



VOICES OF DECISION IN NURSING HOMES: RESPECTING RESIDENTS' PREFERENCES FOR END-OF-LIFE CARE

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Care at the end of life involves not only clinical but legal and ethical decisions. While most elderly people are fully able to make health care decisions for themselves, there are some, especially those living in nursing homes, whose ability to make decisions fluctuates, is unclear, or is completely and permanently absent. In these cases, clinicians may have difficulty determining what is "right" or "best" for a resident, or who is the most appropriate person to make that decision.

The Voices of Decision practical guide, published by the United Hospital Fund in 2001, is intended to assist clinicians through situations of uncertainty. The co-editors are **Mathy Mezey, FAAN, EdD**, Independence Foundation Professor of Nursing Education and Director, The John A. Hartford Institute for Geriatric Nursing, New York University and **Nancy N. Dubler, LLB**, Director, Division of Bioethics, Montefiore Medical Center, and Professor of Bioethics, Albert Einstein College of Medicine. Contributing authors are **Linda Farber Post, JD, BSN, MA**, Bioethics Consultant in the Division of Bioethics at Montefiore Medical Center and an Assistant Professor in Bioethics at Albert Einstein College of Medicine; **Ethel L. Mitty, EdD, RN**, Adjunct Clinical Professor of Nursing and Associate Research Scientist in the Division of Nursing, New York University; **Gloria Ramsey, JD, BSN**, Director of Legal and Ethical Aspects of Practice in the Division of Nursing, New York University; **Melissa Bottrell, PhD, MPH**, Assistant Research Scientist in the Division of Nursing, and Adjunct Professor at the Robert F. Wagner Graduate School of Public Service, New York University at the time of publication; **Terry Hill, MD**, Medical Director of Laguna Honda Hospital and Co-Chair of the California Coalition for Compassionate Care; **Carl H Coleman, Esq.**, Associate Professor and Associate Director of the Health Law and Policy Program at Seton Hall Law School and former Executive Director of the NYS Task Force on Life and the Law; and **Michelle Petruzelli, JD**, senior attorney with the NYS Department of Health, Division of Legal Affairs..

Section I of Voices leads clinicians through a process for determining a resident's decision-making ability for the purposes of appointing a health care proxy. It is predicated on the concept of decision-specific capacity, which holds that a person may be able to make some, but not necessarily all, decisions and that the capacity a person needs to make a decision should be directly related to the type of decision to be made. Hence, many nursing home residents may have the ability to make relatively simple, low-risk decisions, like appointing a health care proxy.

Section II addresses the issue of proxy education and suggests that recent findings about the lack of concordance between patients', residents and proxies' decisions are grounded in proxies' lack of education about decision making and uncertainty about their roles, responsibilities, and authority. The section discusses the issues that

inhibit proxies and care providers from working together to make informed decisions and provides an educational plan to help proxies, unappointed surrogates, and clinicians more effectively develop and implement the care plan that best represents the resident's wishes and interests.

Section III addresses one of the most important yet often ignored decisions in a resident's nursing home stay-transfer to the hospital, particularly at the end of life. Dying nursing home residents are often sent to emergency rooms and admitted to hospitals where they receive aggressive, often invasive, interventions, sometimes over their own and their families' objections. In many cases, the humane and medically appropriate course would be to keep these residents in the familiar surroundings of the nursing home and provide palliative care. Barriers to providing end-of-life care in nursing homes are varied and complex, including ethical uncertainty, fear of litigation, misperception about regulations, lack of nursing home resources, financial incentives and disincentives, and lack of a decision-making process that providers trust. In this section, we describe the transfer decision-making guidelines developed to address these concerns. The guidelines draw on existing standards of practice but also introduce a new way of thinking in that they challenge the presumption that hospitalization is always best for the resident. The transfer guidelines include a benefit-burden analysis that brings the resident's voice into the decision-making process, through the resident's own words or those of the proxy or surrogate. The guidelines will be implemented and tested in a large sample of nursing homes in New York State in collaboration with the NYS Department of Health, Office of Continuing Care, beginning in Spring 2000.

Section IV, co-authored by Carl Coleman and Michelle Petruzelli, examines the multiple approaches suggested for health care decision making on behalf of the incapacitated resident who is without family or surrogate. While there are no statistics, we suggest that there are probably many such residents whose voices are not heard; decisions are made for them, probably by well-meaning physicians acting alone. Among the most frequent approaches to decision making for this population are court-appointed guardianship or court-ordered treatments; the approval of a state-appointed ombudsman; and two-physician concurrence. We suggest that approval by a multidisciplinary "community-based" committee might best represent the voice of the person who is without capacity, family, surrogate or proxy.

The fifth and last section presents principles and recommendations to guide nursing facilities in providing quality end-of-life care. The Guidelines are directed at nursing facility clinicians and administrators, federal and state government officials, and those responsible for the preparation and training of health professionals. The Guidelines help nursing facility leaders establish a process to compare their own mission, leadership, culture, and operations with end-of-life "best practice" in order to align their own policies and standards to promote respectful and collaborative decision making about end-of-life care.

In sum, this practical guide is about the variety of voices that can speak for the resident: the individual him/herself, a proxy or surrogate, a committee, and the professionals who provide care. It is intended to help the clinician sort out and study these various and sometimes competing voices. The hope is that, rather than a clash of adversarial voices, the result will be a blending of different perspectives achieving the common goal of the individual resident's well-being. Whether

decisions are made by a proxy or by a committee, striving to act in a resident's best interest is not without a heavy burden on the mind and soul. The Voices of Decision seeks to lighten that burden by explaining and enhancing each voice in the decision.

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