

## HOSPICE CARE: TRANSFORMING A CULTURE OF DEATH INTO A CIVILIZATION OF LOVE

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By E. Joanne Angelo, M.D.

As death approaches, the final chapter of life's journey can be very beautiful. Unlike the impersonal, institutional setting of many hospitals where death most often occurs, hospice programs offer the alternative of being cared for during a terminal illness at home or in a homelike setting at a hospice facility, surrounded by family and friends. Expert medical care is brought into the home by a team of specially trained nurses, physicians, and home health aides. The patient and the family are offered additional supportive service by social workers and volunteers. The hospice chaplain is available to provide pastoral care and sacramental ministry or to call in clergy of other faiths on request.

Those who would have us believe that death is necessarily accompanied by unbearable pain and suffering and that euthanasia or assisted suicide are the only compassionate alternatives are just plain wrong! As a psychiatric consultant to the Good Samaritan Hospice of the Archdiocese of Boston for the past 10 years, I have seen how the compassionate care provided by the hospice staff has enabled patients to live out their lives with serenity and peace, surrounded by those they love until natural death occurs. In a loving Christian hospice setting such as this, the notions of euthanasia and assisted suicide become irrelevant.

The hospice concept dates back to medieval times when religious orders offered hospitality to travelers and cared for them if they were ill or dying. The modern hospice movement became well known through the work of Dame Cicely Saunders, who founded St. Christopher's Hospice in London in 1967.

Dr. Saunders began her medical career as a student nurse. She became concerned about dying patients who appeared to be suffering excessively—isolated from family and friends and in unnecessarily severe pain. When a back injury cut short her nursing career, she studied social work and returned to the hospital to encourage families and hospital staff to be more supportive to terminally ill patients. However, as time passed, she became aware that because pain medications were ordered “as needed,” or at widely spaced intervals, patients were constantly concerned with their pain and anxious about whether their medication would be available quickly enough and in sufficient dosages when they really needed it. To better care for her patients, Dr. Saunders went on to attend medical school and completed a fellowship in pharmacology. She was then able to assist her patients by ordering pain medication frequently, “around the clock” and in sufficient dosages to prevent pain and anxiety about pain. A deeply religious woman always, she continues to bring a profound spiritual dimension to the care of her patients and their families. Nurse, social worker, physician, and pastoral care worker, Dr. Saunders embodies in herself the entire hospice team.

### FEAR OF PAIN

Fear is what typically motivates the terminally ill and their families to consider euthanasia or assisted suicide: fear of pain, fear of abandonment by those they love, fear of burdensome futile treatments, fear of loss of autonomy and personal dignity, and fear of becoming a burden to others.

In the following case example, Dr. Saunders illustrates how the careful assessment and treatment of pain and anxiety about pain enabled a woman with metastatic thyroid cancer and an infected leg ulcer to withdraw her request for euthanasia:

*During a conversation nearly two months after her admission [the patient] said to one of her doctors, “Of course I believe in euthanasia.” On being asked, “Supposing for the sake of argument you could have it, do you want it now?” she replied, “Good gracious, no!”...Her ankle became more painful during the next few days and she became extremely apprehensive, fearing that any movement was going to hurt her. This fear greatly exacerbated the physical pain. While attempting to relieve her fears, the doctor deliberately discussed euthanasia with her again. To the question, “We were talking about euthanasia same time ago: would you want it now?”; she replied*

*as quickly... as before, "No-I leave things to you." She was given enough medication to ease her apprehension and to control her physical pain and became quiet and peaceful, dying about a week later.*<sup>1</sup>

This patient had come to trust the hospice physician and to believe that her pain and mental suffering would be understood and treated appropriately. She trusted that she would be allowed to maintain her dignity and autonomy to the end.

Physical pain is useful to alert us to illness or injury. A toothache indicates that we should go to the dentist; increasing pain in the recovery period after surgery may indicate that an infection has occurred. But pain in terminal illness serves no biological purpose. It should therefore be created aggressively and totally eliminated if possible. This is entirely in keeping with Catholic moral teaching. The Church's *Declaration on Euthanasia* states, "human and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semi-consciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice." The document goes on to say that the use of narcotics is permitted "even at the approach of death and if one foresees that the use of narcotics will shorten life ...in this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken: the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine."<sup>2</sup>

## FEAR OF ABANDONMENT

For persons facing terminal illness, fear of dying alone is perhaps the most common worry. "A dying person should not have to do it alone. Isolation at such a time is an inhuman experience," says Derek Humphrey in *Final Exit*, the how-to manual for assisted suicide of the Hemlock Society.<sup>3</sup> Unlike the romanticized TV portrayal of family gathered around the suicidal patient who quietly goes to sleep, the text goes on to describe in detail the prescribed dosage of pills and alcohol which must be gulped down by the person attempting suicide and recommends the use of a plastic bag over the head to assure a lethal outcome. Those in attendance are urged not to touch or assist the dying person in any way for fear of legal repercussions afterward.

In contrast, hospice patients are assured that they will be accompanied and affectionately helped by those they love until their last moment. Skilled hospice personnel will ease their terminal symptoms with an armamentarium of medications, comfort measures, and spiritual care. When family and friends are absent or overburdened temporarily, hospice staff and volunteers can be available for patients 24 hours a day. As one elderly widower put it, "I can get my nurse on the phone any time. She is someone I can put my hand out to and say, 'Thank God I have you and can call on you. I have no one else to call on.' "

Death typically comes to a hospice patient with family gathered around, in the patient's home, in quiet, prayerful acceptance. A nurse is usually with them, adjusting medications and seeing to comfort measures to prevent or alleviate distressing terminal symptoms. The family's priest, minister, rabbi, or spiritual advisor is often present as well to offer prayer and consolation to all. Assistance in funeral arrangements and bereavement counseling are natural extensions of these supportive services.

## FEAR OF BURDENSOME, FUTILE TREATMENT

The fear of excessively burdensome treatment may be troubling for the terminally ill and their families. They may live in dread of heroic resuscitation measures, life-support machines, and the isolation of barren intensive care units. The Church does not require that all possible medical technology must be utilized in the care of the terminally ill just because it is available. The *Declaration on Euthanasia* says, "When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms

of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.”<sup>4</sup>

Hospice care focuses on symptom relief and comfort rather than heroic attempts to prolong life which may only serve to lengthen the dying process. When pain is controlled, comfort and companionship assured, and spiritual issues attended to; the patient and family can accept death as a natural event—the final chapter of life as we know it. The last weeks of life can take on special meaning as family gathers and deep conversations occur. Dr. Joanne Lynn describes her experience in the April 1, 1993, issue of *The New England Journal of Medicine*: “I have participated in the care of some 2,000 patients who have died, and nearly all died outside of hospitals and in systems of excellent care (largely the Washington Home and Hospice in Washington, D.C.). I am impressed by how well people can live while dying.”<sup>5</sup>

## FEAR OF LOSS OF AUTONOMY

In contrast to the surrendering of autonomy that routinely occurs for hospitalized patients and their families, hospice patients and their loved ones remain in control of all the aspects of their care. Families may visit seriously ill patients in the hospital only when the medical staff permits. The hospice staff, on the other hand, is invited into the patient’s home and allowed to stay only as long as their presence is judged to be helpful. Each decision in the plan of care is made jointly by patient, family, and staff: For example, some patients may choose to endure a certain level of pain for a time for their own spiritual reasons or to ensure complete mental acuity until all of their affairs are in order; others may be troubled deeply by nausea and vomiting and wish to have these symptoms controlled even if the anti-nausea medication causes sedation.

Derek Humphrey exalts assisted suicide as the ultimate expression of personal autonomy. “If you want personal control and choice over your destiny, it will require forethought, planning, documentation, friends, and decisive, courageous action from you.” However Mr. Humphrey goes on to say, “If you consider God the master of your fate, then read no further. Seek the best pain management available and arrange hospice care.”<sup>6</sup> If the hospice concept of care were better understood and offered more widely, perhaps even those who doubt the existence of a loving God would have the courage to choose to live life fully to the end. In so doing, they may have the opportunity to discover God’s love in the person of their care providers.

## FEAR OF BECOMING A BURDEN

An altruistic wish to avoid becoming a burden on one’s family may move some terminally ill persons to consider euthanasia or assisted suicide. Families may mistakenly seek medical assistance in ending a loved one’s life prematurely for the express motive of avoiding the burden of suffering for the patient. In fact it may be the fear of their own suffering and the burden of caring for the sick person that overwhelms them. (“Let me put you out of my misery,” they seem to be saying.)

In my psychiatric practice I have cared for many families after the suicide of a loved one. Suicide is a terribly burdensome legacy for the family and friends of the deceased. Surviving loved ones must struggle with wrenching feelings of betrayal, rejection, guilt, and anger. Dealing with the death of a family member is never easy, but bereavement after suicide is often prolonged and difficult, and the issues it raises can last a lifetime.

Those who have caused the death of another also have a lifetime grapple with their inner conflicts of guilt and shame. These feelings are intensified by the finality of their action, as I have seen in the tragic lives of post-abortion women and former abortion providers whose guilt is not only a negative feeling but also a stark reality.

Families who come together to care for a dying member, in contrast, often find that they have grown closer to one another and have had a very special opportunity to speak to one another from their hearts. In the hospice setting they are supported and helped to address difficult issues, to “finish their unfinished business,” in the words of Dr. Elizabeth Kubler-Ross. Family members often make funeral plans ahead of time with the active

input of the patient. Bereavement is much less painful for family members after death in a hospice program because many important issues have been addressed and resolved in life; good-byes have been said, and the family can rest assured that they have followed the patient's wishes and that their efforts have been appreciated. The suffering they have witnessed and shared and the sorrow of separation from the deceased take on a new meaning in the context of loving service and grateful acceptance.

## THE PROBLEM OF DEPRESSION

At times a patient's fears may be symptomatic of a clinical depression which exceeds the expected sad mood that may temporarily overcome a patient when the diagnosis of a terminal illness is made or when the hope of curative treatment ends.

Many of the diagnostic signs and symptoms of depression may be mimicked by the disease process or by the medications used to treat terminal symptoms such as weight loss, insomnia, lethargy, lack of pleasure, and feelings of hopelessness or despair. Skilled hospice workers can diagnose and treat underlying depressive illness, thus enabling dying patients to live their last days free of the added burden of depressive illness.

## A CIVILIZATION OF LOVE

Hospice work has helped me to understand something of Pope John Paul II's explanation of the Christian meaning of human suffering: "Suffering is present in the world in order to release love, in order to give birth to works of love toward neighbor, in order to transform the whole of human civilization into a civilization of love."<sup>7</sup>

The compassionate care of dying persons until the last moment of natural life has an importance that extends far beyond the good of the individual and the family served. In the words of the Holy Father to Catholic health care leaders in Phoenix, "Your apostolate penetrates and transforms the very fabric of American society ....[A]s you alleviate suffering and seek to heal, you also bear witness to the Christian view of suffering and to the meaning of life and death as taught by your Christian faith."<sup>8</sup>

Hospice care is an example par excellence of a work of love toward neighbor which can help to transform our culture of violence and death into a civilization of love.

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## NOTES

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<sup>1</sup> Cicely Saunders, "The Problem of Euthanasia-2," in *Care of the Dying*, a Nursing-Times Publication, Macmillan Journals lid., 1981. Originally published in *Nursing Times*, 72 (July 1,1976): 7

<sup>2</sup> Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, May 5, 1980, Section 111, St. Paul Editions, 10.

<sup>3</sup> Derek Humphrey, *Final Exit*, (Eugene, Ore.: Hemlock Society, 1991), 31.

<sup>4</sup> Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Section IV, St. Paul Editions, 12.

<sup>5</sup> Joanne Lynn, Correspondence, *The New England Journal of Medicine*, 328 (April 1, 1993): 964.

<sup>6</sup> Derek Humphrey, *Final Exit*, 21.

<sup>7</sup> Pope John Paul II, *On the Christian Meaning of Human Suffering* (February 11,1984), h.30, St. Paul Editions, 54.

<sup>8</sup> Pope John Paul II, *Address to Health Care Leaders*, (September 14, 1987), Phoenix, Ariz.