

# CARE OF THE DYING: A CATHOLIC PERSPECTIVE

## *Part III: Clinical Context—Good Palliative Care Eases the Dying Process*

Because of the growing movement toward physician-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 third part of that document, "Clinical Context." The first part, "Cultural Context," and the second part, "Social and Political Context," were published in March and April, respectively. Part IV, "Theological, Moral, and Pastoral Response," will appear in the June issue of *Health Progress*.

Copies of the complete text of *Care of the Dying: A Catholic Perspective* are available from CHA, 4455 Woodson Road, St. Louis, MO 63134-3797, 314-253-3458. The cost for one to four copies of the document is \$9 each; five to nine copies, \$7.50 each; and ten or more copies, \$6 each.

**Summary** In the midst of a push for legalized euthanasia and assisted suicide in the United States, the Catholic healing tradition should provide good palliative care and support for dying patients. Catholic healthcare institutions can have a counterinfluence on the euthanasia movement if they strive to relieve all forms of pain—physical, psychological, social, and spiritual.

Care givers must adapt their pain management methods to diverse groups of patients and their needs. Comprehensive pain management includes not only specialized clinical programs to control physical pain, but also counseling and human support to minimize psychological pain, community

Instead of death itself, people more often fear the process of dying, especially the dependency, helplessness, and pain that so often accompany terminal illness. One of the primary purposes of medicine in caring for the dying should be the relief of pain and suffering. While physical pain is the most common source of suffering, pain in dying extends beyond the physical; therefore, effectively managing pain in all its forms—physical, psychological, social, and spiritual—is critical.

One of the major arguments of euthanasia advocates is that for some people dying is too painful to endure and so hastening death is the only merciful way to end their pain and suffering. Catholic healthcare institutions can have a great influence on the euthanasia movement if they strive to properly manage all forms of pain.

### **PAIN**

Pain most often has four different components: physical, psychological, social, and spiritual.

**Physical Pain** Physical pain is the most obvious and the major cause of suffering. It impairs physi-

support groups to counter social pain, and pastoral care resources to address spiritual pain. Truthful communication lies at the heart of the therapeutic relationship.

Healthcare institutions can likewise organize themselves internally to offer optimal support programs for those who are dying, their families, and their care givers. Necessary ingredients for a comprehensive approach include integrated treatment plans, hospitable environments, policies on advance directives and collaborative decision making, ethics committees that are well versed in end-of-life issues, education programs, and a hospice philosophy of care.

cal functioning, mood, and social interaction. Physical pain serves as a clear warning that something is out of order in the normal functioning of the body. But since pain affects the whole person, it can easily exceed its function as a warning signal. Severe pain can drive a person to request its removal at any price, even to the point of asking for death for oneself or for others.

**Psychological Pain** Psychological pain often arises from facing the inevitability of death, losing control over the process of dying, letting go of hopes and dreams, or having to redefine the world one is about to leave in terms that never quite satisfy one's needs. Psychological pain is evident in mood swings and in the strong feelings that often accompany terminal illness.

**Social Pain** Social pain is the pain of isolation, which arises from being forced to reshape relationships. The difficulty of communicating what one is experiencing while dying creates a sense of aloneness at a time when companionship is most needed. The unwillingness or inability of others to keep company with the dying by visiting them, listening to their feelings and experiences, or discussing the implications of what is happening to them only aggravates the isolation.

The loss of a familiar social role is also painful. For example, letting go of the role of being the self-sufficient, caring parent and becoming the one who is dependent and cared for is painful.

**Spiritual Pain** Spiritual pain arises from a loss of meaning, purpose, and hope. Despite society's apparent indifference to the "world beyond this one," spiritual pain is inescapable and widespread. Everyone needs a framework for meaning—a reason to live and a reason to die. People who are dying often seek a larger landscape of meaning and therefore need to feel part of a community that shares that meaning.

**Interrelated Aspects** These aspects of pain are interrelated and sometimes hard to distinguish. If efforts to manage pain focus on one aspect to the neglect of the others, the patient may not experience true relief. Unrelieved pain can lead not only to depression and anger, but to asking for death for oneself or for others. As the Vatican *Declaration on Euthanasia* notes, the pleas of the terminally ill who sometimes ask for death are not to be taken as a true desire for euthanasia or assisted suicide. Rather, they are more likely anguished pleas for effective pain relief, for better medical care, for love (*Origins*, vol. 10, 1980, pp. 154-157).

## MANAGING PHYSICAL PAIN

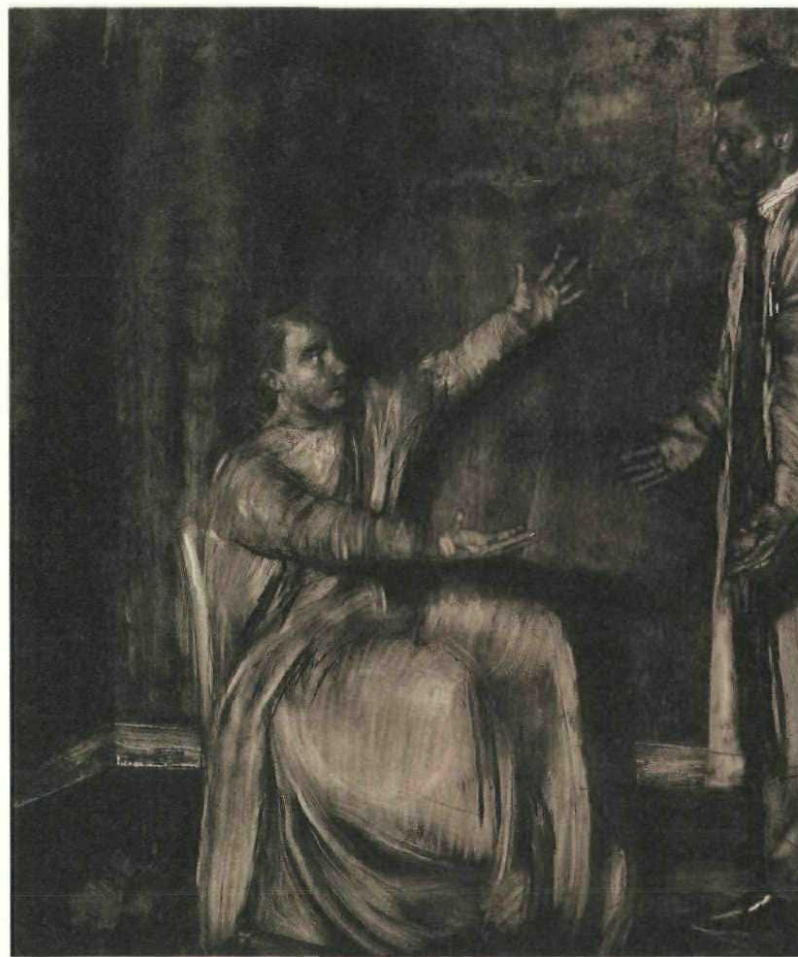
Physical pain is usually the easiest to control, yet standard American healthcare is still doing a poor job at managing it. Although medical texts

describe effective pharmacological and nonpharmacological approaches to controlling pain, most physical pain goes unrelieved. Some experts estimate that as many as 75 percent of patients in pain are inadequately treated, and 60 percent to 90 percent of those who are terminally ill experience severe to moderate pain sufficient to impair physical functioning, mood, and social interaction. Nearly 25 percent of cancer patients die in severe, unrelieved pain. How can we account for these sad statistics?

One of the problems patients have is finding an adequate language for expressing their pain so it can be accurately identified and addressed. Some patients are reluctant to say anything about their pain because they feel others may judge them as weak, as complainers, or as clock-watchers waiting for the next dose.

Other patients choose not to comply with the therapeutic program, perhaps to avoid side effects that could keep them from attending to unfinished business, or simply to assert some control in the face of losing control. Other patients may

*Physicians play a central role in the healing relationship that patients need to find meaning in dying.*



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deny their pain to retain a feeling they are still in control, despite evidence to the contrary. Still others may use their pain in an effort to shield themselves from more unwelcome issues. Others embrace pain, believing it has some redemptive value.

Physicians also contribute to the failure to give patients relief from pain. Some physicians are ignorant of the nature of pain. Others do not accurately diagnose the source of pain, or they fail to assess the patient at regular intervals to detect new pain-causing processes that may demand alternative therapies. Some physicians simply do not believe the patient's description of pain. Still others do not try alternatives to drug therapy, such as electrical nerve stimulation, nerve blocks, biofeedback, deep massage, or non-Western techniques like acupuncture and acupressure.

Some physicians who use drug therapies are too timid in prescribing narcotics, or they neglect the appropriate use of aspirin-like drugs for the relief of bone pain. Narcotics may be underprescribed because of:

- A basic ignorance of the magnitude of the doses needed to combat severe pain
- An inappropriate fear of causing respiratory distress
- A misplaced anxiety about the hazards of addiction
- An irrational fear of civil or criminal prosecution
- An overestimation of the side effects of some analgesics

Recent statistics estimate that more than 90 percent of pain can be relieved, usually with drugs. The challenge to physicians is to accurately identify the pain and then to use state-of-the-art techniques to manage it.

To achieve the goal of successfully managing pain as a major dimension of compassionate care for the dying, care givers need to accomplish certain tasks:

- Hospitals need to formulate policies for the acceptable use of narcotics to treat dying patients; they must not restrict opiate use but sanction it in necessary dosages to control pain without regard to vital signs.
- Healthcare professionals in hospitals need to be trained in the various methods for controlling pain by means of all available modalities, including drugs, electrical stimulation, and biofeedback.
- Medical students need to be trained in the various methods for managing pain.
- Pharmaceutical companies need to educate qualified professionals, such as physicians and registered nurses, on the proper use of pain medications.

- Statewide consultation networks for managing pain need to be developed.

- Clinicians need to engage in dialogue with local medical associations, legislators, district attorneys, and others to ensure they understand the appropriate use of opiates and to prevent ill-conceived policies or sanctions that may discourage appropriate pain management.

### MANAGING PSYCHOLOGICAL, SOCIAL, AND SPIRITUAL PAIN

The pain experienced in terminal illness is more than physical. Psychological, social, and spiritual pain can:

- Overwhelm dying patients' sense of control
- Threaten their sense of purpose or meaning
- Weaken their sense of being connected to others, since dying intensifies isolation by disrupting patients' ordinary ways of making contact with others

**The Need for Emotional Support** Perhaps the most healing remedy to address psychological, social, and spiritual pain is the quality of the relationships sustained between patient and care givers and between patient and family. On the other hand, the healing quality of the therapeutic relationship can be weakened when emotional reactions experienced by patients, families, or care givers are not adequately addressed. Common emotional reactions include denial, anger, guilt, and fear.

Denial is a natural, built-in defense mechanism. Patients, families, and care givers may refuse to admit that a terminal diagnosis is correct or refuse to acknowledge their fear for self, for the future, or for their ability to cope with dying.

But denial is not always bad. Selective attention—dealing with a little of the truth and only a few feelings at a time—can be a way of coping with and alleviating the nonphysical aspects of pain. Ideally, families and care givers should not hide behind denial, which tends to isolate them from patients.

Anger surfaces in many ways. Patients are often angry at themselves for being sick. They also get angry at families and care givers for their patronizing and overprotective behavior, which seems to take away whatever sense of control, privacy, and independence patients may have left. Family members get angry for not being able to do more. Care givers are angry for not being able to give the patient definitive answers, clearer directions, or a cure.

Guilt also emerges in many ways. Patients feel guilty for being a burden on their family or for not making amends for a broken relationship. Family members often feel guilty because they are not able to do enough, they did not identify the

problem early enough, or they did not seek help or get involved sooner. Care givers may feel guilty for not being able to cure, relieve pain, or prolong life with better quality.

Fears are many. Patients fear pain, isolation, loss of control, and dependence. They also fear what will happen to their loved ones, the unknown, their own insignificance. Families also fear the unknown. Care givers fear mistakes and, sometimes, lawsuits.

**The Need for Relatedness and Meaning** Emotions experienced by family members and care givers may tempt them to ignore the dying person. Facing the fact that nothing more can be done to improve the patient's medical condition often produces anxieties, causing people to withdraw from the patient. Sometimes family members and care givers cannot deal with their own feelings about death. Everyone needs to acknowledge these feelings and realize that dying persons need company and comfort more than treatment.

Physicians, particularly, play a central role in the healing relationship that patients need to find meaning in dying. But all care givers play an important role in this matter. The feeling of being connected is at the heart of relieving the patient's social pain. When the patient experiences connectedness with care givers and feels heard and understood, the feeling of social isolation can be relieved. When care givers are willing to listen and to acknowledge the pain, the patient experiences a *feeling of worth, esteem, integrity, and wholeness.*

The family's connection to the patient is also important in relieving social pain. Family relationships are subject to severe stress when a family member is dying. Because of the family's emotional reactions, the dying person may find it difficult to communicate his or her needs. Family dynamics and history can further complicate the relationship. The dying patient may feel as if he or she is failing to sustain the bonds of affection that bring a sense of worth and esteem. These emotions can lead to a sense of loneliness.

Feeling connected also enhances the patient's sense of meaning and purpose. The seeming meaninglessness of daily routines and superficial relationships in the patient's life provides no satisfying reason to live. When patients no longer see themselves as playing any significant part in the scheme of things, as receivers or contributors, then their courage and strength to participate in life weaken.

Pastoral care services can help connect the patient to a larger framework of meaning by drawing on spiritual connections through the use of religious stories, rites, and symbols. These are

## IMPLICATIONS FOR CATHOLIC HEALTHCARE

Euthanasia advocates argue that dying is too painful for some people to endure: Death may be the only merciful way to end their suffering. But the Catholic healing tradition holds that appropriate palliative care (e.g., drug therapy to alleviate pain and active listening to ease loneliness) can help dying patients face death with dignity. Catholic healthcare providers should do the following to help dying patients, families, and care givers on this journey:

- Physical pain is not effectively managed for 75 percent or more of patients. Catholic healthcare providers should become more knowledgeable about the nature of pain and techniques to manage it.

- Since pain in its multiple dimensions often accompanies terminal illness, comprehensive programs for managing all dimensions of pain need to be established. Catholic healthcare providers should take the lead in providing such programs.

- Knowing that pain is more than physical and includes psychological, social, and spiritual aspects, Catholic healthcare providers should encourage positive relationships between patients and care givers, patients and their families, and patients and their religious beliefs and practices to satisfy the need for emotional support, connectedness, and meaning.

- Truthful communication is at the heart of the therapeutic relationship. Catholic healthcare providers must establish programs that help professional care givers present information on terminal illness in a way, at a time, and in whatever increments necessary to allow patients to assimilate and use the information.

- Managing pain effectively requires a comprehensive program such as that exemplified in the hospice philosophy of care. Catholic healthcare providers must be supportive of the hospice concept so that care will be coordinated in a collaborative manner, dying patients will live in a supportive environment, and institutional policies and practices will promote their well-being.

valuable resources in the clinical setting for relieving the spiritual pain that inevitably comes to the terminally ill, who ask questions of meaning and of the place of God in their living and dying.

### THE NEED FOR TRUTHFUL COMMUNICATION

Truthful communication is at the heart of the therapeutic relationship. In the past, withholding information and the "therapeutic lie" were thought to be justified so as not to harm patients by creating more distress through bad news. Today, we realize that deception (stating what is untrue, omitting what is true, or telling what is true but in unintelligible language) undermines the trust that holds the healing relationship together. So the real question for physicians is not, Should I tell the truth? Rather, it is, How do I tell the truth in a way that will benefit the patient?

The patient's comfort can be profoundly affected by the way the physician conveys in-

formation. Tact, timing, and style are as important as accuracy in a therapeutic conversation. Also, since the patient's condition and ability to absorb information change, an honest and open conversation must be ongoing.

Care givers may find the following considerations helpful:

- Good communication begins with good self-understanding and self-acceptance. We

may project our own fears and uncertainties onto others when we are not able to recognize and acknowledge them in ourselves. We betray ourselves most conspicuously in nonverbal ways: physical tension, nervous gestures, or the failure to make eye contact.

- Care givers must talk *with* dying patients, not *at* them. Talking with patients about what is important to them or just sitting with them attentively in silence are ways for care givers to honor the dignity and experience of the patient and to serve as agents of healing. Through active listening, care givers can appreciate the patient's situation and concerns. Such an environment creates a climate of openness for an easy exchange of ideas and feelings.

- Although patients with unmistakable symptoms usually know the gravity of their condition and are rarely surprised by grim news, most other patients want to know their prognosis. Healthcare professionals should disclose all available information unless the patient specifically wishes not to know. In that case, a family member ought to be told.

- Through truthful communication, healthcare professionals tell patients what is known about their condition or prognosis. Care givers who admit their ignorance and describe patients' condition or prognosis factually, without making any false promises or flooding them with pity and sympathy, actually promote confidence. Patients will be better prepared to absorb the hard news and live with the uncertainties if they are assured of being provided good care, of not being deceived, and of not being abandoned.

- Care givers should keep patients in the driver's seat as much as possible by keeping them fully informed. Patients who have access to the facts of their situation know what to expect and

# The team model is the most effective approach for responding to pain.

can feel more in control. Feelings of hopelessness quickly overwhelm those who have no say in determining the course of their own lives.

## INSTITUTIONAL RESPONSES

Healthcare institutions can organize themselves internally to offer optimal support for those who are dying, their families, and their care givers. A few suggestions are described here.

**Integrated Treatment Plans** When the terminally ill patient and the family receive information from a variety of sources—often piecemeal and incomplete—they experience a sense of fragmentation, a lack of appropriate and adequate information, and an absence of clear and holistic goals in overall care.

For these reasons, the collaborative team model is the most effective approach for responding to the diverse aspects of pain in the dying person. This involves a team of healthcare professionals in which the primary care giver coordinates the care plan and communicates with the patient, family or surrogates, and other professionals. All participants, especially the patient, are treated as active decision makers in implementing the care plan. Special effort is made to recognize emotional reactions and their meanings and to make appropriate referrals for professional assistance when necessary.

Collaboration also includes sharing resources within the organization and outside it to ensure continuity of care and the appropriate placement of the terminally ill patient on discharge from the healthcare facility.

**Hospitable Environment** The environment in which care is delivered is an important factor in overall care. To provide the sense of dignity that a dying patient deserves, the healthcare facility should create an atmosphere that avoids noisy surroundings that lack aesthetic quality and privacy.

**Institutional Policies** Policies on advance directives and collaborative decision making can enhance the autonomy of the dying patient and clarify the roles and responsibilities of others involved in making decisions at the final stages of life. Such policies can alleviate physicians' fears of legal liability and foster care that enables the dying to live

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## CARE OF THE DYING

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# Hospice affirms life and regards dying as a normal process.

their last days in as peaceful and uncomplicated a fashion as possible.

**Institutional Ethics Committees** An institutional ethics committee can be a valuable resource in making difficult ethical decisions. As a forum for ethical reflection, dialogue, and planning, this multidisciplinary group serves the institution by promoting education, assisting in the development of policies, consulting in difficult situations, and providing a forum for the resolution of difficult cases, thereby avoiding recourse to the courts.

**Educating the Public** Developments in medicine, especially advances in the use of technology, drug therapies, and surgery, have captured the interest of the public. Recent court rulings have added to the growing concern about the use of these medical advances to prolong life. More people want to learn about the proper use of advanced technologies to sustain life. Healthcare institutions can make a significant contribution to preventive medicine by sponsoring more educational programs.

**Hospice** A comprehensive philosophy of care for people in the final phases of a terminal illness, hospice affirms life and regards dying as a normal process. Hospice emphasizes controlling pain and symptoms to enhance the quality of life rather than to cure an illness or extend life. Hospice allows patients and their families to live each day as fully and comfortably as possible and assists in dealing with the stress caused by illness, death, and grief. Hospice uses a team approach to focus on the physical, emotional, spiritual, and

social needs of patients and their families. The interdisciplinary team of physicians, nurses, aides, social workers, trained volunteers, and pastoral counselors provides coordination and continuity of patient and family care and also offers follow-up services and grief counseling for the family after the patient has died.

Adequate reimbursement for hospice services is a public concern and is currently being addressed by legislators and third-party payers. Improved education of healthcare professionals, the religious community, and the general public about the availability, appropriate referral, and correct utilization of hospice services is necessary to improve awareness and to ensure high-quality care for dying patients and their families.

### APPROPRIATE CLINICAL CARE FOR DYING PATIENTS

By providing appropriate care to dying patients in clinical settings, care givers seek to respect patients' integrity as persons through the final days of life. Through appropriate clinical care, care givers try to guarantee patients will:

- Be kept as free of pain as possible so they may die comfortably and with dignity
- Receive continuity of care and not be abandoned or lose personal identity
- Retain as much control as possible over decisions regarding their care and be allowed to refuse further life-prolonging technological interventions
- Be heard as individuals with personal fears, thoughts, feelings, values, and hopes □

## HEALTH POLICY

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- \$5.06 billion from a 1 percent surtax on personal income tax
- \$935 million from a 1 percent surtax on corporate income tax
- \$772 million from a 10 percent increase in the tax on alcoholic beverages
- \$5.13 billion from doubling the tax on tobacco products
- \$523 million from increasing the gasoline tax by 1 cent per gallon.<sup>7</sup>

Among these options, the tax on providers is likely to appeal to Congress and administration policymakers as an "easier" target than taxing payroll or health benefits of individual Americans. Many in the Congress still remember their hasty retreat from requiring wealthy seniors to foot a larger share of the bill for Medicare catastrophic coverage after the outcry of elderly constituents.

Whether a provider tax and others under consideration are politically viable for Congress and the American people remains to be seen. This month the health reform ball now moves from the administration to the open forum of Congress for debate and action. For policymakers and the public alike, the cost of reform and how it will be financed will be crucial questions for the viability of the president's health reform proposal. □

### NOTES

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