

**WHEN EMOTIONS AND LAW MIX:
END OF LIFE ISSUES FROM BOTH PERSPECTIVES**

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BY

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INDEX

I.	Introduction - End of Life Care Decisions, The Need for Better Control	4
II.	Limitations on Gaining Control -Advance Directives and their Failures	5
A.	Health Care Decision Making - The Legal Framework	5
1.	Two Kinds of Written Instructions	5
2.	Medical Treatment Statutes	5
3.	The Living Will	5
4.	The Medical Power of Attorney	6
5.	Other Substituted Decision Making	7
B.	The Failure of Effectiveness of Advance Directives	8
1.	Competing Values	8
2.	The SUPPORT Study	9
III.	What Can be Done to Gain Control - Legal Issues	10
A.	Personal Statement	11
B.	Five Wishes Project	11
C.	Need for Collaboration	11
D.	Cardio Pulmonary Resuscitation	12
IV.	What Can be Done to Gain Control at the Personal Level	12
A.	Understanding Cultural Norms	12
B.	Understanding Grief as a Part of the Process of Death and Dying	13
1.	Education and Personal Understanding	13
2.	Theoretical Approaches	15
3.	A Stage Theory Approach	15
4.	Support for the Bereaved	17
C.	Education as to Available Resources	17
D.	The Hospice Model	18
1.	History	18
2.	Philosophy	19
3.	What is Hospice	19

V.	What Can be Done to Gain Control - Systemic Issues	20
A.	Living Will Background	20
B.	Physician-Assisted Suicide	20
C.	State Commissions	20
D.	Palliative Care	21
E.	Coding Medical Records	23
F.	Better Funding for Hospice	23
G.	Interdisciplinary Efforts	25
H.	Managed Care - The Great Unknown	25
VI.	Conclusion	25
	Supplemental Materials - Case Studies	26

I. INTRODUCTION - END OF LIFE CARE DECISIONS, THE NEED FOR BETTER CONTROL

During the last couple of years the authors have been discussing their work with people who are dealing with end of life issues from their professional perspectives as an estate planning attorney and as a clinical social worker. End of life planning and care encompasses a broad range of social, financial, psychological, legal, spiritual, and medical issues. Therefore it requires interdisciplinary discussion to begin to resolve the problems that are presented. When an attorney and financial planner participate in the process of preparing wills, living wills, and advance directives, we and our clients need to know that these actions will produce the result that is intended. A disturbing report will be discussed which shows that medical directives are disregarded even with the best efforts to communicate with hospital staff members about them. We end up with people who are distrustful of the legal and medical systems and who are increasing fearful because they have no control over what happens to them at the end of life.

One theme of this paper is that, both individually and as a community, we fail to gain control over the process of dying and death and further that there are both small and large steps which can be taken to remedy this.

At the threshold, an important and potentially embarrassing thing to consider is the state of our own personal end of life planning. Who exactly is responsible for decision making under our powers of attorney? Have we thoroughly discussed our wishes with the agents responsible for their execution? Have all family members been made aware of these plans? Have we really told anyone what kind of care we want should we become ill? Where we want to be cared for? At home? In Hospice? And by whom? Are our instructions clear about cremation or burial?

Why is it so easy to talk about these things in a professional context and why are they so difficult to consider for ourselves? Why is the subject of personal death so hard to think about?

As Stanley Keleman, in a wonderful little book entitled *Living Your Dying*, reminds us our bodies know how to die. Dying is built into us biologically and is happening all the time on the cellular level. Spirit may tell us or not tell us that some part of consciousness continues beyond bodily death. In either case there is nothing to worry about from that perspective as it will be either a vast darkness or, as someone said to a mutual friend, we may get to speak with Homer. Our intellect and our emotions present different problems with our coming to terms with our own death.

In addition to our collective fear of death, we fear the possibility of unbearable pain, becoming dependent and becoming a financial and care taking burden to our families. The possibility of getting caught up in a medical technological nightmare, and an increasingly complex, impersonal, and confusing health care system adds to our difficulties and to our feelings of loss of control over the events surrounding end of life. Those of us who work every day with issues about death are able to stay in a state of denial most of the time. Yet, it makes

sense to take some time to consider our own death and to begin to try to arrive at some meaning about this life event and to try to grapple with some of the emotional issues that arise that may get in the way of our being as effective as we would wish to be with people. We, individually and as financial planners, must also work to make the systems that tend to our needs more effective, humane, and responsive.

This paper presents some of the issues surrounding the lack of control which we have over the process of dying and death, including the failure of advance directives and the failure to deal effectively with pain. It discusses some of the limitations in taking control and what the prospects may be for taking control on the personal level, in the legal context, and at the societal level.

II. LIMITATIONS ON GAINING CONTROL - ADVANCE DIRECTIVES AND THEIR FAILURE

A. Health Care Decision Making- The Legal Framework

1. There are two Kinds of Written Instructions:
 - a. Advance Directive - In which an individual provides his or her own instructions as to what is to be done in the future by health care providers.
 - b. Delegation of Decision Making - Under which an individual, rather than attempting to make his or her own decisions to be effective in the future, provides (or delegates to) a third party the authority to make those decisions.
2. Medical Treatment Statutes. An increasing number of states have modern, multi-faceted statutes which cover the various aspects of health care decision making:
 - a. Primacy of advance directives
 - i. Living Will
 - ii. Health care directives; and
 - b. Health care decision delegation by Powers of Attorney; and
 - c. Substituted Decision Making.
3. The Living Will.

- a. Narrow Coverage. This is an advance directive that covers the narrow circumstance of a near death condition in which one is comatose or unconscious, is certified by a specified number of doctors (usually two) to be in a terminal condition. It allows a person to provide instructions regarding the cessation of medical treatment or the continuation of medical treatment.
 - b. Statutory Format. The enabling statute may provide both principles for the use of a living will and contain a statutory format.
 - c. Specificity Regarding Hydration and Nutrition. Several legislatures, faced with competing views as to whether a living will might be used to include artificial hydration and nutrition among the medical procedures to be continued or discontinued, requires that each person who executes a living will make a specific choice in this area.
 - d. Anatomical Gifts. There may or may not be statutory basis for including instructions regarding anatomical gifts in a living will. It is submitted, however, that the effectiveness of anatomical gifts is so important and, since there is a factual connection between enforcement of anatomical gift instructions and living wills, that anatomical gift authorization is appropriate in living will documents. For example, it may be appropriate to deal specifically with the length of time that a person remains on medical support in connection with organ use. On the one hand, extra time may be necessary for the preparation for the effective "harvesting" of organs. On the other hand, extended time on life support may begin to compromise organs and impair their usefulness for transplantation.
4. The Medical Power of Attorney.
- a. Common Law. At common law agency relationships, including powers of attorney, ceased upon disability. The problem was that disability was the event that made them necessary and useful. Therefore modern legislation allows both property and health care powers of attorney to be durable, that is not to be ineffective upon the disability of the principal.
 - b. How Effective. Property management powers of attorney generally may be either presently effective or effective upon a future specified event. On the other hand, health care powers of attorney,

under the statutes, are generally effective only upon a future event, i.e., a determination of incapacity.

- c. Office Form. The author-JRW's office form is attached as an exhibit (Exhibit A) and represents the delegation model of a health care power of attorney - containing a "laundry list" of decision making which is covered.
 - d. Alternate Model. An instrument can be drafted which is a hybrid between an advance directive and a delegation to a third party. It provides specific instructions as to the extent of medical care desired under various medical scenarios. An example is attached as Exhibit B. There are several issues regarding such a model:
 - i. Since the design is medical, the user needs help from his or her doctor or other health care provider in discussing the options and in filling out the form. This does not fit well into the present constraints on health care provision, especially under managed care arrangements.
 - ii. The document needs to be clear about what happens when the agent under the power feels that a particular treatment (or withholding a treatment) is at variance with the specific direction in the document. Which prevails? This should be covered by the terms of the instrument.
 - iii. The circumstances of a person in a situation of a serious (including terminal) illness may be subtle and extremely fact sensitive. A generally stated intention regarding CPR may turn out to be appropriate in most but not all situations, and its appropriateness may change during the course of the illness and depend upon the availability of treatment. This suggests that there may be greater benefits in a simpler and more general delegation of authority to a trusted agent (or guardian) than in attempting to anticipate and describe in detail the desired methods of treatment under various scenarios.
5. Other Substituted Decision Making.
- a. Court Appointed Guardian. Under state law a court may be called upon to appoint a guardian who will have either limited or unlimited powers of decision making regarding the status of an

incapacitated person. Many states have adopted Article IV of the Uniform Probate Code dealing with guardianship and protective proceedings or have adopted its provisions, as a free standing act, under the Uniform Guardianship and Protective Proceedings Act. This Uniform Act was revised in 1998.

- b. Health Care Decisions Act. Another Uniform Act is the Uniform Health Care Decisions Act¹ which, in the absence of a health care power of attorney, allows health care decision making to be made, without court involvement, by persons close to the patient. Most statutes have a statutory priority providing, for example, for decision making by the spouse, then adult children, then parents, etc. See, e.g. Uniform Act § 5(b). These priority lists are troublesome unless there is flexibility for the court to disregard the priority in the best interests of the patient. The most common case may be that of an elderly couple where the spouse of the respondent is already overwhelmed and immobilized and would be a poor choice. In addition, the statutory lists tend not to provide for "significant others" and for "partners" in gay relationships. Interestingly, the Colorado statute, C.R.S. § 15-18.5-101 et seq., provides for attempts at decision making among those persons close to the person including "any close friend of the patient." In the event of a dispute as to who has authority or how it should be exercised the court can be petitioned for instructions or authority to act.

The lessons which may be learned from the failures in drafting and utilization of advance directives may be instructive to all who may be involved in the authorization and education of guardians who make substituted judgments for incapacitated persons.

B. The Failure of Effectiveness of Advance Directives

1. Competing Values. There is a fundamental tension in health care between two competing values: (1) The importance of patient autonomy - to be responsible for and make (informed) decisions regarding one's own health care, including the right to decline treatment; and (2) the medical ethic to treat illness and preserve life. There had been anecdotal evidence for years that health care professionals have not been sensitive to patient wishes in the areas of chronic illness and especially end of life illnesses.

¹This Act, promulgated in 1993, has been adopted in Alabama, Delaware, Maine, Missouri, and New Mexico.

The following commentary states the issues as follows:

"Public Health and clinical medicine during this century have given Americans the opportunity to live longer and more productive lives, despite progressive illness. For some patients, however, this progress has resulted in prolonged dying, accompanied by substantial emotional and financial expense. Many Americans today fear they will lose control over their lives if they become critically ill, and their dying will be prolonged and impersonal. This has led to an increasingly visible right-to-die movement. Two years after voters in California and Washington State narrowly defeated referenda on physician-assisted euthanasia, Oregon voters approved physician prescription of lethal medications for persons with a terminal disease. Physicians and ethicists have debated when to use cardiac resuscitation and other advanced illnesses. Many worry about the economic and human cost of providing life-sustaining treatment near the end of life." "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients - The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)", JAMA, Nov. 22/29, 1995, p. 1591.

2. The SUPPORT Study. To provide better data the Robert Wood Johnson Foundation designed and funded a five year observative study of care for over 9,000 patients with life threatening illnesses. In the first phase, involving about half the patients, observation was made of standard procedures in five major teaching hospitals. The second phase observed about the same number of patients in the same hospitals with an important intervention, the designation of a kind of nurse advocate or facilitator to work with the patient, the patient's family, and legal representatives and with the physicians to see that patient wishes were better communicated to and respected by the physicians.

Phase One research documented shortcomings in communication, frequency of aggressive treatment, and the characteristics of hospital deaths:

- i. Only 47% of physician knew of the patients documented desires to avoid CPR.
- ii. 46% of Do Not Resuscitate Orders were written only shortly before death.

- iii. 38% of ICU patients and 50% of patients who died in a hospital setting reported that they were in moderate to severe pain at least half the time.

As discouraging as these results were, what was shocking was the results of Phase Two: There was virtually no difference. For example, there was no difference in the number of days spent in ICU prior to death on ventilators or in a comatose condition despite patient directives.

The conclusion of the study is sobering:

"In conclusion, we are left with a troubling situation. The picture we describe of the care of seriously ill or dying persons is not attractive. One would certainly prefer to envision that, when confronted with life-threatening illness, the patient and family would be included in discussions, realistic estimates of outcome would be valued, pain would be treated, and dying would not be prolonged. This is still a worthy vision. However, it is not likely to be achieved through an intervention such as that implemented by SUPPORT. Success will require reexamination of our individual and collective commitment to these goals, more creative efforts at shaping the treatment process, and perhaps, more protective and forceful attempts at change. [Emphasis supplied]. "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients - The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)", supra, 1591 at 1595.

III. WHAT CAN BE DONE TO GAIN CONTROL - LEGAL ISSUES

There is an important threshold question which should be asked both as a matter of general practice and in connection with particular people needs. The question is whether the primary technique for health care decision making in the event of incapacity should be by an advance directive or whether it should be done by a document of delegation. The benefit of a detailed advance directive, covering a range of treatment issues under a range of scenarios, is that it has the direct authority and statement of the person and may have great suasion as a practical matter. A problem, as indicated above, is that the detailed medical advance directive may not be able to predict the exact situation with which the person is confronted and a statement, which has a nice ring to it in the abstract, may not fit the circumstances.

There are similar issues as to whether Judicial grants of authority to a guardian with respect to medical decision making should be broad in general or whether it should be more narrow and specific.

The use of a broad, general delegation of health care decision making has the benefit of at least an appearance of simplicity, and certainly has the benefit of flexibility. The problem is that these health care proxies tend to fail, either because the agent does not have a clear enough idea of the person's wishes or is without the patience and skills to act as an advocate as against a system where health care is provided on a business as usual basis.

Certainly both concepts could be combined in a single document (a statement of advance directives with authority in the agent to enforce them and also to fill in the gaps). The question of which approach to use, the establishment of priority as between the specific instructions of the person and the later judgment of the agent should be clarified in the document. This balance may not be able to be achieved in general standard office forms. It may depend, on a case by case basis, upon the clarity of the person's wishes, an advance determination of the doctor's attitude toward treatment and care issues, and upon the potential advocacy skills of the agent.

- A. Personal Statement. Having a person write out a personal statement regarding health care objectives and end of life treatment preference may be useful:
 - 1. To help the person clarify his or her own thinking;
 - 2. For possible inclusion in an advance directive; and
 - 3. For guidance to the holder of a power of attorney.

- B. Five Wishes Project. There has been a remarkable and useful recent development in connection with advance directives. The Five Wishes Project, with Robert Woods Johnson Foundation funding and the assistance of the American Bar Association Commission on Legal Problems of the Elderly, has formalized for national use an advance directive project begun in Florida. It goes beyond the selection of a health care agent and provides for some instructions regarding treatment in connection with serious illnesses (going beyond the coverage of normal living will forms). In addition, it provides for statements of intent (wishes) regarding personal comfort, level of treatment by others (i.e., wishes for personal caring, not medical treatment), and a statement of wishes for "What I want my loved ones to know."

According to the ABA Commission, the Five Wishes format complies with the advance directive statutes in thirty-three states together with the District of Columbia.

A copy of the Five Wishes packet is attached as Exhibit C.

- C. Need for Collaboration. As suggested above, there has been difficulty in providing advance directives and guides to agents which are useful to the health care

providers. On a systemic level there is a need for collaborative efforts between counselors in the legal, planning, and medical communities to work together to determine the ground rules for more workable documents.

- D. Cardio Pulmonary Resuscitation. An advance directive or court order regarding the use or non-use of CPR is tricky. In institutional settings the "Do Not Resuscitate" order is effectuated by notation of a code in the person's chart or medical records. Most states have statutes designed to facilitate "Do Not Resuscitate" orders in a non-institutional setting.²

The common theme is that the decision making process is a medical one. The physician must review the situation and sign the form. This tends to fragment the process since the authorizing documents are normally prepared by an attorney in the estate planning context or by the court in connection with the grant of authority to a guardian.

IV. WHAT CAN BE DONE TO GAIN CONTROL AT THE PERSONAL LEVEL

A. Understanding Cultural Norms. Professional planners and counselors should become better acquainted with cultural norms and attitudes, particularly within minority groups, as to extent of treatment, withholding treatment, and end of life care. In this regard the Colorado Collective for Medical Decisions, organized in 1992 to address ethical issues in end of life care, sponsored discussion groups with members of the Hispanic and African-American communities. It was learned that many Hispanic families will involve extended relatives, including grandparents, uncles, aunts, and cousins, when there is a decision to be made at the end of life. Family will gather around the bedside of a dying relative in a show of support, respect, and love. It is important for health care providers to honor the Hispanic family's need to include the extended family when providing care to a loved one. The report from the African-American community was that there are strong elements of distrust and skepticism toward the medical community, based on historical reasons and perceptions of prejudice. It is clear, however, that family members want to receive information and make informed decisions. Medical information is often sought through an aunt, nurse, or friend with a medical background in cases where there is not a trusting relationship between the patient and doctor. Guide, Volume 2, Issue 3, Fall 1998/Winter 1999.

²The staff of the American Bar Association Commission on Legal Problems of the Elderly prepares summaries of state statutes dealing with health care decision making. Covered are the statutes on living wills; delegation; surrogate decision making; and do not resuscitate orders. A copy of a summary is attached as Exhibit D.

B. Understanding Grief as a Part of the Process of Death and Dying.

1. Education and Personal Understanding. The ongoing hard work of grief resolution has not only to do with coming to terms with dying and death but reaching some resolutions about life and relationships. When someone close to us dies we must cope with the problems that arise with the shock of sudden death or in illness with the distressing and confusing problems of care and anticipatory loss. This is burden enough. However, underlying these immediate issues are often other life long troublesome problems whose difficulty is also a part of a complicating factor for grief resolution. Whatever conflicts have not been settled in the course of life up to that point will emerge at the time of serious illness or death.

This is life. And life is complex. However, as human beings we have only so many emotions with which to respond to troubling life events. Complications arise when these emotions are either too intense or become stuck and are therefore prolonged.

First, consider the grief process as it operates very generally and then the indications that would suggest referral to a mental health professional.

Just as our bodies know how to die, our psyches know how to cope with trauma. We have built in psychological defense systems that kick in to help us when we need them. Elisabeth Kubler-Ross describes it as the beautiful way we are designed.

Unencumbered by complex circumstances, the psychic response to loss or anticipatory loss is a process that begins with the news of a distressing event and ends with more or less of a resolution that leads to acceptance. That is the goal. It is not the end of sorrow but rather enables us to put the event into what Victor Frankl calls a context of meaning. This context of meaning that brings some measure of resolution comes of the hard struggle with the mysteries that humans have been pondering since time began. It engages every part of us intellectually, spiritually, and emotionally. Although our habit is to think of the process as following a straight path from beginning to end, it is seldom so neat in grief resolution. We need to keep in mind that, as process, its route may be circuitous, lateral, or up and down and that its stages even may occur simultaneously within the course of a conversation.

In a moment life turns around and IS forever changed. An accident happens, a medical crisis occurs, a pathological report or surgery gives the bad news.

What happens?

Bereavement, grief, and mourning begin with an event of loss. Something, someone who has been a part of our life is or soon will be gone. The universal human experience of loss through death is a part of life throughout the life cycle and is thereby familiar. However, that doesn't ease our suffering with each new loss. The good news is that our capacity for suffering deeply is matched by our ability to recover in some way a renewed sense of life after

loss. It is this human condition of suffering loss and recovery that is the subject of this part of this paper.

Bereavement can be understood as the objective face of loss, a forceful separation that results in the loss of something once had and as such, tends to generate increased stress and vulnerability.

Grief is the response to bereavement. It is how we, as individuals, experience and feel about loss. It is important to understand that while there are common patterns for reacting to grief, each individual experiences grief in his or her own unique way. Some people show remarkable growth through the painful process of grief recovery. Others continue to struggle over time. To truly understand an individual's response to loss we must understand that person.³

It is also important to understand that the grieving experience is different depending on the relationship to the one lost. The death of a parent is experienced differently from the death of a spouse or the death of a child.

The grief response can be different in an individual over time. There is an increased vulnerability to loss as well as unique adaptive responses in later adult years as multiple losses accumulate. Suicide and sudden or unexpected death is experienced differently from anticipated death and loss. Traumatic and violent death in the form of murder, war, natural disaster and, more recently, terrorism create an especially intense and complicated grief experience.

Acute grief can place a person at risk physically as well as psychologically, lending support for viewing it as a physical disorder. Behavioral stresses such as improper nutrition, inadequate rest and self-neglect affect people physically. Insomnia, memory failure, absentmindedness, loss of concentration, repetitive behavior, shortness of breath, muscular weakness are some of the possible somatic reactions. The stress of grief can lead to neuroendocrine changes that interact with psychological responses.

When there are multiple losses, chronic stress reactions may lead to immunological changes that seriously affect health over time. Widows, and especially widowers, are at greater risk of dying after the death of a spouse. Younger adult widowers show a greater risk for mortality than elderly adults. The leading causes of death for widows and widowers are heart attack and cancer, the same as the rest of the population. However, the incidence of sudden and violent death are greater.

³Kramer, Kay and Herbert, *Conversations at Midnight -Coming to Terms with Death and Dying*, William Morrow and Co., New York, 1993, explores, in a thorough and personal way, how a husband and wife deal with a serious illness and impending death. The issues of death and dying are raised, coped with, and ultimately resolved.

Sorrow about the loss of a stillborn child, a companion who dies of AIDS, or the loss of a beloved pet are examples of disenfranchised grief in which the individual is not regarded as having the right to grieve fully. Hiding sorrow can delay and intensify it.

Children are often neglected when there is a death in the family. A parent coping with his or her own grief may not be available to attend to the emotional and physical needs of a child. Children with their own anxieties and sorrows feel isolated when related adults fail to recognize their distress signals. They may express their distress in ways that do not seem associated with their loss. Age at the time of bereavement is an important variable in how children grieve.

2. Theoretical Approaches. Taking into account the wide range of individual responses to bereavement there are several theoretical approaches to help us think about and understand grief in general.

The first theory was introduced by Sigmund Freud who was moved to develop his theory of grief work by his own sorrow as well as his observations of widespread grief throughout society after World War I. It was the first serious conceptualization to describe some of the characteristics of grief and give guidelines for helpful interventions. Freud emphasized the intrapsychic response to loss, how we attempt to deal with our thoughts and feelings.

Other theories call attention to interpersonal aspects of grief, how loss affects our relationships. Recent studies in attachment theory add to an understanding of loss from that perspective.

Task theories of grief enumerate certain tasks that must be accomplished in order to move through the grief experience and return to optimum feeling.

Recent theories emphasize interactive patterns among family members.

What are some of the grief responses to bereavement? Professional people, including lawyers and financial planners as well as medical personnel working with people experiencing grief will recognize some the reactions.

3. A Stage Theory Approach. For the purposes of this paper we will look at grief from the commonly used "stage theory" of grieving from Elisabeth Kubler-Ross's theory of dying.

The initial response to psychological trauma is shock. It is not happening. It isn't real It can't be true. The affect may range from extreme agitation to numbness. People may get very busy or may shut down and become immobilized. They may act as if nothing has happened. It is important to remember that it is still a reaction to shock. In general people

characteristically react in a manner that is consistent with the way they react to other stresses. Often a family attorney or financial planner may be involved during this initial phase.

Expressions of denial and bargaining may follow. Denial on some level for a short time is common, but when it persists and become entrenched for a long period of time and there are important decisions to be made, a referral to a therapist familiar with grief may help.

Bargaining may present as a need to get everything in order in the hope that by doing so death will be staved off somehow; or even conversely that by not doing anything the need for it will disappear. When reality sets in depression or anger may follow.

Depression may be marked by sadness, weeping, hopelessness, helplessness, forgetfulness, lack of interest, withdrawal from activities and social relations, poor concentration, physical symptoms such as sleeplessness or too much sleeping, and poor appetite or overeating. Depression may be the reason that phone calls are not returned. These times call for patience and understanding, persistence and gentle guidance when there are legal matters that need attention and action. If a person is unable to return to the usual daily routine after a reasonable amount of time again, therapy can be discussed.

Anger is one of the more obvious grief responses. It is normal for people to feel angry when they feel impotent or when they don't like what is happening to them or to someone they love. But sometimes it is hard for them to identify what it is that they are angry about and so their anger is frequently displaced. They may rage at God, at the gods, someone whom they love who is about to die or who has died, at doctors, other family members by whom they feel let down because they are not grieving the way they are, anyone who gets in their way or on their nerves, from an annoying neighbor to the guy in the car in front of them. They may even get angry with their attorney or financial planner or investment advisor.

Dealing with people in these situations requires empathetic skills and understanding and avoiding taking it personally. It helps to be able to sort out just what it is that the person is angry about. If it is something that is open to resolution they can be helped to find the resources they need to resolve the problem. If there is a relationship problem, it may be helpful to make a family therapy reference. If there is worry about coping, a grief therapist can be recommended. If there is fear about care needs or pain during the end of life illness a referral to hospice may be appropriate.

In time, after dealing with the pain of loss, people find moments of light in the darkness when spirits lift or when grief is moved aside. Although nothing will ever be the same again and fears and some anger and suffering about the loss remain, the person in bereavement begins to feel like he or she will make it. This movement means that healing is taking place, that life will go on. Acceptance and resolution more or less occur.

4. Support for the Bereaved. How can people who are facing death and who are bereaved be supported?

Our culture's prevailing attitudes toward death make the open expression of grief difficult. Jacqueline Kennedy's model of stoic grief following the death of her husband has had an enduring affect on mourning behavior in this country since the 1960s. It was interesting to note that the British would have none of the Queen's stoicism at the death of Princess Diana in 1997. In this country we expect people to return to work and to normal functioning almost immediately after the death of a family member.

Mourning gets in the way of our efficiency oriented culture. However, there have been gains in support for bereaved people despite our prevailing cultural denial of death. The most notable has been the hospice movement.

C. Education as to Available Resources.

_____ It should be useful for financial planners, lawyers, and health care professionals to be aware of the available community resources and care options:

1. Professionals qualified to provide counseling for grief, end of life illness, and chronic illness include:
 - i. Ministers, Priests, Rabbis and other spiritual advisors
 - ii. Licensed Pastoral Counselors
 - iii. Licensed Clinical Social Workers
 - iv. Psychologists
 - v. Psychiatrists
2. Organizations and Groups:
 - i. Hospices - see discussion below.
 - ii. Local division of the American Cancer Society.
 - iii. Professionally supervised grief groups.

3. Selected Book List:

Buock, *Dying Well - The Prospect for Growth at the End of Life*, Riverhead Books, New York, 1997. The author is President of the American Academy of Hospice and Palliative Medicine and Director of the Robert Wood Foundations. A series of essays discuss finding meaning and peace in dying.

Lattanzi-Licht, *The Hospice Choice - In Pursuit of a Peaceful Death*, Simon & Schuster, Inc., New York, 1998.

Neuland, *How We Die*, Knopf, New York, 1994. An account of the various diseases that take away life in an attempt to demythologize the process of dying.

D. The Hospice Model.

- _____ 1. History - The term "hospice" can be traced back to medieval times when it was used to describe a place of shelter and rest for poor, weary, or sick travelers on long journeys. Refuge and medical care was offered to pilgrims traveling to and from the Holy Land by monks and nuns who viewed service to one's neighbors as a sign of love and dedication. The typical medieval hospice was a blend of guest house and infirmary. Some grew into hospitals; others included infirmary-alms houses for the sick and helpless; hospice-hostels for passing pilgrims; and leper hospice hospitals. The notion that hospitality included care of mind and spirit as well as body came from these early beginnings. Through the centuries, as medicine moved from the sacred to the secular sphere, hospices were replaced by hospitals. But some religious nursing orders kept the holistic focus; however, the hospice concept disappeared until a little over thirty years ago.

It reemerged in England largely due to the efforts of Dame Cecily Saunders. Starting as a nurse, then as a medical social worker, and later as a physician, she became intensely involved in improving methods of pain control for seriously ill cancer patients. Dr. Saunders began to synthesize the centuries old hospice concept with modern palliative care techniques. In 1968 she opened the first hospice for specialized care for dying patients at St. Christopher's Hospice near London. It became the model for modern hospice care and has become an established part of the British health care system. The first hospice in the United States was founded in New Haven, Connecticut in 1974. Today there are over 2,600 programs in the United States and Puerto Rico. A National Hospice Organization was created to consolidate hospice purposes

"Hospice" today refers to the concept of humane and compassionate care for the dying and their loved ones which can be implemented in a variety of settings, patient's homes, hospitals, nursing homes, or free standing inpatient facilities.

2. Philosophy - Hospice is a special kind of care that is designed to offer sensitivity and support for people in the final phase of life. It seeks to enable patients to carry on an alert, pain-free life and to manage other symptoms so that their last days may be spent with quality and dignity.
3. What is Hospice - Hospice offers palliative and supportive care and services rather than curative treatment. Control of pain and symptoms enable patients to live more fully and comfortably. Unlike the traditional medical model which focuses on treatment and cure and the prolonging of life with all available technologies and considers death a failure to treatment, hospice recognizes the inevitability of death and, in the context of end of life, attempts to provide a holistic approach to care. An interdisciplinary team of professionals that includes physicians, nurses, social workers, and pastoral counselors, treats the medical, psychological, emotional, and spiritual needs of the patient and the family.

Hospice neither hastens nor postpones death but rather affirms life and regards dying as a normal process. The focus is on quality of life not length of life.

The entire family is regarded as the "unit of care". Families are included in decision making. Bereavement counseling is provided for the family after the patient has died.

Hospice help is available 24 hours a day for people in the home care program.

Hospice volunteers are available to help with a variety of practical chores.

Questions regarding hospice can be answered by contacting the National Hospice Organization:

1901 N. Moore Street, Suite 901
Arlington, Virginia 22209
703-243-59900
FAX: 703-525-5762
HTTP://www.nho.org
E-Mail: drsho@cais.com

V. WHAT CAN BE DONE TO GAIN CONTROL - SYSTEMIC ISSUES

During the past several years there has been a shift in thinking away from physician-assisted suicide to the societal underlying issue of better care for the chronically ill and the terminally ill.

- A. Living Will Background: Concerns for a "good" death or "death with dignity" are not new. The common use of living wills well prior to the enactment of the statutes providing ground rules for use reflects this concern.
- B. Physician-Assisted Suicide: Frustration with the inadequacies of end of life care have found recent expression in efforts around the country, both by legislative initiatives and in court cases, to authorize physician-assisted suicide.

The best known legislative effort has been the Oregon statute. Another model is a "Model State Act to Authorize and Regulate Physician-Assisted Suicide", 33 Harvard Journal on Legislation 1, 23-34 (1996), sometimes known as the Harvard Model Act.

The case law is testing the legal limits on physician-assisted suicide. The recent United States Supreme Court cases determined that there is no federally protected constitutional right to physician assistance in dying. The Court left open, however, the question of the extent of the rights of the states to legislate in the area. Such state legislation might either deny the right as a matter of public policy or might authorize assistance within limits.

- C. State Commissions: With physician assistance in dying apparently being referred back to state legislatures and courts there should be a particular interest in the analysis by state policy making advisory groups which have looked at the issues.
 - 1. The New York Commission on Life and the Law was the first of several state commissions, created to deal with biomedical ethics. Its major study report was in the area of physician-assisted suicide. While the members of the Commission did not develop common rationale, the Commission voted unanimously to oppose physician-assisted suicide. Two major points were: (1) The poor record of the medical profession in diagnosing and treating depression in terminally ill patients. Depression may be a normal affliction in the terminally ill, but once it is identified and treated the death-hastening ideation may be eliminated; and(2) the poor record of the medical profession in treating moderate to severe pain which may accompany an end of life illness.

The report of the New York Commission has done much to lead a shift in thinking away from physician-assisted suicide (a clumsy and limited solution) to the underlying issue of better care for the chronically ill and the terminally ill.

2. Similar Commissions have been created in the last several years:

Arizona's Governor's Commission on Aging and End Of Life Issues
Colorado Governor's Commission on Life and the Law
Hawaii's Blue Ribbon Panel on Living and Dying With Dignity
The Oregon Pain and Symptom Management Task Force
The Louisiana Advisory Committee on Pain of the State Board of
Medical Examiners
Maryland Attorney General J. Joseph Currin, Jr.'s Project on Care at
the End of Life
New York Attorney General Dennis Vacco's Commission on Quality
at the End of Life
Nevada Attorney General Frankie Sue Del Papa's Death with Dignity
and Caring Task Force⁴

The author (JRW) has been a member of the Colorado Governor's Commission on Life and the Law and has been a member of its committee on physician-assisted suicide. The experience of the committee and Commission has been that the more the issues are explored the less clear the solutions become.

D. Palliative Care: The Report of the New York Commission, noted above, highlighted one of the major problems in end of life care, that of the unwillingness or inability of health care providers to deal effectively with the moderate to severe pain which may accompany terminal illness. Too often it appears that the medical energies are directed toward illnesses which may be "cured" and dealing with pain, especially severe pain, is discouraging to the care providers. As discussed above, The Support Study reported that, in the hospital context, approximately fifty percent of terminally ill patients who ultimately died in the hospital reported moderate to severe pain.

The current literature, however, suggests that in virtually all cases pain can be treated so that the patient, perhaps with some dulling of cognition, can be kept comfortable. What then is the problem? It is submitted that too many physicians are simply not knowledgeable enough and

⁴ Charles P. Sabatino, Staff Report on "End-of-Life Case Legislative Directions - 1999"; American Bar Association Commission on Legal Problems of the Elderly.

skillful in this area. The interdisciplinary approach of hospice care, however, includes this knowledge and skill and pain management as one of its main features

Doctors have expressed several fears about effective pain control (which will almost certainly involve higher dosages of opiates than had been their practice).

1. Fear of federal prosecution of alleged violation of the federal control substance abuse laws;
2. Loss of license or other disciplinary action by state medical boards; and
3. Violation of medical ethical rules.

The ethical dialogue has thoroughly discussed the fact that the medication prescribed for pain relief may have the incidental effect of hastening death. This "double effect" has been considered by medical and religious ethicists, and the consensus seems to be, at least in the context of a final illness, that prescription of effective doses of pain medication is permissive.

A number of state legislatures have been active in the area of palliative care to provide protection for physicians who wish to prescribe heavier doses of pain medication. The Colorado experience is illustrative. In Colorado the Legislature established an Interdisciplinary Committee on Intractable Pain. The primary recommendations of the task force were then enacted:

- i. Providing insurance coverage of treatment for chronic pain and access of patients to such treatment.
- ii. Permitting pharmacists to dispense prescriptions without written authorization from the physician in emergency situations involving hospice patients as long as the dispensing is consistent with federal law on emergency prescriptions.
- iii. To ensure that licensed physicians will not be disciplined by the Board of Medical Examiners solely for prescribing controlled substances for patients with intractable pain.

Recent similar legislative activity includes the following:

1997 Ariz. Legis. Serv. Exec. Order 97-8 (West) 1997
Cal. Legis Serv. Ch. 839 (S.B. 402) (West)
1997 La. Sess. Law Serv. Act 1470 (H.B. 2492)
1997 Minn. Sess. Law Serv. Ch. 124 (S.F. 244)
1997 Ohio Laws File 46 (H.B. 187)
1997 Oregon Laws Ch. 567 (S.B. 1071)

1997 Rhode Island Laws Ch. 97-83 (97-S 836)
1997 Tex. Sess. Law Serv. Ch. 233 (H.B. 12)
1998 Mass. Legis. Serv. Ch. 104 (H.B. 4759)
1998 Virginia Senate Joint Resolutions 102, 164 and 165
1998 W. VA. Laws H.B. 4058 adding W.VA. Code § 30-3A-104.

There has been activity on the medical profession front. Boards of Medical Examiners have adopted new guidelines designed to give physicians a higher comfort level in prescribing drugs, even in high doses, to manage pain more efficiently

E. Coding Medical Records. Reimbursement from Medicaid and other third party providers is available only for medical procedures which are given a particular code in a patient's medical records. There are some pilot projects sponsored by HCFA to develop a code for palliative care as a diagnostic related group which will entitle health care providers to get reimbursement. Interestingly enough there has been some resistance to this from the hospice interests on the theory that this may tend to encourage the provision of palliative care in hospitals and other non-hospice type settings.

F. Better Funding for Hospice.⁵ Payment for hospice services is covered as a permanent benefit for those eligible for coverage under Medicare Part A. More than forty states have established hospice care as a covered service under their Medicaid programs and hospice benefits are covered for an estimated of eighty percent of people with employer sponsored health plans.

The Medicaid coverage is described as follows:

"The Medicare Hospice Benefit provides coverage of those hospice services necessary for palliation, such as non-curative medical and support services, for a beneficiary's terminal illness. These services must be contained within the hospice's plan of care. The beneficiary continues to use his own physician, who becomes part of the hospice team. The attending physician continues to be paid directly by Medicare if the beneficiary is eligible for physician services under Medicare Part B insurance.

"Medicare pays the hospice directly a specified rate dependent upon the type of care given each day. The only cost of those services to the beneficiary is limited cost-sharing for out-patient drugs and inpatient respite care. The Medicare Hospice Benefit requires that the hospice provide bereavement services; however, no payments are made to the hospice program by Medicare for these services. In

⁵The following material is summarized and quoted from *The Hospice Choice - In Pursuit of a Peaceful Death* by Marcia Lattanzi-Licht (Fireside Books, Simon & Schuster, 1998).

another departure from traditional Medicare benefits, the hospice is required to provide and document the use of volunteers to augment its services.

"Currently the hospice benefit is divided into multiple benefit periods. The first two benefit periods are ninety days; there is then an unlimited number of sixty-day periods. The benefit periods may be used consecutively, or not.

"To be eligible for the Medicare Hospice Benefit, a beneficiary must be seriously ill, with a prognosis of six months or less "if the disease runs its normal course." The attending physician and the hospice's medical director must agree on the prognosis for the patient to be initially certified as eligible for the benefit. The hospice medical director must "recertify" the prognosis of the patient at the beginning of subsequent periods.

"A beneficiary may choose to leave the Medicare Hospice Benefit and return to standard Medicare benefits to seek curative care or for other reasons; however, if the beneficiary revokes their benefit during a benefit period the beneficiary will forfeit whatever days are left in that particular benefit period, although they will be able to access additional benefit periods if they choose to again elect hospice care in the future. It is important for the beneficiary to understand that standard Medicare benefits provide less coverage than the service-rich hospice benefit, when used for care of a terminal illness. For example, under standard Medicare the patient is responsible for the full cost of outpatient drugs. Additionally, the beneficiary is responsible for Medicare's usual deductible and coinsurance amounts. A beneficiary receiving hospice care under Medicare may also change hospice programs once each benefit period.

"When choosing the Medicare Hospice Benefit, the patient or the patient's legal representative must receive and sign an election form choosing hospice care. This document is essentially an "informed consent", form required of all hospice patients as it describes the nature of hospice services and provides the basis for documenting that the beneficiary chose hospice care. It is particularly important that Medicare beneficiaries complete this document, because when choosing the Medicare Hospice Benefit the beneficiary waives the right to standard Medicare benefits for treatments associated with the terminal illness." pp. 51-53.

Informal interviews by author JRW with hospice administrators disclose the following: While Medicare covers nursing, pharmacy, clergy, social work, and durable medical equipment costs, the problem is that room and board in a facility (which by definition excludes home hospice care) is not covered unless the patient also has Medicaid. The problem is similar to lack of Medicare coverage for room and board portion of nursing home care. Similarly, in connection with most private plans (including HMO coverage), while most of the medical costs are covered, the room and board is not covered.

The hospice administrators feel that the six-month qualification limitation seems arbitrary and also that the daily reimbursement levels authorized by Medicare to hospice are too low and often do not really cover the costs of the services. This is a problem even for the great majority of hospices which operate on a non-profit basis and seek only to cover their costs.

Hospice has become a "hot" item and many facilities, including hospitals, nursing homes, and boarding care homes are styling themselves as hospices or providing a hospice unit. Some of these may simply provide palliative care, but may not embody the holistic hospice approach of dealing with the family unit as a whole and assisting with bereavement issues. Accordingly, it is suggested that a careful inquiry should be made to learn:

- i. The philosophy of the program.
- ii. The breath of its staffing and program.
- iii. The extent of insurance coverage.
- iv. Whether the program is licensed by the state and certified by Medicare.

G. Interdisciplinary Efforts. The Support Study, discussed above, noted a number of systemic problems with the provision of end of life care, including lack of respect for advance directives. The Robert Wood Johnson Foundation, funder of The Support Study, is funding a series of follow up projects to deal with the issues. Pilot project funding has been given to several interdisciplinary efforts at the state level.

H. Managed Care - The Great Unknown. How end of life care issues will be treated in the context of managed care is an open question. On the one hand there are concerns that cost cutting will limit the improvements that need to be made in the area of palliative care. On the other hand there is the prospect of making more comprehensive hospice type care available as a standard procedure. A related question is how can HMOs strategically support increased palliative care efforts without appearing to favor a reduction in the quality of care. The perception may be that the shift from aggressive treatment in terminal illness to comfort care is simply cost driven. The risk of uneven treatments of the vulnerable populations (minorities, the elderly, the disabled) cannot be dismissed. The fact remains, however, that hospice type care, in addition to its other virtues, is cost effective.

VI. CONCLUSION

Frustrations with our lack of control, as individuals, over the process of dying and death is becoming more widespread. The SUPPORT theory verified the anecdotal evidence that the traditional medical system has failed, in connection with end of life care, in at least two important areas:

1. Respecting individual autonomy, and
2. Failing to diagnose and treat pain

Individuals can gain control over their dying and death by becoming better educated and understanding the shortcomings of the existing medical model and by understanding that death is part of the natural process which can be planned for and which can be made more humane by insisting on palliative care including hospice care.

The narrower estate planning framework can be improved by better drafting and utilization of advance directives.

The broad, societal framework can be improved by aggressive, interdisciplinary approaches to palliative care and other end of life care issues and by the improvement of state laws and state medical commission regulations designed to encourage the more effective use of palliative care.

"Case Study #1": Assume that recently you met with new clients, an older man and his wife. He needed help with his estate and financial planning in light of a very recent medical diagnosis of inoperable cancer in one of the soft tissue organs. There were a number of issues to be dealt with including disposition of business interests, asset allocation, review of investments, evaluation of Social Security and other benefits, out-of-state real estate, a family situation involving a potentially hostile son by a prior marriage, a series of charitable objectives and the like.

Dealing under the pressures of time a team of professionals made investment adjustments, and created a revocable trust to deal with the out-of-state real estate, created separate health care and property management powers of attorney, created a revocable trust with dispositive provisions which provided both marital deduction and charitable deduction protection, and devised strategies in dealing with the son, including an anti-contest clause in the trust and pourover will.

The client died a month or so later. The estate plan was successful and the financial plan was implemented. Ancillary administration of business and residential real estate was avoided; there were sufficient trustee powers to facilitate the sale of the business; the tax objectives in connection with protection of the wife and recognition of charitable interests were achieved; and a contest brought by the son was successfully defended. An investment plan was also in place.

Assume the following: One morning, while visiting with the client at his residence, he takes you to one side following the conduct of your "business." He confided to you that the abdominal pain which he was experiencing was almost more than he could stand and that it was extremely difficult for both him and his wife to deal with. He said that he knew that he was dying and wanted your assistance in doing whatever was necessary to help him terminate his life just as soon as the estate planning had been completed.

What should your response be? Recall that even assisting a suicide is a criminal act in virtually every state.

My sense was that his real concern was not his life termination per se, but rather his perception of death as a way to end the suffering from his pain. My response was to share an experience with him regarding the benefits of pain management in a home hospice context. I gave him the name of the local hospice organization together with its phone number. That afternoon a call was made to hospice and at my next visit, which was several days later, I found that he was being cared for at home by a hospice team and that his pain was under control. He died a "natural" death at home under hospice care.

"Case Study #2": You refer a client to an attorney for estate planning and, as a trust advisor, are asked by the client to be involved in each step of the process. You are witness to the execution of a will and irrevocable life insurance for your client. You also witness the signing of a living will, durable property power of attorney, and a health care power of attorney.

With regard to the living will and health care power of attorney:

1. What discussion should there be with the client regarding their use?
2. What instructions should be provided re circulation of the documents?
3. What discussion should there be with the client and his or her agents and family?
4. The client asks you to be agent under both the financial and health care powers of attorney:
 - (a) Can and would you accept?
 - (b) If so, what more would you want to know?

"Case Study #3": You get a call from one of your oldest and best clients. She advises you that she has just received word from her physician that she has a serious kind of cancer and has, in all likelihood a limited life expectancy of three to four months. She wonders if her investments are in order and whether the titling of her investments is consistent with the estate plan under her will. You express your concern and tell her that you will check the file to review these matters.

You are reminded that there is a plan in place to do a partial liquidation of some assets together with reinvestment in other assets. This is no longer appropriate since the capital gains involved can be avoided by retaining them and obtaining a step-up in basis at date of death.

Also, you are aware that a change should be recommended to acknowledge the birth of an additional grandchild.

You provide your recommendations in a letter.

You do not hear from your client. You follow up once by writing and make a couple of calls which do not get returned.

When you finally get through to your client she is vague about things and puts you off.

What is going on? What should you do?

"Case Study #4": ____ You have assisted with estate planning for a husband and wife. The husband dies unexpectedly in an accident. The husband's will has a fairly typical plan of disposition with a marital trust and a family trust. You are designated a co-personal representative with the surviving spouse.

At the initial meeting with the lawyer, the spouse seems to have difficulty in focusing on the basic difference between formal and informal probate and supervised versus unsupervised administration. Finally you decide on informal probate and yet when you have a meeting to sign the application for informal probate and acceptance of appointment, again the spouse is indecisive, questioning, and appears not to remember the prior discussions.

Once the estate is opened a letter is sent out to you and the spouse explaining the personal representatives' responsibilities and noting the critical dates on the tickler system. You find that it is difficult to assign and allocate responsibility to the spouse for collection of asset information both for the probate inventory and for the federal estate tax return. The spouse wants to do as much as possible herself, but is forgetful and does not follow through.

The spouse missed a couple of office meetings or called at the last minute to reschedule them.

You find that the spouse seems angry with you when you provide gentle reminders about deadlines and lack of progress.

Somewhere during this process you find out that the spouse, in looking through the decedent's papers, has found evidence that the decedent was having a relationship with another woman. What is going on? What can you do to keep the process of estate administration on track and to protecting yourself?