concerns about whether we can sustain a "do everything" approach in health care, and what this means for end of life care. Amanda Bennett, an executive editor with Bloomberg News, and Charles Babcock, editor-at-large for *InformationWeek*, write about Mrs. Bennett's experience of the last years of her husband's life. She balances the discussion of the costs of his care with the value of his last years of life, the important family events and experiences that made it worth it to go through expensive treatments.

Issue 8. Are Feeding Tubes Obligatory? 201

YES: Allen G. Sandler, from "The Right to Nutrition and Hydration: A Need for Vigilance," *Intellectual and Developmental Disabilities* (vol. 47, no. 3, pp. 234–238, 2009) 205

NO: David Orentlicher and Christopher M. Callahan, from "Feeding Tubes, Slippery Slopes, and Physician-Assisted Suicide," *Journal of Legal Medicine* (vol. 25, no. 4, pp. 389–409, 2004) 212

Allen Sandler, an associate professor for special education, offers a case that demonstrates that nutrition and hydration were inappropriately viewed as futile treatment in a person with disabilities who was not truly terminal. He argues that persons with disabilities must have access to the same life-sustaining treatment as provided to those without a disability, including feeding tubes, and that decisions about futility must be carefully considered. David Orentlicher, professor of law, and Christopher Callahan, a physician, present the historical underpinnings of feeding tubes and how laws have allowed withholding or withdrawing feeding tubes in persons with serious or terminal illnesses. They provide evidence that allowing refusals of tube feedings has not led to the slippery slope of requiring tube feeding removals as once feared. Rather, there continues to be an overuse of feeding tubes in persons with terminal diseases.

Issue 9. Does Withholding or Withdrawing Futile Treatment Kill People? 227

YES: Nathan E. Goldstein, Davendra Mehta, Ezra Teitelbaum, Elizabeth H. Bradley, and R. Sean Morrison, from "It's Like

Crossing a Bridge': Complexities Preventing Physicians from Discussing Deactivation of Implantable Defibrillators at the End of Life," *Journal of General Internal Medicine* (vol. 23, no. S1, pp. 2–6, 2008) 231

NO: Daniel P. Sulmasy, from "Within You/Without You: Biotechnology, Ontology, and Ethics," *Journal of General Internal Medicine* (vol. 23, no. S1, pp. 69–72, 2007) 239

According to Nathan Goldstein, Associate Professor of Geriatrics and Palliative Medicine at Mount Sinai Hospital in New York, and colleagues, physicians viewed deactivating implanted cardiac defibrillators (ICD) differently than withdrawal of other life-sustaining treatments; physicians also expressed discomfort in approaching this discussion with patients or family members. Daniel P. Sulmasy, a Franciscan friar, ethicist, and physician at the University of Chicago Medical Center, discusses the ethics of withdrawing futile treatments, and establishes the difference between forgoing a life-sustaining treatment (such as deactivating an ICD) and the intent implied in the word "killing."

UNIT 4 ASSISTED SUICIDE 251

Issue 10. May a Dying Person Hasten Her Death? 252

YES: Katrina Hedberg, David Hopkins, Richard Leman, and Melvin Kohn, from "The 10-Year Experience of Oregon's Death with Dignity Act: 1998–2007," *The Journal of Clinical Ethics* (vol. 20, no. 2, pp. 124–132, 2009) 256

NO: Susan M. Wolf, from "Confronting Physician-Assisted Suicide and Euthanasia: My Father's Death," *Hastings Center Report* (vol. 38, no. 5, pp. 23–26, 2008) 269

Katrina Hedberg, the Oregon State Epidemiologist, Public Health Division, and colleagues discuss the characteristics of persons who have taken action under the Oregon Death with Dignity Act. These authors found that most of the dying patients who requested medications to end their lives felt a strong need for autonomy and control. Susan Wolf, the McKnight Presidential Professor of Law, Medicine & Public Policy at the University of Minnesota, discusses her long-standing opposition to physician-assisted suicide and reflects on how her father's death challenged that view.

Issue 11. Can Legal Suicide Really Safeguard Against Abuse? 283

YES: Ronald A. Lindsay, from "Oregon's Experience: Evaluating the Record," *The American Journal of Bioethics* (vol. 9, no. 3, pp. 19–27, 2009) 287

NO: Daniel Callahan, from "Organized Obfuscation: Advocacy for Physician-Assisted Suicide," *Hastings Center Report* (vol. 38, no. 5, pp. 30–32, 2008) 300

Ronald Lindsay, a lawyer and CEO of the Center for Inquiry, reviews the first decade of the Oregon Death with Dignity Act and identifies that key ethical and legal concerns raised by opponents are addressed with legal protections put into place. Cofounder of the Hastings Research Center, Daniel Callahan argues that advocates for physician-assisted suicide describe what they do in confusing terms and prescribe regulations without adequate public scrutiny.

Issue 12. Is Palliative Sedation Actually Euthanasia in Disguise? 315

YES: Margaret P. Battin, from “Terminal Sedation: Pulling the Sheet over Our Eyes,” *Hastings Center Report* (vol. 38, no. 5, pp. 27–30, 2008) 319

NO: National Ethics Committee, Veterans Health Administration, from “The Ethics of Palliative Sedation as a Therapy of Last Resort,” *American Journal of Hospice and Palliative Care* (vol. 23, no. 6, pp. 483–491, 2007) 326

Margaret Battin, a philosopher and ethicist from the University of Utah, argues that clinical practices of palliative sedation and euthanasia are conceptually alike yet different in ways that generate public debates concerning distinctions between misuses and abuses of palliative sedation. The National Ethics Committee of the Veterans Health Administration outlines guidelines for palliative sedation as an approach of last resort for dying patients with intolerable symptoms.

UNIT 5 DETERMINING DEFINITIONS OF DEATH 353

Issue 13. Is Brain Death Dead Enough? 354

YES: Eun-Kyoung Choi, Valita Fredland, Carla Zachodni, J. Eugene Lammers, Patricia Bledsoe, and Paul R. Helft, from “Brain Death Revisited: The Case for a National Standard,” *Journal of Law, Medicine & Ethics* (vol. 36, no. 4, pp. 824–836, 2008) 358

NO: Kristin Zeiler, from “Deadly Pluralism? Why Death-Concept, Death-Definition, Death-Criterion and Death-Test Pluralism Should Be Allowed, Even Though It Creates Some Problems,” *Bioethics* (vol. 23, no. 8, pp. 450–459, 2009) 380

Eun-Kyoung Choi and colleagues at the Charles Warren Fairbanks Center for Medical Ethics in Indianapolis review the current definitions and call for national standard for brain death that would eliminate uncertainty across hospitals, states, and jurisdictions. Kristin Zeiler, a medical ethicist, argues that the definitions of whole brain death as the irreversible cessation of “all” functions of the brain is limiting, because it doesn’t embrace other biological possibilities of death. She

discusses the need to link death definitions with operational criteria and the specific tests that can measure those criteria when someone has died.

UNIT 6 HOSPICE, POLICY, AND COSTS OF DYING 397

Issue 14. Is It Better to Die in Hospice Than Hospitals? 398

YES: Maryjo Prince-Paul, from “When Hospice Is the Best Option: An Opportunity to Redefine Goals,” *Oncology Nurse* (vol. 23, no. 4, pp. 13–17, 2009) 402

NO: David Crippen, Dick Burrows, Nino Stocchetti, Stephan A. Mayer, Peter Andrews, Tom Bleck, and Leslie Whetstone, from “Ethics Roundtable: ‘Open-Ended ICU Care: Can We Afford It?’,” *Critical Care* (vol. 14, p. 222, 2010) 408

Maryjo Prince-Paul of the Francis Payne Bolton School of Nursing at Case Western discusses the hospice model of care and the criteria that need to be met to enroll in hospice. David Crippen, a physician in the Department of Critical Care at the University of Pittsburgh Medical Center, presents a roundtable discussion with physicians around the world who have very different views about how to approach the care of a dying patient who is using an expensive intensive care resource at the end of life.

Issue 15. Should Eldercare at the End of Life Be Subsidized? 419

YES: National Bureau of Economic Research, from “Out-of-Pocket Health Care Expenditures at the End of Life,” www.nber.org/aginghealth/2010no2/w16170.html 423

NO: Li-Wei Chao, José A. Pagán, and Beth J. Soldo, from “End-of-Life Medical Treatment Choices: Do Survival Chances and Out-of-Pocket Costs Matter?” *Medical Decision Making* (vol. 28, no. 4, 2008) 425

In a National Bureau of Economic Research paper, researchers Samuel Marshall and Jonathan Skinner of the Department of Economics at Dartmouth College and Kathleen McGarry of the Department of Economics at UCLA discuss the out-of-pocket costs for hospital and nursing home care at the end of life and how these can be a drain on households even though elders have some subsidized medical care through Medicare. Li-Wei Chao and José A. Pagán of the University of Pennsylvania and Beth J. Soldo of the University of Texas Pan Am identify that older adults were more likely to want expensive end-of-life treatments if they were subsidized by Medicare, but less likely to want treatments if survival chances were poor or their spouse would be impoverished by their care.

UNIT 7 DYING AND DEATH AS CULTURAL PERFORMANCES 439

Issue 16. Is Dying Improved by Belonging to a Religious Community Rather Than Simply Being a Spiritual Person? 440

YES: Carolyn F. Pevey, Thomas J. Jones, and Annice Yarber, from "How Religion Comforts the Dying: A Qualitative Inquiry," *OMEGA* (vol. 58, no. 1, pp. 41–59, 2008) 444

NO: Lamont Satterly, from "Guilt, Shame, and Religious and Spiritual Pain," *Holistic Nursing Practice* (vol. 15, no. 2, pp. 30–39, 2001) 457

Carolyn Pevey and her colleagues at Auburn University Montgomery report findings of a qualitative study which identified several ways in which some Christian religions were linked to better coping with dying. Religious faith provided a source of strength and an avenue of social support through the dying process. Lamont Satterly, Master of Divinity and founder of the SEARCH foundation, raises the issue of religious pain in dying patients. He describes patients who have unresolved issues because of guilt or fear of breaking moral codes of their religion.

Issue 17. Is Dying Made Better by Culturally Competent End-of-Life Care? 478

YES: H. Russell Searight and Jennifer Gafford, from "Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians," *American Family Physician* (vol. 71, no. 3, pp. 515–522, 2005) 482

NO: Amber E. Barnato, Denise L. Anthony, Jonathan Skinner, Patricia M. Gallagher, and Elliott S. Fisher, from "Racial and Ethnic Differences in Preferences for End-of-Life Treatment," *Journal of General Internal Medicine* (vol. 24, no. 6, pp. 695–701, 2010) 494

Professor H. Russell Searight, of Lake Superior State University, and Jennifer Gafford, a psychologist, write about the cultural differences of patients that must be considered when approaching end-of-life decision making and how these approaches can improve care. Amber Barnato, a physician at the Center for Health Research at the University of Pittsburgh, and colleagues describe a study of end-of-life care preferences which found some cultural/racial groups prefer life-sustaining treatments that make their care at the end of life more likely to be in the hospital with aggressive treatments.

Issue 18. Do Funeral Rituals Help Grief? 506

YES: Robert Kastenbaum, from "Why Funerals?" *Generations* (vol. 28, no. 2, pp. 5–10, Summer 2004) 510

NO: Nicholas Köhler, from "We've Been Misled About How to Grieve: Why It May Be Wise to Skip the Months of Journaling and Group Talk We've Been Taught We Need." *Maclean's Magazine* (February 21, 2011) 518

Robert Kastenbaum, Professor Emeritus of Gerontology and Communications at University of Arizona at Tempe, discusses the historic and current reasons why the rituals of funerals are important to those who mourn. Nicholas Köhler, a writer/journalist with *Maclean's*, a national news magazine in Canada, discusses inadequacies in Kübler-Ross's five stages of grieving as protective bereavement, and relates newer research by George Bonanno that indicates how individuals have unique grieving processes that include elements of constructive resilience.

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