An Exquisitely Personal Relationship:

PROPOSALS TOWARD THE COMPASSIONATE CARE OF THE TERMINALLY ILL AND THEIR FAMILIES

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Like any other exquisitely personal relationship, the compassionate care of the terminally ill and their families requires an asking of certain questions that are basically philosophical and religious in nature. In this case, we must ask: (1) What is human life? (2) What is human death, and when is it morally permissible to halt artificial prolongation of biological life signs? (3) What is the responsibility of the medical profession to the loved ones of the terminally ill?

I

Every science that has studied man or the societies that he forms has had to cope (willingly or by force) with the question, "What is human life, and how does it differ from all other forms of life?"

The fact that an adequate definition of human life has not been given by any one special field of thought should not be surprising. Most fields of inquiry (biology and medical science included) approach the subject of Man and human *being* from a special theoretical or practical bias and with a particular goal in mind. In their own ways, our various sciences have reduced man from the totality of his being to a collection of ever-so-many functional parts, systems, and modes of existence. What we have learned about man's physiological, psychological, emotional, and social needs and make-up, as a result of the fragmentation of the intricate wholeness that man is, has been helpful in our quest to understand the complexity of human life. But our knowledge thus far is not adequate to define human life in essence. At best, our efforts to date permit us to define man as being different from all other animals in terms, for example, of certain anatomical and physiological uniquenesses and the innate capacity for speech, reason, memory, and rationality.

The fact that we are unable to define human life adequately, however, gives not one of us legitimate excuse for having a lazy imagination concerning those integrals which fashion us as *human* beings. We are duty bound to see man as an intricate interweaving of body, mind, and spirit, and, in such a holistic view, to search for some understanding and appreciation of man's uniqueness.

We are all aware that biological being is preconditional to human existence. But perhaps we are less aware — or are at least less accepting — of the fact that biological being and human existence are not necessarily coterminous. Simply stated, one of the medical, biological, and indeed philosophical peculiarities of man is that the uniqueness upon which "being human" depends can terminate in advance of the body's total biological demise. Though one cannot say that our uniqueness is totally "other than bodily existence," it is certainly true that human life is recognizably (though perhaps indefinably) more than biological being and process.

An essential aspect of that which is clearly more than biological involves man in relationships with other human beings and the world — relationships, whether casual or intimate, into which he carries a remembrance of things past and a hope for the future. For Martin Buber, the Jewish theologian, the uniqueness of man is to be found in the act of relation or in the meeting of "I" and "Thou." In the words of Buber, man is "the creature capable of entering into living relation with the world and things, with both men as individuals and the many, and with the mystery of being which is dimly apparent through all this but infinitely transcends it."[2] In his affirmation that the essence of man can be directly known only in a "living relation," Buber neither has given answer to the question "What is human life?" nor has he defined the uniqueness of man. Rather, what he tells us about man is *where it is* that *what he is* is to be found.

To be in an exquisitely personal relationship with another person is to be at the beginning of a knowledge of man. It is to stand at the threshold of entering into an awareness of the uniqueness that is each one of us — a uniqueness which allows us to be alike in terms of a classifiable species, but which means in the words of Viktor Frankl "absolute *being different*, absolute otherness,"[3] in terms of our personal being, the human existence that I know as an individual and that you know as an individual. Just as Buber did not define the uniqueness of man, but rather told us that the essence of man can be realized only in living relation, so Frankl does not give a definition of the uniqueness of the individual human being, but tells us that, as individual persons, we are personally different.

The individual differences which are the uniqueness of a terminally ill patient, and which that person shares with no one else, must be seen as of utmost importance by the members of the caring professions. As important as the effect that surgery, hemodialysis, or chemotherapy may have on a patient is the way in which one's illness, restricted life, and impending death affect this unique, never-to-be-repeated human being. Concerning this, Sir Robert Platt notes that "there is a side to human behavior in health and disease which is not a thing of the intellect, which is irrational and emotional but important. . . . Consider, for instance, how the patient's personal reaction to illness is so often what determines his future: how one diabetic becomes an invalid while another, scientifically indistinguishable, carries on a normal existence."[4] In a similar vein, Joseph Fletcher writes: "The sufferer is not just a case of pneumonia or pyloric stenosis or peptic ulcer; the patient is a person, with feelings of hope or despair, of purpose or defeat, of loneliness or fraternity. The patient is not a problem; he is a person with a problem."[5]

How often do we look on patients as problems to be overcome rather than as persons to be cared for? How often are we disgusted by the terminally ill patient who is unable to feed himself, or to manage his toilet needs, or to express his wants in understandable speech? In how many cases of these sorts have we reacted in careless and callous abandon, harshly demanding that a patient eat the food he neither likes nor wants, or reprimanding a stroke patient for garbling his words?

How often do we take time to be aware of, indeed to inquire about, the very real and very painful fears which are a natural human element of terminal illness, of death and dying? Do we recognize ill patients who would rather be dead than be invalids and dependent on others for the management of their daily and hourly needs? Do we care for persons with cancer who see their disease as dirty and ugly, who are ashamed of their illness, and who fear that their loved ones will no longer want to touch them or be near them? How much time do we spend in medical ministry to the young woman who has had a mastectomy and who considers herself less feminine, less of a woman, and who may unconsciously avoid any physical relationship in the future rather than bear the suffering of embarrassment?

What percentage of the time used in "taking care of a patient" is actually spent in "compassionately caring for" the person? In comparison with the time spent in carrying out the routine medical care of patients, how much time is spent in "living relation" with them, seeking to understand their fears and personal sufferings — that is, their sufferings of mind and spirit — and what effect such fears and sufferings are having on the course of their illnesses and their lives?

To enter into compassionately caring for our patients is to be always personal in our actions. To be concerned with the human sufferings of mind and spirit is as intimately a part of quality medical care and "compassionately caring for" as is the act of gently replacing a catheter tube into the body of a confused patient. "Compassionately caring for" is, in essence, a personal relationship: a person caring for another person. It is my affirmation of the unique person that you as person-patient are to me.

Thus the medical ministry of compassionately caring for a terminally ill patient always requires two things. *First,* the members of the health care team must make sure that everything that may *reasonably* be done to promote human well-being either has been done or is being done. This will include all wise and reasonable efforts to effect a cure or to reverse the course of the illness, while keeping the patient as free of pain as possible and respecting his rights as a person. *Second,* our medical ministry requires a living relation in which we seek to recognize and appreciate in our patient the *absolute otherness* which is the meaning of his uniqueness as an individual human being. Such a relation places us under obligation to seek to understand how this person is personally different from every other patient.

To say that we do not have time to be in a living relation with our patients — to say that we do not have time to know our patients as persons — is, in effect, to acknowledge that we do not have time to give quality care. For quality medical care demands a person-centered treatment and maintenance program wherein the patient's personal needs and wants, strengths and weaknesses, shortcomings and fulfillments, spiritual stamina, courage, and fears are matters of concern to the nurses and physicians (and all other members of the health care team) as they seek to compassionately care for their patient, who, as a human being and a person, is, in essence, an intricately delicate interweaving of body, mind, and spirit.

II

The fact that life and death are still defined largely in traditional terms of biological being and process is illustrated in our recent quest to redefine death. Whether one refers to work of the ad hoc committee of Harvard

Medical School and its definition of irreversible coma[6] or to the "dying score"[7] proposed by Vincent J. Collins, life and death continue to be defined primarily (if not entirely) in terms of certain physiological life signs, the presence of which denote life and the absence of which denote death. Biological death, strictly speaking, is purely clinical and by comparison quite precise. Human death, on the contrary, is always personal — involving the cessation of purposeful, responsible, relational life — and, as such, defies exact determination.

The compassionate care of the terminally ill and their families requires an understanding of human death as being infinitely more than the cessation of biological existence. The often-heard statement that "everything will be all right" is, to the dying person and his family, at best a lie and an insincerity offered by the living, who, paralyzed by the stark reality of death and human temporality, attempt to make easy an event which, because of our accustomed denial of it, is exceedingly difficult to accept. The anguish borne by the living after the loss of a loved one is piercingly stated by Gene Hackman in his role as the grown son in the motion picture *I Never Sang for My Father:* "Death ends a life, but it does not end a relationship which struggles on in the survivor's mind toward some resolution which it may never find."

On the other hand, death is hoped for, even joyfully anticipated, by some patients and their families because of the physically, mentally, spiritually, and financially debilitating effects of certain forms of medical treatment and maintenance. This fact (harshly true and perhaps shockingly difficult to accept) that a person may be exhausted and dehumanized to the point of longing for death, should not so much put us in question of the morality of the patient's desire to die as it should bring us to examine our motives and methods of medical care and treatment in prolonging the life of the terminally ill.

Buber's characterization of man as the one "capable of entering into living relation" is not only an informative statement about man, but is also an instructive statement which offers a goal-orientation as we seek to save and prolong life. The corollary of Buber's statement that "the essence of man can be directly known only in a living relation," is the affirmation that to remain a humanly healthy human being one must be able to maintain a living relation with his fellow human beings and the things around him.

If the saving of life and the prolongation of life are to be meaningful in a human sense, beyond the technical achievements of forestalling biological death and prolonging bodily existence, they must be done with some goal in mind. And one might suggest that that goal, morally speaking, should be to return man to human functioning in his human environment of friends and nature. For us not to be intimately concerned with the effect that medical treatment has on a patient's ability and desire to enter into living relation is to stand in a scientific vacuum divorced from medical ministry, from that side of medical practice which is always personal, always concerned with man as a social being who needs human companionship, reinforcement, and interaction.

That it is neither the duty nor the right of a physician to stand in judgment of whether a person's life is worthy to be lived is a fact which always needs stressing. Leo Alexander, referring to certain medical atrocities committed during the Second World War, noted that "it became evident to all who investigated them that they had started from small beginnings . . . with the acceptance of the attitude . . . that there is such a thing as life not worthy to be lived."[8] This statement should remind us to recognize the respect which must be paid to all human life, regardless of its present state or future or medical hopelessness. Such a statement, however, ought not to mislead us into a belief that biological life should be prolonged indefinitely at all costs.

It is difficult at times for the physician, schooled in the "death is the enemy" tradition of medical education and practice, to be confronted with the patient who in waning years calmly but resolutely states, "I am ready to die." So thoroughly frightened have we become of death that we are often shaken to the very depths of our being by the person who is ready in mind and spirit to die and who gallantly awaits the accord and accompaniment of the body on finite life's final journey.

Biological life is invaluable to the human being in that it is preconditional to one's being human. Whether or not, however, one may morally choose death over life is a sensitive issue, one of the most important questions confronting us in our medical ministry to the terminally ill. The patient who sees death as the prize of a life well lived, and who exhorts her physician to keep her comfortable but not to deny her of her journey into death, by the use of penicillin should she contract pneumonia, is a case in point. Here we are confronted with the question of whether one may choose to die of a quite common and easily treatable ailment before stroke, cancer, diabetes, or senility set in. In effect, we are being asked whether this person may choose to die as a relatively independent human being before she becomes a burden to her family and loved ones — or whether a home for the aged, incontinence, wheelchair, and bedsores must be preconditional to honoring her wish to die.

This question is raised in particular because through the use of antibiotics we save, each day, thousands of chronically ill, aged persons into further physical and mental disability and the meanest of diseases. That many of these individuals fear their continued bedridden existence and their confused, restricted lives more than they fear death is a fact that we are all too slowly coming to admit and deal with as we consider their continued treatment programs.

Our medical ministry of compassionately caring for our patients, which requires that we do all we can to make available the best treatment programs possible, also requires that we be concerned to know what limits, if any, they would like to see set regarding the extent to which their biological life should be prolonged. For some people who have done a great deal of honest thinking about death, the wish to leave this life as independent, fully human beings in control of their faculties is honorable rather than immoral.

That life is valuable, and that some are willing to sustain all sorts of discomfort and restrictions in the hope of staying alive and returning home, is something that we are reminded of anew each day. Indeed, the courage and will-to-live with which terminally ill persons often meet the prognosis of death, often give one more than sufficient reason to try to buy for the patient's life one more month, one more week, or one more day, in the hope that remission will come and that at last the long-awaited "miracle" or miracle drug will be ours and his.

But what of the patient who has promised that he will be a "good patient" — that he will carry his burden of the load, taking the doctor's orders and obeying the requirements of the treatment regime — when the pain becomes too much, when his restricted existence makes him aware that his dreams will not come true, when his bed and his room become the perimeter of his physical world, and when he feels that he is losing control of himself — his biological processes and his mind?

What about this person who just last week wanted so fervently to live, and now wants to die? What about my responsibilities to him as a fellow human being, when his life becomes for him more of a nightmare than his fear of death? How does he affect me? Does he anger me? Should I reprimand him and scold him for what I perceive to be childish behavior? Am I disgusted and embarrassed by his fears and weeping? Do I all of a sudden think that there are others — stronger, braver, more cooperative than he — who are more deserving of my time and my skills? When I leave his room now do I pull his door shut behind me when always before I left it open?

III

With regard to certain methods of artificial maintenance — chronic hemodialysis, for example — there is already a growing element of positive concern supporting the freedom of the terminally ill person to elect death and withdraw from a treatment program which he feels is maintaining him at an unsatisfactory and inhuman level of existence, or which he feels is too costly — emotionally, spiritually, or in other ways — for him and his family to bear. Also, earlier in this discussion, a hint of support was given to the request of the elderly woman who wished to be kept comfortable in the event of pneumonia, but who asked not to be denied of knowing death as an independent being in full control of her mind. In such a case, the request seems to come from a human being who wants to confront death with peace and dignity and with a realization of a wholeness of self. We need to consider also what moral obligations we may have to allow death to come to the person who has suffered massive and irreversible damage to the higher levels of brain functioning which control reason and rationality, when we know that death in such an event would be the fulfillment either of a previously expressed desire of the patient or the present desire of the family.

At this point it should be noted that the support which is suggested for permitting death in the three examples given is in no way intended to imply that one is justified in treating as a casual matter a patient's request to withdraw from treatment or his desire to die. Any such approach would be a blatant denial of the fundamental purpose of promoting human well-being. Humanly speaking, life is much too precious to permit easy assumptions or conclusions about its continuance or demise.

Because confusion and inability to make concrete, lasting decisions often mar the mind and emotions of the seriously ill patient, our medical ministry requires a patient-centered, team approach which brings to the sufferer's bedside a caring group of nurses, physicians, psychiatrists, social workers, and chaplains who share the task of understanding the patient's overt and covert pleas. They must be concerned to know what, if any, social and family difficulties may have arisen to influence the patient's decision about further treatment. They need to know, for example, whether the patient has recently lost the emotional or spiritual support of someone whom he loves and needs, or is fearful of losing such support and encouragement in the near future, so that tonight's long, lonely hours and tomorrow's physical struggles and indignities are too painful and meaningless to face. A patient's stated or implied desire for death may overlie certain discouragements, frustrations, and fears that only the most compassionate and sensitive, listening persons will be able to perceive.

Human death and dying, whether anticipated or desired, always involve personal sufferings of mind and spirit on the part of the conscious dying individual and his loved ones. Dying as a thoroughly *personal process* involving all sorts of fears — chief among them the fear of deception and loneliness — is strikingly portrayed in Leo Tolstoy's short story, "The Death of Ivan Ilych": "What tormented Ivan Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill. . . . Apart from this lying, or because of it, what most tormented Ivan Ilych was that no one pitied him as he wished to be pitied. At certain moments after prolonged suffering he wished most of all . . . to be petted and comforted."[9]

To be comforted by the living, to not be abandoned, to not be deceived — only so slowly are we coming to recognize and cope with these very real, very painful needs of man in his dying. To bathe, to keep clean, to manage the toilet needs, to turn on his side or back — these are all required in the care that is owed to the dying person by the living as a part of our human covenant of love and respect; but these medical delicacies and difficulties are not the totality of our medical ministry of compassionately caring for this fellow human being.

All too slowly, but finally, we are coming to hear the dying patient when he says, in effect, "As important to me as your technical efficiency, your syringes, and your hospital regulations is my need not to be feared and rejected by the living because I am dying. More important to me than the platitudinous assurance that everything will be all right and that I have nothing to fear is my need to have with me in my dying days courageous and personable nurses and physicians, who though being at their wit's end of medical knowledge and skill, are willing to sit by my bed and to visit with me on the basis that we are all human, all mortal, all finite."

Our personal and medical ministry of "compassionately caring for" entails the acknowledgment in word and deed that the terminally ill, dying patient is a person. This holistic view, this recognition of man as body (that is, biological being and process), mind (meaning specifically the *cogito ergo sum* aspect of man's being) *and* spirit (that which is realized and expressed through — but is other than — bodily existence), gives content and outline to our responsibilities in dealing with the dying. Essentially, it requires of us an assurance and a promise that the dying person will not be violated in body by the use of futile life-prolonging procedures and techniques, or by the use of unwarranted and unwise medical intervention to forestall, frustrate, or reverse the dying process; that he will not be violated in mind by the use of drugs or surgical techniques which fall outside of the planned medical regime designed to keep the patient humanly comfortable; that he will not be violated in spirit by being treated in the abstract as a personless disease, illness, or condition; and that he will not be violated as a person, a fellow human, by being abandoned or deceived.

IV

In a recent *Life* magazine, Joan Barthel writes movingly and tenderly about her reactions to death and the dilemma of a friend's dying:

> Even now, my headaches linger. So do the bad dreams, the regrets. . . . I know about the natural cycle, to everything there is a season, but I cannot bear to think of the end. I am afraid now because the inner resources I thought I had . . . seem so frail and feeble. I loved her, but if love were enough, wouldn't I have known better what to say to soothe and make her easy? Wouldn't I have known how to use more creatively those last precious hours I spent staring at magazines, pacing the hall, drinking coffee in the lounge? I believed in another life for her, but if faith were enough, wouldn't I now rejoice for her instead of lamenting all that is lost — the cruise she won't take, the book she won't finish, the climbing roses she won't see this June? Or is the fault only in the quality of my faith and hope, in my brand of love? I keep thinking I should have sung for her.[10]

Here is a friend reflecting on the death of a loved one: wondering what she could have done that she didn't do; wondering what she didn't do that she should have done; questioning her brand of love, her faith, her ability and strength to face death again — fearing that she also might die helpless and speechless as her friend died; wondering now if her thoughts are neurotic or normal; wondering if the questions she is asking are natural to such an event — and yet helpless to know whom to trust or to whom to turn.

The author of the article — like God-only-knows how many people who are facing the death of a loved one at this very moment — found herself, in those final days, very much estranged from, and abandoned by, the health care community into whose hands her friend had committed the last few months of her life. The doctors stopped coming; there was a different nurse on duty each day; and the accounting department's only concern was who was going to pay the bills. But medical ministry to the terminally ill requires that we be supportive of the intimate community of persons who have been the source of our patient's strength, courage, and loving. We must comfort the bereaved as well as the dying.

Often during the period of anticipatory grief when the patient and the family are struggling with tears, fears, confusion, and anger, the health care team finds it less of a psychological and spiritual strain to stay away from the patient and his family than to draw near to them. Even when someone must enter the patient's room, to assist with a bedpan or to bring fresh water or medicines, the tasks are frequently done with an air of professional efficiency which (at least covertly, if not overtly) imparts to the family a feeling that they are either unimportant or in the way. Why does the fear of honest confrontation with questions about life and death drive one, time and time again, to abandon the human beings who at this very moment need emotional and spiritual support as they bravely attempt to keep company with their dying loved one?

How we react to the terminal illness and impending death of patients, and how well we are able to keep company with, and be supporting of, the grieving loved ones, largely mirrors how we have coped with death and the reality of human finiteness in our own personal lives through experiences of illness and death in the past. The extent to which we have successfully avoided coping with death (and the prospect of death) in our previous encounters with dying persons directly influences the extent and quality of our relation with a fellow human being who, today, is suffering through the dying and death of a loved one.

V

To the end that we might become a priesthood in medical ministry to man in his totality and in so doing further humanize the art and practice of medical care, I offer the following theses as proposals toward the compassionate care of the terminally ill and their families.

1. *We must face the reality of death and dying, and seek to learn in that reality something more about the uniqueness of man and the meaning of human existence.*

Persons involved in the practice of caring for the sick and injured should be encouraged to continue to do all that is *reasonably possible and advisable* to save and meaningfully prolong life, taking into consideration at all times the human rights of the person-patient involved. We should be aware, however, that if we are to humanize the art and science of medicine, we will need to understand and appreciate the possibility that death and dying may be processes out of which a wholeness of being and a rediscovery of self may occur in the sufferer, in those who love him, and in those who care for him. To this end, our personal and medical ministry to the terminally ill and their families requires that we try to see human death as a positive affirmation that man is knowingly temporal and finite and *precious.* The very fact that one will, in time, be no more makes him at this moment, and at every moment, utterly dear and utterly demanding of our most dedicated, skilled, comforting, and compassionate care for him in his dying — and in his desire to die — as well as in his living.

2. *In all of our efforts to save and prolong life we must be concerned with the issues of quality and meaning in human existence as the patient sees them.*

Though it is not our duty or place to stand in judgment of the quality or meaning of another person's life, we are duty bound — in the name of human decency and loving care — to be concerned with what our person-patient sees to be quality and meaning in his life: what he sees to be a meaningful life worthy to be lived.

This is to say that in our attempts to save and prolong life we must be careful that we do not take more away from man than we restore to him. For example, we must be concerned with what we have done to the diabetic's own sense of well-being and worth when we have removed his gangrenous legs. In effect, we must be concerned that under the rubric of rehabilitation we not "disabilitate" a person into a level of existence that he cannot tolerate — and that we are not justified to demand that he tolerate. One may recall in the film *Johnny Got His Gun* the frightful moment when Johnny, realizing that his arms and legs have been removed, cries to himself, "But what kind of man would do this to another human being?"

3. *We are never justified in abandoning a patient because in our mind "the case has been lost."*

Indeed, the attempt to save a person's life may have been unsuccessful; but so long as the patient lives, he is fully deserving and fully demanding of our visits, our time, and our company. This fellow human being must be fully the recipient of our compassionate companionship and care until his dying is complete.

4. *When a person-patient states that he wants to die or to withdraw from a treatment program, we must seek to understand the underlying reasons for his request, the true meaning of it, while taking the utmost care lest we intimidate the person in the process.*

It ought not be our primary concern to talk every patient out of such a request. Rather, in such a situation, our fundamental responsibility is to be intimately involved with the person in his decision-making process, recognizing his struggles of mind and spirit, and helping him to understand what other programs of treatment, if any, may be available. Our responsibility is to be fully in company with him, discussing what he sees to be a meaningless or worthless state of existence. It is to be in living relation with him as he copes with the thought that there may be a point in life — and that this may be it — when death would be more dignified and blessed than continued existence.

5. *We must seek to release the hidden resources that are there to help our patient meet the challenge of his terminal illness.*

In order to do this we must be concerned to know his strengths and weaknesses; his feelings of personal fulfillment and achievement. What have been his hobbies, his leisure time activities in the past? What has he wanted to do, to learn or to study, that the personal and professional responsibilities of his busy workaday life have never left him time to do? This task is one of the most difficult, and perhaps one of the most neglected responsibilities confronting those involved in the medical ministry of compassionately caring for the terminally ill. To this responsibility we must bring an awareness and an understanding of the "absolute otherness" of this person-patient that makes him entirely and personally different from every other person for whom we must care.

6. *The health care team — as a caring community — must be present when needed to give physical, emotional, and spiritual support to the family and friends of the terminally ill patient.*

Just as our medical ministry of compassionately caring for the terminally ill requires that we make available the best possible program of diagnosis, treatment, and maintenance, so too our medical ministry of compassionately caring for the loved ones of the terminally ill requires that we make available a program of supportive care which concerns itself with the physical, emotional, and spiritual needs of those who bravely — or perhaps not so bravely — attempt to bear the agony of companying with the one who is dying. Into this supportive care must be drawn the expertise and personal ministry of our social workers, psychiatrists, and clergy — as well as our nurses, physicians, and paramedical personnel. While it is true that not every grieving person wants the help of a psychiatrist or the consultation with a social worker, or the ministration of a pastor, it is imperative that such services be made available to all individuals who desire such help.

The foregoing discussion and proposals regarding the compassionate care of the terminally ill and their families spell out neither in entirety nor in detail the responsibilities which must be accepted and fulfilled. Regardless of all that is still left to be said, however, it is to be hoped that we share an increasing understanding of how our medical ministry requires an exquisitely personal relationship in which we willingly stand in a living-loving relation with all who are in need of medical and comforting care.

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