



GUIDELINES FOR END-OF-LIFE CARE IN NURSING HOMES: PRINCIPLES AND RECOMMENDATIONS

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email

pbrooks@uhfnyc.org

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Authors:

Mathy D. Mezey, EdD, RN, FAAN
Nancy N. Dubler, LLB
Melissa Bottrell, PhDc, MPH.
Ethel Mitty, EdD, RN
Gloria Ramsey, JD, RN
Linda Farber Post, JD, BSN, MA
Terry Hill, MD



Authors

Division of Nursing, School of Education, New York University

Mathy D. Mezey, EdD, RN, FAAN
Independence Foundation Professor of Nursing Education
Director, The John A. Hartford Institute for Geriatric Nursing

Melissa Bottrell, PhDc, MPH
Project Director; Adjunct Faculty, The Robert F. Wagner School for
Social Policy

Ethel Mitty, EdD, RN
Research Associate and Adjunct Assistant Professor

Gloria Ramsey, JD, RN
Director, Legal & Ethical Aspects of Practice
Project Director, Decisions About Death in Long-Term Care

Division of Bioethics, Department of Epidemiology & Social Medicine, Montefiore Medical Center

Nancy N. Dubler, LLB
Director, Division of Bioethics
Professor of Bioethics, Albert Einstein College of Medicine

Linda Farber Post, JD, BSN, MA
Bioethics Consultant
Assistant Professor of Bioethics, Albert Einstein College of Medicine

Geriatrics Medical Group, Oakland CA

Terry Hill, MD

Project Participants

Center for Gerontology and Health Care Research, Brown University

Vincent Mor, PhD
Director, Center for Gerontology and Health Care Research

The Marjorie Doyle Rockwell Center, Eddy Health Care Services, Cohoes, NY

Elizabeth Pohlmann, RN, MPH
Director of Education and Research

Scripps Gerontology Center, Miami University of Ohio

Deborah Stanley, MS
Assistant to the Director

Robert F. Wagner Graduate School for Public Service

James F. O'Sullivan, MPH
Melissa Robbins, PhD, MA

Expert Advisory Panel*

(* indicates Panel members endorsing the Guidelines)

Judith C. Ahronheim, MD*
Chief, Section of Geriatrics
St. Vincent's Hospital & Medical Center
153 West 11th Street, NR 1211
New York, NY 10011

Paul Brenner*
Executive Director
Jacob Perlow Hospice
Beth Israel Medical Center
First Avenue
New York, NY 10025

Chris G. Cameron, RN*
Director, Patient Care Services
New York State Health Facilities Assoc.
33 Elk Street, Ste. 300
Albany, NY 12207

Eileen Chichin, PhD, RN *

Co-Director, Center on Ethics
The Jewish Home & Hospital for Aged
120 West 106th Street
New York, NY 100 25

Carl Coleman, Esq.*
Executive Director
NY Task Force on Life and the Law
5 Penn Plaza, Ste. 301
New York, NY 10001-1803

Bart Collopy, PhD*
Fordham College, Lincoln Center
Department of Religious Studies
113 West 60th Street
New York, NY 10023

Beth Dichter, PhD
Project Manager
NYS Department of Health
Office of Continuing Care
Albany, New York

Ellen Flaherty, PhD, RN, MA*
GNP, The Osborne
New York University
50 West 4th Street
429 Shimkin Hall
New York, NY 10012

Amy Furth*
Director of Pastoral Care
Florence Nightingale Health Center
1760 3rd Avenue
New York, NY 10029

David Goldfarb, Esq.*
Former Chair, Legal Problems of the Aging
Goldfarb & Abrandt
200 Park Avenue South
New York, NY 10003

Marianna Kern Grachek, RN,C, MSN, NHA*
Acting Executive Director
Joint Commission on Accreditation of Healthcare Organizations
One Renaissance Blvd.
Oakbrook Terrace, IL 60181

Cindy N. Hock, RN
American Medical Directors Assn.
10480 Little Patukent Pkwy., Ste. 760
Columbia, MD 21044

Amber B. Jones*
President & CEO
NY State Hospice Assn.
21 Aviation Road, Suite 9
Albany, NY 12205

Mark J. Kator, MBA*
President and Chief Executive Officer

Isabella Geriatric Center
515 Audubon Avenue
New York, NY 10040

Bonnie Kelly, MSN
OMBUDSMAN
Division of Senior Affairs
New Jersey Department of Health and Senior Services
CN 80
Trenton, NJ 08625-0807

Patricia Leddy, RN, MA*
Associate Administrator
Silvercrest Extended Care Facility
144-45 87th Avenue
Jamaica, NY 11435-3009

Carla Mariano, EdD, MEd, RN*
Professor, Division of Nursing
New York University
50 West 4th Street
429 Shimkin Hall
New York, NY 10012

Joan McHugh, MS, RN
Principal,
Loeb & Troper
655 3rd Avenue
New York, NY 10017

Jean Murphy, JD*
Director, Friends & Relatives of the
Institutional Aged
11 John Street, Suite 601
New York, NY 10038

Elizabeth Pohlmann, RN, MPH*
Director of Education and Research
Eddy Alzheimer's Services
421 W. Columbia Street
Cohoes, N.Y. 12047

Patricia Tabloski, RN*
Boston College School of Nursing
140 Commonwealth Avenue
Chestnut Hill, MA 02467

Leslie Walker, MPH*
Braceland Center for Mental Health &
Aging
Institute for Living, Hartford Hospital
400 Washington Street
Hartford, CT 06106

Endorsements

Organizations and Associations

National Gerontological Nurses Association

Ann Schmidt Luggen, President

New York Association of Homes and Services for the Aging

Carl Young, President

National Association of Directors of Nursing Administration

Sue Warden-Saunders, Executive Director

Individuals endorsing the Guidelines

Deborah Sherman, PhD, RN.

Associate Professor of Nursing, New York University, New York

**GUIDELINES FOR END-OF-LIFE CARE IN NURSING HOMES*:
PRINCIPLES AND RECOMMENDATIONS**

EXECUTIVE SUMMARY

Over the past 20 years, where death occurs, the circumstances under which people die, and the care that people receive during the dying process has become an increasing societal concern about the provision of aggressive versus palliative care at the end of life. Approximately 17-22% of all deaths in the United States, 380,000 deaths per year, occur in nursing homes (NCHS 1996). Many other residents are transferred to hospitals in the period immediately prior to death. Thus, for nursing home residents, family members, providers and payers, the place where death should most appropriately occur is of critical concern.

Gerontologists and ethicists argue that nursing home residents would receive more humane care at the end of life if they remained in nursing homes rather than were transferred to hospitals. Yet, there are legitimate concerns when advocating that nursing homes care for dying residents. Nursing homes recognize the need to earn society's confidence in their ability to provide the dying the highest standard of care. Many homes do, in fact, deliver principled and compassionate care. Yet, even those homes that adhere to high standards point to the lack of industry guidelines on what constitutes quality end-of-life care as a barrier to their ability to assure that care to dying residents conforms to the highest quality. Nursing homes need public policy that supports their efforts to explore the use of palliative care models. The Guidelines identify seven principles and recommendations for quality end-of-life care in nursing homes. Principles 1 through 5 specifically address recommendations for nursing homes. Principle 6 addresses recommendations for state and federal government. Principle 7 addresses the preparation and training of health care professionals. The principles and recommendations contained in these Guidelines are an intellectual and ethical blueprint for long-term care facilities seeking to bring their end-of-life care into the mainstream of appropriate and compassionate care. The Guidelines are based on a process of self-reflection wherein the home must review the end-of-life literature, and its own values, commitments and practices. The aim is to promote respectful and collaborative decision making that render end-of-life care transparent, open, and empowering for residents, families or surrogates, and staff. The Guidelines do not purport to address all care issues that have ethical ramifications. Thus, this document should be used in conjunction with a nursing home's approach to providing

quality of care to its residents.

The Guidelines speak to the obligations and accountability of all staff in the facility. The principles and recommendations are concrete suggestions for forging a comprehensive, resident-centered, family-supportive process that staff can comprehend and implement with compassion.

*The Omnibus Budget Reconciliation Act of 1987, PL 100-203, designated an entity (all or a distinct part) participating in the Medicare program as a "Skilled Nursing Facility" and in the Medicaid program, a "Nursing Facility." The language in many government reports and in the professional literature continue to refer to these entities/facilities as a "nursing home" and will be the nomenclature used in this document.

Principle # 1. The nursing home is responsible for establishing a culture and organizational process that supports timely, comprehensive, compassionate end-of-life care.

Recommendations for Nursing Homes

1.1 Clearly state a philosophy of end-of-life care based on the best knowledge available.

1.2 Have a mission statement that includes the home's end-of-life care philosophy and directs its structure and policies as well as the expectation that all employees will adhere to the organizational mission

1.3 Distribute the home's philosophy and mission statement to resident, family or surrogate at time of admission.

1.4 Ensure competency and accountability in end-of-life care by professional and non-professional staff.

Principle # 2. The nursing home is accountable for the ongoing communication among staff, residents, and families about goals of care at the end of life.

Recommendations for Nursing Homes

2.1 Create a structure and process that assigns clear responsibility for staff initiating, implementing, updating, and documenting end-of-life care decisions by residents and families or other decision maker.

2.2 Encourage the use of simple, unambiguous language about dying, rather than euphemisms that are easily misunderstood.

2.3 Ensure that communication about end-of-life care is conducted with cultural sensitivity, respect and support for family or surrogate decision makers, and that discussions occur in a timely fashion that allows for full expression, reflection and conflict resolution.

2.4 Allocate resources for staff education in the "language of dying" and the needs of family and staff for closure when death occurs.

2.5 Use ethics committees to inform and support communication and to resolve disputes about end-of-life care between and among residents, families or representatives, and caregivers.

Principle # 3. The nursing home is responsible for supporting resident and family decision making about end-of-life care.

Recommendations for Nursing Homes

3.1 Create a structure and process to facilitate resident, family or other surrogate decision making about end-of-life care.

3.2 Assure documentation of resident, family, or other surrogate preferences about end-of-life care (e.g. advance directives, verbal preferences, do-not-hospitalize orders; comfort care options).

3.3 Educate families about the dying process, and end-of-life and palliative care.

3.4 Require that staff describe and explain end-of-life care treatment options and help residents and families or surrogates evaluate the benefits, burdens, and risks.

Principle # 4. Evidence-based "best practices" on pain and symptom management are the basis for a dying resident's plan of care.

Recommendations for Nursing Homes

4.1 Implement nationally recognized standards for competencies, benchmark criteria, outcomes for pain and symptom management and procedures for correcting unacceptable practices.

4.2 Operationalize end-of-life care assessment, planning, implementation, monitoring and evaluation through research utilization, validated care protocols, continuous quality improvement measures, and staff performance evaluation.

Principle # 5. Hospitalization at the end-of-life is indicated when it is the only feasible way to obtain a short-term benefit for the resident, diagnostic information that will change the plan of care, and/or provide an intervention that will return the resident to a prior or higher level of comfort and function.

Recommendations for Nursing Homes

5.1 Develop criteria and process for transferring dying residents to the hospital.

5.2 Promote resident, family or surrogate, and staff evaluation of the benefits, burdens and risks of therapeutic options, including hospitalization.

5.3 Assure the availability of resources needed to care for the resident in the home that include but are not limited to, the number of professional nurses on duty at all times.

5.4 Furnish services (e.g., laboratory, x-ray, and pharmacy) that allow resident and family choice to remain in the nursing home at the end of life.

5.5 Educate residents, family or other surrogate, and staff about the role of advance directives and do-not-resuscitate (DNR) orders in hospitalization decisions.

5.6 Establish and disseminate a do-not hospitalize (DNH) policy and protocol for dying residents.

5.7 Create a mechanism for mediating transfer decision conflicts among resident, family or surrogate, and staff.

Principle # 6. State and federal government should exercise oversight responsibility for the quality of end-of-life care in nursing homes.

6A. Recommendations for State Government

6A.1 In collaboration with local health departments, nursing homes and hospices, develop and disseminate existing (or where needed, new) standards for quality end-of-life care to all nursing homes, state surveyors and regulators, and the general public.

6A.2 Ensure that nursing homes have plans of care specific to residents at the end-of-life.

6A.3 Establish and disseminate uniform guidelines for the conditions under which advance directives (health care proxies, living wills, DNR orders, do-not-hospitalize orders) are obtained, reviewed and implemented.

6A.4 Require evidence of resident, family or surrogate, physician and interdisciplinary team participation in assessing the resident's end-of-life comfort and care needs.

6A.5 Work collaboratively with nursing homes to more appropriately use resident death rates as markers of end-of-life care.

6A.6 Restore the consultative role of nursing home surveyors' ongoing surveillance responsibilities.

6A.7 Ensure that surveyors understand the context and significance of end-of-life care in nursing homes.

6A.8 Join with nursing homes to educate health care proxies about their role and responsibilities.

6A.9 Test models of advanced nursing practice or physician assistant practice in end-of-life care.

6A.10 Evaluate the Medicaid reimbursement to homes to eliminate or reduce the incentive to hospitalize dying nursing home residents.

6B. Recommendations for the Federal Government

6B.1 Develop national standards of quality end-of-life care for nursing homes.

6B.2 Create regulations and survey criteria for quality end-of-life outcomes for nursing homes.

6B.3 Modify the resident assessment instrument (RAI) classification system (MDS, RUGs, Resident Assessment Protocol [RAP]) to appropriately guide and reimburse nursing homes for quality end-of-life care.

6B.4 Clarify the Medicare hospice benefit in nursing homes.

6B.5 Collaborate with state government and private resources to educate the public about the philosophy, scope and services associated with palliative care.

6B.6 Add the right to quality end-of-life care and pain and symptom management to the Patient/Resident Bill of Rights.

6B.7 Require a defined process or mechanism to address clinical ethics issues as a Condition of Participation in Medicare and Medicaid.

Principle # 7. Health care professionals have a responsibility to acquire and maintain competencies in end-of-life care.

Recommendations for Health Care Professionals

7.1 Learn the language of palliative and end-of-life care and how to modify this language with residents, family members or other surrogates and staff from diverse cultures and ethnic backgrounds.

7.2 Learn how to give "bad news" in a way that assures dying residents and families, verbally and non-verbally, that they will not be abandoned.

7.3 Acquire skills in discussing advance directives and end-of-life care planning with residents, family members or other surrogates, and staff;

7.4 Acquire skills in conflict resolution to help clarify values and preferences among the resident, family or other surrogate and staff..

7.5 Acquire scientific and clinical knowledge in pharmacological and non-pharmacological approaches to pain and symptom management.

7.6 Be familiar with end-of-life care statements in their professional Code of Ethics.

7.7 Gain skills in team approaches to making end-of-life treatment decisions.