



CARE OF THE DYING: A CATHOLIC PERSPECTIVE

The way we care for the dying is influenced by the cultural, political, and clinical contexts in which we live, as well as by the theological, moral, and pastoral framework we endorse. This document draws on Catholic healthcare tradition to derive an essential perspective as a fundamental resource for caring for the dying in the context of the challenges posed by today's society.

Dying has become a process, often involving extended technological and managed care, which may be unwanted or eventually unwarranted. The widespread anticipation of dying as a "tortuous" process characterized by extraordinary pain, solitude, and expense is reflected in the increasing public and professional support for physician-assisted suicide as a humane alternative to an institutionally and technologically managed death.

Under all circumstances, the Catholic tradition believes the primary goal in caring for the dying is to help them live well until they die. To do this, an environment needs to be created within our families, our culture, and our healthcare institutions in which the fear of dying does not supersede the values of living. In short, what is needed is an environment hospitable to dying as part of the natural course of human life.

Because of the growing movement toward assisted suicide and euthanasia, in 1990 the Catholic Health Association (CHA) convened a group of its members to clarify and extend the insights of Catholic theological teaching to address issues at the end of life. From this effort came the foundational document, Care of the Dying: A Catholic Perspective (CHA, St. Louis, 1993).

In this issue, Health Progress presents an excerpt of the first part of that document, "Cultural Context." We will publish excerpts of the other three parts in subsequent issues: "Social and Political Context" in April; "Clinical Context" in May; and "Theological, Moral, and

*Part I,
Cultural
Context: A
CHA
Document
Challenges
Care Givers
To Define
Appropriate
Care for
The Dying*

Pastoral Response" in June.

The complete text of Care of the Dying: A Catholic Perspective has been sent to all CHA members. Additional copies are available from CHA, 4455 Woodson Road, St. Louis, MO 63134-3797, 314-253-3458. The cost for one to four copies is \$9 each; five to nine copies, \$7.50 each; ten or more copies, \$6 each. Two additional resources

Summary In a society tempted to adopt legalized assisted suicide and euthanasia as appropriate responses to dying, the healthcare community is challenged to nurture positive attitudes toward death among all ages and to help those with terminal illnesses to live well while dying.

Whereas family and friends were once the primary care givers, now members of the healthcare professions are. This shift has introduced tensions between medical professionals and patients, including their families, in defining appropriate behavior toward the dying.

To enable the terminally ill to live well while dying, we need to allow them to retain as much control as possible within the limits of belonging to a community. Also, we need to secure their network of significant relationships so they can experience the affective bonds of trust and love that support personal dignity and enhance the meaning of life.

Medical technology is to be used in service of the total good of the patient. This includes not only the relief or cure that therapy can bring, but also what the patient prefers, values about life, and regards as giving ultimate meaning to life.

Catholic healthcare institutions are challenged to promote a sensitivity and respect for cultural diversity as they respond to the needs of the dying and those who care for them.



offering the Catholic perspective on care of the dying will be available later this spring. The first is a manual of comprehensive educational modules for leaders who are key to integrating the Catholic theological, moral, and pastoral perspective in care of the dying. The second is a set of resources to help those who serve as media spokespersons and legislative advocates understand and articulate a deeper message about living and dying.

Death comes to us all, yet how we experience it, the attitude we take toward it, and the manner in which we care for the dying are highly influenced by the culture in which we are nurtured. This cultural context cannot be ignored when trying to provide and assess adequate care for the dying.

The population of those over age 65 is growing more rapidly than the population under 10 years of age. In the early part of this century, the reverse was true. But now, as a result of new technologies, we are able to cure more diseases and repair more injuries than ever before.

The leading causes of death for those over age 65 are heart diseases, strokes, and malignancies. Persons with AIDS and those over age 65 are more likely to die a slow death. In a society tempted to adopt legalized assisted suicide and euthanasia as meaningful responses to dying, the healthcare community is challenged to nurture positive attitudes toward death among all ages and to help those with terminal illnesses to live well while dying.

To meet this challenge, care givers must pay attention to at least four significant features of our culture:

- The higher number of people dying in healthcare institutions
- The ethos of individualism in America
- The dominance of technology in medicine
- The pluralistic character of American society

**Caring
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John Collier

INSTITUTIONAL DYING

The Shift from the Home to Healthcare Institutions Up to 80 percent of reported deaths are estimated to occur in healthcare institutions, where policies and procedures can severely restrict the dying person's freedom and social contacts. Whatever control the dying person may have had at home can be lost to machines or institutions. The dying person can feel out of control and depersonalized in these antiseptic and restricted environments, where he or she is often treated as a person recovering from major surgery instead of one whose life is coming to a close.

Dying in institutions rather than at home also reinforces the denial of death in our society. Most people are shielded from death as a natural fact of human life. The only deaths at home are on television news or police shows, which have an unreality about them. As long as the living are protected from death, they will not be able to accept the fact of their own inevitable deaths, nor will they see that all lives are limited and thus too precious to waste.

The Shift from Parentalism to Self-Determination Institutional dying has also resulted in a shift in the roles of those who care for the dying. Whereas family and friends were once the primary care givers, now members of the healthcare professions are. This shift has introduced tensions between medical professionals and patients, including their families, in defining appropriate behavior toward the dying.

One such tension focuses on the power to make decisions. Until recently a paternalistic model dominated medical practice. "Parentalism" leaves little room for patients to participate in making decisions about their own lives.

The physician's claim to authority and control, as well as the claims of bureaucracy, often conflicts with the patient's right to self-determination. The



patients' rights movement emerged from this cultural climate. The living will, the durable power of attorney for healthcare statutes, and the Patient Self-Determination Act of 1991 are all in keeping with the goals of this movement.

Competent patients' informed preferences should be the moral nucleus of the therapeutic relationship. This often means physicians should respect the informed refusal of life-support therapy. Competent, informed patients should also be allowed to accept or refuse treatment according to their personal values without having such decisions supervised by third parties—the courts, medical societies, insurance agencies, or ethics committees.

Although there is a great value in supporting patients' freedom to uphold their dignity, an inherent danger is that an exaggerated sense of personal control over one's life may arise. As creatures, we do not have as much control as we think; we are limited by divine sovereignty. As patients, we are constrained by the restrictions of illness, the natural history of disease, and bodily impairment. As social beings, we are not free to do whatever we want without concern for the common good. Yet, an exaggerated sense of freedom and control is fueled by the American bias toward individualism.

INDIVIDUALISM: THE AMERICAN ETHOS

Individualism is so much a part of our American heritage that it is one of the most characteristic ways we distinguish ourselves. Individualism disposes each person to look after his or her own independent, self-interested goals, owing no one anything and expecting nothing from anyone. The spirit of individualism prizes self-reliance, self-expression, and self-direction. Thinking of oneself as independent from others becomes a habit, as does imagining that one's whole destiny lies in one's own hands.

This spirit pervades every aspect of our culture. In healthcare, it creates tensions in at least two directions:

- How to respect patients' freedom, yet limit their autonomy
- How to respect patients' uniqueness but not isolate them from the traditional bonds of the community

INDIVIDUALISM AND AUTONOMY

The Rise of Autonomy During the 1960s the philosophies of existentialism and personalism became more popular and heightened our awareness that the patient is a person with values and goals, rather than just a body with a disease. The holistic movement grew out of those idealistic concerns. If a patient's decisions were to be made

solely on the basis of what is medically indicated, a physician would be in the best position to decide. But if a person's values, goals, physical and moral resources, social commitments, and desired quality of life are also to be considered, then the patient remains the key decision maker.

In addition, the growth of mass communication has now made medical information available in lay language to a greater extent than ever before. As a result, many patients want to become partners in the therapeutic relationship. Instead of accepting medical decisions unquestioningly, they are more likely to evaluate physicians on the basis of their willingness to enter into a mutually respectful relationship.

The patient must certainly be the nucleus in decision making, but he or she cannot make decisions without help from physicians and other care givers. The medical relationship needs to be guided by a paradigm of partnership. This ideal model expresses the interdependent nature of the physician's commitment to the patient's welfare and of the patient's dependence on the physician's expertise. Other relationships—with nurses, therapists, insurers, family, and society in general—are also to be considered, along with the contributions each makes and the implications any choice will have on those relationships.

Autonomy and Euthanasia The exaggerated autonomy of individualism is one of the basic ideas used to justify arguments for legalized euthanasia and assisted suicide. As the argument goes, by questioning the ethical acceptability of assisted suicide and euthanasia, we question the dignity of human freedom.

The Hemlock Society promotes assisted suicide and euthanasia as the ultimate civil liberties, reflecting a bias toward individualism's libertarian principle and putting the burden of proof on those who would deprive persons of freedom over their bodies and their lives. The members of that society believe human beings have a unique worth because we are free agents. According to the libertarian view, killing without permission is what makes taking life wrong, rather than the religiously based conviction that we do not have the right to take life.

The Hemlock Society maintains that persons should be allowed assisted suicide or euthanasia when they choose it freely and this choice neither violates another's freedom nor is overridden by any restraining duties. Those with a terminal illness best qualify for assisted suicide or euthanasia, since they cannot fulfill any further obligations to others. These rights even extend to eliciting help from healthcare professionals who are committed to helping those in need. The Hemlock Society sees euthanasia and assisted suicide as the ulti-

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mate rights of individual freedom because control is retained over one's dying to ensure that a person is not dependent on others or helpless in the face of technology.

Criticism of Autonomy The principle of autonomy, especially the idea of extending the right to self-determination to include the right to be assisted in killing oneself, needs to be critically examined. The bias of those who seek complete, solitary independence, free of constraints, is blind to the built-in limits to autonomy.

For one thing, a patient's autonomy is necessarily limited by the very definition of a patient. Therefore, the patient is more or less influenced by the internal and external constraints of being sick or dying.

Moreover, our religious convictions tell us that our freedom is limited, especially when it comes to having absolute control over life. We believe God alone has absolute sovereignty over life and death. We exercise our freedom by accepting the limits of living with a perishable body and consenting to our powerlessness in the face of death.

Furthermore, autonomy is limited by the very nature of being human, which includes freedom and life as quintessential elements. Allowing someone else power over our freedom and life, as is the case in euthanasia and assisted suicide, is giving away too much of what it means to be human.

We are also social by nature, since we are made in the image of God—a community of loving persons. Because we live in a community of interdependent persons, *no one person's freedom is absolute*. Other people's welfare must also be taken into consideration.

To treat euthanasia and assisted suicide solely as private acts of personal freedom is a mistake, because they are actually social actions that involve at least one other person. Insofar as the healthcare profession is involved, euthanasia and assisted suicide are private claims on a social good, namely, the good of the healthcare profession committed to serving the broader healthcare needs of others, not just the preferences of one person. The personal desire to request death from the hand of another, then, ought to be considered a social action, not a private action. And any effort to sanction it should be evaluated in light of how it helps or hinders the common good, not whether it promotes one person's self-interest.

INDIVIDUALISM AND COMMUNITY

To live well while dying, one needs to remain as much in control as possible and to satisfy physical, affective, social, and spiritual needs. These needs are generally met in and through one's pri-

IMPLICATIONS FOR CATHOLIC HEALTHCARE

Today people are living longer, and death is often a slow process. Catholic healthcare providers should nurture positive attitudes toward death as a part of life in order to enable persons to live well while dying. To meet this challenge, care givers must pay attention to at least four significant features of our culture:

- As more people die in healthcare institutions than in their homes, providers need to find ways to enable patients to remain, as much as possible, in control of the decisions that affect their living and dying.
- Today's ethos of individualism can lead to exaggerated demands for autonomy. Human interdependence should be promoted as providers work toward securing therapeutic partnerships. In caring for dying persons, Catholic healthcare providers should secure patients' network of significant relationships so they can experience the affective bonds of trust and love that support personal dignity and enhance the meaning of life.
- Technology is pervasive in the delivery of healthcare today. As a result, healthcare professionals have to critically examine their use of technology to avoid losing the healing touch of the person-to-person relationship.
- In our multicultural society, care givers need to foster familiarity with and respect for dying persons' cultural context and resources of religious, ethnic, national, or familial traditions that provide expressions of meaning, love, and hope to sustain patients.

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mary network of relationships, such as family and friends, and through religious and cultural traditions. Securing that network of support is not always easy. The ethos of individualism contributes a fair share to the difficulty.

The same individualism that exalts autonomy also turns on the person in destructive ways when it inhibits the human bonding that creates the interdependent community that enables individuals to flourish. We find it difficult to ask for help or to become dependent on anyone, because dependence on others is seen as an unreasonable and burdensome imposition. Yet, in reality, we are interdependent already. Rugged individualism is an illusion. We will flourish as individuals only in a nurturing and sharing community.

The ethos of individualism, then, poses a serious challenge to caring for the dying. How are we to balance the dying person's need for independence, whereby he or she can feel respect and exercise freedom, with the need to be part of other people's lives, where he or she can feel loved and cherished and truly flourish? To enable the terminally ill to live well while dying, we need to allow them to retain as much control as possible within the limits of belonging to a community. Also, we need to secure their network of significant relationships so they can experience the affective bonds of trust and love that support per-



sonal dignity and enhance the meaning of life. Designing appropriate caring interventions should neither deny the dying freedom nor isolate them from the living.

TECHNOLOGY

An American Medical Standard The powerful presence of technology in medicine is another characteristic of today's culture. In fact, the medical industry has become a symbol of technological achievement. The American way of delivering healthcare is distinguished by an extraordinary reliance on technology as the instrument for helping people. We seek technological control over nature from womb to tomb.

The availability and ready reliance on technology is a good news-bad news story. Technological advances in healthcare have certainly created new opportunities for curing illnesses and prolonging life. But what price are we paying for its use? Therein lies the bad news. Technology fuels the myth that we are a Promethean society. Our passion for progress, mastery, and control through technological achievement discourages us from facing our limits and subjects us to the tyranny of technological domination.

An increased interest in legalizing euthanasia and assisted suicide correlates with the increased fear many people have of being trapped in unacceptable conditions of dependency and disability brought about by medicine's power to prolong dying by means of machines taking over every vital function in the body.

The Technological Imperative Just having medical technology around creates a mind-set that technologies which can be developed ought to be developed; and, if we have them, we ought to use them. Available technology becomes part of standard treatment, even if its use on a particular patient may create more burdens than benefits. For example, some physicians find it difficult not to use dialysis machines, ventilators, or feeding tubes even when they only prolong dying. Similarly, some patients and families find it hard to refuse them, since technology represents the best standard of care. Some find it difficult to accept that medical treatment can be too burdensome or futile. Thus, available technologies end up overwhelming human freedom rather than enhancing it.

In a society captivated by science and its awesome results and efficiency, we can easily lose sight of the overall purpose to be served by technology. Medical technology is to be used in service of the total good of the patient. This includes not only the relief or cure that therapy can bring, but also what the patient prefers, values about life, and regards as giving ultimate

meaning to life. Achieving only relief or prolonging physical life by means of technological assistance does not necessarily benefit the total good of the patient.

The temptation to be dominated by technological equipment stands in opposition to the unrecognized wisdom that not everything that can be done ought to be done. This is the wisdom that hopes to avoid another form of oppression of the weak and dependent by the healthy and powerful. This is also the wisdom that is firmly based on the long-standing principle that requires the use of only ordinary treatment (i.e., treatment that brings a benefit proportionate to the burdens the patient would have to bear as a result).

The Primacy of the Person The threat of depersonalization makes guarding against the pressure of technological domination critical for the appropriate care of the dying. Our reliance on technology can too easily become a substitute for the healing touch of human interpersonal relationships.

Healthcare professionals whose identities have been fashioned out of a ministry of person-to-person healing must be made aware of the risk of depersonalizing care for the dying. The availability of technology can too easily reduce healing to fixing. Fixing treats bodies as interconnected parts, whereas healing treats the person holistically as a multidimensional being with physical, emotional, intellectual, social, and spiritual needs. Only when healthcare professionals have a concern for the whole person, knowing that the meaning of the patient's life reaches beyond biological existence, can medical technology be made subject to the total good of the patient, rather than the patient being subject to the power of technology.

AMERICAN PLURALISM

Another feature of our culture that influences care for the dying is the multicultural context in which care must be delivered. One's cultural traditions influence not only *how* illness and death are talked about, but even *whether* they are talked about. Protocols established by our healthcare institutions to enhance service must reflect an awareness of these cultural patterns. For example, healthcare professionals' desire to be efficient may overtly or subtly threaten to replace the religious and family traditions that are so much a part of the multicultural groups which make up American society. These protocols can too easily deprive dying persons of those powerfully symbolic expressions of meaning, love, and hope which come from religious, ethnic, national, or

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familial traditions. Care for the dying is impoverished if the patient's cultural context and resources are ignored and he or she is treated as simply a technical problem.

Catholic healthcare institutions today are challenged to respect the diversity of the social and religious values of those who work at and are cared for in the institutions. Healthcare professionals will need courage and humility to affirm their own faith while respecting the diversity around them. Catholic healthcare institutions must strive to promote a sensitivity and respect for cultural diversity as they respond to the needs of the dying and those who care for them.

Sensitivity begins by welcoming the expression of cultural diversity and by promising to respect differences. When cultural differences clash with moral convictions and reconciliation seems impossible, the parties in conflict should disengage with as little disruption as possible. But no one should ever be asked to violate deeply held moral convictions.

VALUING EVERY STAGE OF LIFE

Catholic healthcare institutions should implement policies, educational programs, mission effectiveness committees, and ethics committees to respond to the multicultural dimensions of the care of the dying. As the assisted-suicide and euthanasia movement gains strength, Catholic healthcare providers need to pay attention to how cultural factors influence attitudes about care for the dying in order to fashion responses that will not only prompt them to provide compassionate care, but also give clear Catholic witness to the dignity and value of the person at every stage of life. □

EUTHANASIA

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euthanasia—which otherwise would be unacceptable to them and to society.¹²

I agree with the cardinal. The reasoned and sophisticated arguments against the legalization of euthanasia will never be heard and the real discussion will not take place unless, as individuals and providers of healthcare, we first meet this critical challenge. □

NOTES

1. Joseph Bernardin, "Address: Consistent Ethic of Life Conference," *Consistent Ethic of Life*, Sheed & Ward, Kansas City, MO, 1988, pp. 86-95.
2. Joseph Bernardin, "Euthanasia: Ethical and Legal Challenges," *Origins*, June 9, 1988, p. 52.
3. Arthur J. Dyck, "An Alternative to the Ethics of Euthanasia," as cited in Richard M. Gula, *What Are They Saying about Euthanasia?* Paulist Press, Mahwah, NJ, 1986, p. 169. These reflections are deeply indebted to Fr. Gula's masterful analysis of this important subject.
4. Gula, p. 70.
5. Courtney S. Campbell, "Religious Ethics and Active Euthanasia in a Pluralistic Society," *Kennedy Institute of Ethics Journal*, vol. 2, 1992, pp. 253-284.
6. Edward Shils, "The Sanctity of Life," in Daniel H. Labby, ed., *Life or Death: Ethics and Options*, University of Washington Press, Seattle, 1968, p. 12.
7. Gula, p. 97.
8. Gula, p. 70.
9. Gula, p. 71.
10. Ron Hamel and Edwin DuBose, "Views of Major Faith Traditions," in Ron Hamel, ed., *Active Euthanasia, Religion and the Public Debate*, Park Ridge Center, Chicago, 1991.
11. Robert N. Bellah, *Habits of the Heart: Individualism and Commitment in American Life*, HarperCollins, New York City, 1986.
12. Bernardin, "Euthanasia," p. 56.

MENTAL HEALTHCARE

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found this to be substantially lower than costs reported by a group of area mental healthcare providers. Yet, in spite of its success, no local, state, or federal funding bodies offered support of the project after the grant period. Elderly Services (formerly the EOP) is now a permanent part of the Abbe Center for Community Mental Health. It has continued only because of the center's commitment to services for the elderly and its diversion of profits from other programs to support the program.

The EOP is not the first successful and innovative service to experience this difficulty. However, our experience reinforces the need for state and federal planners to reexamine existing policies and to review methods to fund and sustain successful service delivery programs, especially those serving the rural elderly. □

NOTES

1. For a description and evaluation of the Elderly Outreach Project, see Kathleen C. Buckwalter et al., "Mental Health Services of the Rural Elderly Outreach Program," *Gerontologist*, March 1991, pp. 408-412.
2. J. A. Krout, *The Aged in Rural America*, Greenwood Press, Westport, CT, 1986.
3. M. D. Kermis, "Equity and Policy Issues in Mental Health Care of the Elderly: Dilemmas, Deinstitutionalization, and DRG's," *Journal of Applied Gerontology*, September 1987, pp. 268-283.
4. President's Commission on Mental Health, *Task Panel on Rural Mental Health*, vol. 3, appendix, U.S. Government Printing Office, Washington, DC, 1978, p. 1,164.
5. R. Raschko, "Systems Integration at the Program Level: Aging and Mental Health," *Gerontologist*, October 1985, pp. 460-463; Kermis; B. D. Lebowitz, E. Light, and F. Bailey, "Mental Health Center Services for the Elderly: The Impact of Coordination with Area Agencies on Aging," *Gerontologist*, December 1987, pp. 699-702.
6. Buckwalter et al.