EXCELLENCE IN CARE AT THE END OF LIFE
A Position Paper on the Components and Principles of Care used by Hospice of Acadiana

The human person possesses a special sacredness and dignity from its Creator that must be relished and respected throughout the course of life. This special dignity requires that one always utilize the ordinary means of caring, nurturing and sustaining one's life. When the human person approaches the end of one's life, this same human dignity demands greater attention and care since human life tends to be more vulnerable at its beginnings and toward the end of its earthly sojourn. The focus of treatment when caring for a person with a terminal illness must necessarily change in order to provide the best possible care in this new situation. The care provided at the end of life is excellent only when it addresses the needs of the person seen in its total human dignity. Such care requires sophisticated medical palliative care and symptom management, especially since most terminally ill patients see pain control as a top priority in the care they desire. Professional help in dealing with emotional and relational aspects of one's life when facing death coupled with the spiritual resources made available to provide for facilitation of peace with God and increased hope during the duration of the illness and dying process add the essential human and spiritual touch. Help with the grief being experienced by family and loved ones prior to and after death is essential to assure healthy progress through the grieving process toward healing and a new phase of one's life. Hospice of Acadiana is committed to providing the best possible help to family members and caregivers in each of these areas in order to assist the dying patient to live fully until natural death. Experience has shown that this new focus of patient treatment and care for the new situation of a terminal illness can be most effective in providing for quality time in one's last days, bearing fruit in a beautiful death.

Symptom Management and Palliative Treatments

A patient with a terminal illness becomes medically qualified for Hospice care when aggressive medical treatments are either declined by the patient or when no longer recommended as providing a reasonable hope of effectiveness. An additional criterion is that the patient's prognosis is judged to be a life span of six months or less. Hospice of Acadiana cares for many patients who live beyond the six-month admission criterion. Such patients typically track a gradual decline and are not discharged unless they stabilize or recover to the point where they no longer qualify for or require Hospice services. In event a patient is referred to Hospice with a curable pathology, the patient and family members are encouraged to pursue curative treatments if such treatments offer a reasonable hope for cure and are not excessively burdensome to the patient and family. Stable hospice patients who acquire other curable pathologies such as pneumonia, UTI's, etc. are treated providing the patient responds to the therapy and the treatment in question is proportionate to the expected results.

> *"…I exhort you, as men and women of science responsible for the dignity of the medical profession, to guard jealously the principle according to which the true task of medicine is 'to cure if possible, always to care'" (Address of John Paul II to the Participants in the International Congress on 'Life-Sustaining Treatments…20 March 2004).*

Under Hospice care the focus of medical intervention and treatment shifts from curative to aggressive symptom management and pain control. Compassion and charity for a patient demands that as much as possible be done to control pain and debilitating symptoms which impede living to the full. Adequate pain control allows for patient and loved ones to enjoy activities and conversations in which both can be better prepared for the eventual death of the patient. Hospice of Acadiana utilizes the most effective pain medications according to approved protocols to provide for optimum pain management. Patients have different levels of pain tolerance and many of them find spiritual meaning and maturation in suffering and may prefer less aggressive pain management. Proposed interventions to control pain are always discussed with patient and caregivers and implemented only with the consent of the patient or the person competent to make medical decisions for the patient.

> *"Just as the knowledge of being loved lessens the fear of suffering, so respect for the sick person's dignity helps him in this critical and difficult phase of life to discover something that fosters his human and Christian maturation. In the past, man knew that suffering was part of life and accepted it. Today he strives instead to avoid suffering in every way, as is shown by the wide range of pain-killing medicines for sale. Without detracting from their usefulness in many cases, it must still be pointed out that the overhasty elimination of suffering can prevent a person from facing it and acquiring greater human maturity through it. However, in this growth process, he needs competent people who can really accompany him. Giving practical help to another requires respect for his particular suffering and recognition of the dignity he still has despite the decline that suffering brings with it. Hospice work arose from this conviction" (JP II to Hospice founded in 1919 in Austria, June 21, 1998).*

As every person has a right to consciously prepare for death a serious effort is made to allow for retention of consciousness while at the same time effectively managing pain. Total sedation is used only in the rare case where pain or serious agitation cannot be controlled by other means and when death is imminent.

> *"It is not right to deprive the dying person of consciousness without a serious reason" (Pope Pius XII).*

Even when aggressive pain management could arguably shorten a patient's life it would be morally permitted to continue such treatment, provided due proportion is respected. Besides increasing the quality of a patient's life, adequate pain control is now actually being shown to increase the length of the patient's life.

> *"Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged" (CCC 2279).*

Aggressive medical interventions aimed at curing a terminal illness or merely securing a precarious prolongation of life are not morally obligatory and not deemed

appropriate by Hospice of Acadiana. A patient is always free to choose such treatments and refuse or discontinue Hospice services. However, opting for such medical interventions often impedes facing death with dignity. When possible such decisions are to be made by the patient after consulting with the professionals involved.

As is the case with all medical moral decisions a judgment about whether or not to forgo or discontinue a particular medical intervention should be made through consideration of all aspects of the particular situation. This involves studying the type of treatment to be used, its degree of complexity or risk, the associated cost and possibilities of using it, the state of the sick person and his or her desires, etc. All of these elements should be compared against the expected result of the intervention. In the final analysis, it belongs to the conscience of the patient, or if unable, the person competent to speak for the patient, to make this decision.

> *"Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of 'over-zealous' treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected" (CCC 2278).*

Issues surrounding removing or withholding artificial nutrition and hydration are always difficult, not only for patients and families, but also for doctors and medical staff. It is not permitted to stop feeding by hand and/or giving sips of water to a patient who can swallow and digest food. Providing nutrition and hydration through artificial means (eg. IV fluids and/or PEG) is normally presumed ordinary means of sustaining life and should be given when medically indicated. Hospice of Acadiana will not consent to withdrawing artificial nutrition and hydration on stable patients who need them and are able to assimilate the feedings.

> *"I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in [the case of a person in the vegetative state] consists in providing nourishment to the patient and alleviation of his suffering" (Address of John Paul II to the Participants in the International Congress on 'Life-Sustaining Treatments…20 March 2004).*

> *"There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient" (Ethical and Religious Directives for Catholic Heath Care Services, NCCB, no. 58).*

However, it must be realized that a patient's appetite normally declines considerably as a terminal illness progresses and food and liquid intake as a rule declines steadily until death. Providing artificial feeding and hydration in some cases will only increase the patient's suffering and can even inadvertently cause death, for example through aspiration. Artificial nutrition and hydration are not considered ethically obligatory or

appropriate when death is imminent, when patient can ingest food and drink by mouth, when the feedings are not tolerated by the patient, or when the artificial nutrition and hydration cause serious complications or discomfort to the patient. Hospice of Acadiana will not refuse to admit a patient on the basis that they are receiving artificial nutrition and hydration but may recommend its discontinuation if and when this treatment proves to be more burdensome than beneficial. Hospice may recommend insertion of a PEG tube for feeding if a patient is hungry and unable to eat due to some obstruction, for example, perhaps in the case of an esophageal cancer. The same may be done with regard to IV fluids when they can reasonably sustain life, help overcome a transient pathology, or provide patient comfort.

> *"We reject any omission of nutrition and hydration intended to cause a patient's death. We hold for a presumption in favor of providing medically assisted nutrition and hydration to patients who need it, which presumption would yield in cases where such procedures have no medically reasonable hope of sustaining life or pose excessive risks or burdens" (Nutrition and Hydration: Moral and Pastoral Reflections, U.S. Bishops' Pro-Life Committee).*

Hospice of Acadiana holds that it is never permitted to intentionally hasten or bring about death. A request on the part of a terminally ill patient to be helped to end his or her life is almost always a hidden plea for help and love. With adequate pain and symptom control and the experience of human love and compassion, patients who once entertained desires for euthanasia more often than not experience the joy of living fully until natural death.

> *"By euthanasia is understood an act or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated" (Declaration on Euthanasia). "Whatever its motives and means, direct euthanasia consists in putting an end to the lives of handicapped, sick, or dying persons. It is morally unacceptable" (CCC 2277). A request on part of patient for assisted suicide "is almost always a case of an anguished plea for help and love…What a sick person needs, besides medical care, is love, the human and supernatural warmth with which the sick person can and ought to be surrounded by all those close to him or her, parents and children, doctors and nurses" (Declaration on Euthanasia).*