



Principles for Care of Patients at the End of Life: An Emerging Consensus among the Specialties of Medicine

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Foreword

This report describes an advance in clinical policy for care at the end of life: the adoption of Core Principles for End-of-Life Care by a substantial number of medical specialty societies.

Christine Cassel, M.D., and Kathleen Foley, M.D., convened representatives of medical specialty societies in September 1996 in order to share their organizations' "existing or proposed policies concerning decision-making at the end of life and the quality of clinical management of dying patients." The conveners proposed a draft set of "Core Principles for End-of-Life Care." The representatives distributed policies that had been adopted or were under discussion within their societies.

Each of the specialty societies subsequently considered the core principles as modified during discussion at the meeting. These principles appear in a box in the body of the report below.

Each representative agreed to "return to his/her society and work toward developing" policy appropriate to the specialty. Societies whose representatives could not attend the meeting subsequently joined the project.

Fourteen societies and the Joint Commission on the Accreditation of Healthcare Organizations have adopted policies that embrace the core principles. Other societies may adopt the principles in due course.

This report describes the status of policy development for end-of-life care among specialty societies in the summer of 1999. Eight organizations have adopted the Core Principles as written. Two other societies drafted policies that endorse each of the principles. Four societies adopted the Core Principles with modifications. The Joint Commission reported that its standards for care at the end of life are aligned with the Core Principles.

Many people contributed to this report. The persons listed in the Acknowledgments either represented specialty societies in this project, offered advice based on extensive clinical experience, or provided staff support. A state legislator and a state human services director represented the broad public interest in explicit and appropriate clinical policy for end-of-life care.

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Principles for Care of Patients at the End of Life

Almost every medical specialist at some point interacts with patients who are dying. With its dramatic advances in biomedical research and the ability to treat disease and prolong life, however, modern medicine—until recently—has neglected its traditional role of comforting patients and their families when end of life is near. Moreover, one characteristic of modern medicine in the United

States is the absence of any specialty of palliative medicine as such. The few specialists who have focused most of their efforts on end-of-life care have come from internal medicine, family medicine, and oncology as well as—to some degree—neurology and anesthesia, with their expertise in pain management.

Since 1997, a significant number of specialty societies, as well as the Joint Commission on Accreditation of Healthcare Organizations, have endorsed or adopted a consistent set of Core Principles for End-of-Life Care (see box). Some have adopted these principles with minor modifications. Others have issued policy and/or other statements elaborating on the principles in the context of their specialties. Certain principles are common to all and the groups have come to consensus on these. This report summarizes how some of these specialty groups have adapted these principles to their own unique circumstances and describes how they have identified their important roles in end of life care.

The Problem of End-of-Life Care

Almost 2.5 million Americans die each year; the majority are over the age of 65. The leading causes of death—cardiovascular disease and cancer—vary with age, however. For example, of those over 65, only 23 percent die of cancer. With progressive aging, many die with disorders complicated by neurobiological disorders such as Parkinson's or Alzheimer's disease or by stroke. This wide range of clinical disorders demands that improved care of the dying become the focus of all medical specialists who will encounter dying patients during the course of their practice.

In addition, the Institute of Medicine report of 1997 points out that there are different trajectories of dying, depending on the underlying health status of the patient and the nature of the terminal illness.¹ A person dying from congestive heart failure or liver disease may have very different clinical needs than someone dying from lung cancer, and some people may need highly specific specialty care. In our scientifically advanced health care world, different specialties may see different aspects of the care of dying patients. It is therefore imperative that they agree on the basic principles underlying their roles and responsibilities in end-of-life care.

Addressing the Problem: Palliative Care and the Specialties of Medicine

American medicine is specialty based, and much of its strength lies in the strength of its specialty societies. To broaden the specialty base of attention to end-of-life care, we convened representatives of 13 surgical and other medical specialties, as well as subspecialties in internal medicine (including the American Medical Association), in September 1996 to discuss access to and quality of clinical care at the end of life.

At this meeting, the group agreed that the medical community needs to strengthen clinical competency and specialty skills in order to ensure quality care at the end of life. To that end, representatives promised to work within their individual societies toward developing clinical methods, tools, or guidelines to meet those needs.

The group also agreed to accept both the term *palliative care* to identify the range of clinical services appropriate for dying patients and the World Health Organization's definition of the term: "Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families."²

Core Principles for End-of-Life Care

Drawing on the discussion at the September 1996 meeting, we drafted an early version of the Core Principles for End-of-Life Care and distributed it to the meeting's representatives for review and

comment. The responses we received led to a final list of 11 Core Principles (as shown below in the box), which we again distributed to the representatives to present to their individual societies for further consideration. At that time, we asked each specialty to prepare a general policy statement that encompassed the Core Principles and that explained which issues the specialty viewed as most important in end-of-life care for its particular patients. In addition, we asked each society or specialty to summarize its special role in care at the end of life and to describe the following points: Which aspects of care are relevant to the specific specialty? At whose request do referrals occur? What are the typical duration and effects of the specialty's involvement? And what problems do its specialists face in carrying out their professional role?

To date, the following organizations have formally adopted the Core Principles exactly as written: the American Medical Association, Academy of Psychosomatic Medicine, American Academy of Hospice and Palliative Medicine, American Board of Hospice and Palliative Medicine, American College of Chest Physicians, American Pain Society, and the National Kidney Foundation.

Moreover, both the American Academy of Neurology (AAN) and the American Society of Clinical Oncology (ASCO) drafted their own specific statements on palliative care and/or end-of-life care that embody all the Core Principles. The AAN statement, drafted by its Ethics and Humanities Subcommittee, was approved by the AAN executive board in July 1995; the final version was published in the Academy's journal the following spring, reinforced by an editorial that appeared in the same issue.³ The ASCO statement was adopted in February 1998 and published in May as a special article in its journal.⁴

Four societies have formally adopted the Core Principles with modifications: the American Academy of Pediatrics, the American College of Surgeons, the American College of Physicians–American Society of Internal Medicine, and the American Geriatrics Society. In addition, the American Society of Bioethics and Humanities unanimously agreed that its members would support these principles, although the organization does not officially support specific policy statements.

The Joint Commission on Accreditation of Healthcare Organizations also participated in the development of the Core Principles. The Commission's focus is on the health care organization, rather than on the interactions of individual practitioners with their patients, but it states that its standards on end-of-life care for hospitals and health care organizations are aligned with the Core Principles.⁵

The following discussion surveys the policy and summary statements that were submitted to us by some of the specialty groups with regard to the Core Principles and end-of-life care. It should be noted that not every group submitted a policy statement and/or summary statement. Hence, oftentimes one organization's position on end-of-life care is discussed in greater detail than that of another organization. In the few cases in which a society has since published its positions on end-of-life care, bibliographic information is provided.

Core Principles for End-of-Life Care

Clinical policy of care at the end of life and the professional practice it guides should:

1. Respect the dignity of both patient and caregivers;
2. Be sensitive to and respectful of the patient's and family's wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other physical symptoms;
5. Assess and manage psychological, social, and spiritual/religious problems;
6. Offer continuity (the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);

7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or nontraditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences;
11. Promote clinical and evidence-based research on providing care at the end of life.

Societies That Have Adopted the Principles as Written

American Medical Association

The American Medical Association (AMA) submitted its eight Elements of Quality Care for Patients in the Last Phase of Life as its policy statement, developed at the same time as our Core Principles. The AMA contends that since people in the last phase of life seek peace and dignity, they should be able to expect these eight elements of care from physicians, health care institutions, and the community: ⁶

- The opportunity to discuss and plan for end-of-life care;
- Trustworthy assurance that physical and mental suffering will be carefully attended to and comfort measures intently secured;
- Trustworthy assurance that preferences for withholding or withdrawing life-sustaining intervention will be honored;
- Trustworthy assurance that there will be no abandonment by physicians;
- Trustworthy assurance that dignity will be a priority;
- Trustworthy assurance that burden to family and others will be minimized;
- Attention to the personal goals of the dying person; and
- Trustworthy assurance that care providers will assist the bereaved through early stages of mourning and adjustment.

In summarizing its role in caring for patients at the end of life, the AMA referred to the AMA/Robert Wood Johnson Compassionate Competent Care Initiative, whose goal is to ensure that practicing physicians are equipped with the knowledge and skills to provide the best possible care for dying patients. The initiative seeks to educate physicians throughout the country in the practicalities of discussing and completing advance care planning and in the goals and interdisciplinary clinical skills of palliative care. The program also seeks to promote endorsement of these skills by the leadership and general culture of medicine.

The initiative's advance care planning activities train physicians in practical communication skills and familiarize them with the content and processes of, as well as methodologies required for, effective and supportive family/patient sessions. The palliative care therapeutic model attempts to improve quality of life for the patient and family by ameliorating those factors that contribute to suffering and

impair physical, psychological, and existential functioning. Underlying this educational intervention is the philosophy that every physician should be able to recognize suffering and either provide palliative care personally or enlist help from an appropriate colleague to provide it.

Academy of Psychosomatic Medicine

The Academy of Psychosomatic Medicine (APM) encourages education about the prevalence and morbidity of psychiatric complications of terminal illness. Among the remedial efforts that the APM promotes are (1) research into these complications, including their effects on suffering and quality of life among dying patients and their families, interactions with other comorbid conditions such as pain, fatigue, shortness of breath, anorexia, and nausea, and reliably effective treatment strategies used at the end of life; (2) collaboration with governmental funding agencies and private foundations to develop research in these areas; and (3) training of young investigators in research related to the psychiatric complications of terminal illness.

The APM encourages education and advocacy to ensure that legal or regulatory barriers do not hinder excellent psychiatric care at the end of life. It maintains that laws and regulations must allow physicians to provide appropriately aggressive care for psychiatric complications of terminal illness and protect qualified physicians who provide this care. For example, the APM states in its policy statement that excellent treatment of depression at the end of life often requires the use of controlled substances (psychostimulants), analogous to the use of opiate analgesics to treat pain. It asserts that appropriate treatment of agitated and delirious patients who are dying may require sufficient sedation to relieve suffering, that, when clinically indicated, such sedation is the standard of care—even if it hastens death—and that such treatment is ethically sound and not an act of assisted suicide or euthanasia.⁷

In looking at the Core Principles from its own perspective, the APM prepared the following brief summary describing its role in end-of-life care:⁸

"Excellent end-of-life care requires explicit attention to psychiatric problems. Psychiatric morbidity in the setting of terminal illness is exceptionally high. Psychiatric complications of the end of life are treatable but often go unrecognized and untreated. Additionally, depression is the strongest determinant of suicidal ideation and desire for death in those with serious or terminal illness.

"The role of the psychiatrist in care of the dying patient involves attending to the psychiatric, neuropsychiatric, and psychosocial complications of terminal illness. Dealing with issues of loss (related to both the disabilities of the illness and the patient's death) is a universal challenge at the end of life. Psychiatric care should also address resources, strengths, problems, and suffering related to: anxiety symptoms and anxiety disorders; depressive symptoms and depressive disorders; delirium and other cognitive disorders; suicidal ideation; consequences of low perceived family and other social support; personality disorders or personality traits which cause distress; questions of capacity to make informed decisions; grief and bereavement; spiritual and religious beliefs and practices (including both personal faith and relationship to a community of believers); and general and health-related quality of life.

"We believe that several factors or barriers contribute to the underrecognition and undertreatment of psychiatric problems at the end of life. These include: difficulty in diagnosing psychiatric disorders in the setting of significant physical illness; the beliefs held by many patients, family members, physicians and hospice and palliative care providers, that psychiatric symptoms, especially depression, are viewed as normal parts of the dying process; the fact that many patients and physicians do not understand that mental disorders at the end of life respond to treatment; the presence of structural and economic barriers to coordinated care of dying patients; the stigma experienced by patients and families due to psychiatric evaluations or the assignment of a psychiatric diagnosis; the occurrence of countertransference hopelessness on the part of families and healthcare providers; and the fact that treatment based on formal diagnosis (as opposed to symptomatic treatment) is not sufficiently emphasized in palliative care. The role of the psychiatrist involved in end-of-life care addresses these barriers to excellent care for dying patients."

American Board of Hospice and Palliative Medicine

Established in 1996, the American Board of Hospice and Palliative Medicine's role is to enhance the competency of palliative and hospice care through both physician certification and the promotion of national standards of care. In its policy statement, the ABHPM notes that hospice and palliative medicine "recognizes the multidimensional nature of suffering, responds with care that addresses all dimensions and communicates with language that conveys mutuality, respect, and interdependence." The Board recognizes palliative care as a model, although appropriate for all chronic illnesses, that focuses on life-limiting and incurable illnesses and addresses quality-of-life and end-of-life concerns of both patient and family. The Board notes that while the specialty of hospice and palliative medicine "represents the physician element in the interdisciplinary milieu," it also recognizes the social, economic, spiritual, and cultural dimensions that accompany chronic illness; thus, it also considers specialists from the social sciences and spiritual disciplines as part of this specialty.

The ABHPM views the certification process as "the cornerstone for the establishment of national standards of practice by physicians in Hospice and Palliative Medicine in the United States." To qualify for this certification, a physician must (1) be ABMS board-certified; (2) demonstrate extensive prior investment in caring for patients (and their support unit) with life-limiting illness; (3) display referenced evidence of effective participation in an interdisciplinary setting; and (4) pass a written examination that represents the increasing body of knowledge, skills, and behaviors needed for competent care of patients with life-limiting illness.

American Academy of Hospice and Palliative Medicine

Among the principal goals of the American Academy of Hospice and Palliative Medicine (AAHPM), which represents 1,500 physicians, are (1) establishing for those living with terminal illness excellence of care that not only treats their medical needs but also includes their family and friends in their care; and (2) attending to quality-of-life issues that are faced at life's completion by the patients and their loved ones.

In its policy statement, the AAHPM lists, as one of its major goals, dissemination of information to those who might be caring for patients living with terminal illness. It supports and participates in teaching all physicians, regardless of their level of experience, about the role of the physician on the interdisciplinary care team and about principles of ethical practice relevant to the total care of persons confronting advancing terminal illness. Additionally, the Academy participates in public education in matters concerning end-of-life care. It also maintains a central repository of up-to-date information for physicians concerning the multifaceted care of the person at the end of life.

In summarizing its role in caring for patients at the end of life, the AAHPM wrote:⁹ "It is the belief of the AAHPM that the dying person and their care unit have the right to determine the amount and type of medical care that will enhance the quality of their lives during a terminal phase of life. The Academy contributes to clinical training and supports certification of physicians with demonstrated knowledge and expertise to carry out this mission. A physician certified by the American Board of Hospice and Palliative Medicine has met the rigorous standards and is qualified to practice and supervise comprehensive care for the dying person and [his/her] family. In addition, the physicians in our Academy have the ability and desire to teach, function on the interdisciplinary team, and pursue ethical issues that affect the care of the dying."

American Pain Society

The American Pain Society (APS) focuses on pain treatment and research. It is not a clinical specialty, but a multidisciplinary scientific society that includes, among others, basic scientists, physicians, nurses, psychologists, and pharmacologists.

In its position statement,¹⁰ the APS asserts that patients' and families' values and preferences regarding end-of-life care must be respected. It believes that, although pain and other end-of-life

symptoms can usually be relieved if clinicians have the training and resources to focus on this goal, current treatment often falls short. Often the control of pain and other symptoms has been underemphasized because the American health care system has been oriented to the curing of disease rather than to palliation; therefore, its programs must be redesigned to incorporate many aspects of palliative care delivery. In general, the APS believes that health care organizations and professionals must be accountable to all patients for attentive treatment of pain; that pain must be routinely charted as a "fifth vital sign" so that unrelieved pain triggers a prompt response; and that available expert consultants and "high technology" pain treatment interventions must be provided for the minority of cases in which simpler measures do not suffice.

The APS also addresses specific educational, research, and policy needs. For example, it urges educating physicians, nurses, patients, and families about pain treatment and disseminating guidelines to clinicians to assist them in providing such treatment.

Since medical research has traditionally focused on curing disease, with relatively few resources devoted to improving symptomatic treatment, the APS encourages basic and applied research related to the mechanisms and treatment of symptoms of disease. It notes that the achievements over the past 20 years of a small group of basic neuroscientists and clinical researchers who have focused on the study of pain illustrate the dramatic results that biomedical research can produce when applied to symptom research: for example, the development of spinal opioid treatment, patient-controlled analgesia, sustained-release opioid compounds, and effective new treatments for pain related to nerve injury and migraine. But now that such treatments exist, a crucial research question is how to ensure their broad application. In addition, many other symptoms of advanced illness (e.g., poor appetite, fatigue, shortness of breath, constipation, and pain related to the heart, gastrointestinal tract, urinary tract, and female reproductive organs) have received relatively little basic or clinical research. The APS posits that governmental and private foundations should encourage the development of research, and the training of young investigators, in these areas. The APS states that policies on reimbursement for health professionals, medications, and other palliative treatments (e.g., counseling, cognitive treatment for symptoms, and other supportive care) must be redesigned to remove barriers to symptom treatment. The same holds true for controlled substance regulations. The APS states that laws and regulations must allow health professionals to aggressively treat pain with analgesic drugs and, when needed, with heavy sedation, even if these treatments hasten death. At present, physicians and nurses are often reluctant to give large doses of analgesics to dying patients, fearing that they will be vulnerable to prosecution if the drugs contribute to respiratory arrest. Regulations must specify that an intent to relieve pain, supported by documentation of the patient's report of pain or of the patient's behavior that suggests pain (e.g., grimacing or moaning), can justify the use of high doses of analgesics or sedatives, even if they depress respiration or hasten death in some other way.

National Kidney Foundation

Based on the ethical principle of respect for patient autonomy and the legal right of self-determination, the National Kidney Foundation respects the right of competent patients to forgo dialysis. It urges nephrologists to integrate psychological and spiritual aspects of patient care and to identify a support system for patients and families (e.g., counselors, case managers, social workers) that would help them cope during the patient's illness and facilitate the family's bereavement and recovery after the patient's death.

In its policy statement,¹¹ the Foundation asserts that nephrologists provide their patients with relief from pain and other distressing physical symptoms. It recommends that nephrologists obtain education and skills in advance care planning so that they are comfortable in addressing end-of-life issues with patients and their families.

The Foundation provided the following summary of its specific role in end-of-life care: ¹²
"Nephrologists commonly treat patients with end-stage renal disease [ESRD], some of whom refuse to undergo dialysis or choose to stop it. Because ESRD patients who are forgoing dialysis usually die in less than a month, they are, by definition, terminally ill. Nephrologists need to possess knowledge and skills in the principles of palliative medicine to ensure that end-stage renal disease

patients and their families receive multidimensional, compassionate, and competent care at the end of life. After a patient or patient's surrogate has made a decision to forgo dialysis, the nephrologist, in conjunction with other members of the renal team, should adopt a palliative care approach to patient care or refer the patient to a hospice. In either case, nephrologists and other members of the renal team need to remain active in the patient's care to maintain continuity of relationships and treatment. Nephrologists need to ensure that advance care planning is conducted with all their patients so that their patients' wishes for end-of-life care are known and respected even after patients lose decision-making capacity and are no longer able to participate in decision-making. The National Kidney Foundation has developed brochures for both patients and dialysis units to facilitate advance care planning."

Societies That Have Adopted the Principles with Modifications

American Academy of Pediatrics

The American Academy of Pediatrics (AAP) also endorses the Core Principles but with the explicit provision that the third principle ("Use the most appropriate measures that are consistent with patient choices.") not encompass physician-assisted suicide. The AAP also suggested that the principle might be reworded to read "measures that are consistent with patient *or surrogate* choices."

American College of Surgeons

The American College of Surgeons (ACS) agreed to a modified version of the Core Principles and published it in the ACS *Bulletin*.¹³ The modification deleted the call for research (Principle 1) in order to give emphasis to needed clinical improvement. In addition to including "legal surrogate" in the third principle and deleting "including alternative or nontraditional treatments" in the seventh principle, the ACS Statement on Principles Guiding Care at the End of Life varies from our Core Principles as follows (changes are italicized):

- Principle 4: *Ensure* alleviation of pain and *management of* other physical symptoms;
- Principle 5: *Recognize*, assess, and *address* psychological, social, and spiritual problems;
- Principle 6: *Ensure appropriate* continuity of care by the patient's primary and/or specialist physician;
- Principle 8: Provide access to *appropriate* palliative care and hospice care;
- Principle 9: Respect the *patient's* right to refuse treatment;
- Principle 10: Recognize the physician's responsibility *to forgo treatments that are futile*.

American College of Physicians

The American College of Physicians (ACP) agreed with Principles 1, 2, 3, and 11 as written, but reworded the other seven principles:

- Principle 4: *Make* alleviation of pain and other physical symptoms a *high priority*.
- Principle 5: *Recognize that good care for the dying person requires quality medical care, but also entails services that are family- and community-based to address, for example, psychological, social, and spiritual/religious problems.*
- Principle 6: *Make* continuity of care a *priority* (for example, the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers).
- Principle 7: *Advocate* access to *therapies* which *are reasonably* expected to improve the

patient's quality of life *and provide that patients who choose alternative and nontraditional treatments not be abandoned.*

- Principle 8: *Advocate* access to palliative care and hospice care.
- Principle 9: Respect the *patient's* right to refuse treatment, *as expressed by the patient or an authorized surrogate.*
- Principle 10: Respect the physician's professional *judgment and recommendations*, with consideration for both patient and family preferences.

The ACP also added the following principles:

- *Recognize that although medical care has a critical role to play in supporting patients (and families) at the end of life, dying is fundamentally a profoundly personal experience and part of the life cycle;*
- *Encourage health care professionals to work within their care environment to help ensure the provision of quality care and accountability for performance.*

The American College of Physicians–American Society of Internal Medicine (ACP-ASIM) notes¹⁴ that its Board of Regents has made the improvement of end-of-life care an ongoing priority, as evidenced by the substantial content on end-of-life care in its recent educational programs.¹⁵ Moreover, in 1997, the ACP convened a panel of experts on end-of-life care to develop consensus-based ethical, policy, and clinical recommendations that would promote high-quality palliative care. The ACP-ASIM End-of-Life Care Panel identified issues for which consensus recommendations would especially help general internists who care for some dying patients but who are not experts in palliative care. The recommendations have since developed not only in discussions among the Panel itself, but also in literature reviews and in an extensive external review process by other experts in the field as well as by clinicians in practice. A series of articles about end-of-life care receiving final approval by the Board of Regents is being published periodically in the *Annals of Internal Medicine*.¹⁶

Among the frequent themes identified in the ACP-ASIM End-of-Life Care Consensus Panel are pain treatment and the need for patient autonomy and inclusion of family members in end-of-life care, for physician education, for research related to the treatment of symptoms rather than just to the curing of disease, and for public policy that reduces barriers to the provision of quality care at the end of life.

To address the barriers to appropriate pain treatment, the ACP-ASIM proposes the following:¹⁷

- Improved training in pain assessment and treatment for physicians, starting at the undergraduate level and continuing throughout medical school, residency, and culminating with continuing education programs for practicing physicians;
- A public education campaign for patients about pain treatment;
- Development of quality indicators to measure how effectively patients' pain is being treated;
- Increased research on pain management, including the best approaches for translating research findings into practice; and
- Reduced regulation of physicians prescribing of opioids.

American Geriatrics Society

The American Geriatrics Society (AGS) also agreed with Principles 1, 2, 3, and 11 as written, but made some minor revisions to the other seven principles; these revisions often matched those of the ACP:

- Principle 4: *Make* alleviation of pain and other physical symptoms *a high priority;*
- Principle 5: *Recognize that good care for the dying person requires quality medical care, but also entails services that are family and community-based to address, for example,*

psychological, social, and spiritual/religious problems;

- Principle 6: *Help assume continuity of care* (for example, the patient should be able to continue to be cared for, if so desired, by his/her primary care and specialist providers);
- Principle 7: *Advocate access to therapies which are reasonably expected to improve the patient's quality of life and provide that patients who choose alternative or nontraditional treatments not be abandoned*;
- Principle 8: *Advocate access to palliative care and hospice care*;
- Principle 9: Respect the *patient's* right to refuse treatment, *as expressed by the patient or an authorized surrogate*;
- Principle 10: Respect the physician's professional *judgment and recommendations*, with consideration for both patient and family preferences.

The AGS also recommended two additional principles similar to those of the ACP:

- *Recognize that although medical care has a critical role to play in supporting patients (and families) at the end of life, dying is fundamentally a profoundly personal experience and part of the life cycle*;
- *Encourage health care professionals to help ensure that their care environment is capable of providing quality care and ensure accountability for performance*.

As indicated in its policy statement,¹⁸ the AGS considers attention to physical and cognitive function to be a vital part of palliative care: the patient should be assisted in achieving a high degree of independence for as long as possible—unless efforts to do so would cause the patient to suffer.

The AGS also emphasizes the importance of giving attention to biological aspects of aging that alter responses to treatment; physiological and pathological age changes may, for example, enhance the side effects of medications in frail or very old patients. Therefore, the practitioner should anticipate such complications and exercise vigilance, while at the same time making every effort to palliate symptoms effectively.

The AGS believes that the autonomy of patients must be protected regardless of their level of cognitive and/or physical incapacity. Their inability to make certain care decisions should be assessed at the outset, however. For patients who are no longer able to make decisions, their previously expressed wishes regarding end-of-life care should be respected. For patients who are vulnerable (e.g., frail, elderly) but who are still able to make decisions for themselves, the AGS cautions relatives, friends, and health professionals against insulating them from participating in decisions about their own care. In these cases, geriatricians should first assess the actual willingness of these patients to cope with the truth about their condition and to make decisions about their subsequent care.

Also in its policy statement, the AGS notes the importance of geriatricians paying attention to atypical presentations of pain, especially among the very old or the neurologically impaired. It also notes that pain and discomfort are often due not to the disease but to medical procedures that do not contribute significantly to the patient's quality of life. Therefore, a fundamental aspect of palliative care is to avoid these iatrogenic causes of pain and discomfort and allow death to occur naturally.

The AGS states that public policy must be changed to enhance the delivery of palliative care services across care settings: "There should be reform of regulatory and administrative policies that serve as disincentives to the delivery of good end-of-life care or that disrupts continuity of care. Such policies include disproportional reimbursement for invasive procedures, acuity-based rather than non-skilled, time-intensive care, and pressures to transfer patients when care needs change."

In summarizing its role in care at the end of life, the AGS noted that the role of geriatric medicine in end-of-life care is to: ¹⁹

- Promote clinical practice that focuses on the patient's functional as opposed to chronological

age;

- Promote the interdisciplinary care model in order to best address the complex problems frequently faced by older adults at the end of life;
- Address special principles of palliative care, such as attention to atypical presentation of pain, avoiding iatrogenic pain and discomfort, maximizing independence, and respecting the autonomy of patients with limited capacity, incapacity, or other vulnerabilities;
- Develop and share expertise in the management of the patient with end-stage dementia and related illnesses;
- Develop and share expertise in the management of the end-stages of cancer and other medical illnesses in the geriatric patient;
- Understand physiologic and biologic aspects of aging in order to best select medications and treatments that produce symptom relief, while avoiding toxicities or complications that occur commonly in frail elderly patients;
- Promote nonpharmacologic relief of symptoms, including behavioral management of agitation and avoidance of iatrogenic causes of pain, such as intrusive procedures and devices and mechanical restraints; and
- Promote education on these special geriatrics issues for trainees at all levels of all health care professions.

Conclusion

The expertise of medicine is specialty based, and much of the strength of American medicine lies in the strength of the specialty societies. Shining a brighter light on the need for better care for patients at the end of life has shown the specificity of many of those needs. Needs for a patient and family in the context of end-stage cancer, liver disease, renal failure, or Alzheimer's disease differ. Each is special and individual. Certain principles are common to all and we were pleased that the groups came to consensus on these. But every bit as important is the awareness of each specialty that it has a defined and particular role to play.

This document does not represent all specialties of medicine, but it does show how some of the wide diversity of specialty groups can identify their important roles in end-of-life care. We hope this process can be extended and continued.

Notes

¹ M. Fields, and C. Cassel, eds. *Approaching Death: Improving Care at the End of Life*, Institute of Medicine, National Academy Press (Washington, D.C., 1997).

² World Health Organization. *Cancer Pain Relief and Palliative Care*, WHO Technical Report Series 804 (Geneva: World Health Organization, 1990): 11.

³ American Academy of Neurology, Ethics and Humanities Subcommittee. "Palliative Care in Neurology." *Neurology* 46 (1996): 870-2; J.L. Bernat, M.L. Goldstein, and K.M. Viste, Jr. "The Neurologist and the Dying Patient." *Neurology* 46 (1996): 598-9.

⁴ "Cancer Care during the Last Phase of Life," *Journal of Clinical Oncology* 16, no. 5 (1998): 1986-96.

⁵ P.M. Schyve, Senior Vice President, Joint Commission on Accreditation of Healthcare Organizations, personal communication to Christine K. Cassel, June 24, 1997.

⁶ The American Medical Association, Eight "Elements of Quality Care for Patients in the Last Phase of Life"; subsequently published in the editorial "Caring to the End: Conscientious End-of-life Care Can Reduce Concerns about Care of the Terminally Ill," *American Medical News* (December 15, 1997). For more information, see the AMA Web site: <http://www.ama-assn.org/>

⁷ Roger G. Kathol, President, Academy of Psychosomatic Medicine, personal communication to Christine K. Cassel, May 30, 1998; subsequently published in *Psychosomatics*: J.L. Shuster, Jr., W. Breitbart, and H.M. Chochinov, "Psychiatric Aspects of Excellent End-of-Life Care," Ad Hoc Committee on End-of-Life Care, Academy of Psychosomatic Medicine, *Psychosomatics* 40, no. 1 (1999): 1-4.

⁸ Kathol, *ibid.*

⁹ Dale C. Smith, Executive Director, American Academy of Hospice and Palliative Medicine, personal communication to Christine K. Cassel, September 12, 1997.

¹⁰ American Pain Society Task Force on Pain, Symptoms, and End-of-Life Care (Mitchell Max, Chair; James Cleary; Betty Ferrell; Kathleen Foley; Richard Payne; Barbara Shapiro), "Treatment of Pain at the End of Life: A Position Statement from the American Pain Society." See the APS Web site: <http://www.ampainsoc.org/advocacy/treatment.htm>

¹¹ Garabed Eknoyan, President, National Kidney Foundation, personal communication to Christine K. Cassel, September 11, 1997.

¹² Eknoyan, *ibid.*

¹³ American College of Surgeons, "Principles Guiding Care at the End of Life," *Bulletin of the American College of Surgeons* 83, no. 4 (1998): 46.

¹⁴ Walter J. McDonald, Executive Vice President and Chief Executive Officer, American College of Physicians, personal communication to Christine K. Cassel, October 23, 1998.

¹⁵ Relevant sessions at the Scientific Meeting of the American College of Physicians-American Society of Internal Medicine in New Orleans (April 20-25, 1999): J. Tulsky and R. Frankel, "Decisions at the End of Life," and "Talking with Patients and Families at the End of Life"; C. von Gunten, "Management of Pulmonary and GI Symptoms at the End of Life"; J. Lynn et al., "Quality Improvement: End-of-Life Care" and "End-of-Life Care: Family and Patient Perspectives"; D. Weissman, "Teaching Palliative Care"; E. Cassem, "End-of-Life Care: Psychiatric and Spiritual Issues"; E. Bruera, "Assessment and Management of Pain"; and L. Kitchens et al., "End-of-Life Care: Cases to Learn From."

¹⁶ B. Lo, J.D. Snyder, and H.C. Sox. "Care at the End of Life: Guiding Practice Where there Are No Easy Answers," *Annals of Internal Medicine* 130 (1999):772-4; B. Lo, T. Quill, and J. Tulsky. "Discussing Palliative Care with Patients," *Annals of Internal Medicine* 130 (1999):744-9; and J.H.T. Karlawish, T. Quill, and D.E. Meier. "A consensus-Based Approach to Providing Palliative Care to Patients who Lack Decision-Making Capacity." *Annals of Internal Medicine* 130 (1999):835-40. This list is updated periodically as more papers by the ACP-ASIM End-of-Life Care Consensus Panel are completed and published. See the ACP Web site: <http://www.acponline.org/ethics/papers.htm>

¹⁷ Harold C. Sox, Jr., President, American College of Physicians-American Society of Internal Medicine, "Governmental Affairs and Public Policy," in a statement written for the Forum on Improving Pain Management, November 13, 1998, sponsored by Senator Ron Ryden. See the ACP Web site:<http://www.acponline.org/hpp/wydenforum.htm>

¹⁸ American Geriatrics Society Policy Statement, submitted to Christine K. Cassel, October 23, 1997. See also: American Geriatrics Society. "Measuring Quality of Care at the End of Life: A Statement of Principles," *Journal of the American Geriatrics Society* 45 (1999):526-7. For the AGS Position Statement "The Care of Dying Patients," developed by the AGS Ethics Committee, approved by the AGS Board of Directors in May 1994, and reviewed and updated in May 1998, visit the AGS Web site: <http://www.americangeriatrics.org/>

¹⁹ American Geriatrics Society Summary Statement, submitted to Christine K. Cassel, October 23, 1997.

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