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DO NOT RESUSCITATE, DO NO HARM, DO NOT STAND IDLY BY:

A Biomedical Ethical and Jewish Bioethical Discussion of
Do Not Resuscitate Orders

by

John L. Bush

Thesis Submitted in Partial Fulfillment
of the Requirements for Ordination

Hebrew Union College- Jewish Institute of Religion

Cincinnati, Ohio

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Do Not Resuscitate, Do No Harm, Do Not Stand Idly By:
A Biomedical Ethical and Jewish Bioethical Discussion of
Do Not Resuscitate Orders

John L. Bush

The purpose of this thesis is to provide a survey of cases and materials concerning the implementation of Do Not Resuscitate Orders and to develop a framework for analyzing and resolving conflicts that arise with their use. The thesis begins with a history of the development of resuscitative therapies from their initially limited use to their status today as the prescribed treatment in all cardiac or pulmonary arrests unless limited by a Do Not Resuscitate Order or Advance Care Directive.

In chapter two, selected cases and policies are examined to illustrate problems that arise with the usage of such orders and advance care directives. Questions are raised that are then addressed in the remainder of the thesis.

In chapter three, utilitarian theories and the so-called deontological or duty-based theories are examined. The historical and philosophical roots of bioethics are reviewed to enable the reader to see how a bioethicist may help others deal with Do Not Resuscitate order cases and conflicts. Bioethical terms and concepts are defined and explained.

Chapter four provides a survey of different religious approaches to bioethical questions. These include a survey of Protestant, Roman Catholic, and Jewish approaches to bioethics. The Jewish materials include a survey of approaches from traditional to more liberal approaches. The author's own liberal approach is provided. The thesis also distinguishes between a bioethic based upon rights and one based upon duties, and presents a case for the latter. The role of a bioethicist working within a particular faith

tradition is distinguished from that of the secular bioethicist. The role of the clergy in the end-of-life situation is also discussed.

In the concluding chapter of the thesis, the author presents his own model for analyzing bioethical matters. This model incorporates elements of bioethical theory as well as elements from Jewish traditional approaches to these questions. Finally, the author lays out questions that should be asked, procedures and guidelines that should be followed, and recommends who should be involved in the decision-making process. The author also identifies approaches to these issues that he believes to be illegitimate.

In general, the author maintains that a liberal Jewish approach to these end-of-life questions provides a useful structure for analyzing biomedical dilemmas. The author describes what he learned in the process of writing the thesis and developing such a framework.

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PREFACE

The issues raised in this thesis are difficult ones to deal with at best. Death and dying are not easy matters to discuss. The discussion of Do Not Resuscitate orders, bioethics, and end-of-life issues is a daunting task because of the special language involved and the concepts and theories that form the basis for that discussion. I have attempted in this paper to keep in mind the three groups of probable readers-- the medical care provider, the clergyperson who might seek guidance within these pages, and the lay reader. Each reading audience requires a different level of discussion. I have attempted to make the language accessible by explaining terms and concepts either in footnotes or within the text itself.

When I began to do the research and conduct the interviews I quickly became aware that the scope of the proposal that I had submitted to my thesis advisor was ambitious at best, and impossible to achieve at worst. Dr. Terry Perlin advised me as such when he read the proposal and suggested that it sounded like a good proposal for a lifetime of work rather than a thesis proposal. He was correct in that I believe work in this field will be a major part of my rabbinate.

Dr. Barry S. Kogan, Rabbi u'mori (my master and teacher) and my thesis advisor, saw the mountain that I sought to climb, but he served as a true and sure guide on my journey. His love of Philosophy, Judaism, and his students is a great blessing not only for me but also for all who come within the circle of his great light. That the end result of this project is in any way lacking is no fault of his. He has been unwavering in his support and direction.

I am not a medically trained person. The issues that are raised in this paper are complex. Throughout the process of researching the materials for the thesis I had the support of many physicians, nurses, chaplains, and specialists in different fields. All were patient with this "non-doctor" and provided guidance through the medical maze. Among these, I must give a special acknowledgement to my supervisor and teacher, Rabbi Julie Schwartz, who suggested in typical Jewish fashion when I raised questions about death and dying issues, "Go read a book!" From that book, I moved on into a broad survey and an in-depth look at the issues involved. The resulting work is not the last word in this area. It is only a first word on a complex subject. It is my hope that the reader will be able to use the survey materials and the proposed model to help them deal with these difficult decisions when they must do so.

I also wish to acknowledge the support that I have received throughout this thesis project from my classmates. I believe that no one in the history of the Hebrew Union College-Jewish Institute of Religion has had a better class with whom to grow and learn. Each of my classmates took time to help me work through questions and issues that I faced even though they each had their own thesis project that they had to complete.

I must also acknowledge the help, guidance, and sustenance that Dr. Steven Weaver provided to me both before my first year studying in Israel and in the years since. He elevates the term "friend" to new heights.

My children-if they may still be called that-Jennifer and Ben, have my gratitude for their great patience and understanding as I embarked on the path to become a rabbi. They are truly a blessing to me. They have taught me immeasurable and valuable lessons as they have grown up.

I also must acknowledge the influence of Ryan Schick throughout this thesis. He has been in my mind constantly since I first thought about writing on this subject. Ryan was the son of a law school classmate of mine who lost his life at the age of six in an automobile accident. His parents, Bill and Leslie, struggled with the decisions and issues raised in this paper. They chose to donate Ryan's organs for transplantation when it became clear that he could never recover from his injuries. In his death, he gave a second chance for life to several recipients of his vital organs and tissue. If the memory of the righteous is for a blessing, may his memory continue to bless us and those whom he touched.

Most of all I would like to thank my wife, Joanna. She has been an anchor and an inspiration to me as I worked my way through the initial questions, through the times when I seemed overwhelmed in the research, and enabled me to keep the goal in sight. Throughout the many years of our marriage, as she has watched me try new endeavors, she has been unfailing in her support and love. If, as our tradition teaches, God has been busy making matches since the creation of the world, the day that our match was sealed was surely one of the greatest ones since the creation of the world.

John Louis Bush
2 March 1998
4 Adar 5758

CHAPTER ONE

INTRODUCTION AND OVERVIEW OF RESUSCITATION ISSUES

Introduction

Up until the middle of the twentieth century, if a person's heart stopped or the individual stopped breathing, he or she was considered to be dead. But as Robert Weir notes, medical technology has given us the ability to circumvent this traditional definition of death, which he characterizes as "...the irreversible cessation of spontaneous respiration and heartbeat."¹ The definition of death as we reach the end of the twentieth century is very much in flux. As we have moved from the simple definition stated above to one driven by changing medicine and technology, we have attempted to redefine death variously as cessation of brain stem activity, absence of higher brain activity, and for some, merely the absence of cognitive abilities.

What lies behind the need to redefine death are questions and issues that have pragmatic implications and still others that seem to reflect a societal need to face a process of dying that one writer claims has been made worse by modern medicine.² Whether one agrees with that assessment of dying and its relationship to modern medicine or not, there can be no doubt that death has become complicated. Whether one is struggling with the reality of an elderly parent residing in a long-term care facility or one is attempting to predetermine the circumstances of one's own death, medical and technological advances have made the decision-making process more difficult.

During the summer of 1996, I worked as a chaplain intern in a Clinical Pastoral Education program in Cincinnati, Ohio. As I confronted death and dying and worked with families in a hospital setting, questions concerning death began to form in my mind: "Under what circumstances should a person be prevented from dying?" and "Under what circumstances should a person be allowed to die?" I addressed these issues to my supervisor who suggested that I read the book: How We Die, by Dr. Sherwin Nuland. In that book, Dr. Nuland describes the process of dying while leaving the ethical and moral questions faced at the time of death largely unexamined. As I finished the program, I realized more and more that I did not have satisfactory answers to questions raised by end-of-life situations. This thesis is an attempt to address some of the questions about "what to do" and "how to decide" that arise in such circumstances.

In addition to these questions which arose for me I began to see evidence of dilemmas that could arise in these settings. By looking at the dilemmas faced by doctors and families every day concerning both the implementation of treatments and the termination of those treatments under "Do Not Resuscitate Orders (DNRs)," I intend to present a discussion of end-of-life issues. Through a discussion of these problems from both a general and bioethical perspective, I will undertake to define some of the key terminology used when talking about death. Concepts such as "time of death," "healing," "intervention," "treatment," "patient autonomy," "patient's rights," "best interest of the patient," etc. are all subject to differing interpretations, and a clarification of such terms and their applicability will be helpful when these terms are used in the materials presented.

Case studies and anecdotal information about the decision-making process have been gathered from hospital personnel, medical ethicists, medical societies and organizations, hospices, chaplains, and others involved in DNR decisions. I have conducted interviews with administrators and ethics committee members in order to obtain anecdotal information, statistics, and guidelines that have been established for implementing DNR orders and directives. These case study materials will be presented in chapter two.

In chapter three, I describe the role of general bioethics in addressing the dilemmas that arise under DNRs and examine how the general ethicist applies a general framework of ethical concepts to the practical questions at hand. Then, in chapter four, I compare and contrast how an ethicist who works within a particular moral framework such as Judaism might approach these same issues. My own moral framework throughout this thesis is that of a liberal, Reform Jew. Thus, my own particular approach to the ethical questions raised will be within that liberal, Jewish framework. In the interest of addressing the issues on a broader scope, I also present other particularistic, Jewish approaches to the DNR question. Admittedly, Jewish approaches to resolving such issues cover a spectrum from the liberal to the halachic. Therefore, I will examine viewpoints representing Reform, Conservative, and Orthodox treatment of the issues.

In the concluding section of the thesis I will review the problems posed by the case studies, review who, in general, was involved in making the decisions with regard to terminating treatment or withholding the same, and on what grounds, and use the examples involved in resolving these problems to develop a framework for addressing similar bioethical dilemmas. This framework will include proposed answers to the

following questions: What questions should be asked in these settings? What procedures should be followed? Who should be involved in the decision-making process? What approaches to these questions would be recommended for dealing with these issues? What approaches might be illegitimate, and why? I will make specific recommendations based upon my findings. We will begin our discussion of the issues involved with a preliminary discussion of the medical terms and framework for the end-of-life issues^{*} raised by the cases presented in chapter two.

Defining Death

Robert Morrison and others have argued that death is not an event but a process.³ By viewing death this way one may more readily accept death since it is viewed as a long-term process – happening gradually over time. If death is an event, one may attempt to delay the event or have a more difficult time accepting the reality of such a sudden event. According to Morrison's approach, the end of a **process** is easier to accept and define than an **event** that many are reluctant to accept. However, until such time as society at large accepts his views that death is a process rather than an event, we must address the decisions that are made concerning death, and to do this, we must know when death has occurred.

One of the most important reasons for being able to determine when death has occurred is knowing when to terminate medical treatment of the patient. Physicians practice their medical arts under ethical guidelines that impose upon them the duty to heal the patients that they attend to. When a patient dies, the physician is no longer obligated

to treat the patient. There is no further duty to heal. Therefore, knowing when the sick person has died becomes important in deciding when to terminate treatment. The traditional definition of death was based upon the cessation of breathing and the cessation of heartbeat. Once the physician witnessed these signs He could terminate any medical treatment that he was providing. However, with the medical advances made during this century, the clear line between life and death became blurred.

Now with the ability to sustain a heartbeat for an indefinite period of time, and with the ability to keep a patient breathing through use of a ventilator, these traditional signs of death are inadequate. Now the physician must determine that a patient is dead by other criteria. She must do so not only to know when to stop treatment from a medical standpoint, she must be aware of allocating the healthcare resources in a responsible fashion. The physician will also seek to fix the time of death so as to avoid legal liability that might arise if the healthcare givers terminate treatment prematurely. In order to assist physicians in determining the time of death, the Harvard Medical School developed a set of criteria in 1968.⁴ These criteria are commonly said to define "brain death," and suggest to the physician when it is permissible to withdraw treatment. Since this initial description of brain death other definitions have been suggested.

Sherwin Nuland has described the tests for brain death as: (1) the loss of all reflexes, (2) the lack of any response to vigorous external stimuli, and (3) the absence of electrical brain activity as tested by electroencephalogram over a fixed period of time. Once these criteria have been met, the physician may cease providing medical treatment to the patient.⁵

Another important reason for determining the time of death of the patient is the issue of organ donation and transplantation. From the standpoint of the donor, the concern is that the removal of the donor's organs not be carried out before the patient has, in fact, died. Since the removal of vital organs such as the liver and heart would certainly lead to the death of the donor, the medical team must be certain that the donor has been pronounced dead before the organs are removed. Protocols have been developed which require two doctors not connected with the transplant team to independently verify that the donor is in fact dead.⁶ From the viewpoint of the recipient the organs, tissue, etc. being donated to him or her must still be viable, so the removal must be performed expeditiously. Where the heart is concerned viability means that the heartbeat and circulation must be maintained even after the donor is pronounced dead.⁷ This aspect has profound implications both with regard to the concept of resuscitation and with regard to those theological and ethical systems which prohibit any action which hastens death. Where the classic definition of death included the cessation of the heartbeat, can someone be declared "dead" whose heart still beats, albeit by mechanical means? With this question in mind we will now focus our attention to the process of resuscitation itself.

Describing Cardiopulmonary Resuscitation

The term "resuscitation" means many different things in many different settings. In the medical setting itself the term may include various different types of therapy used for many different types of medical conditions. In this paper we will focus on the procedure known as cardio-pulmonary resuscitation, (CPR). I will attempt through a

brief survey of the literature to describe the scope of treatment that comes under this term.⁸

"Advanced CPR involves higher technology and must be administered by trained and experienced personnel. It involves three types of treatments: (1). Drugs, usually given intravenously to try to slow an erratic rhythm or to restart the heart; (2). Electric shock, often necessary to restart the heart; (3). Endotracheal intubation and mechanical ventilation for artificial respiration."⁹ This description presents a summary of the range of procedures that may be used in a resuscitative intervention. It does not convey the awe-inspiring reality of what may take place when the procedure is successful, which another writer has described as: "... a dramatic intervention; it actually brings the patient back to life after the traditional signs of death have already appeared."¹⁰ It is likewise inspiring to consider that the possibility of this type of resuscitation did not exist as recently as forty years ago. A review of the creation of the procedure and its development over the past thirty-seven years will assist us in our analysis of issues that arise concerning resuscitation procedures.

In 1960 a group of physicians reported in the Journal of the American Medical Association, (JAMA), the success that they had achieved in resuscitating patients who had gone into cardiac arrest. The method employed was described as closed chest pulmonary resuscitation.¹¹ Various forms of resuscitation had been described for centuries, but this technique described a method by which circulation could be restored to the heart muscle and breathing could be reestablished without opening the chest of the patient.¹² The procedure used was administered to relatively healthy individuals who suffered cardiac arrest as a result of reaction to medications, surgery or who had suffered

sudden and traumatic injury. It is important to note that the subjects were in the hospital setting when the arrest occurred, and thus, cardiopulmonary resuscitation could be administered immediately.¹³ Kouwenhoven and the other physicians, who reported the results of their resuscitation efforts in the article in JAMA, had read of experiments performed on animal subjects who had been resuscitated.¹⁴ They reasoned by analogy, that a similar procedure might work with human subjects as well. In the article they described the procedure as requiring only the pressure of human hands exerted on the sternum in a rapid fashion, some sixty times a minute. Through the chest compression, blood flow and respiratory function could be maintained or restored. If more than one person were available, the second person would concentrate on breathing air into the lungs of the patient.¹⁵

In this initial paper describing CPR techniques, a long-term survival rate of 70% (14 of 20 patients) was reported. This high rate has never been duplicated. Papers since have described survival to discharge rates of 5 to 23 percent. Most papers report less than 15%.¹⁶ How do we explain the discrepancy between the first reports and these latter success rates? What was lost in the discussion and the proliferating use of CPR was that the success in the initial medical cases described was largely a function of the type of arrest that the patient was encountering. The type of arrest in those cases primarily consisted of ventricular fibrillation that responded favorably to the CPR intervention. Nevertheless, the high success rate described in the first paper on the subject led others to inquire whether they might use the procedure in their medical practices.

"Although CPR was initially used selectively on patients with acute illness - mainly because those trained in its use were cardiologists, anesthesiologists, and

surgeons, whose patients tended to have ... reversible causes of cardiac arrest ... the increased training of nurses and physicians in the techniques and the development of 'code teams' rapidly expanded the patient population undergoing CPR."¹⁷ Within seven years of the appearance of the article in JAMA, the American Medical Association was recommending that all physicians obtain training in the procedures. The American Heart Association in 1974 granted its approval to the procedure fourteen years after its initial description. Over time protocols were developed which called for CPR to be begun on any patient who went into cardiac arrest regardless of the underlying illness. Since these protocols applied across the board, CPR was instituted on patients for whom CPR was, in the opinion of some, inadvisable. It became the standard practice to attempt CPR on any patient who had a cardiac arrest regardless of the underlying illness.¹⁸

This broad ranging use of the procedure took the technique far beyond the setting in which it was originally attempted. "In 1983, the President's Commission on Biomedical Ethics rejected the notion that a physician could withhold ...CPR without a patient's consent and established firmly the standard of presumption favoring resuscitation... Fear of litigation for withholding this standard of care ... further reinforced the indiscriminate use of CPR."¹⁹ Some blamed an over-enthusiastic and uncritical media for spreading the use of the technique beyond its initial setting.²⁰ In any case, demand for the procedure, government decree, and refinement of the original techniques continued to spread its implementation to ever-greater populations of potential candidates. As a result, some physicians began to call for limitations on use of the procedure.²¹ Some of them called for a return to the status quo before the adoption of the procedure. Under this approach the procedure would not be instituted in every case in

which arrest occurred, but only in certain well-defined circumstances. Whether this is the proper approach to determining who is an appropriate candidate for CPR is the subject of continuing debate.²² The answer depends not only upon medical judgments but upon philosophical questions as well. These issues will be discussed in a later section of this thesis. For now, we will turn our attention to the use of CPR in different settings. Since we have raised the issue of the appropriateness of utilizing the technique in situations beyond its initial scope, we must look at how the procedure is actually used in different settings.

The Use of CPR in Different Settings

The use of CPR procedures varies in different settings and circumstances. Some aspects are universal. Some are not. In order to restore breathing and a regular heartbeat to a person, CPR must be performed within three minutes of the respiratory and cardiac arrest. The longer one waits beyond this window of optimal treatment, the greater the risk that the rescue attempt will not be successful and that damage to the brain will occur.²³ In all of the settings where CPR attempts are made the need for a rapid response is critical. However, the area of pre-hospital administration is the most critical. This is because the provider of the treatment is usually an Emergency Medical Squad, (EMS), which has been called to the scene by someone at the scene of the cardiac and respiratory arrest. The time that lapses between the call and the start of the CPR procedures is crucial when considered in terms of the timeframe of three minutes. Fortunately, with the

emergency dialing system of "911" and with the advance training that EMS squads receive, many resuscitation attempts in the field are successful.

In hospitals, resuscitation efforts are usually begun earlier than they might be in the field because of the availability of trained staff, equipment, pharmacological treatments, etc. The training which personnel receive to serve as part of a "code team," that is a group of medical personnel trained to respond to an alert that a patient has "coded" or gone into cardiac arrest. Further, since the odds are greater in a hospital that the arrest will be witnessed by someone on the healthcare staff is a crucial factor in beginning treatment in a timely fashion. In the emergency department of the hospital, personnel with the necessary equipment and training is always immediately at hand. Thus, resuscitative efforts may be begun instantly when an arrest occurs.

Similarly, if a patient goes into cardiac or respiratory failure in the operating room, the personnel have the training, equipment, and medications necessary to begin the CPR techniques immediately. Yet the treatment provided by the medical team in the operating room has its own risks beyond those encountered in the rest of the hospital. Resuscitation plays a different role in the operating room.²⁴ Indeed, in open chest surgery, resuscitation is a necessary part of the treatment protocol following surgery.

The areas of the hospital known as intensive care units (ICUs), critical care units (CCUs), skilled nursing units (SNFs, or "Sniff" Units), etc. also provide a high level of attention to the patient who is at a greater risk of going into cardiac or respiratory arrest, and therefore have both the equipment and trained personnel readily available to begin CPR procedures when required. Since the time from the onset of the arrest to the time of beginning the resuscitation attempts is so critical, these areas of the hospital provide the

best opportunities for successful outcomes from a timing standpoint. If the patient is in a more severe medical situation or suffering from an underlying medical condition that will not respond to the CPR procedures, successful outcomes may be fewer when the attempts are made.

Once one moves beyond the hospital setting, one finds that resuscitation attempts may also be made in the context of long-term care facilities such as nursing homes and senior care facilities.²⁵ Since the average age of the residents of these facilities is greater than that of the population at large, there are situations where resuscitation attempts may not be made. For example, if the vigorous chest massage procedure were attempted on a patient who is frail, with poor bone mass, or who is well advanced in years, the risks are high that the attempt at resuscitation will result in the death of the patient because of a broken sternum, damage to the heart muscle itself, or other complicating factors. Because of this risk, resuscitation attempts in the long-term care facility will usually involve a greater use of defibrillator equipment and medication to restore a regular heartbeat rather than a chest massage. I will discuss CPR and treatment options in a long-term care facility in greater detail later.

Cardiopulmonary resuscitation is different in a hospice than in other settings where the procedure may be utilized. The first critical distinction is that a hospice is an organization whose purpose and function is to provide palliative care to terminally ill patients. Thus, when a patient is admitted to a hospice facility or is enrolled in a home hospice care program, it is understood that the patient is at the end of life and that the main goals of the caregivers are to help the patient and the patient's family prepare for death. Thus, to admit a patient who has expressed a wish to have CPR performed on him

should he cease respiration or cardiac function seems to be counterintuitive to the role of hospice. In interviewing a particular hospice worker concerning the use of CPR, I asked her: "Should hospices be permitted to refuse admitting terminally ill patients who still wish to be resuscitated?" The response was that hospices that receive funds from Medicare or Medicaid may not refuse admission to such a patient.²⁶

While a hospice may not refuse admission to a hospice program to patients who wish resuscitative measures to be attempted should they go into arrest, hospice personnel will not handle the resuscitation, and the patient will be required to pay for the treatment at his or her own expense and must make their own arrangements to have a CPR team available to institute such measures. The philosophy of a hospice program is to not artificially hasten death nor to prolong the act or process of dying. Since administering CPR to a dying patient may in fact prolong the act of dying, hospice programs do not advocate nor provide CPR care. However, it should be emphasized that hospice care personnel do discuss the patient's request for CPR as part of their counseling program.²⁷ Hospice programs are designed to address a full range of issues surrounding death. Unfortunately, in these days of cost-containment and capitation payment arrangements, hospice is becoming involved later and later in the dying process. According to an interview with one hospice worker, the hospice programs are no longer becoming involved six months to a year before the death of the patient. Today the norm is to take the terminally ill patient in a day or two before the death of the patient. In some instances, hospice care workers have described to me the phenomenon of having patients die in the elevator on the way to the hospice program. Needless to say, advance care

planning or discussion of resuscitation options is meaningless at that point. Similarly, for many, the awareness of hospice programs comes too late, if at all.²⁸

Like the hospice situation, there are other circumstances where the use of CPR may be inappropriate or otherwise not instituted. These may be categorized as limitations based upon the circumstances and location in which the arrest occurs and restrictions that are placed upon the use of CPR because of advance directives to make no attempt. We will look at these more closely in the next section.

Limitations on the Use of CPR

Among the many categories of situations where CPR may be limited, one of the most important is the situation in which a medical order has been written that such procedures should not be attempted. This order, called a "Do Not Resuscitate Order," (DNR), is written by a family doctor or attending physician and is placed with the patient's medical chart or records just as any other medical order is handled. However, there are critical differences involved in this type of order. It is an order written by a medical doctor, yet the direction for the order may be from the patient himself. As one author states it, "...although the DNR order is written by a physician, its legitimacy comes from the patient; the order signifies that a patient has refused a procedure."²⁹ That the patient has the right to refuse a medical procedure has become well established in the past twenty years. Ruth Macklin has said that: "...patients have a right to refuse medical

treatments if they have mental capacity to grant informed consent..."³⁰ This notion of informed consent will be looked at more closely in a later section of the study. For now we will concentrate on the nature of the order itself.

A DNR order instructs the medical staff that resuscitative measures should not be instituted should the patient go into cardiac or respiratory failure. The necessity of the order is a result of the practice of beginning resuscitation procedures in every situation where a patient's heart or breathing stops as a default medical procedure. In order to prevent the medical staff from starting CPR, the medical order directs personnel not to implement CPR. "In theory, a DNR order is precise and narrow... In clinical practice, however, DNR orders are often associated with withholding or withdrawing life-sustaining therapies other than CPR, and thus may lead to less intensive care....commentators argue that DNR order[s] should specify whether electrical defibrillation, anti-arrhythmic drugs, open chest cardiac massage, temporary pacemakers, or any other CPR measures are to be withheld."³¹ That the orders may be read broadly or narrowly attests to the broad range of medical procedures that have evolved since CPR was first described in 1960. Because there is such a wide range of procedures that may be used and because the medical conditions under which they may be administered are so diverse, the American Medical Association has issued "Guidelines for the Appropriate Use of DNR Orders."³²

Before we proceed to a discussion of how DNRs are implemented, we must first distinguish between other types of medical orders with which DNRs are frequently compared and confused. In recent literature, do not resuscitate orders have been referred to as "Do Not Attempt Resuscitation Orders, (DNARs)." This has been done largely to

reflect the scope of meaning that the term, "do not resuscitate" has come to include. If "DNR" means to one healthcare provider "do nothing at all if a patient goes into arrest," another might interpret it to mean to attempt chest massage and breathing support but give no medications nor put the patient on a mechanical ventilator. For another it might mean do all of the available procedures up to intubation, but do not intubate the patient. By using the label "do not attempt resuscitation," it has been felt that physicians and patients will understand that no efforts will be made of any kind to restore breathing or heartbeat. This then means that resuscitation attempts will be foregone entirely rather than abandoning resuscitation efforts after a period of time or at a certain level of treatment. Likewise, "Do Not Intubate Orders," (DNIs), may be written so that all procedures up to but short of intubation may be used.³³ Such orders offer greater clarity on which specific procedures are being refused. This hopefully encourages more open and honest discussion of treatment options between the physician, the patient, and those family members who may be involved in choosing treatment options. Clarity is what one writer has suggested we need more of when he said: "Sometimes the consent notion gets a bit muddled - as where patients are asked to 'consent' to DNR (do-not-resuscitate) orders. The idea of consenting to an 'order' is strange, but the idea of consenting to non-treatment is even more so. A more appropriate language would refer to refusal of consent to resuscitation rather than consenting to non-resuscitation."³⁴ We should note carefully that this position advocates a return to the situation before 1960 where one was considered dead if his heart stopped beating or he had stopped breathing. In other words, one would be required to affirmatively request CPR rather than requesting that CPR not be instituted in certain, well-defined circumstances.³⁵

Where CPR is considered inappropriate for the patient, the medical order is written to withhold CPR should the patient go into cardiac and respiratory arrest. The doctor writes the order. The DNR or DNAR remains with the patient's chart while in the hospital. However, there are circumstances where a victim of arrest may not be in the hospital setting. What if there is no chart with a DNR order to guide the medical personnel? Given that the standard protocol in arrest situations is that a resuscitation attempt will be made if a do not resuscitate order has not been written, we must now look at situations which may alter or limit the standard CPR protocols.

The Use of Do Not Resuscitate Orders in Different Settings

The pre-hospital setting for CPR provides one of the most difficult situational limitations on the implementation of life-saving procedures. The nature of the EMS situation is such that the medical personnel are trained and equipped to assess the medical situation and to begin immediately to administer CPR. What role, then do DNRs play in this situation? Many problems have been experienced in this area. Among these are those cases where the individual has signed advance care directives that indicate that no resuscitation attempt should be made if the person is in arrest, but a relative or someone else calls an emergency team to assist the person. If called to the scene of an arrest, the emergency medical squad has no choice but to start resuscitative treatment even though the written document indicates otherwise. Many jurisdictions are drafting new policies that will enable life squads to refrain from starting resuscitative procedures where clear, advance direction of DNR status has been given. In some instances, DNR bracelets have

been adopted as the way to indicate to EMS personnel that the patient has given an advance indication of his preference that no resuscitation attempts be made. Since the patient herself is most often unconscious when the life squad arrives, she cannot indicate her choice at the time. Further, the EMS squad does not have the time to contact a hospital nor the patient's family physician to obtain the proper course of treatment. Because of the need for beginning the treatment as soon as possible, the law in many jurisdictions requires that the EMS personnel must begin resuscitative efforts unless the victim is obviously dead.³⁶ And to further complicate the decision as to whether to start resuscitative efforts, EMS personnel may not terminate resuscitation procedures once started unless ordered to do so by a physician.³⁷ In an attempt to address the problems with the pre-hospital CPR situation, the American College of Emergency Physicians has issued guidelines governing DNRs in the field.³⁸

Another area of medical treatment with difficult CPR complications is the emergency department of a hospital. At the time the victim is brought to the emergency department, whether by life squad or family, the medical team has no indication whether the patient has DNR status. Often the EMS team has started resuscitative efforts, but the ER staff must then decide whether to continue the treatments. Likewise, if the patient goes into arrest in the department, the ER staff must determine whether to begin resuscitative efforts. Since the default protocol calls for beginning CPR in all arrest situations, the staff has little or no opportunity to determine whether the patient has DNR status. Often, because the patient's primary care physician has been reluctant to discuss DNRs with the patient, the emergency department physicians must consult with the patient or the patient's family to suggest that a DNR be written. Obviously, a trauma or

critical care situation is not the best place to initiate this consultation at the time of the emergency.³⁹ Similar types of issues arise in the context of intensive care and critical care units in hospitals. Mary Ann Jezewski, a registered nurse with a Ph.D. conducted a survey based upon interviews with staff, patients, and families involved in critical care. Not only did she confirm that too many DNR orders are being written in the stressful situation of ICU and CCU units, she confirms that much conflict arises because the staff who are dealing with the DNR issue are not the medical personnel who know the patient best.⁴⁰

The next complicated resuscitation situation involves the role of CPR in the operating room. Since the initial description of CPR involved patients who went into arrest in the operating theater, operating rooms have maintained equipment and trained personnel to administer CPR should a patient go into arrest in this setting. This has been the place where CPR has been used most often. What then happens if the patient's physician has written a DNR? Does the medical staff then abandon any resuscitation attempts regardless of the underlying medical cause of the arrest? Much of the discussion in the medical journals dealing with surgery, emergency medicine, etc. has dealt with this question.

One of the physicians with whom I conducted an interview is a thoracic surgeon. In this type of surgery, the heart must be stopped, breathing must be taken over by a machine, and the blood must be circulated through the body by artificial means. In this scenario, *every* operation concludes with an attempt at resuscitation that had better be successful, since the goal of the surgery to begin with was to restore health to the patient. As the doctor described it to me, it would make no sense to honor the DNR in such a

situation. To do so would render the underlying medical procedure meaningless. If the patient with DNR orders went into arrest before being taken into the operating room, resuscitation attempts probably would not be made since the arrest occurred before the surgery was begun.

Anesthesiologists have much the same concerns and take the same approach with regard to "honoring" a DNR. As part of a critical care team in the operating room, their use of anesthesia and treatment is profoundly tied to the restoration of vital body function to the patient. A DNR order can not be honored within the context of general anesthesia and major surgery.

Another difficult situational limitation on the implementation of CPR procedures involves the concept of "medical futility." This term should not be confused with the general bioethical term of "futility" which will be discussed in chapter three of this paper. What is meant by the term "medical futility" is a medical situation "... in which CPR offers no conceivable benefit and much possible harm..."⁴¹ Medical futility encompasses the notion that the "...underlying illness that leads to the arrest [will not be treatable] and that patients with certain conditions very rarely survive... it [CPR] is almost never successful in patients with chronic debilitating illnesses."⁴² If the procedure itself has no potential to cure the underlying illness of the patient, and if the prospects for survival are not good after an attempt is made to resuscitate, then the situation may be medically futile. Medical futility has clear application in many areas of medicine, but when it is applied to resuscitation procedures and do not resuscitate orders, some are uncomfortable with its usage. The concept of medical futility as a basis for DNR orders is controversial. "... CPR is inappropriate if it 'will probably fail, or at best, will succeed only to the extent

that the patient will be subjected to intensive and repeated resuscitation before death inevitably occurs.⁴³ In these cases, the physician's judgment may indicate a DNR order is appropriate, however, there are those who say that it is impossible to predict in all cases what is futile.⁴⁴

Reinhard Priester, in materials prepared by the University of Minnesota Center for Biomedical Ethics, discusses medical futility in the resuscitation setting.

The term 'futility' here is used narrowly to refer to the probability of restoring cardiac and respiratory function to a patient experiencing cardiac arrest. From this perspective, CPR would be futile in the absence of a reasonable potential of restoring these vital functions. If the treating physician considers CPR to be futile in this narrow sense, he or she can **unilaterally**, [emphasis mine], execute a DNR order.⁴⁵

He further suggests that there must be at least "a modicum of medical benefit."⁴⁶ What constitutes a "modicum of medical benefit," I would suggest, is a matter of medical judgment as well as an elusive standard to follow.

The hospice situation also presents situational limitations on the use of CPR techniques. In an earlier section of this chapter we examined the use of CPR as part of a hospice program. Now we will look specifically at how DNRs are implemented in the hospice setting. As stated earlier, a hospice facility that receives Medicare or Medicaid funds cannot refuse, as a general policy, to admit a patient who wishes resuscitation efforts to be made should an arrest occur. They might require that someone admitted to the program sign consent to DNR orders as a condition of admittance to the program. However, in general, hospice programs have made DNR the default position for CPR administration, and they require that an incoming patient make her or his own arrangements for CPR treatment and payment if the patient does not want to be

considered DNR status. An exception may be made in some instances where a hospice has an in-patient facility. One in-house facility which I encountered requires the patient, (or the patient's surrogate), to sign a DNR upon admission to the facility. The principal reason for this policy is that the facility has only twelve beds. Since the facility and the medical resources are limited, resuscitation therapy is not provided. Those patients who refuse to consent to DNR status are referred to a regular hospital for hospice and medical care. By treating the DNR cases in this fashion, hospice programs that take this approach meet the requirements of laws requiring that healthcare organizations address CPR and DNR limitations.⁴⁷

Limitations on the Use of CPR Through the Use of Advance Care Directives

Beside the limitations placed upon resuscitation procedures imposed by medical conditions, do not resuscitate orders may be written based upon a category of written limitations called "advance care directives." In an advance directive, a person may predetermine whether resuscitative therapies will be used should a cardiac and respiratory arrest occur. These legal documents derive from the necessity of a patient to consent to medical procedures. This legal doctrine has been established in Anglo-American law in the last century. Since the concept of consent was established the legal doctrine which governs medical treatments has become one of informed consent. Thus, it is insufficient that a patient consent to a given medical procedure. The patient must give his or her consent based upon full information concerning the proposed treatment. In the case of

DNRs, the patient is in fact consenting to a medical procedure not being performed. This is almost the only case where the patient must consent to the doctor refraining from a medical procedure.⁴⁸ Informed consent also rests upon the concept that the patient must have the mental capacity to grant that consent."⁴⁹

There are two main forms that advance care directives take. The first of these is a document called a "living will." The second type is generally known as a "durable power of attorney for healthcare." A third type that encompasses features of both is often called a "hybrid advance care directive" or "living will with proxy healthcare designation."

The Living Will

The living will is called such in order to distinguish it from a "last will and testament" which an individual may also sign. A last will and testament is a legal document that does not take effect until the testator has in fact died. However a living will takes effect while the patient is still alive and can still determine the types of treatment which will be provided him or her at a point when he or she can no longer make these decisions. The person who signs a living will sets out with specificity what treatments are to be provided in specific medical situations. Thus the healthcare providers have advance direction as to what the incompetent patient would have wanted to happen in a variety of medical situations. Like a will that awaits a future date for its terms to be enforced, a living will determines treatment options only when the signer can no longer personally make these decisions. Further, the provisions of the living will go into effect only when the patient is

in a terminal condition and cannot make treatment decisions for himself or when the patient is in a persistent coma.

The Durable Power of Attorney for Health Care

Durable powers of attorney for healthcare operate in a different manner. Like the living will, they provide direction to medical treatment givers once the creator of the document loses his or her own decision-making capacity. However, unlike the situation with the living will, the maker of the document need not be in a terminal condition or in a persistent coma. The document, rather makes provision for how medical decisions will be made should the person signing the document become unable to make medical decisions for him or herself. In this type of document, the grantor does not choose treatment options at the time of signing the document. Rather, the grantor gives the authority and right to make these decisions in her place at the time the decisions must be made to another individual named in the document. This designated person, also known as the proxy or attorney-in-fact for healthcare decisions, is someone chosen by the creator of the advance care directive.

"For a proxy to carry out the patient's wishes, several things must happen: First, patients must designate a proxy. Then they must discuss their treatment preferences with that proxy. Next, the proxy must understand the patient's preferences, and finally the proxy must make the same choices as the patient would have..."⁵⁰

Advance directives were promoted initially to:

- (1) extend the right of self-determination in health care decision-making enjoyed by competent patients to people who become mentally incapacitated;
- (2) approximate the goal of shared and informed decision-making even when mentally incapacitated; and
- (3) help patients and proxy decision-makers (speaking on behalf of mentally incapacitated patients) avoid unwanted and non-beneficial death-prolonging treatment or physical states considered to be without dignity.⁵¹

The concept of extending to incompetent persons the same right to make treatment decisions as a competent person is an important one. The goal is to create parity between these two types of patients. Since this seemed an important factor to Congress, it passed as part of the Omnibus Reconciliation Act of 1990 The Patient Self-determination Act of 1990. This law requires healthcare organizations that receive any form of federal funding to provide training for staff concerning advance care directives and, more importantly, requires them to honor them subject to individual differences determined by state governments. Since the law was enacted the use of advance care directives has mushroomed. Hospitals now inquire whether patients who come to the hospital for admission have executed advance care directives. If they have not, they are given such forms to complete and execute before they are admitted.

We have examined in this paper thus far many of the medical aspects of resuscitative procedures. We have also reviewed limitations on the use of CPR when it is deemed medically inappropriate or when the victim of an arrest has indicated his or her preferences in an advance care directive such as a living will or durable power of attorney for healthcare. Now we will consider other concerns with advance life-saving techniques that may have an impact on the decision to forgo medical resuscitation therapy.

The first factor, which may make treatment choices difficult, is that the underlying technology and state of the art of medicine is changing at such a rapid pace. Many more patients can be resuscitated today than were possible just thirty years ago. This is due in no small part to the possibility of getting at the arrest scene sooner with "911" technology advances in pharmaceutical treatments, a better understanding of the dying process, etc. Technology is changing at such a rapid rate that not only is the state of medicine in flux, those who deal with death are having to constantly redefine the term itself. Technology has brought healthcare advances, but it has created problems as well.⁵²

Another factor that may have an impact on the decision whether to begin resuscitation or not is concerned with the success rate for the procedure itself. We have seen in our discussion so far that the success rate of resuscitation attempts has never duplicated the rate reported in the JAMA article in 1960. Further, the success rates appear to have a correlation with many different factors such as time from the beginning of the arrest until the time that CPR is begun, the underlying illness of the patient, the setting in which the resuscitation occurs, the age and demographic background of the patient, etc. Beyond the "rate of success" one must also examine what is meant by the term. Kane reports that "...success is typically measured only by the presence of adequate circulation and respiration, and discharge from the health care facility 'alive,' without considering neurological status. These rates would be significantly lower if poor neurologic status were considered to be a 'failure.' In fact, about 10 percent of all 'successes' are actually permanently vegetative. Only forty percent of survivors are free of neurologic deficit. The rest have varying degree of brain damage ranging from mild to severe."⁵³

The concept of medical futility has been briefly discussed. We will look at instances where futility plays a significant role in making medical choices concerning resuscitation and we will look at ways in which the medical definition impacts the ethical decisions that are made. There are other factors that make these decisions difficult. Many of them deal with the nature of the relationship between the patient, the patient's family, and the medical staff involved in providing care to the patient.

Some authors have reported that relatives of the patient as well as competent patients fear that they will receive less care if they execute a do not resuscitate order. Tomlinson and Czlodka described this problem in the context of discussing hospital futility policies. "... [T]he authors see the problems as being similar to the CPR situation where families feel that if they consent to a DNR, the medical staff will give up on the patient, will forego treatment options, or will not do as much to provide comfort to the patient."⁵⁴

Further problems with implementation occur because people in most situations do not understand the medical options being presented to them. If offered the choice to do a procedure that may save their loved-one's life, who would refuse? But if told that the outcome of the procedure may have only a five to twenty percent chance of success, would the relative answer the same way? Tomlinson and Czlodka suggest that those called upon to make the choices need only more clarity and more information to make these choices.

From the perspective of the patient and her family the choice was less clear. When asked to make their choice, they were not well informed about the likely outcome of CPR. They had never been in an intensive care unit or seen a respirator. For them the choice appeared to be between a Chance of Life and

Certain Death. When they chose CPR, they were actually choosing something that did not exist - a chance for the patient to live. Problems like these are not easily solved. Sometimes all that is required is more information about the choices involved.⁵⁵

Beyond the low success rate which has been described, another facet of the procedure is that beyond the question of whether the medical staff are successful in restoring a heartbeat and breathing, the patient may be revived only to go into a persistent vegetative state or that the patient may be revived only to die after an indefinite stay in an intensive care unit. A persistent vegetative state may be defined as: "... a condition of permanent unconsciousness in which the patient loses all capacity for interaction with their environment or other people. It is usually caused by an injury to the brain. It is not normally regarded as a terminal condition and with the aid of medical care and artificial feeding and hydration patients can survive for years."⁵⁶ The medical staff may have justifiable grounds for believing that this may be the case, while the family wants everything possible to be done for their loved-one.⁵⁷ What if the result is that the patient suffers some intermediate level of brain damage? What of the role of informed consent?⁵⁸ The answers are not easy.⁵⁹ We will examine some of these issues and the conflicts that result in the next chapter of this study.

CHAPTER ONE NOTES

¹ Robert F. Weir, ed., Ethical Issues in Death and Dying (New York: Columbia University Press, 1977), Introduction.

² Sharon Gay Stolberg, "Embracing a Right to Die Well," The New York Times, Week in Review, 29 June 1997, sec. 4, p. 1. The author says that: "There is no blueprint, however, for a good death. Death can't be neatly packaged with a red bow. It is messy, irrational, [and] most often filled with pain. More than two million Americans die each year; there are as many ways to die as to live. And so unanswerable questions arise: Not only what constitutes a good death and how can it be achieved, but who, ultimately, it is for-the person dying, or those going on living?" She goes on to portray death as a "liberation."

³ Robert S. Morrison, "Death: Process or Event," Ethical Issues in Death and Dying, ed. Robert F. Weir, (New York: Columbia University Press, 1977), 60-61.

⁴ New Jersey Commission on Legal and Ethical Problems in the Delivery of Healthcare, definitions- reprinted in: UAHC Committee on Bio-Ethics, Program/Case Study, Case Study IV - Winter, 1991, 4.

⁵ Sherwin Nuland, How We Die: Reflections on Life's Final Chapter. (New York: Alfred A. Knopf, 1994): 123.

⁶ Mr. Brian Glenville, Rabbi Dr. Nisson Shulman, "Ethics of Cardiac Surgery," Transcript of proceedings at Jews' College, London, 1993, Reprinted in the Yearbook of the Centre for Medical Ethics, Jews' College, London, Vol. 1, (1993), Rabbi Nisson Shulman, ed. This document may also be found on the Internet:

<http://ccme-mac4.bsd.uchicago.edu/CCMEDocs/Judaism>.

Some documents that are found on the Internet have pagination similar to that found in a printed volume. Others do not have standard pagination and may consist of one long page. The document referred to above was downloaded from the Internet and archived as a standard word processing document. In the version that I archived, these comments appear on page three.

⁷ Ibid.

⁸ There are many medical journals and texts that provide descriptions of advance CPR techniques. One of the most complete that I found was reprinted courtesy of the American Association of Respiratory Care in the Journal of Respiratory Care, vol.38 (1993):1179-1188. It may be found on the Internet at:

<http://proteus.mig.missouri.edu:80/shrp/rtwww/rcweb/aarc/rachcpg.html>

This site describes the procedures, risks, protocols, and guidelines for infection prevention as well as the actual equipment, etc. to be used. The setting for the procedure is described as "resuscitation in Acute Care Hospitals." An extensive bibliography on the subject is included at the web site.

- ⁹ Richard S. Kane, MD, "Cardiopulmonary Resuscitation in the Nursing Facility," The Journal of Medical Direction, (February 1992): 24.
- ¹⁰ Stuart J. Youngner, "Do-Not Resuscitate Orders: No Longer Secret, But Still a Problem," The Hastings Center Report, vol.17 no.1, (1987): 24.
- ¹¹ Kane, "Cardiopulmonary Resuscitation in the Nursing Facility," 24.
- ¹² *Ibid.*, 22.
- ¹³ *Ibid.*
- ¹⁴ W.B. Kouwenhoven, Dr. Ing., James R. Jude, MD., and G. Guy Knickerbocker, M.S.E., "Closed-Chest Cardiac Massage," The Journal of The American Medical Association, (July 9, 1960): 94.
- ¹⁵ *Ibid.*, 95.
- ¹⁶ Leslie J. Blackhall, MD. "Sounding Board: Must We Always Use CPR?" The New England Journal of Medicine, vol.317 no.20 (1987): 1281.
- ¹⁷ *Ibid.*
- ¹⁸ *Ibid.*, 1282.
- ¹⁹ Kane: 22.
- ²⁰ *Ibid.*
- ²¹ Blackhall, 1281-1282
- ²² *Ibid.*, The author of this article sets out 3 categories of patients: 1. Where CPR is medically futile and should never be offered; 2. Cases where CPR may have potential for benefit and "patient autonomy" should govern, and 3. Cases such as those for which CPR procedures were initially developed.
- ²³ Kane, 21.
- ²⁴ Mary V. Clemency, MD, and Nancy J. Thompson, MPH, Ph.D., "Do Not Resuscitate' (DNR Orders in the Perioperative period- A Comparison of the Perspectives of Anesthesiologists, Internists, and Surgeons," Anesthesia and Analgesia, vol. 78 (1994): 656. This article followed up on an article that appeared in an earlier issue of the same journal a year before. It broadened a survey that the authors had conducted of internists, anesthesiologists, and surgeons on their attitudes towards resuscitation attempts and the role of DNR in the operating room. The article demonstrated that the attitudes of these types of doctors in this setting differed towards DNR status and orders from the attitude of non-operating room medical staff.
- ²⁵ Kane, 21. The author notes that the success rate among residents of nursing facilities is "bleak."
- ²⁶ Mary G. Brosky, LSW, interview by John Bush, 10 September 1997. Ms. Brosky is a social worker with the Hospice of Louisville hospice program. The question posed about admitting patients who do not wish DNR status to hospice programs was suggested by Reinhard Priester, Editor. "Resuscitation Decisions," University of Minnesota Center for Biomedical Ethics, Packet #6, (Feb. 1993): 8.
- ²⁷ Brosky, interview 10 September 1997.
- ²⁸ John E. Freyer, "Why Hospice?" A paper presented at the "Hospice for the Jewish Community," Synagogue Council of America Conference, Beth Israel Medical Center, (June 13, 1984): 6-8. Dr. Freyer of the Temple University School of Medicine tells a heart-wrenching story about a gentleman, aged fifty-four, who in the end-stages of cancer shot himself at the Hanneman Hospital in Philadelphia using a weapon that his

former wife had smuggled into the hospital. The patient, Abe Pearlman, could no longer tolerate his life and the dying he was going through. Ironically, says Dr. Freyer, he killed himself in the hospital with one of the premier hospice programs in the country..

²⁹ Blackhall, 1281.

³⁰ Ruth Macklin, Mortal Choices: Bioethics in Today's World, (New York: Pantheon Books, 1987): 4.

³¹ Priester, 2.

³² American Medical Association: "Guidelines for the Appropriate Use of Do Not Resuscitate Orders," Council on Ethical and Judicial affairs, A. M. A., The Journal of the American Medical Association, vol. 265 (1991): 1981.

³³ Priester, 6.

³⁴ Robert M. Veatch, "Abandoning Informed Consent," The Hastings Report 25, No. 2 (1995):5-12.

³⁵ I have read papers in the medical literature calling for a move to "Resuscitate Orders" rather than "Do Not Resuscitate Orders" and in interviews with several physicians, heard them make the same argument.

³⁶ Denis J. Fitzgerald, David P. Milzman, MD, Daniel P. Sulmasy, OFM, MD. "Creating a Dignified Option: Ethical Considerations in the Formulation of Prehospital DNR Protocol," American Journal of Emergency Medicine, vol.13, no.2, (March 1995): 223. The author states that CPR must be begun unless the victim has been decapitated, rigor mortis has begun to set in or the body is decomposed. In all other situations, CPR must be begun and cannot be terminated without the direction of a physician with whom the EMS squad is in contact. I did not complete an exhaustive survey of what protocols had been established in every jurisdiction. I did find that Wisconsin, New York, Washington, DC, Texas, New York, Virginia, and South Carolina were all grappling with the issue over the past few years. Much of the literature in the journals of emergency medicine dealt with the issue over the same period. North Carolina has both eased the situation and made it more difficult for EMS personnel to make the decision in the field. They authorize the EMS to withhold CPR from "the terminally ill patient" who has a do not resuscitate order for emergency services. Whether EMS personnel are qualified to determine whether an arrest victim is "terminal" is questionable. Virginia allows the pre-hospital DNR to be rescinded ORALLY by the patient or a relative if the patient is unable to speak.

³⁷ Ibid., 223.

³⁸ Ibid. Fitzgerald, et al. discuss these guidelines and raise ethical issues that arise under them in this article. The guidelines themselves may be found on the Internet at:

<http://www.acep.org:80/policy/PO004165.HTM>.

Note: In this article the ACEP has adopted the use of the DNAR terminology rather than the previous DNR designation.

³⁹ Keith Wrenn, MD, FACP, and Steven L. Brody, MD., "Do Not Resuscitate Orders in the Emergency Department," The American Journal of Medicine, vol. 92, (February 1992): 129. The author also notes that more and more terminally ill patients

are seen in the emergency department whereas in the past most patients were the victims of trauma. This seems to support the observation that I made last year while working as a chaplain intern at a suburban Cincinnati hospital.

⁴⁰ Mary Ann Jezewski, RN, Ph.D., "Do-not-resuscitate status: Conflict and Culture Brokering in Critical Care Units," Heart & Lung, vol. 23, no. 8 (November/December 1994): 458-465.

Another study of DNR/CPR phenomenon in the intensive care setting within a hospital was done by Robert L. Jayes, MD, Jack E. Zimmerman, MD, Douglas P. Wagner, Ph.D., Elizabeth A. Draper, MS, RN, and William A. Knaus, MD, "Do-Not-Resuscitate Orders in Intensive Care Units: Current Practices and Recent Changes," The Journal of the American Medical Association, vol. 270, no. 18 (November 10, 1993): 2213-2217. This study involved a review of DNR practices and policies in 42 ICUs in 40 United States hospitals with 200 or more beds. The sample size was 17,440 patients. We will look at this study in greater depth in a succeeding chapter.

Still another extensive study was conducted by John Rapoport, Daniel Teres, and Stanley Lemeshow: "Resource Use Implications of Do Not Resuscitate Orders for Intensive Care Unit Patients," reported in the American Journal of Respiratory Care Medicine, vol. 153 (1996):185-190. The sample size of this study was 6,290 consecutive admissions to ICUs.

⁴¹ Blackhall, 1283.

⁴² Ibid., 1281-1282.

⁴³ Priester, 4.

⁴⁴ Ibid.

⁴⁵ Ibid., 5.

⁴⁶ Blackhall, 1281-1282.

⁴⁷ Brosky interview 10 September 1997.

⁴⁸ Medical personnel have informed me that testing for the HIV antibody likewise requires the patient consent to a non-disclosure of results as well as the test procedure itself.

⁴⁹ Macklin, 4.

⁵⁰ Linda and Ezekiel Emmanuel quoted in Benjamin Freedman, Duty and Healing: Foundations of A Jewish Bioethic. Published on the Internet. Copyright: 1996.

⁵¹ Robert Allan Pearlman, "Are We Asking the Right Questions?" Special Supplement, The Hastings Center Report, Vol. 24, No. 6 (1994):524.

⁵² Robert S. Morrison, 60-61.

⁵³ Kane, 21.

⁵⁴ Tom Tomlinson and Diane Czlonka, "Futility and Hospital Policy," The Hastings Center Report 25, no. 3 (1995): 30.

⁵⁵ Blackhall, 1284.

⁵⁶ New Jersey Commission on Legal and Ethical Problems in the Delivery of Healthcare, definitions- reprinted in: UAHC Committee on Bio-Ethics, Program/Case Study, Case Study IV - Winter, 1991, 39. Similarly, the New Jersey commission

defines "terminal" as "the terminal stage of an irreversibly fatal illness, disease or condition... a prognosis of a life expectancy of one year or less, with or without the provision of life-sustaining treatment, is generally considered terminal."

⁵⁷ Blackhall, 1284.

⁵⁸ Tomlinson and Czlonka, 30. The authors in discussing the role of informed consent and the conflicts generated when physicians are confronted with a medically futile situation state: "Due to the traditional importance of informed consent in patient care, in medical futility situations, the doctor will often lapse into the consent mode of speaking by asking the patient or the proxy what they wish to have done, even though they know that any treatment is futile."

⁵⁹ Youngner, 24. The author suggests that: "[after then years of debate on limitations of life-sustaining treatment]... many issues surrounding treatment limitation have been openly and often hotly debated... Is there a limit to our obligation to save and prolong life? If so, who should draw the line? When do personal values and beliefs supersede a more objective medical 'wisdom'? Should the financial burden of life-sustaining treatment ever dictate its termination?"

CHAPTER TWO

A REVIEW OF DO NOT RESUSCITATE CASES AND POLICIES

The advances made in medical knowledge and technology over the past thirty years have not been without costs. With new procedures have come new alternatives to be faced when deciding among various treatment options. Medical advances that can prolong life in general may prolong life beyond a point when that life would naturally come to an end. Conflicts arise between those who are providing the medical care and those being treated. Family members may disagree with the treatments proposed for a loved one. The patient herself may have indicated a preference for one treatment over another in an advance directive. Often, the patient may not have made any advance directive and may have become incompetent to make decisions. In this chapter, we will look at cases and empirical studies that raise basic questions involving the implementation of Do Not Resuscitate orders. We will look at who was involved in the decision-making process, what policies and procedures govern these situations, and establish a foundation for a discussion of bioethical norms in the succeeding chapter.¹

DNR and Advance Care Directives Cases

In researching materials for the cases presented here and in conducting interviews with medical care-givers, chaplains, bioethics committee members, and other people who

are, or have been, involved in DNR cases, many common themes appeared. First, most people commented that the decision-making process doesn't work very well. Second, many people had strong feelings about who should make treatment choices for patients who do not have the capacity to make decisions for themselves. Third, the choice as to who should be involved was not uniform. Finally, most agreed that advance care directives should be used more often than they are at the present time.

In the first case that we will consider, the patient had lost the capacity to make decisions for himself concerning medical treatment options. A nurse at a Midwestern suburban hospital offered the case for consideration. The names of the patient, family members, and medical personnel have been changed to protect the confidentiality of those involved in the case. This is the pattern in general for those cases that I obtained from medical personnel and families involved in the decision-making process. Generally speaking, people involved in these cases were reluctant to speak about the circumstances of their cases without some assurance of confidentiality. I also found that most were willing to speak candidly given these assurances and if they believed that others might be helped in future situations by sharing their stories with me.

Once individuals began to know me and to place their trust in me, they began to reflect on problematic cases and to offer to share details of them with me. I must give the standard disclaimer that any resemblance of the facts and situations presented to actual cases and facts is purely coincidental. Even as I have attempted to allow many of the details of these cases to remain behind a veil, sufficient detail is presented to raise those issues that are involved in most DNR cases.

Case 1

An operating room nurse in a Midwest suburban hospital reported this case. She provided details of the case to me in an interview dated July 25, 1997 and in subsequent phone interviews. The patient was a 66 year old male. He was currently married, and had one previous marriage. He had children from each marriage. All of his children lived in the same town as the patient and the patient's second wife. All were grown and had left their parents' household. The patient was admitted to the hospital on April 9, 1997. He was not able to sign any advance care directives because of dementia. No DNR order was written at the time of admission. According to the emergency room nurse, the medical staff did not bring up the issue of DNR since they felt that the patient was not in a life-threatening situation although he was in poor health. After appropriate pre-operation preparation, he underwent surgery for a Coronary Artery Bypass Graft (CABG), & Aortic Valve Replacement (AVR).

The medical history of the patient prior to surgery contained the following information: Dementia, insulin dependent, hypertension, elevated cholesterol, peripheral vascular disease. His right leg had been amputated below the knee twenty years earlier. This amputation was due to trauma to the leg and not due to complications from diabetes.

The surgical procedures were successful in repairing the damaged elements of the patient's circulatory system, but he had some initial ventilation problems post-CABG. The medical staff, after consulting with his wife, put him on a mechanical ventilator to assist with his breathing. He made continued progress in post-op recovery. During this time, no DNR was written or discussed. On day 35 post-op, just prior to being

discharged from the hospital, he "coded" on the 15th of May 1997. This terminology is commonly used to mean that his heart stopped beating, and he stopped breathing. The medical staff initiated resuscitation efforts since he had not previously expressed a desire to forego resuscitation attempts and no DNR had been written. His heart was successfully restarted. Once resuscitated he went on an intra-aortic balloon pump, intravenous pressor drugs (to elevate depressed blood pressure levels) & sedation. While the initial resuscitation efforts did start the heart beating again, he went in and out of arterial fibrillation, an irregular heartbeat post-resuscitation. He needed a mechanical heartbeat regulator and drugs to regulate his heart. He also was unable to breathe without mechanical assistance. Based upon his poor health status, his physician suggested that his wife consent to have the attending write a Do Not Resuscitate Order (DNR) in June. This was done after a consultation between the patient's wife, the surgeon, and the attending physician. His wife canceled the DNR within the 48-hour waiting period prescribed by statute in Ohio.

After a few weeks with no improvement in his condition and with no regaining of consciousness on the patient's part, the doctor wrote another DNR order, again with the consent of the spouse, and a terminal wean of the ventilator was scheduled for three days later. Under a terminal wean, the ventilator support is gradually turned off to determine whether the patient may resume breathing on his own. If the patient does not do so, the respirator is not turned on again. Rather, the patient is allowed to die. The patient's daughter from the first marriage canceled the scheduled ventilator wean before it was begun. The wife was ambivalent about which course they should take with her husband. But the daughter was firm that the ventilator should not be removed. The attending

physician had three electroencephalograms (EEGs) done over the period of a day and a half. All showed brain death. A computerized tomography (CAT), scan of the brain was also done. It confirmed that there had been extensive damage sustained by the brain.

A new DNR was written on 22 June 1997. A terminal wean was again ordered and was done on 7 July 1997. To everyone's surprise the patient resumed breathing on his own when the ventilator was turned off. This, according to the nurse, was due to brain stem activity sufficient to sustain breathing. This level of brain stem activity would not necessarily show up on an EEG. Since the patient was now apparently able to breathe on his own, although still unconscious, plans were made to transfer the patient to a long-term facility. In order to keep his lungs clear, and to assist in his breathing, a permanent tracheostomy tube was to be implanted in the patient's tracheotomy. A "peg tube," for feeding through the abdomen, was likewise scheduled.

On the 15th of July he went to the operating room for the necessary procedures to be done. During surgery, the patient went into ventricular tachycardia, (accelerated heartbeat), and ventricular fibrillation, (rapid convulsion or contraction of the ventricular muscles of the heart). The medical, surgical team was unable to restore a regular heartbeat. He died on the operating table.²

This case raises several issues. First, we might ask: "Whose life is it anyway?" The patient at the time of admission to the hospital was incompetent. He did not have the capacity to consent to the surgical procedures that were performed on him. He did not have the capacity to make any medical treatment decisions based upon advice of his physician. He did not have the capability of saying, "It's my life, and I'll decide when it

should end." We may ask, "In such cases, who should make the medical decisions for the patient?" In this instance, doctors as well as family members made these decisions for the patient. We may call such an approach to the issues "substituted judgment" or "substituted decision-making" - that is, another person or a group of persons steps in to make decisions for the patient who can not do so on his or her own.

There were many instances in this case where a competent patient could choose which medical treatment options he wished to choose. At his admission on April 9th, the patient could have elected which surgical procedures he wished to have performed. When he developed trouble with his breathing, he could have chosen whether he wished to have some type of mechanical breathing apparatus connected to him to assist with his breathing or not. When his heartbeat and respiration stopped on May 15th, he could have chosen whether resuscitation attempts should be made. And when the doctors decided that he should undergo surgery yet again to have a tracheostomy tube and a feeding tube inserted, he could have chosen whether these procedures were ones which had value for him and his life. But since he was incompetent, he could not make these choices. Since choices about treatment options had to be made, we must look at who made these decisions, and perhaps consider who should have made these decisions.

As we saw in chapter one of this study, some indication of the choices that the patient might make could have been given in an advance care directive. However, in this case, the patient had not written such a document before he became incompetent. Thus, there was no concrete direction for the medical care providers as to what the patient's wishes may have been. The attending physician had to determine which procedures were medically appropriate and sought the consent of the patient's wife and her input as to

what the patient would want done in his particular situation. The wife gave conflicting directions. At times she was certain that her husband would not want "extraordinary measures" taken to extend his life, and at other times she requested that the doctors "do everything you can for him." The doctors had two options for making decisions concerning this patient's care: First, they could make the decisions on what they deemed to be the best medically appropriate alternative for the patient given all the information which they had about his medical condition and the range of treatment options of which they were aware. Second, they could present this information to the patient's next of kin, and have them make the decisions concerning treatment options. In this case, the next of kin was the patient's spouse. Or was it? His wife consented to a DNR in early June, only to revoke it a couple of days later. She again consented to a DNR order, and then the daughter canceled the order. We ask the question: Who should be involved in the decision-making process? Who should take priority - the wife? The daughter? The doctors? In Ohio as in most states, the statute that authorizes advance care directives gives a priority ranking to those relationships closest to the incompetent patient.³

A second issue concerns the question of when one should be allowed to die. Most disinterested observers would agree that the patient's medical condition when he was admitted to the hospital was not good. Most would agree that his physical problems and his dementia had reduced the quality of his life so that no longer was what it may have been when he was younger. We might also agree that his time to die might have arrived. However, the people called upon to make the medical decisions for the patient-the family and the doctors-are not disinterested. The life of the patient means more to the family

and the medical staff than the sum of his medical conditions. He is a husband, a father, and someone to be healed.

The doctors who attended the patient had an interest in the patient. They were facing medical conditions in the patient which they were trained to heal. They had a life to save. This idea raises a third issue, that we may call "medical futility." We may ask: "Are the doctors required to provide medical treatments to a patient who has no hope for recovery or if the intended medical treatment has no chance of success?" When the doctors confirmed by EEG and CAT scan that the patient had sustained considerable brain damage, did they have a duty to provide medical treatments beyond providing comfort measures, even though those treatments might be deemed to be futile-that is, of no possible medical benefit?

All of these issues were faced by the medical caregivers and the family in deciding the course of treatment that the medical staff should follow in treating the patient. All were involved in the decision-making process. For their part, the doctors were content to allow the relatives of the patient to make the decisions since the patient could not do so himself. This process seemed to be working until the daughter and the wife disagreed on the appropriateness of the DNR order. The doctors believed that such an order was appropriate, but left the decision up to the family. When the mother and daughter disagreed on the order, the doctors clearly had the legal authority to side with the wife over the daughter. Instead, they allowed the daughter's wishes to govern the course of treatment. According to the nurse, this attitude, which the doctors adopted, appeared to be an accommodation of the daughter's need for additional time to reconcile

herself to the imminence of her father's death. That this approach worked is evident by the fact that the daughter eventually consented to his removal from the ventilator.

This case presented another question, and that is how do we know when someone is going to die? Perhaps we can never know with certainty. In this instance, the patient "coded" when he seemed to be making a good recovery. And even though, the EEG showed brain death, he managed to resume breathing on his own after the ventilator was turned off. Yet after having been stable for some time, he died in the operating room after the medical care providers had determined that with a feeding tube and a tracheotomy tube, he could be discharged to a long-term care facility. In interviewing the nurse who provided the details of this case, she admitted to me that the medical care providers often are poor predictors of when a patient may die, even in cases where the patient is considered to be terminal. In this case, the patient died when it was time to die -not before, and not after. Yet had other medical choices been made as to resuscitation, treatment etc., he could have died as much as eight weeks before he did die.

When the medical decisions were made, and when conflicts arose between one family member and another, the medical staff allowed the family to work through the options and to make the choices. In this instance, people made rational choices for him while he was incapacitated. Problems were resolved with minimal conflict on behalf of the patient. The substitute judgment of the relatives seems to have worked in this instance in the place of the judgement of the patient. We will see other situations where the decision-making was not so easy.

Case 2

This case was one with which I became familiar working as a chaplain intern in the summer of 1996 in Cincinnati, Ohio. It involves implementation of advance care directives and conflicts that arose concerning those directives. The specific medical issues did not involve a decision to make a resuscitation attempt per se. Rather a DNR order was written under the authority and direction of written advance care directives that the patient had executed prior to the trauma that rendered her incompetent. Even though the ultimate issue involved termination of life-sustaining treatment, reviewing this case may be beneficial for resuscitation issues as well. Further, it will help us focus on ethical issues and decisions about who should be involved in making treatment decisions.

- A Suburban Hospital, Cincinnati, Ohio

The patient, S, was a forty-six year old female who was in a permanent unconscious state (PUS), due to traumatic head injuries incurred in an automobile accident. Life squad had brought her to the emergency room of the hospital. They had performed CPR on S and, under the orders of the hospital, had intubated the patient in order to sustain respiration. Once admitted to the emergency department, S was placed on an IV drip with electrolytes, glucose, and various medications to sustain her blood pressure, fight infection, etc. She was catheterized, placed on a ventilator, given nutrition and hydration through tubes, and placed in the Skilled Nursing Unit for close monitoring of her condition.

After two weeks it began to look like S was not going to recover and that she would remain in the PUS indefinitely.⁴ Prior to the automobile accident, S had executed standard Living Will and Durable Power of Attorney for Health Care Forms prepared under the joint auspices of the Ohio State Bar Association and the State of Ohio Medical Association. Under the terms of the Living Will, the patient had indicated that if she were to be in the condition described, a permanently unconscious state, that she did not wish to be kept alive through artificial means. Thus the medical staff had clear authority to remove the external means of nutrition and hydration.⁵ S had never been married but had a partner to whom she had given the authority to make medical decisions for her if she were not competent to do so. She had done this by means of the Durable Power of Attorney under the Ohio statute. It should be noted at the outset that under Ohio law, if there is a conflict between the Living Will and a decision made by the health care proxy under the durable POA, the terms of the Living Will are given priority. There is no dispute about this in the state of Ohio.⁶

After a period of about four weeks of agonizing, S's family, which was footing the medical bills, decided to let the doctors terminate treatment since they were now convinced that S would never regain consciousness, and that it was in their daughter's best interest to "let her die in peace." As stated above, the terms of the Living Will authorized the medical staff to withdraw the medical treatment to accomplish this wish. However, the attorney-in-fact under the Durable POA, who was the partner of the patient, refused to permit this course of action, since she believed that S would recover, if "they would only pray harder and hope stronger." Since the terms of the Durable POA gave her the right to make medical decisions for S, and since her decision not to terminate

treatment and the advance decision made by the patient under the terms of the Living Will were in conflict, the medical staff decided to continue the treatment until such time as the decision S made in the Living Will could be reconciled with the decision made by her health care proxy. As noted above, under the Ohio Living Will Statute the hospital clearly had the authority and the duty to follow the terms of the Living Will rather than the wishes of the health care proxy. Whether it was a fear of being involved in litigation over the issue or merely to accommodate the wishes of the partner whom they felt was closer to the patient than her family, is unclear.

The family of S and her partner had never had good relations, and at the time that I was initially made aware of the case, the parties would not visit the patient at the same time. The family had given the nursing staff orders that if the partner came into the hospital while the family was there that they were not to allow her into the room until the family left. In fact, I often saw the partner and the family in the hospital at the same time, although they were careful to be at opposite ends of the hospital at all times. The staff was enlisted to inform the parties as to where the other was in the hospital to avoid contact between the parties.

At this point a chaplain resident got involved in the matter. Over the course of two days the chaplain and a hospital social worker worked with the family and the partner and finally succeeded in getting the parties to talk about S's condition, her prospects for recovery, and S's best interest. After eight hours of talking, the patient's partner was convinced that it was in S's best interest to withdraw treatment by means of a three day wean and let her die. The social worker and the chaplain devoted many hours

working around the clock with the partner and the family helping them begin the grief process. Authorization for organ donation was also secured. This latter aspect of the case-the ability to give life to someone else-was what persuaded the partner to let S go. After the three-day wean, the patient died. In conclusion, I would note that while I was not with the family at the end, the work that I saw the chaplain do with the parties was some of the finest pastoral care I have ever seen. The chaplain (together with the social worker) was able to achieve a resolution of the matter that the medical staff had not been able to achieve.

This case involves issues of personal autonomy in conflict with substituted judgment in an incompetent patient. The patient, S, had exercised her autonomy by executing an advance care directive, a living will, in which she gave clear indication of her wishes for treatment options should ever be in a permanently unconscious state. However, she also exercised her autonomy by choosing to name someone to make treatment decisions for her should she become incompetent. She could have chosen a family member to make the decisions for her. Instead she chose the person whom she felt was closest to her and knew her best. And yet, when a decision had to be made, this person chose an option (keeping the patient on life-support measures) even when the patient had said in specific terms that she did not wish this option.

As an aside, I would like to point out that in my years of practicing law after the passage of the Ohio Living Will Statute in 1991, I envisioned the potential for conflict between living wills and durable powers of attorney for healthcare. Although the practice in the law firms with which I was associated was to have clients execute both types of

documents, I explained the pros and cons of each and then required my clients to choose one or the other. Since I tended to view the living will as an inflexible document which spoke to the state of medicine at the time the document was crafted and provided no mechanism for different decisions should the state of medical arts and science change, I generally steered my clients toward the durable power of attorney for healthcare. Only after the case of S did I appreciate how difficult the decision-making process can be for someone who is closely tied to the patient. I also did not consider the impact that having to make the tough decisions could have on the grieving process for the person who had to make those decisions. In retrospect, I believe that it was probably easier to grieve and to accept the death of a loved one when the decisions about treatment options were left up to the doctors.

In this case the doctors were content to let the family and the partner of the patient "fight it out."⁷ Their attitude was one that said if the patient is not in pain, we'll keep her alive forever on life support. Fortunately, the social worker and the chaplain at the hospital were not content to maintain the status quo and sought to resolve the issues. Did they act in the best interest of the patient? Did they choose sides between the family and partner to the detriment of the patient? Is the substituted judgment of a person close to the patient always the best method of making these end-of-life decisions? All of these questions involve ethical issues.⁸ If the goal of the decision-making process is to determine what choice S, herself, would make given the prognosis which she faced and knowing the conflicts between her family which faced not only the emotional task of saying good-bye to her but the financial burden of her care as well, and the emotional needs of her partner. What value should be placed upon the hope and the power of prayer

that the partner invested so much in? Can we relegate these factors to the realm of being extraneous to the medical decision-making process? We will look at these issues more closely in the next chapter.

Case 3

The next case is reported in the actual words of the attending physician in the case. Many of the issues raised by the case are similar to others we have seen. The case is presented to give an indication of how the medical care providers feel in these DNR cases. Internal conflict is often the result of these cases. Physicians who are trained to heal, who are trained to fight death at every turn, are often the ones forced to make the tough decisions as to when it is appropriate to say that a life is at an end, and that no further treatment should be provided. It is one of the more challenging aspects of the medical profession. As stated at the outset the names of the parties have been kept confidential.

- Metropolitan hospital, New York City, reported by a resident physician.

"A man with various medical problems (including Parkinson's disease), noted chest pain went he went to sleep and took some Tylenol 3. The next morning his wife found him cold and barely responsive to her. Panicking, she called an ambulance; the EMTs immediately intubated him despite the fact that he had signed a Living Will stating his wishes not to have life support. The wife came to the hospital with her husband,

showed us the Living Will, and asked us to remove her husband from the ventilator. It was clear to me that he had suffered a massive coronary during the night and had no chance of a meaningful recovery. I believe that he suffered tissue damage, including permanent brain damage, from lack of blood flow secondary to the heart attack. I explained to the wife that I could not extubate her husband on the basis of the Living Will but that she could sign DNR papers, which she did. I decided to do nothing for the patient except make him comfortable. This meant not giving heart attack medication, IV fluids, and not adjusting the ventilator's breathing rate and oxygen flow.

The patient never regained consciousness and died during the night. This occurred during the weekend, and I remember being concerned that I might be criticized on Monday for violating some hospital policy. I called the administrator on duty to find out the proper procedure for such a situation. She told me that it was a case of medical judgment. Of course, I agreed. I wrote a detailed note justifying my decision on my best guess as to the patient's actual wish, using the Living Will as a supporting document. In this case the patient died fairly soon after being intubated, but I had many other cases where I was the resident and the family insisted that every possible intervention be made in the medical care of the patient even after it was abundantly clear that the patient was dying. The residents involved in these cases were very frustrated and often commented that these family members were no doubt driven not by love but by guilt."

This case raises the following questions? What is the proper approach to honoring a living will if its provisions have already been violated at the time the patient is admitted to a hospital? May life support be withdrawn based on retroactive adherence to

the provisions of a living will? The hospital administrator told the physician that the case was a case of "medical judgment." Can "medical judgment" serve as substituted judgment in the same manner as the family's substituted judgment in the previous case? In this instance, it is the judgment of the attending physician that decides "who shall live and who shall die." The patient has not made a choice about dying. The physician, in this case, made the choice for him. Is the attending physician the appropriate person to make the decision in this case? I do not raise the question to condemn those physicians who must make decisions about life and death on a daily basis and on the spot. Rather, I wish to add another factor to the decision-making process and the underlying ethical framework that supports these decisions. In this case the attending physician stated that she made her choice based on what the patient had stated in his Living Will and the choice that she felt that the patient would have made given his medical condition had he been competent to do so. Prior to the days of Advance Care Directives and Do Not Resuscitate Orders, medical judgment was the ultimate decider in all end-of-life cases. Physicians felt that all decisions should be made based upon the medical factors involved in the case and their own specialized understanding of these medical conditions. In most cases, the physician made the determination as to treatment and then had the duty to inform the patient's family when death occurred.

This approach may have been appropriate under a system which saw paternalism as the best way to insure that patients were properly cared for. Today, however, paternalism has given way to "patient's rights" and the notion of "autonomy." This transition has caused as much discord within the medical community as it has within the patient's family. With the advent of DNRs treatment decisions became much more

complicated. The possibility of resuscitation made end-of-life decisions more complicated, not less. We are only now beginning to study the ramifications of the medical choices now available to us as a society.

Case 4

In the previous cases we looked at the issue of substituted judgment for patients who are in a position where they cannot make medical decisions for themselves. We will now consider a case that involves decision-making on the part of the patient while still competent, or by a proxy decision-maker, if incompetent, under advance care directives in an institutional setting. This case involves, however, not one patient, but many. It involves decision-making at the macro level - that is, by matter of policy rather than based on the circumstances of an individual case.

A long-term care facility in the Northeastern United States

The long-term care facility is a three hundred plus bed, assisted living facility which is labeled a "Traditional Jewish Home." The average age of the residents of the home is approximately eighty-seven. Since its inception, the home has never been licensed as a hospital. In practical terms this means that the facility can not provide certain medical treatments such as blood transfusions, hemodialysis, intubation, extubation, etc. Under the laws of the state where the home is located the staff is not licensed to provide resuscitation beyond basic level CPR. The nursing staff is trained and

annually recertified to provide basic CPR procedures to patients who go into pulmonary or cardiac arrest. Anyone trained to administer CPR may do so without having a specific license from the state. No levels of resuscitation efforts that would come under the rubric of Advance Life Support (ALS) procedures are permitted to be performed in this long-term care facility. Advance Life Support procedures involve a greater degree of use of prescriptions and invasive procedures than routine CPR. Such procedures do require training and licensing. Across town at another traditional Jewish long-term care facility, such procedures may be performed since that home has been certified and licensed as a hospital facility.

At the long-term nursing care facility, which is the focus of this case, the policy of the home has been to require all new residents to either personally, or through a proxy, if unable to do so, sign a document which recognizes that should the resident go into arrest, there will be no resuscitation efforts made. In essence, the official policy of the facility was one of "DNR." Further, in a separate document provided to the incoming resident or his proxy at admission, the individual was given the choice to have the "comfort measures protocol" invoked should they become terminally ill, or to indicate that they did not desire cardiopulmonary resuscitation done at any time. This document was called: "Medical Care Directives." At no point were other options offered to the residents. The home based this policy on several criteria. Since the facility did not qualify as nor was the facility run as a hospital, it was felt that the home did not have to provide any resuscitative medical treatments beyond basic level CPR. The law required that nurses be trained to administer CPR, but it did not require the nurses to provide CPR in all arrest cases. Second, since any attempt to perform CPR on a resident eighty-seven years of age

would, in all likelihood, result in serious injury to them of a nature which the patient could not survive, resuscitation attempts did not seem appropriate. Third, the administration of the facility was aware that the medical literature indicates that success rates for CPR, and post-CPR survival are not very high, in general, for elderly patients.⁹ Many studies of CPR in the elderly describe the results as "dismal."

When the current chaplain became the resident chaplain at the facility and became aware of the DNR policy, he was disturbed that such a policy might not in fact serve the best interest of all the residents, and that such an umbrella approach to end-of-life questions did not accommodate the variety of halakhic views toward resuscitation that traditional Jews might subscribe to. These, according to his understanding, range from an approach which seems to require resuscitation attempts be made in every case to others which would see no duty to prolong life in every case by whatever means available.¹⁰ Since the home is a traditional Jewish one, and since the chaplain is an Orthodox rabbi, he felt that the only way to respect the autonomy of all of the home's residents, whatever their halakhic preference, was to have a policy which allowed residents to choose to not be placed under a DNR status should they choose not to do so. The Nursing Home Review Board of the state in its annual audit, became aware that no resuscitative efforts were being offered in arrest situations, and as a result, required the home to provide at the minimum, basic CPR procedures, for use in "code" situations. The home has since complied with this demand.

Today, according to the chaplain, ninety-nine percent of the staff and the medical director of the facility still encourage their new residents to agree to a DNR status when they are admitted to the facility. The provisions of the Patient Self Determination Act of

1991 now require the home to talk about advance care directives, but does not require a DNR status at admission nor the opposite. The home still presents the residents with a form that encourages a DNR position at admission. However, a person may become a resident of the facility even if they choose not to be labeled "DNR." The chaplain could not provide statistics as to portion of the incoming residents who choose to have DNR status. The current protocol of the facility in arrest situations calls for resuscitation only if the cardiac arrest is "witnessed" by a member of the staff. It has been suggested in other places that a witnessed arrest in which CPR is started quickly has the best chance for success, thus the home is on solid ground in preferring CPR only in witnessed arrests.¹¹

Because of a review by the nursing home board and mandates by the state, the default policy at the facility has changed from one which presumes that the residents do not desire any resuscitation attempt to one which presumes that they do wish resuscitation absent any clear indication to the contrary. However, new residents are encouraged to give that clear indication by agreeing to the DNR policy at admission. If the resident does not agree to this policy, they will be admitted to the home but with the understanding that if they should go into arrest, no attempt will be made on the part of the facility staff beyond basic CPR, and that if the resident wants a higher level of life-saving treatment, the staff will do nothing more than call the emergency medical squad through dialing 911.¹²

This case raises important issues concerning DNR policies in healthcare facilities. It raises the issue of whether a "one-size-fits-all" DNR policy makes sense. One may ask the question: "Should the medical condition of the 'average eighty-seven year old

resident' be used as a standard to determine the policy of the medical staff for all residents of the facility where the actual age of a resident may be sixty or seventy rather than eighty-eight?" Likewise, shouldn't a case-by-case approach be used in determining the appropriateness of any medical treatment rather than a blanket policy affecting all residents? Can broad principles be applied to these cases to facilitate the decision-making process? Or, if a blanket policy is applied, should it not be structured to favor resuscitation rather than non-resuscitation? This is a difficult question to answer.

Another question that we might ask is whether such a policy of presumed preference for DNR status might lead to a diminished level of treatment and care? Such reduction of treatment level is known as "medical abandonment." Later on, I will present the results of surveys that indicate that such diminished level of care may indeed be the case in these DNR situations.

In the previous cases we asked the question: "Who should be involved in making treatment decisions?" In this case, a change in the policy of the facility came only with the help of the state. This raises the question: "To what extent should the state or another outside party be allowed into this decision-making process?" "Does the state have any interest in these cases?" "Does the state have the primary interest in these cases?" "Does society play a role in how we decide these questions?" "Should we have to go to court for redress in these cases or to determine which medical course should be followed?" Policies are written, and protocols are established in order to avoid such an approach to dealing with these complicated matters. "Do we want Congress to determine the course to be followed?"

In fact, in 1991 Congress adopted the so-called "Patient Self-Determination Act of 1991." The goal of this legislation was to encourage the use of advance care directives by requiring all medical facilities which receive federal funds under the Medicare program to provide information to patients at admission on Advance Care Directives such as Living Wills and Durable Powers of Attorney for Healthcare. The legislation did not require that patients sign such directives upon admission to a hospital. Rather, it required only that the patient be advised about the option of giving an indication in advance of preferences for medical care should they at some point be unable to make the choices themselves. Today, it is estimated that only about fifteen percent of patients actually execute one or both of these documents at admission to a healthcare facility. And even though the law requires that the healthcare facility discuss the advance directive options, the specifics of what that discussion must include are left up to the individual states to determine in accordance with their own Advance Care Directives statutes. Thus, a survey of the various states indicates a wide variance in what the documents must (or should) contain, and what policies must be adopted in conjunction with them.

In the next section of this chapter we will look at some of the results of studies which have begun to be made about the use of DNRs in medical settings. We will also look at policies and procedures that attempt to provide guidance to those who must be involved in the decision-making.

DNRs in Policy and Practice

Terry Perlin has stated the issues well:

Who will speak for you when you can no longer decide what sorts of medical treatment you want to accept or decline? How will such persons know your views and values? Is there any way that you can provide, in advance and with a reasonable degree of certainty, that the kinds of treatments you may receive will serve previously declared interests? And if you are unconscious or without cognitive capacity, can there be assurance that you will not be kept alive indefinitely by sophisticated machines or medications? These questions are at once clinical and ethical. Even if they can be answered satisfactorily, it still remains a challenge to find practical and concrete ways of stating one's views and trying to guarantee that advance planning will be carried out. There is perhaps only one certainty when health care determinations must be reached: a physician of record will be at or near the center of decision-making.¹³

A physician may be at the center of the decision-making process, but today it is likely that he or she will not be the only one. Today, the physician may have to deal with a proxy decision-maker, a staff attorney, an administrator, and probably, family members of the patient. Since many separate decisions may be involved in writing and implementing a Do Not Resuscitate Order, the potential for problems and conflicts is great. In addition, if one considers that a small number of patients actually make use of advance care directives, a huge number of cases remain for which some other mechanism must be used to make the treatment decisions. Second, even when the patient has written an advance care directive, decision options or questions may be raised which neither the patient nor the medical care providers could have anticipated. Many health care facilities have attempted to deal with these situations by drafting policies and protocols that will

govern these types of cases. There are problems that arise with such an approach. A survey of some of the literature on the use of such policies will help to illustrate them.

In the January 1995 issue of the Journal of Family Practice, a multi-disciplinary group reported on the results of a study which they had conducted to determine how accurately health care professionals could predict what the wishes of a patient would be as to DNR status, if the patient were unable to convey those wishes to the practitioners. The health care professionals who participated in the study were given only clinical and demographic data about the cases that they reviewed. These cases were actual cases drawn from institutional records of admissions. The patients who were the subjects of the case studies were all chronically ill and institutionalized. The medical care givers were not given specific information concerning the patient which might indicate a religious preference and thus a set of specialized moral values that might have changed their determination as to DNR status preference. After making a prediction as to what the patient's code status choice would be in each of twelve scenarios, the health care professionals were asked to state whether the patient would wish to be considered DNR or not. The health care workers were then asked to state on what basis they had made their judgments. In the twelve case scenarios presented, the professionals were able to accurately predict what the patient's actual wishes were in slightly better than half the cases, in short-only slightly better than a chance guess as to "code status" preference. What may be more disturbing is that they based their decisions in more cases than not on whether the patient was able to "perform the basic activities of daily living or not" rather than objective medical criteria such as underlying medical condition, prognosis, etc. As the authors state, "In the absence of documented information about patients' wishes,

physicians sometimes must make code status decisions (e.g. for cardiac resuscitation) informally. Under these circumstances, physicians have no alternative but to guess what a patient's preferences might be rather than basing their decision on such pivotal factors as the patient's value system and attitude toward quality of life."¹⁴

If this study accurately predicts how well the healthcare providers are able to predict those decisions and how well they are able to judge the values of the patient, perhaps the approach to these DNR cases should be that the doctors are never allowed to make the DNR choice for their patient. But this approach is simplistic and does not reflect the time constraints, the issue of allocation of scarce health care resources, and the role of the patient, family members and others in these types of decisions. Perhaps, since these physicians were not dealing with actual cases that they were managing, their decision-making may have not reflected how they would have actually decided the case, but rather represented an idealized choice. Perhaps. In any case we see that the substituted judgment of the doctor for that of the patient may not coincide with what the patient himself would have decided. Further, the experience of the doctor, the nature of his specialty, if any, or experience making code status decisions did not seem to have any correlation with the ability to actually predict the preference of the patient. The authors of the study conclude that caregivers should discuss treatment options and DNR status much earlier with their patients than they do now. This is important and certainly reflects an ideal. However, an emergency room physician, an EMS squad crew member, or a surgeon or anesthesiologist rarely gets the opportunity to discuss DNRs in a non-emergency situation.

As mentioned above, DNR orders when written are often subject to varying interpretation as to what they mean. In another study conducted by Uhlmann, et al., and discussed by Stuart J. Younger in The Hastings Center Report, the authors followed the cases of fifty-six patients who had DNRs written for them by their physicians. No additional direction of various treatment options was put in the chart of the patient beyond the fact that they were "no-code."

The specific interventions to be withheld varied from patient to patient, and when cross-covering physicians were questioned about their interpretations of specific no-code orders, both 'the intention and interpretation of the orders was characterized by variability, and the interpretation of the orders was characterized by uncertainty as well.' The authors suggested that: '...this potential for misinterpretation of a no-code order increases with the number of physicians, nurses, and other personnel who may become responsible for patient care when the primary physician is not available, a common situation in large teaching hospitals and in urgent care situations'.¹⁵

So far we have looked at problems with implementation of DNR orders from the medical care provider side of the equation. We have highlighted the physicians low success rate in predicting the patient's preference for DNR status. We have also focused on the problem with interpreting the DNR orders once written, given different treatment options and levels of treatment which may be appropriate under the broad written order. Bedell and Bianco, in a study that is several years old, looked at the issue of the infrequency with which doctors discuss DNR orders with their patients in advance of the time when they become medically indicated. In their study they, like the previous study mentioned, reveal a dissonance between the patient's actual wishes concerning resuscitation and the actual number of attempts at resuscitation of those same patients. They call for physicians to discuss the issues of resuscitation for all patients who are admitted to hospitals.¹⁶ Since their study, this has indeed become the requirement in

those facilities which receive federal funding under Medicare as required by the Patient Self-Determination Act at least to the extent that resuscitation may be considered to be within the purview of a discussion on advance care directives. Still, we have noted that only about fifteen percent of patients actually elect to write an advance care directive.

Are there others who may succeed where the doctors failed in making a decision for the non-competent patient? How about the relatives or spouse of the patient? Underlying this option is the idea that those persons who are close to the patient, those who have known the individual for many years, will be able to choose those treatment options that the patient herself would choose. N. Zweibel and C. K. Cassel reported in a study which they conducted that family members were no better at predicting the wishes of the patient than their medical care counterparts.¹⁷ This raises the question: "If surrogate decision-making by family members for an incompetent patient is for the purpose of enabling the patient to exercise his rights to autonomy, and if family members are no better than the medical personnel at accurately predicting what the patient's wishes might have been, can we call the result of such decision-making a reflection of the patient's autonomy?" And the question that follows might be: "Should such exercise of autonomy override the treatment decision made by medical care givers who are entrusted with looking out for the best medical interest of the patient?"

Leslie Blackhall, a medical doctor, has framed the question in this way: "Infrequently discussed (although perhaps not infrequently encountered) is the situation in which a patient wants CPR but the physician believes that it is contraindicated. In these cases, patients almost invariably remain 'full code,' and physicians feel obligated to provide a treatment that they have reason to believe will not be beneficial and may

actually be harmful."¹⁸ Clearly what is called for in these situations is better communication among all of those involved in the decision-making process. But even then, there may be disagreement about the proper course to be followed. Blackhall adds: "When a patient's request for treatment is in conflict with a physician's responsibility to provide what he or she believes to be good medical care, the calculation is difficult."¹⁹

With a medical situation that invites conflict, and when so many people are likely to be involved in the decision-making process, hospitals and other medical facilities have begun to adopt policies and protocols on the writing and implementation of DNRs. Today all medical care facilities are required by accreditation boards to have such policies and procedures in place. We have noted above the potential problems that can arise where a pro forma approach is taken with regard to these decisions. Nonetheless, policies reflect an underlying societal view that end-of-life decisions must have some moral or ethical framework on which they are based. Most of the policies that I reviewed were clearly developed in response to the mandates of the Patient Self-Determination Act of 1991 (PSDA). In a large majority of the documents I reviewed, the written policy stated specifically that the policy had been adopted to comply with the provisions of the PSDA act. Further, the documents indicated that the purpose was to inform incoming patients or residents that they had the right under the act to execute advance care directives that would be provided by the hospital or long-term care facility. Beyond uniformly offering the statement or a pamphlet that contained this information, the policies that I reviewed varied in their terms and in their application.

In one hospital policy that I reviewed, the hospital had done an excellent job in outlining not only what rights the Patient Self Determination Act had given to the

incoming patient, the written materials also outlined what the advance care directives were meant to do, listed the types of treatments which were covered within the treatment options which the advance care directive sought to cover, disclosed that the advance care directive would take effect only when the patient was unable to make treatment choices for himself, clearly distinguished between advance care directives and DNRs, and accomplished all of this in language that was easy to read and understand. That is, the language of the document would be easy to understand if one were not in an emergency situation.

Even though the hospital had done an excellent job of crafting a document which was meant to foster open and frank discussion of the patient's medical condition and the treatment options which might be offered at a later time, there was no coherent follow-up policy to ensure that those frank discussions would ever take place. The social work department felt that the responsibility for these discussions lay with the medical staff who would be treating the patient and working with the patient's family. The admitting department felt that they were not competent to discuss such issues beyond giving the information packet to the patient or the patient's next of kin at the time of admission. The medical staff felt that they did not have the time to engage in these discussions when their role in the hospital was to provide medical procedures to patients with limited resources and limited time.

The result of this was that while the hospital had done a superb job of creating a good document to explain the implications of advance care directives on treatment options, no one was taking the next logical step of actually discussing the documents with the patient. In this particular facility, the signing of advance care directives did not

exceed the overall national rate of about fifteen percent. What is worse, there seemed to be the same sense of reluctance on the part of the staff to discuss end-of-life issues at the time of the admission to the hospital even though the studies indicate that, in general, this is the best time to discuss those issues, and that doing this earlier in the hospital stay causes the patient and her family much less pain and suffering.²⁰

In the long-term care setting, the policies that a home may draft are more involved and must be even clearer in the terminology chosen. In a long-term care facility Dr. Kane has suggested that the traditional terminology of "No Code" and "DNR" should be abandoned in favor of "No CPR" or "No cardiopulmonary resuscitation." According to his view since the term "DNR" encompasses many levels of treatment which are not offered in the long-term care setting, to continue to use such terms may only add to the confusion surrounding the placement of a loved-one in a long-term care setting.²¹ This is an important point, and to adopt his suggestion may help reduce some of the confusion that often results in the long-term care setting.

We have thus far in this chapter looked at specific cases that raised issues concerning implementation of DNRs in specific cases. We have also looked at implications in drafting DNR policies and advance care directives policies. We have seen that problems with DNR implementation may be a result of the language used in the documents that discuss advance care directives. We have seen that confusion may result from differing interpretations of the DNR orders themselves. And we have seen that there may be problems because of the manner in which the medical staff applies the DNR order in specific cases. In the next section of this study we will look at the results of studies that seem to indicate that patients who have DNR orders signed for them by their

physician may receive a diminished level of care based upon the medical staff's perception of what DNR status means. The studies show that patients with DNR status may not receive certain treatment options if a DNR order has been written, where those who do not may receive more aggressive treatment. Further, there are studies that indicate that age may play a factor in the formation of such attitudes. Demographic factors such as race, location of the hospital, the insurance provider, and length of hospital stay may also play a role in determining how a DNR order is implemented.

In reviewing the studies, one may see that some of the authors tie the incidence of DNR, particularly in ICU or emergency room settings, to increased levels of underlying illness, that is, to particular illnesses from which the patient may be suffering. Two studies with large population sizes have tried to factor out those patients who had medical conditions that did not predict a recovery and eliminate their DNR status as a factor in higher death rates or failure to survive the hospital admission. Both of these studies were reported in the Archives of Internal Medicine, October 23, 1995 issue. Both studies had shared authors, although not all participated in both studies. In the first study titled: "Outcomes of Patients With Do-Not-Resuscitate Orders," Neil Wenger and others retrospectively looked at the cases of 12, 821 Medicare patients admitted to the hospital with congestive heart failure, acute myocardial infarction, pneumonia, cerebro-vascular accident or hip fracture. Using the patients' charts and medical records they looked at 180 day mortality rates, length of stay in the hospital, and compared the death rates for those with DNRs written while in the hospital, and looked at when during the course of the stay the DNR was written.

"Hospitalized older patients with DNR orders have a much higher mortality than predicted by admission demographic and clinical characteristics. The differential association of early and late DNR orders with mortality indicates that DNR orders represent a heterogeneous group of interventions that may be a marker of unmeasured sickness and a determinant of quality of care."²² In other words, the review of the case indicated a certain death rate for given medical conditions. Beyond this basic death rate, however, a certain number of additional deaths occurred that could not be explained based upon the objective medical data. In each of the underlying cases a DNR had been written. The higher death rate for those who had DNR status could be attributed to an underlying illness that had not been set out as a separate variable in the study. In the alternative, the higher mortality possibly could be attributed to a reduced level of care once a patient was assigned DNR status. The authors consider each of these possibilities.

Wenger notes that those patients with increased severity of illness at admission had a DNR order written for them earlier in their hospital stay than those who were less critically ill. He also observes that patients with DNRs have high mortality rates because the use of DNRs and the likelihood of death are tied to the same variables. According to his study, underlying the increased incidence of DNR patients is a higher incidence of sickness that in general is tied to higher mortality and reduced prospects for successful resuscitation efforts.²³

As to the question of whether the increased usage of DNRs is related to a reduced level of care the authors of this study state: "Mortality rates probably do not reflect quality among these patients; a definition of good quality care for patients with DNR orders is still evolving. The timing of DNR orders may be one aspect of quality. Among

patients who would want a DNR order (if such a group could be identified prospectively), earlier orders might represent better quality... Ensuring good quality care for patients with DNR orders is essential."²⁴ Of course it is, and this is why the issue of quality is beginning to be the focus of more studies.

In the second study by Wenger, et al., titled: "Epidemiology of Do-Not-Resuscitate Orders," the authors examined the records of 14,008 Medicare patients with the same medical conditions as reported in the first study. However, in the second study they looked at additional factors such as impaired functionality, gender, race, place of residence prior to admission, and insurance status among others. Among their conclusions, they found that DNR orders were written more often for elderly patients after adjustment for sickness than for younger patients. According to the study: "After adjustment for patient and hospital characteristics, DNR orders were assigned more often to women and to patients with dementia or incontinence and were assigned less often to black patients, patients with Medicaid insurance, and patients in rural hospitals."²⁵

Variation in implementation or assignment of DNR status in patients based upon age criteria or other demographic factors is undesirable. A basic principle underlying the treatment of the ill is that patients in similar medical conditions will have access to the same treatments based upon objective standards related to the medical condition of the patient and not to some other factor such as age, race, means, etc. Disparities in treatments provided violate these basic principles. What remains to be determined is whether such disparities occur because of differing DNR policies or protocols, poor communication between doctors and patients, or problems inherent in the DNR concept itself. In their conclusion to the second study Wenger et al. state: "Sickness at admission

and functional impairment do not explain the increase in DNR orders with age or the disparity across diagnosis. Further evaluation is needed into whether variation in DNR order rates with age, diagnosis, race, gender, insurance status, and rural location represent differences in patient preferences or care compromising patient autonomy."²⁶

"Care compromising patient autonomy." These words state euphemistically what in fact might be called inappropriate substituted judgment, medical abandonment, bias, or more. These statistical studies may show that DNRs are sometimes written in medically inappropriate situations or are applied to categories of patients without regard to individual case considerations.²⁷ Or underlying these differences in application may be a general problem with implementation that is based upon the physician-patient relationship (or lack thereof), or a physician-surrogate relationship (or lack thereof).

Cammer Paris, et al., in a study reported in the July 26, 1993 issue of Archives of Internal Medicine, conclude that poor communication may be the underlying cause of the disparity in application of DNR status.²⁸ The questions asked in their study and the results are abstracted in the notes at the end of this chapter. In the study, they had physicians answer a battery of questions concerning possible "problems" with DNR implementation and rank the frequency with which they had encountered certain situations. The type of problem most often cited was a problem with either consulting with or coming to an agreement with a surrogate decision-maker. Yet other problems are evident as we have seen and as the authors determined based upon their study. We will now look at the conclusions which may be drawn from these studies and look at proposals to reform the DNR decision-making process.

Summary and Conclusions

The cases which we have looked at and the empirical studies which I have presented indicate some of the problems that arise in conjunction with the making of DNR policies or in the implementation of DNR orders. In the first case, we saw conflict between family members about consenting to DNR orders or in decision-making concerning the withdrawal of life-support treatments. We also saw that the time of death of a critically ill person cannot always be predicted, and we encountered resumption of respiration in a man who was supposed to die when a ventilator machine was disconnected. We saw decisions made concerning treatments by relatives of a patient who was incompetent to make those decisions for himself, and we saw the problems which may arise when advance care directives are not executed in advance of the time when the DNR and treatment decisions must be made.

In the third case we saw potential problems that may arise when advance care directives are in fact executed, but when the direction given in one document is contradicted by another who has authority to make "substituted judgments" for the patient. We saw that despite the best intentions of the creator of the advance care directives to avoid the type of futile treatment that she received (and which could have been legally and ethically terminated by her physicians), those treatments were continued by her physicians in order to accommodate the wishes of a daughter whose interest was subordinate to that of the wife.

In the fourth case we raised issues concerning possible problems with adopting wholesale policies concerning DNR status. Likewise, several of the studies which we

reviewed presented problems with DNR implementation based upon broad categorizations of patients because of gender, race, age, etc. Most of these studies reinforced the notion that much of what is done with regard to treatment options and the use of DNRs and resuscitation procedures is subjective, may be based upon poor communication between the parties, or may be based upon medical judgement that is not a good predictor of the patient's actual wishes. A non-competent patient may have little or no autonomy.

Through the cases and the studies we can also see where the evolution of resuscitation procedures and their uses have become problematic in moving from a procedure first recommended for limited-use, to one that must be performed unless the patient has indicated that he does not want the procedure done. Beneath all of the conflict that arises and the questions which have been raised about resuscitative treatments is a social view that saving life is a good, and that dying when life-saving procedures can be used is bad. The principle that has driven the explosion of resuscitation since its initial description in 1960 is that life has value, and that no one person's life is more valuable than another's. In fact, the underlying principle may even be stated as "one moment of life has as much value as any other moment." This perception or societal value may be changing as a result of the advances in medicine over the past thirty years. A life that consists only of a beating heart and artificial respiration may not be the same as a life that is filled with work, play, laughter, etc. The moments that are pain-free could possibly have more value than those that are spent in pain and illness. Yet to make distinctions between moments of a life and to place more value on some than others raises other problems.

Consider the following commentary from the Archives of Internal Medicine. Drs. Donald Murphy and Thomas Finucane call for the development of new DNR policies. Do they do this for the purpose of resolving some of the problems we have raised? Only in part. Their article is titled: "New Do-Not-Resuscitate Policies: A First Step in Cost Control." I quote them at length:

To control the cost of health care and to improve access to care for the uninsured, our society will have to set limits on health care use. We believe that new do-not-resuscitate (DNR) policies would be just and relatively painless ways of beginning to set these limits. New policies could be developed with public input at the hospital, city or county levels. We suggest a DNR policy that eliminates cardiopulmonary resuscitation (CPR) for certain groups of people who are near death and that CPR no longer be considered part of standard care for these patients. The major rationale for this policy change is cost control. Our society cannot achieve real cost control until we agree to set limits. This new policy would have many additional advantages. It would help to (1) protect many patients who are near death from overtreatment, (2) operationalize the concept of futility, (3) reflect the majority's view of marginally beneficial life-sustaining care, and (4) protect professionals who care for patients who are dying. The policy would have some disadvantages in that it would limit individual patient autonomy, be legally risky, depend on imprecise data, be difficult to communicate, and result in an earlier death for some patients who would have wanted CPR and who would have survived as a result of CPR. We believe the advantages outweigh the disadvantages.²⁹

The fact that cost could be the determinant of a policy designed to save lives is alarming. That the authors of the commentary are medical doctors who presumably write such orders is beyond alarming. And yet, we have seen the results of categorization of patients by certain demographic characteristics. The abandonment of societal values concerning death and dying is progressing in the area of DNRs just as it proceeds with regard to physician-assisted suicide and euthanasia. But the latter two categories are not

the subject of this work, even though some of the issues and concerns are applicable to questions of euthanasia and physician-assisted suicide.

How then do we deal with increasingly scarce medical resources? How do we determine what is in the best interests of the patient? How do we decide who shall make treatment decisions for those who are unable to do so? How do we determine when a proposed medical procedure is futile? What do we mean when we say that patients have autonomy? How has the "majority's view of marginally beneficial life-sustaining care" been measured, and how has it changed over the past thirty years? Should the majority's view on what is marginal life-sustaining care be the determinant of what care, in fact, shall be provided? Is there any way to make our way through the maze of late twentieth century medicine and end-of-life decisions?

Over the past twenty years or so the field of bioethics has blossomed to assist in answering these tough questions. In the next chapter we shall look at the field of bioethics and see what kinds of answers this approach, which grew out of philosophy, can provide to the field of medicine.

CHAPTER TWO NOTES

¹ Terry M. Perlin, Ph.D., has written a concise guide to understanding the role of Advance Care Directives in the patient-doctor relationship in Ohio. His publication is titled: "The Patient-Doctor Relationship and Advance Directives: Implications for Long-term Care in Ohio," This publication is a product of the Ohio Long-term Care Research Project through the Scripps Gerontology Center at Miami University, in Oxford, Ohio. The overview of the use of advance care directives is oriented towards the situation in Ohio but provides general guidance for those who wish to learn more about advance care directives.

² Another case with similar medical circumstances was presented and discussed in an article titled: "Failing to Discuss Dying, Experts Say, Adds to Pain of Patients and Families," The New York Times, Wednesday, March 5, 1997. The article contains not only the words of those involved in the case but facsimile copies of various documents, notes, etc. as well as a timeline of the death of the patient. It is illustrative of the anguish of these cases beyond what the statistics report.

³ §1337.16(D)(1)(b) of the Ohio Revised Code provides that if the patient cannot make a decision for himself concerning treatment and has not made an advance declaration concerning treatment options, the following should be consulted in descending order to make the decisions:

- (a) a guardian, if any, who may have been appointed for the person;
- (b) the person's spouse;
- (c) the person's adult children who can be contacted within a reasonable period of time;
- (d) the person's parents;
- (e) an adult sibling of the person, or if there are more than one sibling, a majority of those siblings.

Most jurisdictions with which I am familiar follow this scheme. However, caution should be used when making assumptions about one's own situation and the law of the jurisdiction where one resides should be consulted.

⁴ Deciding the proper course of treatment for a patient in a permanently unconscious state is a particularly difficult one. In theory a patient could remain on nutrition and hydration and live a long life free of pain. On the other hand, since there are cases where people who have been in such a state for an extended period of time have regained consciousness, it is difficult to decide not to resuscitate or to withdraw life-support treatments. A Summary Report prepared by The Center for Biomedical Ethics of the University of Minnesota titled: "Managing Mortality: Ethics, Euthanasia, and the Termination of Medical Treatment," reported on a conference held at the Center concerning many end-of-life issues. One section of the summary report dealt with patients who had been in a persistent vegetative state and had regained consciousness. Two cases are mentioned specifically. The first is that of a woman by the name of Jacqueline Cole who, at the age of forty-three opened her eyes after forty-seven days in a vegetative state. In her case a probate judge in Baltimore had refused, just six days prior

to her regaining consciousness, her husband's request to withdraw nutrition and hydration. After extensive therapy, Mrs. Cole has returned to an active life with occasional memory lapses being the only permanent sign of her time in the vegetative state. Today, according to the summary report, physicians will not consider removal of life-support after such a short period of time in a vegetative state.

The second case did not have the same good result over time. It involved a policeman in Minneapolis who was shot in the line of duty and went into a vegetative state for twenty-two months. During that time his weight declined to a mere eighty-six pounds. After twenty-two months, he regained consciousness, and through therapy began to make a remarkable recovery. However, he never regained the ability to swallow nor speak. As the benefits of the therapy reached a plateau, Officer Mack's spirits began to sag, and he made no further progress. He died seven years after the initial injury from an infection apparently related to his diminished physical condition. His wife said that after his initial recovery of consciousness, she was sure that he wished to die. At the end he asked only that he be given pain medication and no antibiotics.

Another study done in Scotland reported on one hundred forty patients who had been in a persistent unconscious state. Of these, sixty of the individuals recovered consciousness within twelve months. All of the patients who recovered consciousness after three months were severely disabled after recovering consciousness. The only ones who were able to reach an independent living status were under forty years of age.

⁵ Under Ohio's Living Will Statute a patient in a permanently unconscious state may direct her attending physician to administer no life-sustaining treatment or withhold such treatment if begun. Another physician must concur that the patient is permanently unconscious before the treatment may be withdrawn. By statute, "permanently unconscious state" means a state of permanent unconsciousness that to a reasonable degree of medical certainty as determined in accordance with reasonable medical standards by an attending physician and one other physician who has examined the patient, and is characterized by both of the following conditions: (1) the patient is irreversibly unaware of herself and her environment, and (2) there is a total loss of cerebral cortical functioning, resulting in the patient having no capacity to experience pain or suffering. (See appendix A for pro forma copies of advance care directives under the Ohio statute).

⁶ In some jurisdictions the term "health care surrogate" or "attorney-in-fact for health care decisions" is used rather than "health care proxy." The terms mean the same thing.

⁷ I do not use the phrase "fighting it out" lightly. I heard the brother and the father of the patient verbally threaten to "beat-up" the partner of the patient. I did not see such statements as idle threats, and was very relieved to hear that the parties had been able to get past this stage of their relationship and begin to consider the best interests of S.

⁸ Some of the ethical issues raised by the questions include how one may determine choices in the case where a patient's autonomy has been impaired, who should be allowed to exercise substituted judgement for a person incapable of making decisions, does a patient in a medically futile situation still retain rights to treatment, and who should be allowed to make decisions for the patient when advance care directives give inconsistent direction? There are, of course, many others that may come to mind.

⁹ This long-term care facility is not unique in terms of its policy to encourage DNR status for its residents. In conducting interviews for this thesis I found that in the admittedly limited survey which I conducted, most homes with an aged population encouraged their new residents to sign advance care directives which called for DNR status. What was different about this home was that it required DNR status of all residents until the state required the facility to provide CPR treatment as a minimum. In the state in which this facility is located, a clause in the standard living will form says: "I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged." DNR questions are at the core of this expression. DNR orders allow the person who has one written to choose not to have their life artificially prolonged.

¹⁰ The range of halachic and other Jewish positions will be presented in chapter four of this study.

¹¹ Richard S. Kane, MD, "Cardiopulmonary Resuscitation in the Nursing Facility," The Journal of Medical Direction, (February 1992): 21-27. In this article Dr. Kane discloses that the American Medical Directors Association (AMDA) proposes that the use of CPR in long-term care facilities should be strongly discouraged. He also says that the AMDA will recommend a standard no CPR policy which will require a written "Do Resuscitate Order" signed by an attending physician before any CPR attempts would be made in a long-term care facility. Dr. Kane's position is that in the vast majority of cases performing CPR on nursing home residents results in inflicting harm on them for a very slim chance of potential benefit. He believes that the diminished chance for benefit and the increased likelihood of potential harm permits the physician to refuse to provide CPR. He says that the physician's responsibility to "first do no harm" allows this approach to resuscitation questions.

¹² An article by Hayley et al. presents a good review of the ethical and legal issues that long-term care facilities face which may be distinguished from those that other health care providers may face. We have alluded to some of these in chapter one and in chapter two. This article, however, provides a review of issues beyond Do Not Resuscitate Orders. Deon Cox Hayley, DO; Christine K. Cassel, MD; Lois Snyder, JD; Mark A. Rudberg, MD. "Ethical and Legal Issues in Nursing Home Care," Archives of Internal Medicine, vol. 1196, no. 156: 249-256.

Another study involving CPR in the long-term care setting is: Sissay Awoke, MD; Charles P. Mouton, MD; and Marian Parrott, MD, "Outcomes of Skilled Cardiopulmonary Resuscitation in a Long-Term-Care Facility: Futile Therapy?", Journal of the American Geriatrics Society, vol. 40, (1992): 593. The authors conclude that even with highly trained personnel CPR has little benefit for elderly long-term care residents.

Another study involving 196 nursing home residents in Wisconsin concluded that CPR should be performed only on residents whose arrest is witnessed and who are experiencing ventricular fibrillation. All others, they conclude, should not receive CPR. See: Donald M. Tresch, MD; James M. Nearing, MD; Edmund H. Duthie, MD; David H. mark, MD, MPH; Susan K. Kartes, RN; Tom P. Aufderheide, MD, "Outcomes of Cardiopulmonary Resuscitation in Nursing Homes: Can We Predict Who Will Benefit?", The American Journal of Medicine, vol. 95, (August 1993): 123-130.

¹³ Terry M. Perlin. "The Patient-Doctor Relationship and Advance Directives: Implications for Long-Term Care in Ohio," (Oxford, Ohio: Scripps Gerontology Center, Miami University: January 1996): 1.

¹⁴ Barbara A. Morris, MD; Suzanne E. Van Niman; Terry Perlin, Ph.D.; Karen S. Lucic, MA; Jane Veith, RN; Karen Agricola, FNP; Mary Kay McMurry, FNP, "Health Care Professionals' Accuracy in Predicting Patients' Preferred Code Status," The Journal of Family Practice, vol. 40, no. 1 (Jan., 1995): 41.

¹⁵ Stuart J. Youngner. "Do-Not-Resuscitate Orders: No Longer Secret, But Still A Problem," The Hastings Center Report 17, 1 (1987): 24-33.

¹⁶ Susanna E. Bedell and Thomas L. Delbanco, "Choices About Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk with Patients?" New England Journal of Medicine, vol. 310 (1984): 1089-93.

¹⁷ N.R. Zweibel and C. K. Cassel, "Treatment Choices at the End of Life: A Comparison of Decisions By Older Patients And Their Physician Selected Proxies," Gerontologist, vol. 29, (1989): 615-21.

¹⁸ Leslie J. Blackhall, MD. "Must We Always Use CPR?," The New England Journal of Medicine, vol. 317, no.20, (1987): 1281.

¹⁹ Ibid., 1281. Blackhall presents a scenario in which a patient who is dying of leukemia is offered CPR by the physician when clearly the woman was in a terminal state, and the CPR procedure offered no potential benefit of any type. Rather, she says that the offer of CPR represented the physician's own inability to talk realistically about death with the patient and her family. Further, Dr. Blackhall believes that the proposed treatment also served to make the physician feel better about not being able to defeat death in this instance.

²⁰ The statement provided to the patient did list the phone number of the Social Service Department of the hospital and recommended talking to the physician and other medical personnel. However, the policy and procedures guidelines that the staff consults for guidance in DNR and advance care directive issues did not specifically assign follow-up responsibilities to any one person or to any specific department of the hospital.

²¹ Kane, "Cardiopulmonary Resuscitation in the Nursing Facility Setting," 25.

²² Neil S. Wenger, MD, MPH; Marjorie L. Pearson, Ph.D., MSHS; Katherine A. Desmond, MS; Katherine L. Kahn, MD, "Outcomes of Patients With Do-Not-Resuscitate Orders," Archives of Internal Medicine, Vol. 155, (October 23, 1995): 2063.

²³ Ibid., 2063.

²⁴ Ibid., 2067.

²⁵ Neil S. Wenger, MD, MPH; Marjorie L. Pearson, Ph.D., MSHS; Katherine A. Desmond, MS; Ellen R. Harrison, MS; Lisa V. Rubenstein, MD, MSPH; William H. Rogers, Ph.D.; Katherine L. Kahn, MD, "Epidemiology of Do-Not-Resuscitate Orders," Archives of Internal Medicine, Vol. 155, (October 23, 1995): 2056.

²⁶ Ibid. 2056.

²⁷ As to the issue of inappropriate DNR assignment to elderly patients see: Hamel, Mary Beth, MD, MPH; Russell S. Phillips, MD; Joan M. Teno, MD, MS; Joanne Lynne, MD; Anthony N. Galanos, MD; Roger B. Davis, ScD; Alfred F. Connors, Jr., MD; Robert K. Oye, MD; Norman Desbiens, MD; Douglas J. Reding, MD, FACP; and Lee Goldman, MD, MPH for the SUPPORT Investigators, "Seriously Ill Hospitalized Adults:

Do We Spend Less On Older Patients?," Journal of the American Geriatric Society, Vol. 44, (1996): 1043-1048. The authors conclude: "Compared with similar younger patients, seriously ill older patients receive fewer invasive procedures and hospital care that is less resource-intensive and less costly. This preferential allocation of hospital services to younger patients is not based on differences in patients' severity of illness or general preferences for life-extending care."

²⁸ Barbara E. Cammer Paris, MD; Victor G. Carrion, MD; James S. Meditch, Jr., MD; Carol F. Capello, M.Ed.; Michael N. Mulvihill, DrPH, "Roadblocks to Do-Not-Resuscitate Orders: A Study in Policy Implementation," Archives of Internal Medicine, Vol. 153, (July 26, 1993): 1689-1695. The study interviewed physicians at two large New York medical centers. Several "problems" were given to the physicians, and they were asked to rate them in the order of their prevalence in the clinical setting. The rankings went from a scale of 5 to 0, with "5" being "common" and "0" being "rare." A list of seventeen questions was asked about implementation of DNR orders, and three questions about demographics were asked. The questions are set forth in Appendix A.

It is interesting to note that with both populations, attending physicians and house staff, the same five situations ranked at the top with both groups, although the placement within the top five disagreed between the samples. It is important to note that four of the top five involved issues involving surrogate decision-makers. The fifth most frequent situation encountered was that the doctor does not discuss DNR with the patient. The implication of the ranking is that failure to communicate and/or a lack of communication with a surrogate are often implicated in DNR problems. According to the authors of the study, one of the results of this lack of communication is that the implementation of DNR orders may be applied inappropriately but also that DNR orders are implemented later than they should be. The authors conclude on the basis of their study that policies may need to be reassessed and reformulated to facilitate DNR implementation.

²⁹ Donald J. Murphy, MD and Thomas E. Finucane, MD. "New Do-Not-Resuscitate Policies," Archives of Internal Medicine, vol. 153 (July 26, 1993): 1641. Compare this language and this reasoning with the following quote:

Problem 97:

A mental patient costs about 4RMS [Reichmarks], a day to keep, a cripple 5.50 RMS, a criminal 3.50 RMS. In many cases a civil servant only has about 4 RMS, a salaried employee scarcely 3.50 RMS, an unskilled worker barely 2 RMS for his family. (a) illustrate these figures with the aid of pictures. According to conservative estimates, there are about 300,000 mental patients, epileptics, etc. in asylums in Germany. (b). What do they cost together per annum at a rate of 4 RMS per person? i) how many marriage loans at 1,000 RMS each could be awarded per annum with this money, disregarding later repayment?

(From Adolf Dörner [ed.], Mathematik im Dienste der nationalpolitischen Erziehung mit Anwendungsbeispielen aus Volkswissenschaft, Geländekunde und Naturwissenschaft [Frankfurt am Main 1935], p. 42.)

Assuming an average daily outlay of 3.50 RM there hereby results:

1. a daily saving of RM 245.955
2. an annual saving of RM 88.543.980
3. assuming a life expectancy of ten years

RM 885.439.800

in words eight hundred and eighty-five million four hundred and thirty-nine thousand eight hundred Reichmarks,

i.e. this sum will have been, or has already been saved by 1 September 1951 by reason of the disinfection of 70.273 persons which has been carried out to date
(T-4 internal statistical digest found at Schloss Hartheim in 1945. National Archives Washington, T 1021, Heidelberger Dokumente, Roll 18, Item Nr 000-12-463, Exhibit 39, p. 34.)

Reprinted in:

Burleigh, Michael. Death and Deliverance: Euthanasia in Germany 1900-1945. Cambridge, GB: Oxford University Press, 1994): frontispiece.

CHAPTER THREE

ETHICAL THEORIES AND TERMS

In chapter one, we reviewed the development of procedures included in the term "resuscitation." We looked at the use of resuscitation treatments in different settings. We examined the development of resuscitation from its initial status as an optional medical treatment to its current status as the default protocol when an arrest occurs. In chapter two we looked at particular cases in which problems or conflicts arose in providing or denying resuscitation therapy. We also looked at policies and protocols that have been developed to deal with conflicts and to attempt to provide some uniformity in how "Do Not Resuscitate" orders are implemented. In this chapter, we will look at how the field of bioethics attempts to ensure that the decisions that are made concerning DNR orders are made rationally and morally. In order to do so, we will first survey the philosophical framework out of which bioethics grew and discuss different philosophical theories that are applied to moral and ethical choices. We will also seek to define terms that are frequently used in bioethical discussions. In the final section of this chapter, we will focus on the role of the bioethicist in defining medical choices for medical personnel, patients, and their families.

Throughout our discussion thus far, we have used terms such as "futility," "autonomy," "patient's rights," "best interest," etc. We have used these terms, but we have not defined them. Further, we have not shown where these terms come from, nor

have we established a bioethical framework that can provide a structure for making the end-of-life decisions associated with DNRs. We will now attempt to establish that framework and clarify what is meant by the terms used within that framework.

Admittedly, the discussion of bioethics and philosophical theory in a paper of this scope is daunting. In attempting to define the moral and bioethical framework in which DNR decisions are made and in defining terms used in that framework, I have relied principally on two works. The first of these is Principles of Biomedical Ethics, 4th ed.,¹ by Tom L. Beauchamp and James Childress. The second is Tough Decisions: A Casebook in Medical Ethics,² by John M. Freeman and Kevin McDonnell. The first work is, in my opinion, the best source for materials on both the development of the field of bioethics and defining the terms that are used in the medical decision-making setting. The second work is perhaps the best practical work that I have seen on actual bioethical cases and the theory that has developed to deal with them. The authors use a case study approach to put the reader in the decision-making process. Cases are presented and the reader follows different decision-tree approaches based upon the decision that he or she is forced to make. The cases used cover the full spectrum from euthanasia to resuscitation of the elderly to decision-making for incompetent adults and children. Since the reader does not have the treatment choices made for her, she must experience the difficulty with which such decisions are made. There are real consequences that follow each of the choices made. Real dilemmas are presented, and the difficulty of dealing with dilemmas is experienced. Many times in reading the book I found myself squirming as I attempted to decide what the right thing to do was in a particular setting. This is the nature of end-of-life decision-making, and the authors have put the reader squarely in the hot seat. No

guidance is given concerning the role of ethics or the nature of different ethical theories before the reader is plunged into the case studies. Only after the reader has been forced to make actual decisions are ethical theories discussed per se. We will survey some of these theories now.

Ethical Theories

Freeman and McDonnell explain that: "...the function of an ethical theory is to organize and systematize our morality."³ Here, these terms: *ethics* and *morality* have different meanings. Therefore, we must state what is meant when the terms are used in this discussion. Let us first define what *morality* means. Freeman and McDonnell tell us that when they use the term in their discussion it means: "...the actions or activities for which a certain kind of praise or blame is awarded."⁴ This definition does not presume that a moral act is necessarily a good act. Rather, morality refers to all human action, good or bad. Under this definition, there are two types of activity: actions that are moral and those that are amoral. According to the authors, the latter types of action would include such things as breathing, chewing gum, etc. What is unstated in such a definition is where the boundaries between moral and amoral actions may be drawn.⁵

Ethics, according to Freeman and McDonnell, is a grid superimposed on the field of moral actions. It is the: "...discussion about and theory of morality." The authors go on to suggest that ethics is not really separate from morality even though they view it as a grid. Rather the two are intertwined based upon what we think and what we do. Humans perform certain actions because of the way they think. Under this approach, "...ethics is a theory of morality for participants."⁶

Beauchamp and Childress define ethics somewhat differently. "*Ethics* is a general term referring to both morality and ethical theory. (The terms *ethical* and *moral* are here construed as identical in meaning)." What Freeman and McDonnell call *ethics*, Beauchamp and Childress call *ethical theory* and *moral philosophy*.⁷ Thus, their usage of the term, *ethics*, would include both the actions which Freeman and McDonnell call *morality* as well as the ethical grid that they superimpose upon the moral actions. According to Beauchamp and Childress, *common morality* consists of behavioral norms that have been adopted or approved by society. Thus, the two, *ethics* and *morality*, coincide.

Freeman and McDonnell carry the discussion further. They distinguish between *public* morality and *private* morality. Such a distinction is useful for the purpose of discussing problems that arise in the field of bioethics. Many of the problems that we encounter in the field of medical ethics arise because there is no clear distinction between what is a private act and a public act. What may appear on the surface to be a private act, (e.g. abortion), may have public ramifications because of public policy implications. Likewise, what appears to be clearly a public morality issue may have an impact on personal behavior. The authors maintain that the boundary between public and private morality is where most of the bioethical dilemmas arise.⁸ In the discussion that follows I will use the definitions of ethics and morality in the manner that Freeman and McDonnell use them.

Defining ethics and morality as we have done above serves us by providing a framework through which any act or action may be viewed. Ethical theories also provide us with a means to determine whether an act is morally good or morally bad and why it is

such. That an action may be viewed under one theory as morally good whereas under another theory it might be viewed as bad is less important than that one has a consistent means to measure them. What we are looking for in applying moral theories is to provide consistency in the results of the decision-making process and to be clear in stating the moral issues under consideration. We will now look at two major theories of ethics that are most often proposed as ways of understanding moral choices.

“Since the early part of the nineteenth century, ethics has been dominated by two approaches to distinguishing good from bad.”⁹ The first of these is *utilitarianism*. Jeremy Bentham and John Stuart Mills developed this theory. Utilitarianism judges the goodness or badness of an act based on the happiness it generates. “A utilitarian considers those acts to be right that ‘produce the greatest happiness for the greatest number’.”¹⁰ This defines utilitarianism on the broadest level. Within this category of ethical theory, however, many different subtheories have developed over the years. All of the theories that we might call utilitarian do have certain aspects in common. Freeman and McDonnell state that all are consequentialist, that is the rightness or wrongness is based upon the consequences of the act. But all actions have both good and bad consequences. Therefore, utilitarian theories are really measures of proportionality. That is, the good results must outweigh the bad results for an action to be deemed good. One familiar example of this type of ethical reasoning is applying a cost-benefit analysis to actions. In chapter two we saw this type of thinking connected to a call for new DNR policies.¹¹ We also saw the implications of carrying a cost-benefit approach to the farthest extreme with the policies of the Third Reich.¹²

Utilitarian theories also share a common element in that they all set a standard for the "good" to be achieved. In Jeremy Bentham's definition, good is equal to happiness. Other more modern theories use a "quality of life" standard to measure the good. "Good actions are those, "...that proportionally produce more good than any alternative."¹³ "Good," in this context, means benefits, advantages, and favorable or desirable consequences.

Beauchamp and Walters use a slightly different approach to describe utilitarian ethics. They define utilitarian ethics as "rule utilitarianism." In explaining the role of moral rules and codes of rules, they state that a code is justified if and only if no competing rule or code would have a higher utility value for society.¹⁴ This approach looks also at behavior in relation to its place in society at large, but unlike Hume, rule utilitarianism focuses on the macro level in testing the goodness or badness of a code of conduct. This ethical theory appeals to reason. It says that if you put the good results in one column and the bad results in another, that reason will dictate which approach results in the greatest good. Such an approach, according to Freeman and McDonnell, "...has the advantage of somehow feeling right."¹⁵ We appear to fairly balance out the pros and cons of any action and to come to a conclusion based upon reason.

David Hume, the philosopher (1711-1776), held that: "... the concept of right and wrong is not rational but arises from a regard for one's own happiness. The supreme moral good, in his view, is benevolence, an unselfish regard for the general welfare of society, which Hume regarded as consistent with individual happiness."¹⁶ Thus, this philosopher saw moral good as not arising from reason but from one's own concern for happiness. We shall look at the concept of benevolence in greater detail shortly.

Utilitarianism promises to look at actions rationally. The theory appeals to our sense of what is right. It seems to provide what we need in an ethical theory of decision making. However, there are drawbacks to the utilitarian approach. Since one must determine all the possible consequences of a particular act or rule and then balance the good against the bad, one must carefully make sure that all of the relevant consequences have, in fact, been determined and considered. Further, since risk and probability are involved in making medical decisions, one must be careful to assign the proper risk factors to different treatment options. Doing the calculations once one has made these determinations can be unwieldy. One must take into account not only the costs of a medical decision to a patient, one must consider the costs to a patient's family, the costs to the medical facility, and to society at large. When the costs are balanced, in theory a patient could morally be required to die if it was in the best interest of society at large for him to do so. The results of such a process can be irrational.¹⁷ Are there any other ethical theories that might offer a different or better answer to such questions? We will now look at a second category of theories that focus on duties rather than results or consequences.

"Typical theories of duty pay a great deal of attention to the integrity and importance of the individual and, since they do not rest their moral evaluation on consequences, they do not get snarled in the objectionable calculations of utilitarianism."¹⁸ There are those who would disagree with this statement. Many would argue that utilitarianism does, in fact, provide an appropriate framework for looking at end-of-life decisions. Theories based upon duty attempt to deal with the problems encountered by the utilitarian approach by developing rules that help us determine the

right and wrong in a given case based upon universal principles that will apply in every similar case. This type of ethical theory is often called *deontological*. Deontological theories rely on a system of moral duties to determine whether an act is right or wrong.

Immanuel Kant, a late eighteenth century philosopher (1724-1804), is the father of this type of ethical theory. This type of ethical theory is called *deontological*, that is, it creates duties which we owe one another. Kant described moral duty as being based upon universal rules of right action that he calls *categorical imperatives*. This is how he described such imperatives:

On this positive conception of freedom in the practical relation certain unconditional practical laws are founded, and they specially constitute moral laws. In relation to us as human beings, with an activity of will modified by sensible influences so as not to be conformable to the pure will, but as often contrary to it, these laws appear as *imperatives* commanding or prohibiting certain actions; and as such they are *categorical* or *unconditional* imperatives.... According to these *categorical imperatives*, certain actions are allowed or disallowed as being morally possible or impossible; and certain of them or their opposites are morally necessary and obligatory. Hence, in reference to such actions, there arises the conception of a duty whose observance or transgression is accompanied with a pleasure or pain of a peculiar kind, known as moral feeling... Obligation is the necessity of a free action when viewed in relation to a categorical imperative of reason. An imperative is a practical rule by which an action, otherwise contingent in itself, is made necessary.¹⁹ [Emphasis added].

Kant revised his work on categorical imperatives and treated the matter in his work: Fundamental Principles of the Metaphysic of Morals. About the subject he said::

When I conceive a hypothetical imperative, in general I do not know beforehand what it will contain until I am given the condition. But when I conceive a *categorical imperative*, I know at once what it contains. For as the imperative contains besides the law only the necessity that the maxims shall conform to this law, while the law contains no conditions restricting it, there remains nothing but the general statement that the maxim of the action should conform to a universal law, and it is this conformity alone that the imperative properly represents as necessary. There is therefore but one *categorical*

imperative, namely, this: Act only on that maxim whereby thou canst at the same time will that it should become a universal law.

Now if all imperatives of duty can be deduced from this one imperative as from their principle, then, although it should remain undecided what is called dutyyet at least we shall be able to show what we understand by it and what this notion means. ...since the universality of the law according to which effects are produced constitutes what is properly called nature in the most general sense (as to form), that is the existence of things so far as it is determined by general laws, the imperative of duty may be expressed thus: Act as if the maxim of thy action were to become by thy will a universal law of nature.²⁰

Kant was concerned with morals and duties, and he saw these as being distinct from the empiricism of thinkers like Hume, that had characterized philosophy before him. An act was to be determined right or wrong based upon whether such act measured up to the duty owed to another human being rather than because empirical data indicated that the results of such act would result in the greatest good. In short: "Act so that you treat humanity, both in your own person and in that of another, always as an end and never merely as a means."²¹

In today's terminology this categorical imperative is often referred to as the "respect principle." While it is couched in terms of "respect," it still represents the underlying theory of duty. Under a Kantian theory we have certain, specific obligations because of the universal categorical imperative. Thus, we may have duties to our children which arise out of a rule of promise keeping, the rule imposed upon us as parents, etc. Beauchamp and Childress see the potential for conflict under such a system. They give an example where a parent has promised to take a child on a long awaited trip, and at the moment of departure, they learn that one of their parents is ill and must be attended to. Since there are obligations that arise under each of the separate duties, the parents cannot fulfill both sets of obligations. Yet, Kantian theories of moral choices

seem to require just that. Beauchamp and Childress say: "...yet no clear path exists out of Kant's absolutist framework...Either we must accept a system with only one absolute, or we must give up absolutes altogether unless their meaning and scope can be specified to avoid conflict."²²

Having said this, Beauchamp and Childress propose a refined way of looking at Kantian theory. I summarize their position as follows:

- Principles are central to a common-morality.
- Principles are *prima facie* binding.
- Principles are specifiable.
- Principles must be subject to revision. That is they cannot be absolute and unchanging.

They give an example of this: "...although murder is absolutely prohibited because of the normative word *murder*, it is not plausible to hold that killing is absolutely prohibited. Killing persons is *prima facie* wrong, but killing to prevent a person's further extreme pain or suffering is not wrong in every circumstance. Killing may be the only way to meet some obligations, even though it is *prima facie* wrong. However, when a *prima facie* obligation is outweighed or overridden, it does not simply disappear or evaporate. It leaves what Nozick calls 'moral traces' which should be reflected in the agent's attitudes and actions."²³ I will examine the concept of killing in more detail later in this chapter.

Beauchamp and Childress say that their position toward the respect principle and their formulation of a theory based upon the centrality of principles has led some to conclude that: "...the principles upon which men reason in morals are always the same; though the conclusions which they draw are often very different."²⁴ The authors respond by saying that there is an inevitable relativity of judgment but not a relativity of the

principles. Thus the common morality is left intact along with the principles that are derived from it.

Let us return for the moment to the notion of the respect principle. One of the more important principles in bioethics that arises from the respect principle is the concept of *informed consent*. Since we have the duty to respect others, we cannot provide medical treatments to them to which they do not consent. If we treated them without their consent we would be controlling them and treating them as objects. We would be violating their moral autonomy. We would not be respecting them. We would violate our duty to treat others as autonomous people. Kantian theorists would argue that the respect principle serves as a good ethical guide because it may be universally applied. That is, if you do not want to be treated without your consent, you must treat others likewise. Thus, "...the Kantian perspective in medical ethics...has strongly criticized paternalism...while emphasizing truth-telling, autonomy, and informed consent."²⁵

Duties may be further subcategorized into positive duties and negative duties. Positive duties require us to act in specific ways. Negative duties require that we refrain from acting in certain ways. Typical of this type of duty are the Biblical duty, "Thou shall not murder," and the duty from the Hippocratic oath, "First, do no harm."

Positive duties may arise out of social obligations, out of a contractual relationship, or because of duties imposed by a code of professional conduct under the guidelines of the American Medical Association, the American Bar Association, etc. These duties arise because of the relationship between the parties. If there is no professional relationship between two people, there can be no duty other than the duties imposed under a Kantian system of categorical imperatives that would apply to all

members of society. Thus, if a doctor has refused to see a patient (because of caseload, limited medical practice, or whatever), there will generally be no duty to heal a given patient. Once the physician establishes a relationship with a patient, the duties imposed by the profession come into play. Let us look a little more closely at the duty to heal.

The duty to heal has different meanings in different settings. In the secular realm, this duty may be viewed in terms of attending to the "best interest" of the patient, a term which we shall look at more closely shortly. In his essay titled, "On (Only) Caring for the Dying," Ramsey states the physician's duty as one "to heal and to save life." He says that there are three interrelated distinctions involved in this duty: "...the distinctions (1) between 'ordinary' and 'extraordinary' means of saving life; (2) between saving life by prolonging the living of it and only prolonging a patient's dying; and (3) between the direct killing under certain conditions of specifiable sorts of 'hopeless' cases (called euthanasia), and merely allowing a patient to die by stopping or not starting life-sustaining procedures deemed not morally mandatory."²⁶

In using this terminology Ramsey intends to provide a framework, which enables end of life decisions to be made free of a moral bias that may obscure the options which should be considered from a strictly medical point of view. But in creating his framework he has used terms such as "ordinary," "extraordinary," "hopeless cases," and "morally mandated." Each of these terms is subject to differing interpretation. Each of these terms may take on a different flavor if one is basing one's decisions on a deontological theory of ethics or one is approaching the same questions under a utilitarian theory. One physician may react differently to these words than another physician. The patient may react in his own way to these terms. If the terms that we use to describe the

treatment options are inevitably subjective, how do we then determine the proper course of conduct? How do we decide what is "morally mandatory?" Beyond determining which ethical theory seems to provide a better framework for answering these questions, we must also seek to define the terms used in that discussion as clearly and as universally as possible. The field of bioethics attempts to answer, or at least, to help frame these questions and to come up with the definitions. But one further element of a theory of duty must be noted before we set out to define and discuss certain terms. We must first look at the two subcategories of duties: positive and negative duties.

Ethicists generally regard negative duties as more basic or fundamental than positive duties, which may or may not apply in a given situation. Sometimes the distinction between the two is not always easy to set out. Freeman and McDonnell give the example of the difference between killing, (prohibited by a negative duty), and "letting die," or active vs. passive euthanasia.²⁷ The distinction between the two may not be as clear as the distinction between other duties that may arise if one views withdrawal of nutrition and hydration as the withdrawal of "medical treatments" vs. the "starvation" of a patient. There are moral theorists who view such withdrawals in each of these ways. Each may be basing her decision on a theory of duty. Yet each comes to a different perception of whether the withdrawal of treatment is warranted, or permissible, or right or wrong based upon his or her own concept of duty.

The duty to provide medical care varies from medical situation to medical situation. The duty to refrain from killing does not vary nearly as much. Society has carved out exceptions to the general duty not to kill to provide for wartime circumstances, capital punishment, and other very specific cases. Thus, the negative duty

of not killing is much stronger than the duty to treat a patient. A theory of ethics based upon duty may fall short of providing a solid framework for making medical and moral choices when there is a conflict between a negative duty and a positive duty and the duties are not clearly defined or that may involve more parties than just the doctor and the patient. An example of this is the problem of making distinctions between ordinary care and extraordinary measures. The distinction between the type of treatments that may be included in the former category and those which fall into the latter may not be apparent to all involved in the decision-making process. Likewise, not all those involved in making the decision may agree on whether certain duties are in fact positive or negative ones. Codes of professional ethics and protocols for medical treatment have been created to determine the course of treatment in such cases. In response to some of the perceived shortcomings of both ethical theories that are based on utility and those based upon duties, new approaches have been set out that are allied to the theories based upon duties, but which speak in terms of rights.

“The theory of duties and the theory of moral rights are usually thought of two sides of the same coin.”²⁸ If someone has a right to receive something, someone else must have the duty to provide that something. Similarly, if I have a duty to perform an action, someone else must have the right to be the recipient of that action, assuming two parties are involved in the act. Generally, we may say that rights and duties have a correlative relationship. Philosophers differ as to whether duties arise from rights or rights result from duties. Each position has its advantages. If one believes that duties are primary, there is a clear philosophic theory to uphold such an approach, as we have seen. However, if one begins with the primacy of rights, all of the founding documents of our

republic as well as two hundred years of case law have reinforced the centrality of rights as the foundation of our society. As Freeman and McDonnell say: "No one can have too many rights."²⁹ Having rights and lots of rights is seen as a "good" in itself. And yet it has been because rights sometimes conflict that the end of life questions which this paper discusses become difficult to resolve and the need for a bioethical framework for making decisions becomes more essential. An issue that is outside the scope of this paper, but which serves as an illustration of this point involves the issue of abortion. Much of the conflict which arises in the abortion arena comes about because of a perceived conflict between the rights of the mother for autonomy and the control over her body and the rights of the fetus which have up until this point not been articulated in the Constitution or in a consistent manner in state law.

A second reason for conflicts arising under the umbrella of rights is that there may not be a clear understanding of the source of the rights claimed. Do certain rights arise out of a commonweal? Are they created under a governing document? Are they "inalienable" and "God-given?" Many moral dilemmas arise because of these questions. Some theorists derive rights from the respect principle. The result is that they become subservient to the duties under which they arise. Their moral force is somehow weakened if they cannot stand on their own.³⁰ But one may ask whether any right or anything else is self-evident. This is a legitimate question. Adherents to rights-based theories would propose that the rights are based on reason even if not self-evident.

A third problem with basing medical decisions upon theories of rights is that medical rights have mushroomed as medical treatment options have developed. A right to refuse resuscitation did not exist prior to the possibility of resuscitation. If we consider

the tremendous medical advances made in the past thirty-five years, it is easy to see that theories based upon rights would have a difficult time keeping up with the changing technologies. It is because the creation of rights within the judicial arena moves so slowly that courts have to resort to legal fictions such as "a penumbra of the tenth amendment," (literally, a "halo" of the amendment), in order to protect a right to privacy where an explicit one did not exist.³¹ The right to privacy in matters of birth control was the first right that was found to be within the "penumbra" of privacy rights. The court, in this instance, could not find a specific right to privacy within the constitution of the United States, but it found the right to privacy in the marital relationship so important, that it used a process based upon reason to "find" such a right.

Another point that may serve our discussion of the theory of rights is making a distinction between what some call *claim rights* and what may be called *liberty interests*. Claim rights create a duty on the part of another to respect that right. Freeman and McDonnell see voting rights as just such rights because they cause elected officials to provide the opportunity for citizens to vote. Liberty interests, on the other hand, are broader. They are generally created by a system of law or governance, and require others to refrain from interfering with one's liberty. Examples of these types of rights might be freedom of speech, of the press, etc. These latter types of rights are ones that are generally created by a social contract or a governing instrument. Since they tend to impose negative duties, members of the society more generally support them than claim rights which may give way to budget cuts, changes in political winds, etc.

In all of the forgoing discussion concerning ethical theories, moral duties, and moral rights, the underlying reason for examining different ethical theories has been to

arrive at a system or framework that will enable us to resolve the difficult, end of life questions with which we as a society are faced every day. These questions and issues arise because of what may be termed moral dilemmas. "A lemma is a subsidiary proposition assumed to be valid and used to demonstrate a principle proposition."³² A dilemma arises when two subsidiary propositions appear to conflict even though both claim to support the principle proposition.

Moral dilemmas are of two types: (1) a certain act may be viewed as morally right and the same act may be viewed as morally wrong; there is some evidence for each position. (2) A person is obligated under one set of moral norms to do one act, and is obligated under a different moral norm or norms to do another. Neither set of moral norms seems to outweigh the other.³³ Yet the defining terms and the moral issues still must be categorized before rational choices can be made about alternatives in treatment. Ruth Macklin, speaking about the two principal types of ethical theory that we have looked at-the utilitarian and the duty based theory-says:

"One of the leading methods of moral decision-making requires an assessment of the probable consequences of each alternative facing the decision maker. The decision is then based on the course of action likely to yield the best consequences. However difficult it is to predict the consequences accurately, it is a worse failure to ignore the task altogether... Another leading method of moral decision-making requires a determination of the rights and obligations of all relevant parties."³⁴

What is critical here is not to restate the theories already presented, but to focus on her statement that the failure to deal with the dilemmas that are at the heart of the treatment-decisions is an abandonment of the purpose of the ethical theories themselves.

One further point should be made about the nature of ethical questions. It is necessary to distinguish between substantive ethical questions and procedural questions.

Substantive questions are rooted in moral principles, most of which have their basis in philosophical ethical theories or in religious precepts. Substantive moral questions ask 'What is the ethically right thing to do?'... Procedural questions are 'Who should decide in morally troubling cases?'... It is not uncommon for substantive and procedural questions to be lumped together in discussions about cases, but it is important to keep them distinct.³⁵

The importance of framing ethical issues clearly and making distinctions between substantive and procedural issues will become more apparent as we look at specific bioethical concepts and terms and examine the role of the bioethicist in the following sections of this chapter.

Bioethical Terms and Concepts

Our discussion thus far has focused on the description of different ethical theories within philosophy. We have discussed the two major theories of bioethics, utilitarianism and what may be called deontological or duty-grounded theories. We have traced the development of duty-based theories from Kantianism to modern theories based upon the respect principle. We have seen how the duty-based theories have given rise to corollary theories based upon rights. Throughout the discussion we have left terms and concepts such as bioethics, autonomy, utility, etc. largely undefined in order to focus on the theories themselves. Now we turn to a closer examination of some of the aforementioned concepts that were raised in passing

Ethics

As stated at the beginning of this chapter, this term as well as others has differing meanings in different settings. For our purposes the definition given by Beauchamp and Childress will suffice for the moment. "*Ethics* is a generic term for various ways of understanding and examining the moral life."³⁶ There are two subsets of the body of ethics: *Normative ethics* and *non-normative ethics*. Beauchamp and Childress describe normative ethics as: "Inquiry that attempts to answer the question 'Which general norms for the guidance and evaluation of conduct are worthy of moral acceptance and for what reasons'...?" Attempts to work out the results of applying the theories are called alternatively *applied ethics* or *practical ethics*³⁷. The use of the term practical or applied is meant to suggest going beyond the development of theory to actually using the theory to answer questions and problems that arise in certain areas (for our purposes, those that arise in the area of biomedicine).

Non-normative ethics moves beyond the scope of normative ethics outlined above. Rather than trying to evaluate conduct to determine whether the conduct is moral and should be followed or to establish rules, non-normative ethics is more concerned with the reasoning process that people use and how they act. There are two categories of non-normative ethics: *descriptive ethics* and *metaethics*. Descriptive ethics uses scientific methods to determine how people *in fact* act and not how they are *supposed to* act. *Metaethics* looks at the methods of reasoning, the language and terminology used, and the concepts that are discussed. It relies on logic and patterns of reasoning to categorize issues and problems.³⁸ A good example of descriptive ethics would be a sociological or

anthropological study of what a group of people within a particular society actually do as opposed to what the laws or rules say that they should do.

Biomedicine

Biomedicine is a term used to define the areas of biological science, medicine, and healthcare in general.³⁹ The term is a broad one that has evolved over the past few years to define the area that is the focus of bioethics. It is a term that contains elements that are included in other fields and that may stand alone as distinct subcategories of the sciences. By incorporating them within a general category, the distinct elements may be viewed together as having special relationship to one another. Thus, the act of dying may be viewed as more than a biological fact, more than the failure of medicine to find a cure, more than the end of a life. Rather, all of these disparate elements may be brought together under one label to facilitate the answering of questions and the formulating of policies. Bioethics may be viewed as the application of ethical thinking and theories to the area of biomedicine. As such, bioethics is a very young discipline or school of ethics. Although the field existed before the mid-nineteen seventies, it began to rapidly grow in the "aftermath" of the Karen Quinlan case in 1976.⁴⁰ The terminology used and the principles that are applied to the cases that come under consideration are from the broader field of ethics. However, the development of modern medical treatments and the corresponding changes in lifespan and the dying process have driven the creation of a new role in the field of ethics: the bioethicist. The role of the bioethicist will be discussed later in this chapter.

Beneficence

Beneficence is a fundamental principle in the area of bioethics. In balancing between interests and weighing benefits versus harms, one must choose the "...course of action likely to result in a balance of benefits over harms. In bioethics this ethical principle is commonly called the principle of beneficence. It directs doctors and other health-care workers to do good."⁴¹ Doing "good" is not always easily defined. Yet this is one of the goals of bioethics.

The principle of beneficence directs the decision-maker to choose the action with the best probable consequences. For medical professionals, the consequences almost always refer to the patient alone. Yet more generally, the consequentialist approach to ethics mandates taking into account the interests of all who stand to be affected by the decision...Since the ethos of medicine and health care directs physicians, nurses, and medical social workers to focus primarily, if not solely, on the health and well-being of the patient, the principle of beneficence is as individualistic as the respect-for-persons principle.⁴²

A utilitarian approach to the ethical issues involved is being used in the forgoing discussion. An approach that uses a duty-based theory would focus on duties owed and rights to be respected. It would not seek to determine or balance consequences. The patient would be respected as a human being and a patient. Rules for ensuring that the rights were respected would be formulated. Rules and guidelines would clearly specify the duties to be performed in individual cases. The idea that beneficence is individualistic certainly seems appropriate for a utilitarian approach to the questions. What may not be as apparent is that a duty-based theory might be individualistic as well in that different principles may be called into question from case to case.

Nonmaleficence

If beneficence means doing good, then the "...version best known to the medical profession is the ancient injunction 'Do no harm.' In that form it is sometimes termed the 'principle of nonmaleficence...'"⁴³ Clearly one principle is related to the other. In this regard the idea of thinking of the principles in terms of positive and negative duties may be useful. If I respect another individual, if I have a duty to that person based upon our roles within society I will try to refrain from causing them harm. If we have a professional relationship, I may have a further, positive duty to heal them. Nonmaleficence requires me to act towards another so as not to cause them harm. We must also respect the person's autonomy.

Autonomy

The principle of autonomy has become increasingly important in the field of bioethics as more and more medical treatments have been devised to prolong life and to restore a person to life in circumstances in which previous generations had no such options. Autonomy has become the focal point for many bioethicists when dealing with patients who are incompetent or were never competent.

"To respect the autonomy of a competent patient is a moral requirement in the physician-patient relationship, a requirement only recently acknowledged and accepted by many doctors. However, the principle of autonomy has an important corollary: patients with diminished autonomy stand in need of protection. Such patients suffer an impairment in their capacity for self-rule, yet that capacity is not entirely lacking..."⁴⁴ An impairment of capacity cannot act as the negating agent of a person's autonomy. It

can only serve to change the extent of that autonomy quantitatively and the manner in which it is exercised. One may retain some autonomy even if one is currently incapacitated. A person may make medical decisions through the use of a living will, a durable power of attorney for health care, or some other arrangement. The medical care providers must respect those decisions and choices. Thus, the autonomy of the individual is preserved.

In speaking of a class of cases that came before the courts involving the rights of members of the Watchtower Bible Tract Society, (Jehovah's Witnesses), to refuse specific medical treatments, Ruth Macklin has said:

For the physician the conflict is between respecting the patient's autonomy, the right to refuse a recommended medical treatment, and striving to promote the patient's best (medical) interest. Everything in a physician's training propels him in the direction of prolonging life, curing disease, and bringing about the best possible outcome for the patient. But in these Jehovah's Witness cases, the 'best outcome' is viewed quite differently by doctor and patient. The best medical outcome is not always the same as the outcome the patient prefers—a variance that underlies numerous conflicts between physician and patient.⁴⁵

Note that autonomy is a concept that has been given legal standing by the courts in recent years. We describe autonomy in this context as "patients' rights." Robert Veatch has discussed the role of rights in the ethical decision-making process at length. He argues that autonomy is supreme even as he admits that this autonomy must have limits placed upon it when other rights may come in conflict.⁴⁶ As stated above, such a position sounds correct since it seems to be a restatement of those principles enumerated as God-given rights and liberties guaranteed by the governing founding documents of the

United States. Denial of autonomy in the medical setting may also be evidence of paternalism that is not viewed favorably by philosophers.

Paternalism

In an earlier comment, I criticized behavior that I considered to be paternalistic. I do not believe that physicians should act in a paternalistic manner. They should not operate on the basis that whatever they decide is best for the patient.

Robert Veatch of the Hastings Institute has introduced the phrase '*generalization of expertise*' to characterize the tendency of physicians to move from what he terms their legitimate area of medical expertise to assume the status of moral experts... The view that physicians and nurses should stay within their technical and medical expertise and not venture into the sphere of moral decision making is widely held in the medical ethics community. Philosophers are very wary of *paternalism* or interfering with someone's choices for that person's own good.⁴⁷

In speaking to bioethicists, I found that this concern was very high on their lists of problems with end of life decision making. When speaking with physicians and nurses, I found that they generally assumed that when they stepped outside of what Robert Veatch calls their "legitimate area of medical expertise," they viewed such actions as medically necessary or an extension of their medical treatment of the patient. They also defended such acts as being in the "best interest" of the patient. Such a view of the role of the physician suggests problems with what philosophers call *paternalism*. "Put simply, paternalism is the denial of autonomy. It is direct interference with the individual's exercise of self-rule through either coercion or deception. A key element in paternalism is the reason given for the coercion or deception; it is alleged to be for the welfare or in the best interest of the person being coerced or deceived."⁴⁸ Failure to convey

information to the patient or her family could also be paternalism. This is one reason that many call for clear guidelines for procedures, regular ethical consults, and oversight of the medical staff.

Best interest

"Best interest" is a term which suggests that whatever course of action is taken produces a "good" result or outcome for the patient. The term comes from "...the realm of trust accounts and financial management, where trustees or guardians act in the financial interest of others. In a financial context the meaning of best interest is clear because, when it comes to money, more is better."⁴⁹ Applying such a standard where a life is concerned may not be so clear cut. Defining what the best interest of the patient is can lead to conflict when the family, patient, and medical caregivers do not share the values underlying the decision-making. Ruth Macklin says:

In the clash of values-the conflict between respecting the family autonomy and acting in best medical interest of the child [or incompetent person] who is a patient-the moral weight lies in the side of preserving life and health. In other instances, where the risks of medical treatment are greater and the benefits less certain, that moral conclusion would not be so compelling. There are no absolute values, either in medicine or anywhere else in human activities. It is that feature of our moral life that makes dilemmas so frequent and so difficult to resolve.⁵⁰

In short, there is no single best interest standard that may apply to every situation that doctors, patients, and families confront.

Substituted judgment

When we have discussed cases involving patients who were comatose or did not have the mental capacity to make medical treatment decisions, we have looked at who made the decisions for them and how those decisions were made. We have reviewed ways in which treatment decisions may be made in advance through the use of advance care directives such as Living Wills, Durable Powers of Attorney for Health Care, and Do Not Resuscitate orders. Each of these mechanisms seeks to preserve the autonomy of the individual by giving that person the right to make medical choices directly or through another should they become incapacitated. The use of such mechanisms has provided greater autonomy in certain medical situations. It has not, however, eliminated all problems, as we have seen.

Each of these documents provides for the preservation of some level of autonomy by enabling medical care givers to make treatment decisions based upon the wishes of the patient. We have seen how there may be shortcomings in each of the different approaches. One of the greatest of these shortcomings may be that in the case of incapacity, another must make the judgment as to treatment options. This decision-making capacity rests in a third party and constitutes "substituted judgment." One of the drawbacks of the notion of substituted judgment is that such a standard assumes that the person who is, in fact, making the decision knows the exact wishes of the incapacitated person. We saw in chapter two that doctors in one study were poor predictors of the actual wishes of the patient with regard to DNR status. We have also seen that relatives of the patients may be only slightly better than doctors in predicting such status.

Likewise, we have seen that attempting to make the decisions based upon policies has its shortcomings as well.

One problem with substituted judgment is that "...there is no single best interest standard to apply."⁵¹ What the best interest is may vary from case to case and from person to person attempting to substitute his or her judgment. If there is no universal best interest standard to apply to these cases, can we come up with another substituted judgment standard that will work?

Some have suggested that we should use a "reasonable man" standard. This standard comes out of the field of tort law. The reasonable man standard requires that a person act as a reasonable person would under the actual circumstances that govern the case in question in order to avoid legal liability for harm sustained by a plaintiff. If one acted as the reasonable person would, no liability would ensue. If one did not, then one may be found liable for the harm sustained.

In the area of medical practice as well as other special areas of the law, a different, higher standard may be applied to the case. If the defendant is a doctor, he or she must act as the "reasonable doctor" would in the same circumstances in the same location. The courts have used an implied reasonable man standard in some of the bioethics cases that they have reviewed. As Freeman and McDonnell state: "The problem with this standard is that we are using it to invent the actions of infants or the retarded."⁵² Such is the nature of decisions based upon substituted judgment. One may never really know what a given patient in a given situation would have wanted if they did not state their wishes in advance in an advance care directive. Substituted judgment is invoked in medical cases only because it somehow how seems to be a more ethical way

of making decisions than any other. It further seems to be more supportive of the autonomy of a patient. Yet as we have seen, there are still problems with such an approach.

Justice

Another term that has parallels in the world of law is the concept of justice. In society and on the individual level we say that: "A person has been treated justly if treated according to what is fair, due, or owed." A minimal theory of justice might "like cases should be treated alike."⁵³ Within the overall category of "justice" there are different theories of justice. The first of these we will call "egalitarian ethics." Such a system of justice would require that all should have equal access to goods, services, etc. This type of theory coheres well with the categorical imperatives of Kantianism and notions of common morality. Many different descriptions of such a system abound in the literature. All have in common the notion that there is a distribution of goods or services to everyone similarly situated in a similar fashion.

Diametrically opposed to any egalitarian theory of justice are libertarian theories. Fundamental to characterizations of this type of theory are an emphasis on liberties, a respect for autonomy, and equal access to the instruments of economic practice. According to Beauchamp and Walters, in some libertarian systems, pure autonomy may be the only governing principle. They point out that most philosophers criticize such an approach because it ignores the fact that communal efforts and interactions are what creates economic value to begin with. Thus, to make autonomy the sole principle, ignores the reality of the communal aspects of society, whether they are economic, health

related, or other.⁵⁴ Further, if we base health care decisions on economic libertarian theories alone the resulting policies and decisions may lead to results that we do not want. We saw the terrible consequences that an economic approach to the treatment of individuals brought about in the case from chapter two dealing with the Nazi "disinfection" program.

Futility

In making health care decisions medical treatments are discussed that are classified as "futile." Medical personnel use the term to mean that a given treatment will not restore a person to a state of being healthy. But when the term is used in this context, there are often two meanings for the word "futile." Often this is done deliberately in order to allow the medical personnel to pursue the treatment option that they prefer. For our purposes, however, we must distinguish between quantitative futility (low probability of success of treatment) and qualitative futility (e.g. poor quality of life if CPR were performed).⁵⁵ In a system where actions are to be evaluated based upon notions of utility, either type of futility may lead to the same result. Under a duty-based theory, where duties are universal and consistent, independent of a cost/benefit analysis, abandonment of or failure to start a treatment may be appropriate under the first type of futility, but not on the other, which depends upon a subjective quality of life standard.

Definitions of futility err too much... when the definition is tied to specific quality of life judgments. Such judgments make assumptions about the proper goals of medicine that have not been validated through broad and open dialogue. Why is it 'futile' for instance, to provide resuscitation or other life-prolonging intervention for someone who is permanently unconscious? Assuming the patient is not suffering from other medical conditions that would mitigate against it,

resuscitation of such a patient could well be successful at expanding the patient's life.⁵⁶

Most medical treatment decisions that involve issues of futility are deeply connected with values of the patient and values of the medical care providers. Because of this, most medical facilities have futility policies.

Tomlinson and Czltonka tell us that they consider hospital futility policies "ethically defensible," but they feel that futility questions need to be a part of an overall decision-making process dealing with the limitation of treatment.⁵⁷ They suggest a model to deal with the value-laden nature of futility policies. Their model includes the guidelines that I paraphrase as follows:

- The policy should not allow the attending physician to make the futility judgment on his or her own without peer input.
- Where there are conflicts or potential conflicts between the values of the professionals and others, broad validation of the values should be gathered across the spectrum of opinions.
- The policy should require disclosure of DNR decisions, and promote discussion around death and dying issues.
- The policy should not define the term *futility* narrowly and should take into consideration of nonbiomedical goals for medical treatment.
- The policy should encourage patient and family acceptance of futility judgments. They should not require the patient's or the relatives consent to a Do Not Resuscitate Order as a condition of the acceptance of the futility judgment.⁵⁸

What the authors are suggesting in the article is that too often futility policies are used by physicians in inappropriate ways. They also suggest that once a physician has made a determination that CPR is futile, they may withhold scarce resources or expensive treatments. While the decision concerning futility of CPR may be appropriate, the abandonment of other treatments may not be appropriate. Minimally, the authors suggest that the patient or the patient's surrogate decision-maker should be informed of the

futility decision and the basis for the decision. They say that this is frequently not done. Another problem appears to be that often the futility policy and the resulting decision is ignored when talking with the patient or family members.

Even in cases where the physician has made a sound prior determination of futility, when she gets face-to-face with the family, she will often revert to the language of consent by faithfully presenting the dismal facts of prognosis and then asking the family what they would like done...It may also seem to be less 'threatening' or 'confrontational' than directly asserting any claims of medical authority.⁵⁹

This way of dealing with the difficult medical choices can lead only to confusion and anger between the parties. If policy precludes treatment based upon objective medical criteria, and the implementation of the policy follows clear guidelines such as those set forth above, there is no reason to invoke the language of consent. Medical authority is a sufficient argument. How the results of the decision-making process are conveyed to the patient or family is another matter.

The medical staff frequently does not "get it" when they use unclear language to talk to the patient or his relatives or when there is no consistent presentation of the futility decision to the parties. "Frustrated by the family's persistence in making the wrong choice, physicians will turn to the futility policy and the authority it grants to physician judgments as a trump card that is played as an ultimatum. Rather than being used in a manner that facilitates family understanding and acceptance of the futility of CPR, the policy becomes just one more ratchet in an escalating confrontation."⁶⁰

Futility is not an easy thing to define or measure. In the medical field, criteria have been established to facilitate the making of futility judgments. According to

Tomlinson and Czlonka, a procedure is quantitatively futile if it has less than a one percent possibility of succeeding. A procedure is qualitatively futile if it only preserves permanent unconsciousness or fails to bring the patient to a state in which she is no longer dependent on intensive medical care.⁶¹ One can see where such definitions are subject to disagreement by physicians, ethicists and lay people. "Success" is too vague a term without further definition. What a physician who makes a million dollars per year, spends her time attending conferences, and who leads an active lifestyle considers to be a success may not agree with what the patient considers to be a success. If the term "success" means that the medical procedure restores the patient to a state in which the underlying medical condition is no longer present, that measure of success may be too restrictive. Likewise, a qualitative definition that relies upon ending dependence on intensive medical treatment falls short of precision.

Take, for example, a medical situation with which I am familiar. The patient has been admitted to the hospital for treatment of multiple illnesses related to impaired kidney function. While in the hospital, hemodialysis treatments were begun to cleanse the blood. After one week in the intensive care department and one week in the Skilled Nursing Unit of the hospital, the patient was discharged from the hospital to the nursing facility, where she and her husband reside. By all measures, the treatments restored function to her kidneys and circulatory system. However, following the criteria set by Tomlinson and Czlonka, the treatments are a failure in that the patient must have these treatments for six hours a day, three days a week, in order to prevent her death. By their criteria, the treatments are futile in that they do not end her dependence on intensive medical care. Perhaps, in fairness to the authors, they do not consider medical

procedures that require a patient to be connected to a dialysis unit for six-hour sessions on three days a week "intensive medical care." Perhaps not, but the definition of futility that they construct depends upon a subjective assessment and valuation of treatment options and their suitability for particular patients. Accordingly, the second element of their guidelines seems crucial to me. Any policy for futility decision-making must include some element of peer input as well as opinion from non-specifically related field of expertise. We must be careful when we put a measure of quality on a person's life.

Quality-of-Life

Much of the discussion in the popular press today concerning death and dying and physician-assisted suicide raises the question of quality of life. In the area of CPR and DNR orders, the term has become a part of the discussion as well. We have seen that the concept of the quality of a life is completely subjective, and may differ among physicians and patients, patients and families, and from individual to individual under similar circumstances. When we discussed the concept of justice, we established that systems of justice might be egalitarian or libertarian. When looking at allocating medical resources or when determining who gets medical treatments, an egalitarian approach to justice would require that the resources be allocated in an equal manner. All patients similarly situated should receive similar treatment. Under libertarian theories, a patient's autonomy must be respected, in some cases, at all costs. In order to respect the autonomy of the patient medical care providers must ensure that the patient is given every possible treatment option that is deemed appropriate.

Yet a quality-of-life argument may be easier to make under a libertarian theory of justice. If the patient decides that his life no longer has "quality," he may choose to end that life. In order to make that decision and to support the patient's autonomy, the physician must take the person's convictions about quality-of-life into account when discussing treatment options, even if that means withholding treatment that the physician has determined to be necessary and not medically futile. An egalitarian theory seems to force a decision to treat regardless of the quality-of-life after the treatment is performed, while a libertarian theory seems to place too much emphasis on the quality-of-life argument. Ruth Macklin asks:

Is choosing continued life over certain death always the morally best decision? Should quality-of-life considerations be allowed to enter the picture, and if so, which standards should prevail and who should determine them. Who has the right to decide when patients or families and physicians disagree? And when should the law be brought in to override or circumvent decisions by patients or their families? Most cases in which these and other ethical questions arise are problematic because they are dilemmas--situations in which there is no clear right or wrong answer, but in which there is something to be said for both sides of the issue.⁶²

The problem that Macklin raises by asking who should be involved in deciding cases other than the patient, is one that Leon Kass has written about. Though family members may have an interest in treatment decisions for a loved-one, and though the medical care staff may have an interest in healing and alternatively allocating health care resources rationally, it is the patient who has the greatest interest in the outcome of the proposed treatments. "However valuable any life may be to the society, each life is primarily and preeminently valued by the person whose life it is."⁶³

Under the respect principle every life has value because of the place that the person holds in society by virtue of being a human being. Duties are owed to the patient because he has inherent value as a human being. Kass asks: "Is the life of another human being to be respected only because that person (or society) *deems* or *wills* it respectable, or is it to be respected because it *is in itself* respectable? If the former, then human worth depends solely on agreement or human will; since will confers dignity, will can take it away, and a permission to violate nullifies the violation. If the latter, then one can never be freed from the obligation to respect human request to do so, say, from someone who no longer values his own life."⁶⁴

Kass further emphasizes that one life does equal another in absolute terms. He says that the *lex talionis*, and the idea that if one sheds the blood of another he must lose his own life, illustrates this concept. No life is worth any more or less than any other life.⁶⁵

Informed Consent

The concept of informed consent plays an important role in bioethics. A physician may not treat a patient nor perform any medical procedure for which a patient has not given explicit consent, based upon complete information concerning the procedure, the risks involved, and the possible outcome of the procedure. The genesis of the doctrine of informed consent was the Nuremberg trials following World War II. At those trials evidence of medical experimentation on individuals in the concentration camps was brought to light. Since the procedures were not undertaken for the purpose of treating medical conditions, but rather to serve the purpose of "confirming" some wild

genetic or racial theory, it was presumed that persons who had such procedures performed on them could not and would not have consented to such procedures. "The term *informed consent* did not appear until a decade after these trials, and it did not receive detailed examination until around 1972."⁶⁶

At the core of the concept is the principle of autonomy and the respect principle. By subjecting a person to a medical procedure without having obtained their prior, informed consent to the specific procedure, one has removed the person's autonomous decision-making capacity. In the case of a Do Not Resuscitate Order, the patient is consenting to *non-treatment*. The doctor writes the order saying that the default protocol of starting resuscitation attempts in the case of cardiac or pulmonary arrest is not to be followed. Although in the majority of cases the patient is consenting to a medical procedure and in the case of DNRs, the patient is consenting to non-treatment, the consent in either case must be based upon knowledge of the procedure, the consequences, the likely outcome, etc.

Informed consent consists of various elements. Beauchamp and Childress characterize these as: (1) Competence, (2) Disclosure, (3) Understanding, (4) Voluntariness, and (5) Consent.⁶⁷ Other characterizations may differ with regard to some of the elements, but this characterization seems to provide a good standard (that is, the elements serve as criteria), by which third parties can measure whether informed consent has been given in a particular case. Each of the elements may be implicated where DNR orders are involved and where there is some diminished mental capacity. Every case of substituted judgment should be tested against these five criteria since the risk of

interfering with the autonomous choice of an incompetent patient is easier to achieve than for the case of the fully conscious patient.

By looking at informed consent cases in the light of the five elements that the authors propose, medical care providers will be held to a higher standard than that traditionally required by the courts. The consent doctrine began in the legal system with the landmark case of *Mohr v. Williams*.⁶⁸ In that case a patient consented to an operation on her right ear. After the surgeon had placed the patient under anesthesia he determined that her left ear needed the operation and not the right. He proceeded to do the surgery on her left ear, and was sued. The court held that the patient had not consented to the operation since her consent was specifically to an operation on the other ear. Thus, although she had consented to the operation, she had not consented to the specific surgery that occurred.

Informed consent in the medical setting is governed by higher standards than that imposed by courts. There are two levels to that higher standard. First, the medical care giver is held to a reasonableness standard. Second, the care-giver is held to a subjective standard based upon the actual facts and circumstances of the case, the knowledge and skills of the physician, and the actual medical and mental condition of the patient regardless of what a reasonable person might do under similar circumstances. This higher standard is often imposed by the code of conduct of the medical professional or other professional guidelines.⁶⁹

One exception to the principle of informed consent is an exception that doctors often cite--the concept of *implied consent*. Ruth Macklin summarizes this concept as follows: "The patient contracts for care and treatment by the physician, the expert in

medical matters. In consenting to a particular treatment, the patient implicitly consents to whatever else the physician believes is medically necessary. The trouble with this defense is that it is simply false."⁷⁰ She goes on to point out that despite the fact that there is no such doctrine or rule, many medical practitioners put such language on the consent forms that they have patients sign before surgery or other medical procedures. Another term for this notion of implied consent is *medical necessity*. This term attempts to rescue the case in which the medical staff did not obtain informed consent before a procedure was done and complications arose while the procedure was being performed. It is clear that implied consent or medical necessity are clearly opposed to patient autonomy. Yet many medical personnel would choose to invoke these concepts in many medical cases.

In a journal article titled, "Abandoning Informed Consent," Robert Veatch argues that consent is a transitional concept. He traces its relative recent history and argues that its recent vintage may reflect the fact that the standard is only a temporary standard as we move on to something better. In large part, he bases his case for needing a replacement on the idea that the principle of *informed consent* is too closely tied up with the best interest for the patient standard of care. He is convinced that the best interest standard of care is not a good one, and that since the treatment proposed by the doctor is determined by using a best interest standard, consent to a procedure can be no better than the "best guess" of the doctor as to what is in the best interest of the patient. Instead of the "best interest" standard, he proposes a "reasonable person" standard.⁷¹ We have briefly examined the pitfalls of such a reasonable person standard and have seen that such a standard only can direct behavior in hindsight, that is, after the treatment has been done.

Such a standard would do nothing to insure that the correct procedure is proposed at the time of decision-making and that informed consent by the patient or proxy has been given. A reasonable person standard can only be applied after the fact, and this is its weakness. Beyond this, a reasonable person standard would seem to invite a return to the paternalism of medical practice in earlier generations. More writing and more investigation will have to be done, in my opinion, before informed consent should be abandoned.

Throughout the presentation of ethical theories and discussion of relevant concepts and terms we have seen how the issues and the decisions made may be measured using various ethical principles and by applying different theories of ethics. We have not found in the process any magic formula for answering every question that arises. We have not as yet determined if there can be a framework or a set of guidelines that can govern every case or whether, in fact, the best that we can do is to apply rules and theories on an ad hoc basis as the need arises in the medical setting. I have noted that rapidly changing technology has made the process of medical decision-making more and more difficult. Policies and protocols, ethical guidelines, and codes of conduct help with the decision-making process, but they cannot keep up with the rapid pace of changing biomedical technology. We must turn to other resources when these fail.

The Role of the Bioethicist

Technological change has made decisions at the end of life much more difficult. But it has not been the only thing that generates conflict in these situations. "Many of these issues arise because there is no longer a broad social consensus about the meaning

of life, death, sickness, and medical care."⁷² Freeman and McDonnell suggest that in the absence of a broad consensus, parties frequently turn to the courts for resolution of the conflicts that arise concerning treatment options. I would suggest that turning to a legal forum to deal with these issues may not be the best approach. First, the legal process is not designed to operate in a rapid fashion. Rather its goal is to find truth, protect rights, and to dispense equity where the law may not provide an adequate remedy. When a patient is in cardiac arrest or is in a life-threatening situation in an intensive care unit, there frankly is no time to go to court to seek a resolution of conflict.

A better approach is to use the services of a bioethicist or to have a bioethical consult with a bioethics committee of the healthcare facility. Bioethics committees were formed in response to the decision in the Quinlan case and others. In the decision of the Quinlan case, the court as much as assumed that hospitals had bioethics committees or their equivalent in place already. Given this assumption on the part of the court, medical facilities considered that if they did not have such committees or if they did not have someone serving as an ethicist to help in these cases that if they were brought to court, not having a committee would be viewed by the court as *negligence per se*. Thus, there was a mad scramble to form such committees and to hire such experts. Philosophers were the natural candidates to head up these committees or to serve as consultants in end-of-life cases. As Ruth Macklin says: "I am a philosopher specializing in bioethics, an interdisciplinary field that has come into existence only in the past two decades."⁷³ She is a bioethicist who comes from a philosophy background. Others come from the law, from medicine, or other disciplines.

"... I began to see what role a philosopher might play... I realized that as a philosopher, I could make a unique contribution: I could identify the ethical principles available to such a resolution, and I could show how those principles might provide a satisfactory conclusion when reasonable people disagree. I could also demonstrate how that approach might fail, and delineate the reason for the failure of exalted ethical principles to settle a moral dilemma... The role of the philosopher is to provide an ethical analysis."⁷⁴ Not all bioethicists see their role as being merely to analyze medical situations according to ethical theories or guidelines. Some have seen their role as doing the analysis, but then, in addition, making a recommendation or making the actual treatment decision. Taking either of these steps seems to violate the principle enunciated earlier of having the medical personnel stick to their area of expertise while others take other responsibilities. By going beyond the advisory role to one of advocacy or more, the objectivity necessary to see the ethical issues and the options available disappears or may appear to be compromised.

One bioethicist with whom I spoke serves on multiple ethics committees of healthcare facilities. In each of those settings, he sets an a priori condition on his serving as a consultant to those ethics committees. He will not actually vote on any particular case that comes before the committee. He will not choose treatment options, nor will he choose sides in a conflict situation. He sees his role as being one of making sure that the ethical principles that are implicated are clear to all of the participants in the decision-making process. He believes that his role is to provide clarity and objectivity in these situations to all that may be concerned.

"Just what is the role of the bioethicist... one contribution a philosopher can make is to identify the values that come into conflict, giving rise to ethical dilemmas, and to demonstrate what ethical principles are at play."⁷⁵ Values are another way of stating principles. The danger is that the person who appears to have the best knowledge of ethical principles and values may be deemed to be the best decision-maker where the medical aspects of a case are concerned. The temptation may be too strong to let the ethicist decide the difficult questions because they will know what the moral thing to do is.

Ruth Macklin has said that she began to call herself a bioethicist only after the modern role of the bioethicist developed and the profession had moved away from the notion of the ethicist as the person who , "... knows the morally right thing to do in every situation." Once the role of the bioethicist became one of advising and helping spell out factors in decision-making and stating in clear terms the options which posed the ethical dilemmas in order for others to better make those decisions, she felt comfortable using the title and acting in that capacity.⁷⁶

Even though the temptation to let the ethicist call all of the shots when it comes to treatment options may be stronger when the ethicist is from a philosophical background, I believe that such a person is still the best choice to fill the ethicist's role. An ethicist from a philosophy background may be better able to categorize and describe the relevant values or principles than someone from a legal or theological background. This is not to diminish or negate the role that a clergy person might play. Rather, it is to demonstrate that someone may better fill the role of bioethicist with such a background. The role of the clergy person in medical ethical dilemmas will be looked at in the next chapter.

CHAPTER THREE NOTES

¹ Tom L. Beauchamp and James F. Childress. Principals of Biomedical Ethics, 4th ed., (New York: Oxford University Press, 1994).

² John M. Freeman and Kevin McDonnell. Tough Decisions: A Casebook in Medical Ethics, (New York: Oxford University Press, 1987).

³ Ibid., 152.

⁴ Ibid., 144.

⁵ Ibid., 144-5. The authors use a Venn diagram approach to illustrate how they define what is included in each of these two types of action. All activity is included in a rectangle. Moral action is a circle within that closed rectangle. Everything outside the circle is amoral or morally neutral.

⁶ Ibid., 145.

⁷ Beauchamp and Childress, Principals of Biomedical Ethics, 4th ed., 5.

⁸ Freeman and McDonnell. Tough Decisions: A Casebook in Medical Ethics, 146.

⁹ Ibid., 148.

¹⁰ Ibid.

¹¹ Donald J. Murphy, MD and Thomas E. Finucane, MD, "New Do-Not-Resuscitate Policies," Archives of Internal Medicine, Vol. 153 (July 26, 1993): 1641.

¹² Michael Burleigh. Death and Deliverance: Euthanasia in Germany 1900-1945, (Cambridge, GB: Oxford University Press, 1994): frontispiece.

¹³ Freeman and McDonnell, 149.

¹⁴ Tom L. Beauchamp and LeRoy Walters, Contemporary Issues in Bioethics, 4th ed., (Belmont, CA: Wadsworth Publishing, 1994): 446.

¹⁵ Freeman and McDonnell, 149.

¹⁶ "Hume, David," Microsoft® Encarta® 98 Encyclopedia. © 1993-1997, Microsoft Corporation, All rights reserved.

¹⁷ Freeman and McDonnell spend some time criticizing the utilitarian approach to making medical decisions because of the complexity of the factors involved and the difficulty of anticipating all of the possible results of a decision made under utilitarianism. In short, they suggest that utilitarianism is not as easy to apply to a given medical decision as one might first think. Under a utilitarian approach, if two actions have the same results, the actions are morally equivalent. They illustrate this point by using the example of a decision that concludes that it is in the best interest of a patient to die. Under a utilitarian approach since the result, the patient dies, is the same under either act, there is no moral distinction between letting a patient die and directly causing the death of that patient. They say that the means of death becomes unimportant. Tough Decisions: A Casebook in Medical Ethics, 150.

¹⁸ Ibid., 154. The authors also state: "many of the consequences of our action depend on chance, luck, or other factors beyond our control." (p. 154). In other words, we may never be sure that we have taken into account all factors and every risk that may apply in using a utilitarian approach to ethical problems.

¹⁹ Immanuel Kant. Introduction to the Metaphysic of Morals. (Translated by W. Hastie). World's Greatest Classic Books. Copyright © 1995 Corel Corporation. All

Rights Reserved. Page 25. This is a work on CD-ROM and hence, the page numbers may vary depending on the version read.

²⁰ Immanuel Kant, Fundamental Principles Of The Metaphysic Of Morals. Translated by Thomas Kingsmill Abbott. World's Greatest Classic Books. Copyright © 1995 Corel Corporation. All Rights Reserved. Page 50-51.

²¹ Freeman and McDonnell, 154.

²² Beauchamp and Childress, Principals of Biomedical Ethics, 4th ed., 60.

²³ Ibid., 105. The reader should not conclude that there is consensus on the permissibility of killing someone to put them out of their pain. This issue is very much still the subject of debate. Because the issue is so unsettled, the importance of palliative care has become ever more important as new ways are sought to end the type of pain that the authors are discussing.

²⁴ Ibid., 105. Quoting David Hume in *An Inquiry Concerning the Principles of Morals*.

²⁵ Freeman and McDonnell, 155.

²⁶ Paul Ramsey, "On (Only) Caring for the Dying," in Ethical Issues in Death and Dying, Robert F. Weir, ed., (New York: Columbia University Press, 1977): 192.

²⁷ Freeman and McDonnell, 156.

²⁸ Ibid., 157.

²⁹ Ibid., 158.

³⁰ Ibid., 159.

³¹ See *Griswold vs. Connecticut*, 381 U.S. 479 (1965). This case dealt with the dispensing of contraceptive devices in violation of state law. The enumeration of this privacy interest has been cited, supported, and applied in every other conceivable area of life since the Supreme Court "discovered" the right in the *Griswold* case. It continues to form the foundation for the arguments in abortion, physician-assisted suicide, and other types of legal matters.

³² The American Heritage Dictionary of the English Language, William Morris, ed. Boston, Houghton Mifflin Company, 1980.

³³ Beauchamp and Childress, Principals of Biomedical Ethics, 4th ed., 11. There are those who view the withdrawal of life-saving therapy as in the Karen A. Quinlan and Nancy Cruzan cases as being examples of this type of dilemma.

³⁴ Ruth Macklin, Mortal Choices: Bioethics in Today's World, (New York: Pantheon Books, 1987): 25.

³⁵ Macklin, 21-22.

³⁶ Beauchamp and Childress, 4.

³⁷ Ibid.

³⁸ Ibid., 5.

³⁹ Ibid., 4.

⁴⁰ Ruth Shalit, "When We Were Philosopher Kings," The New Republic, (April 28, 1997): 25.

⁴¹ Macklin, 31.

⁴² Ibid.

⁴³ Ibid.

⁴⁴ Ibid., 11.

⁴⁵ Ibid., 13.

⁴⁶ "If we begin by considering the competent patient or the formerly competent patient whose wishes are known, these are fundamentally problems of autonomy and the related ethical principles needed to preserve autonomy-- that is, truth telling and promise keeping. If there is an ethical problem at all, it is whether the health care professional or anyone else is ever justified in infringing upon the autonomy of the individual patient as a decision maker about his own health care. I am for the moment not considering cases where we might want to restrict medical care for purposes of conserving scarce resources, but only those cases where the welfare of the patient is the decisive consideration. The ethical problem is one of whether some other decision maker might, on paternalistic grounds, attempt to promote the welfare of the patient in violation of the patient's own autonomy. I take it as a conclusion of both law and ethics resulting from the last decade's debate that there is considerable agreement now that in such a simple case the principle of autonomy must dominate. The competent patient has the right to consent to treatment or refuse treatment on any grounds whatsoever, provided that treatment is offered for the patient's own good. Thus, one possible ethical mandate for a committee is to be patient-centered, not focusing exclusively on the welfare of the patient in Hippocratic fashion, but on the rights of the patient, as well as on helping the patient preserve his or her autonomy in decision making." Robert M Veatch, "The Ethics of Institutional Ethics Committees," in Ronald Cranford and Edward Doudera, eds., Institutional Ethics Committees and Health Care Decision Making, (Ann Arbor, Michigan: Health Administration Press, 1984): 42.

⁴⁷ Freeman and McDonnell, 166.

⁴⁸ Macklin, 23.

⁴⁹ Ibid., 164. The authors ask: "Is it ever in one's best interest to be dead?" The answer to the question may not be as obvious as we first assume.

⁵⁰ Macklin, 12-13.

⁵¹ Freeman and McDonnell, 164.

⁵² Ibid.

⁵³ Beauchamp and Walters, Contemporary Issues in Bioethics, 4th ed., 26.

⁵⁴ Ibid., 27. The authors include in this book a chapter on the allocation of health care resources. The arguments there deal most intensively with a discussion on egalitarian and libertarian theories of justice. See p. 675, et. seq.

⁵⁵ Curtis, J. Randall, David R. Park, Melissa R. Krone, Robert A. Pearlman. "Use of the Medical Futility Rationale in Do-Not-Attempt-Resuscitation Orders." The Journal of the American Medical Association, 273(2): 124.

⁵⁶ Tom Tomlinson and Diane Czlonka, "Futility and Hospital Policy," The Hastings Center Report 25, no. 3 (1995): 32.

⁵⁷ Ibid., 28.

⁵⁸ Ibid., 30.

⁵⁹ Ibid.

⁶⁰ Ibid.

⁶¹ Ibid., 31. The authors have devised a model for making futility decisions that follows the guidelines established above. The full text of the proposed model may be found in the article: Tomlinson, Tom and Diane Czlonka, "Futility and Hospital Policy,"

The Hastings Center Report, 25, no. 3 (1995): 33-35. Professor Tomlinson is an associate professor at the Center for Ethics and Humanities in the Life Sciences, Michigan State University, East Lansing, MI. Ms. Czlonka is a clinical nurse specialist at Sinai Hospital of Detroit.

⁶² Macklin, 7.

⁶³ Kass, Leon R., "Death With Dignity and the Sanctity of Life," A Time to be Born And a Time to Die, Barry S. Kogan, ed., (New York: Walter de Gruyter, Inc., 1991), 124.

⁶⁴ Ibid., 125.

⁶⁵ Ibid., 126-7.

⁶⁶ Beauchamp and Childress, 142.

⁶⁷ Ibid., 145.

⁶⁸ *Mohr v. Williams*, 95 Minn. 261, 265, 104 N.W. 12, 15 (1905).

⁶⁹ Veatch, Robert M. "Abandoning Informed Consent" Hastings Center Report 25, no 2. (1995): 5-6. In this article, the author notes that: "Up until the revision of 1980, the American medical Association's published *Current Opinions* did not include any notion of consent either. To this day the AMA *Opinions* permit physicians to treat without consent when the physician believes that consent would be 'medically contraindicated.' [The Hippocratic oath has no provisions requiring consent of the patient]."

⁷⁰ Macklin, 37.

⁷¹ Robert Veatch, "Abandoning Informed Consent," 6.

⁷² Freeman and McDonnell, 167.

⁷³ Macklin, 6. (Written in 1989).

⁷⁴ Macklin, 17.

⁷⁵ Ibid., 7.

⁷⁶ Ibid., 15.

CHAPTER FOUR

THE ROLE OF THE BIOETHICIST AND RELIGIOUS APPROACHES TO BIOETHICAL ISSUES

In the preceding chapter we examined ethical theories and approaches to end-of-life dilemmas. We briefly discussed the role that a bioethicist might play in helping others make the decisions concerning treatment options or refusal or withdrawal of treatment. The bioethicist does not make the decisions for others, but should be considered a resource to help with those decisions. The bioethicist fills one role. Other members of the hospital staff fill other roles. Social workers, patient representatives, clergy, etc. play specific roles in the care of the patients. Each draws upon training in specific areas and specific skills to help in the decision-making process. "As important as these roles by other professionals are in the hospital setting, they should not be confused with the special expertise in ethical analysis that the bioethicist has to offer."¹ Ruth Macklin does not imply that the role of the bioethicist is superior to the others or that ethicists sit on some Mount Olympus in a pantheon of gods. Rather, she seeks to point out that the role of the bioethicist is a special one that other personnel should not attempt to fill. The training of the ethicist enables the ethicist to evaluate and analyze specific cases in order to ensure that the values of the parties involved are respected and that the moral consequences of medical care are understood by all involved.

In the first case presented in Chapter Two, the patient was incompetent to make treatment decisions. Furthermore, he had not given any indication prior to his admission

to the hospital in an advance care directive of his preferences with regard to treatment options. He had not discussed these issues with his spouse previous to his becoming incompetent. With no advance indication of what the patient would have chosen with regard to the specific surgical procedure to be performed on him (a coronary artery bypass graft, or CABG), or what his preference was with regard to resuscitation status, the medical staff called upon the patient's spouse to make these decisions for her husband. As noted in Chapter Two, most legal jurisdictions have enacted provisions within their living will or advance care directive statutes that ranks the order in which family members are to be consulted concerning treatment decisions. The nurse who reported this case to me indicated that the staff complied with the direction given by the Ohio Revised Code that governed this case by first consulting with the patient's spouse and then his adult children.

The decisions that were made in the case were made as a result of consultations between the hospital medical personnel and family members. A bioethicist was never part of any of these consultations. The medical personnel involved believed that the only issues to be resolved were medical choices. The family cooperated with the staff and agreed to the treatment options offered. As we saw, the patient did not die when expected after being weaned from the ventilator; and he did die when it was unexpected, namely, when surgery was being performed to insert a feeding tube into his abdomen. From every indication, the family members and the medical staff made appropriate choices for the patient. That the patient died under circumstances in which he was not expected to die, seems to indicate that in the final analysis, different treatment choices would not have made any difference to the final outcome of the case. Fate, luck, or

God's will seem to have played as much a part in his death as the decision-making process itself.

Could a bioethicist have made a difference in the outcome of this case? Probably not. Yet there were times when a full airing of the ethical issues involved could have been helpful. Why should this be, if the medical treatment options seem appropriate and if something other than proper medical treatment seems to have been involved with the death? We have acknowledged that the patient himself did not have the capacity to make the treatment decisions. In bioethical terms, we would say that he did not have autonomous decision-making capacity.

Following an ethical theory based upon duty it appears that the medical personnel fulfilled their duties to heal or at least attempt healing. There was no question that the surgeon who performed the bypass operation used his skills to fulfill his duty to the patient. That the patient survived for a relatively long time after the surgery proves that the surgeon fulfilled his duties. Those who provided comfort care to the patient and saw to his respiratory needs likewise fulfilled their duties. So how could a bioethicist have changed the situation for the better?

At each step of the patient's hospitalization, choices had to be made: Should the patient be admitted to the hospital? Was the patient a suitable candidate for surgery? Was the quality of his life sufficient to require that he have thousands of dollars worth of medical resources used on him that might have been better used on another patient, or were the treatments an exercise in medical futility? Did the medical staff have his best interest in mind at every turn? Was there informed consent given for the medical procedures performed? Each of these questions could probably be answered with some

degree of certainty. However, without the input of a specially trained third party each of the decisions made could be viewed by an outsider as violating rights of the patient, as possible paternalism on the part of the medical staff, as medical abandonment, or as not acting in the best interest of the patient.

Without the careful analysis of the patient's medical condition, a review of the possible treatment options to determine that all of the relevant factors and ethical principles had been considered and understood by all of those connected to the case, and an attempt to "discover" what the patient in an autonomous state would have chosen, we can only speculate that the right course of action was taken. An ethicist could ensure that all of the relevant principles involved in patient care and treatment were considered at each step of the way.

In the third case that was presented in the words of the attending physician, the conflicts that the physician may feel when deciding treatment options and the concern "...that I might be criticized on Monday for violating some hospital policy," give some indication of the role that a bioethicist might have played in that situation. Not only could the ethicist have gone through the possible treatment options with the physician and listed the ethical principles involved, she could have made sure that the doctor had evaluated the factors involved and presented them in a fashion that the wife could understand. Had there been an ethical consult, the physician would have been sure that she had treated the patient and dealt with the patient's spouse in a manner that was ethically consistent and appropriate, and she would not have had to wonder if she had possibly violated some hospital policy. Even with the choice of those words: "...that I might be criticized on Monday for violating some hospital policy," I sense a certain level

of paternalism, (in this case "maternalism"). Perhaps this is an accurate assessment of the situation--perhaps not. In any case an ethical consult could help the medical staff be aware of and avoid paternalistic attitudes. It is just such paternalism that in years past violated patient's autonomy routinely.²

In the second case presented, the case of the woman in the permanently unconscious state, the need for an ethicist's input is clear. Here, the patient had given prior indication of her treatment preference, should she ever be in the situation that she was actually in. She had said in a living will, that if she were ever in a permanently unconscious state that she would wish for nutrition and hydration to be withdrawn, if previously started and that only comfort measures be instituted. By signing this document she had clearly indicated her autonomous choice for treatment. Yet when the doctors faced the difficult decision of whether to follow the treatment she had voluntarily chosen for herself or to follow the wishes of her partner who was acting as the attorney-in-fact under the Durable Power of Attorney for Healthcare, the doctors did not immediately follow her directive. An ethicist could have explained the role of autonomy in making treatment options and shown that there was no need for substituted judgment to be applied in the case since the patient herself had made the choice already.

I am not suggesting that there would not have been conflict between the family members and the partner had an ethicist been involved in the case. Rather, I am suggesting that a resolution of the problem could have been reached earlier had one been involved as the relevant ethical principles that ultimately were brought in to resolve the matter could have been disclosed to the parties much sooner, and a few tense weeks of conflict might have been avoided. In addition, the medical staff could have been

educated as to the impact that advance care directives should have in these treatment decisions.

In the fourth case, incoming residents of a traditional Jewish long-term care facility were asked to sign documents that placed them on "do-not-resuscitate" status as a condition of admission to the facility. There are many issues that an ethicist can raise with regard to this case and the implementation of DNR policy at a facility level rather than at the patient level. The principal one, of course, is the interference with the personal autonomy of the patient and the notion of informed consent. One might argue that if a person being admitted to a long-term care facility does not like the DNR policy of the facility, they can exercise their autonomous choice best by not entering that particular facility. On the face of it, this statement is true. However, if the facility is the only long-term traditional Jewish facility in the area, and an individual is a traditional Jew, one may not have the choice to go to another facility. Thus, by virtue of the exclusive nature of this facility and its inflexible policy on DNR status, the autonomy interests of the potential resident are clearly affected. In some ways the chaplain acted in the role of the ethicist when he raised these issues and sought to have the state change the policy. However, he did not state the ethical issues as explicitly as an ethicist might have. I will discuss the role of clergy in these matters later on in this paper. For now, I would like to discuss how a religious ethicist might approach these same issues and whether such an approach might be different from that of a secular bioethicist.

The Role of the Religious Ethicist

We have examined the role of a secular bioethicist in the decision-making process in the cases from Chapter Two. We have looked at the application of ethical principles and standards in problematic cases.³ We may ask: Would a bioethicist who works within a particular religious framework approach the issues in a manner different from that of a secular bioethicist? Would the person coming from a religious vantagepoint come to different conclusions concerning treatment options and whether they would violate any ethical principles? Would the input of a denominational ethicist vary qualitatively or quantitatively from that provided by a secular bioethicist? These are all important questions. The response to each of them would vary from religious tradition to religious tradition. Yet the religious approach is different from a purely secular approach. One denominational bio-ethicist, writing from a traditional Jewish perspective, has put the distinction in this way: "Secular bioethics is free to innovate new distinctions and approaches, or to adopt or adapt old ones, from a variety of normative traditions, provided these satisfy accepted principles of ethical reasoning. The rabbinic Jewish ethical and legal system is, by contrast, self-contained, constrained by Divine scriptural rules, and by precedents accumulated over thousands of years."⁴ What he says about the Jewish bioethical system, as he understands it, might also apply to other religious bioethical traditions. An in-depth analysis of these religious traditions and frameworks is beyond the scope of this thesis. However, a survey of different approaches may be helpful. Further, since my own thesis aims at developing a liberal Jewish approach from

traditional Jewish sources, Jewish approaches to bioethical issues and the framework for working through such issues needs to be developed in greater detail.

Protestant Approaches to Bioethical Questions

The first group of religious approaches to bioethics that we will look at may be labeled as "Protestant." The use of the term does not mean to imply that all Protestant denominations would agree with my presentation of the issues or concepts involved. Further, since I am an outsider to Protestant theology and certainly not a scholar in this area, I cannot assume to speak for the various Protestant churches. I must rely upon what believing members within that religious tradition say about the issues involved.

Martin Marty is a respected Protestant theologian. In an essay titled "How to Draw Guidance From a Heritage: A Protestant Approach to Mortal Choices," he speaks about the wide range of Protestant approaches to death and dying and the place of faith in the decision-making process concerning bio-ethics. He admits that the scope of Protestant belief and practice is wide. He acknowledges that modern society is sometimes in conflict with theology and religion. Yet he maintains that faith has to be acknowledged as an important part of discussion of bioethics. He says: ...no single universal principle of reason moves the entire modern enterprise; that science operates within a changing set of paradigms that illustrate the partly mythic construct of each [that is, science and politics]. Reason, argue not a few philosophers, is also conditioned by the persons who express it, colored by the communities that give expression to it. Faith communities, the Madisonians among us remind us, have as much right to speak up as do

'reason' communities, as they often see themselves. Religion is not to be the element that disqualifies a person or community from seeking to make a contribution or to have her or its way in a republic." In short, he says, faith has a role to play as well as "secular rationality."⁵ Marty acknowledges the sources of his own, Protestant approach to bioethics. He admits that such approaches come from the "Judaean-Christian" tradition, and that he is equally an inheritor of the tradition established by Martin Luther. He also admits that these "received traditions" have been modified by his own experiences and have been influenced by his local setting. He also admits that the "God of the Republic" is not necessarily the same as the "God of Revelation."

Yet Marty acknowledges breadth within the tradition ascribed to the "God of Revelation." Lutheran theology places central importance on the concept of grace and hence does not put as much emphasis on the role of suffering (or healing) in the human experience. Other Protestant theologies, particularly those associated with Christian Science, Seventh Day Adventist, etc. focus more intently on the role of healing in alleviating suffering.⁶ In speaking about the issue of abortion he says:

The reason it is hard to 'move' magisterial Catholicism on the issue of abortion is that its position is grounded in a view of the transmission of life which is located near the center of what the church regards as 'natural.'...Liberal Protestantisms may be as eager to protect life, but they may have other definitions of the status of life in respect to fetal or comatose existence; here theological doctrines of 'rights' to which such Protestantism helped give birth or which influenced it are part of the core and have to be reckoned with. The best 'how-to' advice, both for those in a tradition and those who would or must deal with it strategically, is to make an effort to find central and grounding themes, of which other teachings and ideas are corollaries.⁷

If this is an accurate depiction of the Protestant view towards dealing with modern bioethical issues in the marketplace of ideas, it is possible to see how such an approach forms a considerable part of the ethic that produced patient's rights, general theories of

rights over duties, and the concept of personal autonomy. Rather than depending upon a "magisterium" to determine the principles that guide ethical decision-making, the principles are arrived at by using both reason and revelation.

Other religious traditions would argue that their tradition also includes input from these two sources. Marty acknowledges as much. He calls this blend of tradition and rationality "...part of the non-negotiable core of fundamentalisms, be they Jewish, Islamic, Catholic or Protestant."⁸ Yet, a Jewish approach, a Catholic approach, or a Muslim approach would work within the context of that core to resolve ethical dilemmas. What seems to characterize a Protestant approach is that the Protestant approach seems to place more emphasis on a hermeneutics of reliance on tradition than a strict reliance based upon a received tradition of "Law" or "Din" or "Magisterium." A hermeneutical approach uses the received text to give guidance to a rational decision-making process without constraining that process with laws, canons, or strict dogmas. The tradition may be consulted in a "proof-texting" way, and to lay down ethical principles, but reason **and** faith supply the criteria for the resulting decision. Working with other faith traditions and acknowledging the validity of other revealed traditions or being understanding of those traditions necessitates a rational approach to applying Protestant traditions in ethical decision-making settings where others may not share the same tradition.⁹ Marty says that we draw on a religious heritage by listening to voices from the past and listening for clues that come from that heritage.¹⁰ Such an approach may not sound familiar to Catholic ears or to Orthodox Jewish ears, but this approach seems fairly typical of Protestant approaches to ethical questions.

Another Protestant approach to the ethical issues of death and dying is that of the Society of Friends, or Quakers. The Quaker philosophy in general is one of pacifism and respect for all people. It is not surprising, therefore, that the Quaker position on a range of issues from abortion to death and dying is at the more liberal end of the spectrum of Protestant thought. The Quakers dealt with issues of death and dying long before bioethics blossomed into the prominent field that it is today. In 1966 the Society of Friends issued a call for a working party to look into the issues of abortion, birth control, life-support, etc. and make recommendations. The resulting report was issued in 1970. Due to the relatively free authority structure in the Society of Friends, the report is not binding but serves as a guideline for those involved in making decisions in these areas.

With regard to what they refer to as "prolongation of life in the dying," the report says:

In arriving at answers to some of the questions...[relating to end-of-life issues], we took into account considerations of morality, compassion, and concern for the quality of life of all who are affected. We believe human life is a gift that is meaningful only as long as the receiver is able to function as a person. The quality of the potential life left to the dying person must be a consideration constantly before concerned physicians and society to help guide their actions in specific cases. We approve withholding therapy or withdrawing supportive therapy that is keeping an unconscious person alive if, by evidence of brain death or such other evidence as the medical profession deems valid, it is the best judgment of the medical profession that the patient's brain is irreparably damaged and he will never recover consciousness.

The authors of the report specifically declined to deal with the issue of euthanasia, since they felt the issue was too complex and that society was just beginning to grapple with the issue. They were clear that when they spoke of "quality of life" and "functioning as a person," they did not intend to indicate authorization for the practice of euthanasia.¹¹ It is

clear from the brief statement presented here that the position of the Quaker segment of Protestantism is a liberal one and that the ethical framework of an ethicist coming from this tradition would tend to focus more on a best interest approach or the rights of the patient.

Roman Catholic Approaches to Bioethical Questions

Roman Catholic approaches to DNR questions and the larger field of bioethics would tend to be more conservative than the liberal approach just described. For the presentation of Roman Catholic approaches to bioethical issues I have drawn from three sources that cover a spectrum within the Catholic tradition. The first of these is an essay entitled "How to Draw Guidance from a Heritage: A Catholic Approach to Mortal Choices" by Richard A. McCormick, S.J.¹² Father McCormick's approach to these issues is fundamentally different from that presented by Martin Marty. McCormick does not speak of accommodating of pluralist tendencies in bioethics. He does not speak in terms of different understandings of and interpretations of revealed truth. He does say that the individual conscience is the ultimate determinant of the choices made. However, that choice is always guided by the Christian heritage as defined by Catholic theology and tradition. In contrast to Martin Marty's discussion that has a pluralism theme, McCormick's essay begins with theology and includes a catechism of some thirteen "perspectives, themes, and insights" that provide the foundation of making mortal choices. I will not enumerate them all, but they include the concepts of God being the author of life, life as a gift, the focus on eternal life rather than the earthly existence, the

role of Jesus in human lives, etc. He says: "If we are thinking *theologically* (obviously, I refer to Christian theology) about the ethical problems of biomedicine, it is out of such framework, context, or story that we will think. The very meaning, purpose, and value of a person is grounded and ultimately explained in this story."¹³ If he starts with theology does that mean that he is forced to make all ethical decisions within a narrow confine of the Christian theological story? He states that the story provides the framework and the reason for making moral choices, but there is a place for individual emphasis on certain elements of that story and certain values that emerge from that story.

If as Father McCormick says, life is a gift and has great value because of the value that God has placed on life, then life is sacred and the segment of a life at the end of a life is as sacred as that at any other point in the person's life. He would state this as a Christian principle, and yet, he says that there is room to call one type of existence life and another type "not life." Thus, he concludes that many years of "living" in a persistent vegetative state is not "a great benefit to the patient." Thus, not all "life" is qualitatively the same or not all types of existence are "life." He says that "...life is a basic good but not an absolute one. Excessive concern for the temporal is at some point neglect of the eternal"¹⁴ In short, McCormick appears to suggest that Catholic approaches to mortal choices such as DNR decisions could be compatible with a utilitarian approach. The quality of a life is good, but it can be tempered by other factors. The results of a particular mortal choice will take into account the value of a life, but other factors may be brought in to evaluate that life. If the greatest good, for the greatest number of people, can be accomplished by taking that life, or giving up that life, then that course of action should be taken. Thus, the life of a fetus does not equal the life that is

taken in battle or the life that an executed prisoner forfeits, or the life that a person in a persistent vegetative state may have. Let's compare his view with others within the Catholic tradition.

Bruno Schüller, like McCormick, is a Jesuit writer on Catholic subjects. He has written an essay titled "The Double Effect in Catholic Thought: A Reevaluation."¹⁵ In his essay, responding to a theory of P. Knauer, he summarizes and distinguishes the different ethical theories: deontological and teleological (what we have called utilitarian, or consequentialist). He further breaks down deontological theories into two sub-categories. He says: "Reflecting on the discussions held in the past few years among moral theologians, I believe it is necessary to draw a distinction at least between the two following views, both deontological in character: (2a) The moral rightness of any action is determined always *also*, but not always *solely*, by its consequences. (2b) There are at least some actions whose moral quality is completely independent of their consequences. Obviously traditional Catholic theology holds a deontological theory of the stronger type (2b)." According to this view "...anyone who holds that at least some actions are morally determined *not exclusively* by their results has to be counted among the deontologists."¹⁶

Schüller uses the example of telling a lie to illustrate the distinctions between ethical approaches. Under a Kantian or deontological system, telling a lie is always wrong. Under a consequentialist or utilitarian approach, a lie may be justified if telling the truth will cause harm to another. He says that Catholic moral theologians would say that the lie is wrong and that another means must be found to prevent the harm from occurring. By using ambiguous phrases or what he calls "the broad mental reservation"

one is able to reduce the scope of the deontological prohibition so that the consequences become smaller and smaller to where they are insignificant. In the case of euthanasia the results of applying a deontological approach would be to condemn such an act as being morally wrong in every case. Results or consequences of the act are not considered at all. Killing is wrong. Period. But in the case of letting someone die, (passive euthanasia), the deontological argument never needs to be made because no "killing" is involved. In short, we do not define letting someone die as killing, therefore, we do not need to apply the deontological standard because we have moved the action from the category that must meet the deontological standard.

In practice, Schüller suggests much of the debate in Catholic bioethical discussions takes this approach to resolve the difficult issues that are raised by end-of-life decisions. This is what he refers to as the double blind. Stated another way: "A positive law is always valid, but it is not valid for *every* instance; a negative law is always valid and is so for *all* instances [emphasis mine]".¹⁷ Clearly, the impression that he presents of the Catholic approach to bioethics is different from that presented by McCormick. Perhaps the disparity reflects the possibility that the Roman Catholic position is in flux. While a deontological approach was the approach to such questions in the past, church theologians are moving more towards a more utilitarian approach as the biomedical frontier has moved continually forward beyond the ability for the Church to keep pace with a rule-making approach. Those who work within the Catholic sphere will have to resolve this issue. We will now consider Jewish approaches to these issues.

Jewish Approaches to Bioethical Questions

In the materials that follow in the next section, I have chosen to present ideas and concepts that are a part of the Jewish tradition that all streams within Judaism draw upon. Those elements that form the basis for a Jewish bioethic are presented first. Distinctions among the various branches within Judaism will be noted in passing and then in greater detail in subsections of the Jewish materials. Issues of death, the importance of life, duties *ben adam l'chavero*, between man and his fellow man, have formed a central part of Judaism for thousands of years. They are part of the life of a Jew. Yet they are not the only component. Judaism acknowledges the role of God in the world, which imparts duties upon an individual, duties *ben adam l'makom*, that is duties that an individual owes to God. The relationship between the two is at the heart of a traditional Jewish system of bioethics.

For Jews the Torah is the final expression of God's will and the standard for how humans are to behave towards one another. If the answer to a question cannot be found in the written Torah, (referring to the first five books of the Hebrew Scriptures), the answer must be sought within the guidelines provided by the Oral Torah as developed in the Rabbinic tradition. Such an approach is usually referred to as being *Halakhic*. *Halakha* is a Hebrew word meaning "the way one should walk," that is, the one way in which one should conduct oneself. If, as in our case, the Torah, the *Halakha* does not discuss cardio-pulmonary resuscitation, how do we then determine what the proper course of conduct is? The rabbis established means for dealing with such situations by a process of reasoning by analogy. Using such a reasoning process in our times has resulted in decisions in all areas of what has come to be called bioethics or biomedicine. "Israel's

Ashkenazi Chief rabbinate has ruled that donating organs is a major mitzvah and that brain stem death is sufficient criteria for organ removal.”¹⁸ Lest one should think that the *halakhic* process is designed to reason in a backward-looking fashion in order to give approval to whatever life-saving or life-extending procedures medicine can develop, some procedures that have been approved by the medical profession have not been approved by modern *halakhic* authorities. As Velvl William Greene, the director of the Lord Jakobovits Center for Jewish Medical Ethics in Jerusalem puts it: “The fact that we know how to do a certain procedure or intervention doesn’t automatically confer on us the right to do it, or tell us when and to whom and in what circumstances...[such a procedure may be done].”¹⁹

In addition to consulting the Torah to determine the answers to bioethical issues, guidance also is found in the Talmud.²⁰ The Talmud broadens the scope of the Torah to include specific issues that are not discussed in the written Torah. When the Talmud itself does not explicitly deal with a specific issue, (e.g. organ transplantation), other mechanisms had to be developed. In all, the reasoning process, often referred to as “Talmudic” or “rabbinic” reasoning, remained the same. Analogy, expansion of rules, and restriction of rules to certain cases was the methodology used.

Once the canon of the Talmuds had been set, by about the year 600 of the Common Era, other means for determining the proper course of conduct had to be established.²¹ The more formal method was that known as “Codes.” Codes were collections of the *Halakha* that could be consulted by a Jew who had a question on a specific issue. The chief codes in the Jewish tradition are the *Tur*, the *Mishneh Torah*, and the *Shulchan Aruch*. However, even the codes could not always provide all the

answers to every question that came up over the centuries when the Jewish community grew, became dispersed to many lands, and encountered situations and questions that had not had to be dealt with before. Using the rabbinic reasoning process and a process known as *she'elah and teshuvah*, specific questions could be sent to respected rabbinic authorities, known as *poskim*, who would consult the wealth of rabbinic sources from the Talmud to the Codes and determine the proper action to be taken. This body of Jewish law is known as *Responsa*. The process of *she'elah and teshuvah* remains in place today. All movements within Judaism have such a process.

In Israel, some of these questions are submitted to the office of the Chief Rabbinate--either Sephardi or Ashkenazi.²² Within the Orthodox community, questions are sent to various rabbis of one's own choosing rather than to a central rabbinic authority, since outside Israel there is no office of Chief Rabbi. The Conservative movement also relies upon a system that sends individual questions to individual rabbis for a response or *responsum*. If the matter is of sufficient import that the movement feels that a determination should be made as to whether the teshuvah should be adopted as the position of the movement as a whole, the Conservative movement has established a committee, known as The Committee of Jewish Law and Standards which then acts to affirm the responsum for the movement. This committee also determines the Conservative Movement's platforms.

The Reform movement has had a Responsa Committee for many years. Questions are submitted to the committee, usually by individual rabbis, for an answer by the whole committee. In the Reform setting, *Halakha*, the Codes, other responsa, etc. are all consulted in formulating the responsum. The resulting teshuvah may affirm a

halakhic position or it may affirm a more modern Reform principle. Over the years various questions of a bioethical nature have been addressed. Further guidance for Reform Jews has been given concerning specific issues, like abortion, euthanasia, and withdrawing of life-support, through the UAHC Committee on Bioethics.²³

Traditional Jewish bioethics has centered on key concepts and mitzvot (commandments). Chief among these has been the concept of *pikuach nefesh*, the saving of a life. The rabbis in the Talmud view the saving of a life as requiring the violation of Sabbath prohibitions. In fact, *pikuach nefesh* takes precedence over every other mitzvah in the Torah with the exception of three: murder, idolatry, and adulterous or incestuous sex.²⁴ With regard to *pikuach nefesh* taking precedence over Shabbat, this is so even if there is some doubt as to whether the person is in fact still alive. Thus, if a wall has collapsed on a person so that the lower half of her body is not under the wall but her top half is, the wall must be removed, even on Shabbat, to determine whether the person is still breathing in order to save her life if she is still alive. Removing a wall is clearly work that is forbidden on Shabbat, but in this instance, in order to save a life, the work is permitted to be done.²⁵

Traditional Jewish bioethics focuses on *duty*. This is not the focus of secular bioethics in the United States today. In secular bioethics the discussion for the past twenty years has centered on the word *rights*. Rights are synonymous with the American approach to liberty interests. Justice Cardozo expressed the rights-based approach in a decision rendered in 1914. "Every human being of adult years and sound mind has a right to determine what shall be done with his body and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in

damages."²⁶ Yet even under the secular framework of jurisprudence there are limits as to what one may do with or to one's body. There is no pure personal autonomy. Rabbi J. David Bleich, a leading Orthodox authority, has stated it in this manner.

Despite our society's commitment to individual liberty as an ideal, it recognizes that this liberty is not entirely sacrosanct. Although there are those who wish it to be so, self-determination is not universally recognized as the *paramount* human value [*emphasis mine*]. There is a long judicial history of recognition of the State's compelling interest in the preservation of the life of each and every one of its citizens, an interest which carries with it the right to curb personal freedom. What the jurist calls a 'compelling state interest' the theologian terms 'sanctity of life'. It is precisely this concept of the sanctity of life which as a transcendental value, supersedes considerations of personal freedom... Were autonomy recognized as the paramount value, society would not shrink from sanctioning suicide, mercy killing... under any or all conditions.²⁷

But as patient's rights and autonomy become increasingly central to bioethical discussions, society's attitude towards suicide, mercy killing, etc. seem to be in considerable flux. Perhaps, the interest of the state is changing from what Rabbi Bleich perceived it to be a mere nine years ago. Surveys today show considerable support for physician-assisted suicide.²⁸ That the Supreme Court unanimously refused to recognize a constitutional right to physician-assisted suicide in June of 1997 merely indicates that the attitude in society may be ahead of the rule of law at this point in time.²⁹ Whether the rule of law will eventually or should ever catch up with popular opinion remains to be debated and seen. Contrast this discussion of rights with the traditional Jewish view.

In a traditional Jewish approach, the parties involved in attending to the sick have duties rather than rights. Thus, the physician has a *duty* to heal. The person who is ill has a *duty* to seek healing. Members of the family and the community have a *duty* to perform the mitzvah of *bikkur cholim*, that is, attending to the sick. A person, according to

tradition, even has a duty to live in a town where there is a physician. If someone has a duty with regard to another person, that other person has a *right* to something from the other. However, traditional Judaism does not focus on those rights. Instead it focuses on the duties.

Illness in the traditional view comes from God, who also brings healing. At times, this meant that there were those who said that a sick person must rely solely on a divine act of intervention to cure the illness. However, the view prevailed over time that the physician had a role to play in the healing process since he was serving as an agent of God's healing power. This focus on the role of the physician even took a fascinating turn in the Talmud, *Avodah Zarah* 27b. There the question is raised: May an individual receive a possible life-saving treatment from a heathen physician who may in fact kill him, if such a treatment offers the possibility of healing and the person would not live for more than two days without such treatment? A Talmudic principle states that normally an item of certainty may not be superseded by one of doubt. However, in the instance of certain death within two days or the uncertainty that a treatment may restore oneself to health and for a greater length of time, the treatment may be taken even with the risk involved because of the possibility of long-term survival.³⁰

On the broader bioethical front, there are other distinctions between a traditional Jewish approach and a secular one. Benjamin Freedman, the late bioethicist at McGill University Centre for Medicine, Ethics and Law and the Sir Mortimer B. Davis Jewish General Hospital, has drawn one further distinction between secular and Jewish bioethics. He observes that secular bioethics is mostly preoccupied with procedural questions about

who will make decisions and less concerned with process questions like *how* the decisions are made. He says:

The success of secular bioethics at achieving consensus on social ethics, more often than not, involves approaches that are either directly or indirectly procedural. For example: The endorsement and analysis of the patient's right to informed consent, among the pillars of contemporary bioethics, is wholly derivative of the procedural resolve to allow competent patients to make their own medical decisions. By contrast, most current Jewish writers on bioethics concentrate almost exclusively upon substance—which decisions should be made, and for what reason—and scarcely at all upon procedure.³¹

This appears to certainly be the case with regard to a traditional Jewish view of the issues involved. The more liberal streams within Judaism would place more emphasis on procedural issues along with what Freedman calls the substantive ones.

As noted above, the concept of *pikuach nefesh*, the saving of a life, plays a central role in Jewish discussions of bioethics. Other principles are involved as well. I would like to discuss two other important concepts that play a role in the traditional discussions on end-of-life questions. Much of the analysis of current ethical issues within traditional Judaism starts with a discussion of these two concepts. The first of these is the notion of *goses*. In the context of the Talmud, a *goses* is a person who is literally in his last days of living. A *goses* is compared to a flickering lamp, that is, one that is about to go out on its own. Since a duty is owed to a sick person and since a physician has a duty to heal, the Talmud uses the *goses* as a paradigm for dealing with end of life questions.³²

The term, *goses*, appears in eight tractates of the Babylonian Talmud.³³ The term is discussed further in other traditional materials.³⁴ Thus, we read in section 234 of Sefer Hasidim (The Book of the Pious):

Do not feed a *goses* for he cannot swallow [food], but he should be given liquids... to enable him to speak. One may not yell at him [at the time his soul departs] in order that his soul should return.... for he cannot live but for a few days and during those days he will suffer pain....If, however, there was a possibility of curing him or even temporarily relieving his condition so that he no longer would be classified as a *goses*, even though he would live for only a short period afterward, one would be obligated to do so [to feed the dying person] even if it were 'a time to die'.³⁵

Likewise Moses Isserles, known as the RAMA (1525 or 1530-1572), commenting on Joseph Karo's (1488-1572), *Shulhan Arukh*, says: "If there is anything that causes a hindrance to the departure of the soul, such as the presence near the patient's house of a knocking noise, such as wood chopping, or if there is salt on the patient's tongue, and these hinder the soul's departure, it is permissible to remove them from there because there is no act involved in this at all but only the removal of an impediment."³⁶ Lord Immanuel Jakobovitz, a modern Orthodox authority, has stated it: "...Jewish law sanctions the withdrawal of any factor – whether extraneous to the patient himself or not – which may artificially delay his demise in the final phase."³⁷ The issue of what constitutes the "final phase" is what divides most modern Orthodox authorities on issues of organ transplantation, "extraordinary measures," and "brain death."

With regard to this latter issue of brain death and the end of life, one Orthodox authority has permitted the withdrawal of life support treatments when the patient has no independent brain function and cannot breathe. Since the turning off of a ventilator to see whether the patient breathes on his own would require a positive act, which may not be permitted in the case of a terminally ill person who may not yet be categorized as a *goses*, this authority permits the ventilator to be hooked up to a twelve or twenty-four hour timer

to turn off the respirator so that the breathing of the patient may be observed.³⁸ One could likewise argue that connecting the ventilator to a timer is a positive act and thus may be prohibited.

A second concept found in the tradition is that of *terefah*. We normally think of the term *terefah* in the context of kashrut and whether an animal may be eaten or not. In the traditional meaning, the term was used to denote an animal with a fatal organic defect that may not be eaten even if slaughtered in an appropriate fashion according to the dietary laws. However, the term also has a usage in the context of the laws on murder. Maimonides, known as the RAMBAM (1138-1204), laid out the definition of *terefah* in the context of someone who killed a person suffering from a fatal organic defect that was incurable by a physician, and whether the murderer could be subject to capital punishment. Under Rambam's scenario one could argue that the person with the defect was dead already and thus the killer could not be held liable for his death. Under the traditional definition of *terefah*, an animal was *terefah* if it would die of the disease or defect within twelve months. Maimonides thus reasoned by analogy that the category could apply to a human being if the person were suffering from a disease or defect from which he would die in a similar twelve-month period. The *terefah* condition must be established by irrefutable medical evidence.³⁹ The Tosafot maintained that the period of twelve months in certain instances may not be appropriate for a human being, since a person may indeed live longer with a terminal condition than an animal may. Therefore, many modern authorities argue that an inevitability of death standard is more appropriate than a strict time limit guideline.⁴⁰

Elliot Dorff, writing in the journal, *Conservative Judaism*, quotes Dr. Daniel Sinclair concerning the concept of *terefah*:

The outstanding feature of the category of human '*tarfut*' for the current debate concerning the treatment of the terminally ill is the exemption of the killer of a '*terefah*' from the death penalty. This feature focuses attention upon the fact that a fatal disease **does** detract from the legal status of a person and also introduces a measure of flexibility into the issue of terminating such a life [emphasis mine].⁴¹

We will survey the halakhically grounded approach to the end of life questions and see how the concepts of *goses* and *terefah* provide guidance in current bioethical debates.

Halakha at first glance appears to be a rigid framework that would permit no deviation from what appears to be concrete rules. Such a view, however, would distort the dynamic nature of Jewish law from the time of the Mishnah up to today.⁴² Human life is sacred under the Halakhic scheme. However, the sanctity of human life is not absolute. "Halakhic insistence on the inviolability of human life is balanced – and at times outweighed – by its concern for the alleviation of human suffering. Thus, patients are allowed to undergo risky surgery to relieve severe pain, even though the operation places them in mortal danger...a physician may administer a powerful dose of morphine...even when the drug may shorten the patient's life, for pain itself is seen as a disease deserving of treatment."⁴³ This concept, of not hastening death, which we see here in the negative—death may be hastened in certain cases if such action is not intended to hasten the death but rather is an unintended result—is central to discussions of *goses*, *terefah*, and care of the dying person. A collateral principle is that we do not have a duty to prolong the process of dying in an artificial manner. We especially have no duty to do so when the person who is dying is in pain.

Modern authorities look to the case of Rabbi Judah the Prince, mentioned previously as the compiler of the Mishnah, and a story related to his final illness.⁴⁴ According to the story recounted in the Talmud, when Rabbi Judah was dying, his students were praying that he would not die and that he would be healed. His maidservant, seeing his suffering, prayed that he would die and interrupted the students' prayers by smashing a vessel on the floor in order to distract the students so that the great sage could die. The Talmud relates the story without criticism of her actions. "Contemporary authorities have applied this passage to the treatment of the critically ill in extreme pain, by allowing them to refuse 'extraordinary' lifesaving measures, and to receive intensive doses of pain-killers."⁴⁵ While one may refuse extraordinary measures, one may not refuse beneficial, non-threatening treatment.⁴⁶ If one could be revived with CPR, and such a procedure would not in any way threaten the life of the patient, such procedure could not be refused. This is at least the thinking of some Orthodox authorities. This is part and parcel of the duty to seek healing.

Proceeding from the duty to seek healing and the prohibition against refusing beneficial, non-threatening treatment, *Halakha* also bans suicide. Such an act is prohibited in all streams of Judaism across the spectrum except for those Jews who consider themselves as adherents to a philosophy of *Polydoxy*.⁴⁷ "While traditional Judaism recognizes each individual's autonomy, such autonomy is not unlimited. A person's life is not his or her own possession, but belongs to God."⁴⁸ But even though the act of suicide is forbidden, modern approaches to the issue take the position that the act is condemned, but the person who has as a result of anguish and suffering committed suicide is not condemned.

I would now like to turn to an examination of the specific issue of CPR in greater detail. We will examine how the decisions made concerning resuscitation therapy are viewed within *Halakha*. One Jewish writer has described the traditional view of the sanctity of life in this way: "Jewish law vigorously asserts that life, even that of a terminal, demented, elderly patient is of infinite value; it must be preserved no less than the life of a young and alert child with a hopeful long-term prognosis."⁴⁹ When one makes the distinction between an elderly, demented, terminal patient and a young, healthy, and alert child, the importance of the sanctity of life principle becomes apparent. But what would be the value if the comparison is made between patients in similar medical circumstances but with different insurance, family or other relevant factors? *Halakha* attempts to minimize these other factors by stressing the importance of all life whatever the moment, whether at the beginning of life or at the end.

Rabbi Zev Schostak illustrates this principle with the following example:

A...dramatic illustration of this principle is that of a triage decision in a facility which has only one respirator. The machine is connected to a deathly ill, disoriented 90-year old. May this patient be removed from the respirator in favour of a young accident victim who has just arrived, who will surely die without it? Here, too, halachic authorities rule that the dying elderly patient *already on the machine* may not be removed from the respirator. By removing the old man from the respirator in favour of the young one, we would be, in effect, declaring that the old man's life is less valuable than that of the young one. *De facto*, we play God when we pass judgment on the 'quality of life'. However, in such cases where neither of them has been placed on the respirator, priority is, of course, given to the young accident victim who has the better prognosis for long-term recovery.⁵⁰

In this example, different ethical approaches may be used. If neither person has been started on the respirator, a utilitarian "best results" approach may be used. If the respirator has already been attached to the old man, "best results" are ignored. In short,

the *Halakha* would use a utilitarian standard in the one instance, but the same *Halakha* would use an authoritative rule, "the sanctity of life" to keep the old man on the respirator despite the relative outcomes of treatment in the two men. Realizing that decisions made in such fashion are not easy, Rabbi Schostak says: "In this paper I have attempted to formulate resuscitation and tube-feeding guidelines that are medically viable, *halachically-sensitive*, and compatible with state and federal law. [Emphasis mine]."⁵¹ *Halachically sensitive* does not sound like a formulation that is based upon absolutes or immutable principles. It sounds like an approach that the Conservative movement might utilize. *Medically viable* at least seems to acknowledge that some treatment options are medically futile and thus, may not be used in certain circumstances.

In the specific setting of the nursing home or long-term care facility, special ethical choices face the residents, physicians, and family members. We have examined some of these in previous chapters. Here, we will focus on these same issues from a standpoint of *Halakha*. Specifically, we must ask: Is the refusal of CPR either through oral communication from the patient or in an advance care directive permissible under *halakhic* guidelines? If CPR is viewed as a life-saving, beneficial, non-threatening treatment, may a competent person refuse it? Rabbi Schostak reviews various studies that I have cited in earlier chapters that report on the success rates of CPR attempts in the elderly population as well as studies that I did not survey. His conclusion based upon the studies that he reviewed is that while survival rates among the elderly are generally low (varying from 2 to 9 per cent, depending on the underlying medical condition of the patients), there is a certain number of elderly that do benefit from CPR procedures. He further concludes: "This would support a clear halachic position: attempts to resuscitate

the elderly are mandated in the absence of a DNR order unless they are medically futile. As long as a percentage of elderly patients survive after CPR-however small-the doctor must attempt resuscitation...⁵² We have reviewed in the fourth case in Chapter Two, the situation in which a DNR policy in a traditional long-term care facility was changed because the policy to make no resuscitation attempts was determined to be inappropriate for all residents of the facility. The reasoning in that case seems to coincide with the reasoning stated here.

But what does *Halakha* say about the refusal of CPR treatment? According to Rabbi Schostak, the answer would depend upon whether the procedure was deemed to be "ordinary" treatment or "extraordinary" treatment. Admitting that these labels can change in meaning as circumstances and medical treatment options change, he defines them as follows: " 'Ordinary means of preserving life are all medicines, treatments, and operations, which offer reasonable hope of benefit for the patient and which can be obtained and used without excessive expense, pain, or other inconvenience' 'Extraordinary means of preserving life...mean all medicines, treatments, and operations, which cannot be obtained without excessive expense, pain or other inconvenience, or which, if used would not offer a reasonable hope of benefit' ."⁵³

These definitions are laden with 'terms' that themselves beg definition. What is "excessive" expense, pain, or inconvenience? What is "a reasonable hope of benefit?"

According to Rabbi's Schostak's interpretation of the terms:

It would appear that attempts at CPR in a medically futile situation would be deemed 'extraordinary' according to this definition. Resuscitation would not offer a reasonable hope of benefit and much pain and inconvenience would likely accompany the procedure...halachic authorities rule that the patient may refuse to

initiate extraordinary treatment when his condition is irreversible (i.e., the proposed treatment promises only to extend his life somewhat but not to cure the illness), particularly if he objects because of the pain involved. Thus, a patient whose medical condition is futile, who stops breathing or experiences cardiac arrest, does not have to be resuscitated if this procedure will contribute to his pain.⁵⁴

Presumably, Rabbi Schostak has witnessed CPR being performed on a patient. Even younger patients will experience pain while receiving the treatment. It is not a pain-free procedure in the best of circumstances. But a judgment concerning relative pain must be made.

Before we move on to other viewpoints, I would like to point out one more distinction between types of treatments. In the *halakhic* view, a distinction must be made between positive acts (acts of commission) and negative acts (those of omission). Schostak says that *Halakha* prohibits removing a person from a respirator if such treatment has begun (an act of commission) and might permit one to refrain from ever connecting certain patients to the respirator in the first place (an act of omission).⁵⁵

Having looked at several aspects of a traditional approach to ethical questions and the results that have been obtained by using such an approach, we now turn our focus to the more liberal streams within Judaism. The first of these will be that of the Conservative movement. I have chosen to discuss Conservative Judaism as the first of the more moderate branches of Judaism deliberately. The Conservative movement, unlike the Reform movement, claims to be a halakhically based movement in Judaism. As the oft-quoted expression has it: "We give Halakha a vote not a veto." Reform Judaism finds its guiding principles

in broader expressions of values found in the writings of the prophets of the Hebrew Scriptures. Therefore, we will continue with the movement that most closely follows a halachically grounded approach to these issues.

Conservative Judaism on Bioethical Questions

We have discussed previously the functioning of the responsa procedure and the role of the Committee of Jewish Law and Standards within the Conservative movement. Rabbi Elliot Dorff, a member of the Committee on Law and Standards, recently summarized the approach of the Conservative movement to bioethical questions.⁵⁶ The Conservative approach builds upon the idea that the human body belongs to God, a notion that was discussed briefly within the section on traditional Jewish approaches to these questions set forth above. The Conservative movement elevates this principle above other concepts outlined above. A person may have the use of his or her body, but the ownership of that body belongs to God. Thus, a person may not do anything that interferes with God's dominion over the body. The second major premise of the Conservative approach is that "...the body, mind, emotions, will, and soul are all an integrated whole."⁵⁷ That is, there can be no separation between the mind, the soul, the human animal, etc. All elements of a human person form essential parts of a whole. Thus, a physician is not only treating the physical conditions in a particular case, he or she is also having a direct impact on the person's soul, mind, etc. Therefore, treatment decisions have to take into consideration the whole person under the physician's care.

A third premise of the Conservative approach is that medicine is good. According to Rabbi Dorff, repairing the world is part of our duty as human beings. One of the aspects of that repair is the returning of lost objects. By analogy, tradition reasons, if a person is ill, they have lost their health. Thus we have a duty to return their lost possession to them. If a person loses a watch, a wallet, or any other physical object, that item must be returned. There is no "finders keepers" rule in Judaism. We must return the physical object. Kal va-khomer, if this holds true in the case of the former, trivial item, how much the more so does it hold true where a person's health is concerned. We must try to heal her.⁵⁸

Another decision that the Conservative movement has reached is that it is not only permissible to donate an organ to save a life, it is a mitzvah. At first blush, there appears to be no distinction between what is permitted and what is a mitzvah, but within the traditional view of mitzvah, one becomes obligated to perform the act. Thus, one would not be merely permitted to donate an organ for transplantation, one may be required to do so in order to save a life; that is to say, one is directed to donate the organ by way of exhortation. There is no agency that can punish or sanction the person who does not donate the organ. We should note that the Chief Rabbinate in Israel has reached the same conclusion with regard to the issue of organ donation.

Conservative Judaism is a dynamic and vibrant movement within Judaism. As one might expect, there is a broad range of views within the movement. Another leader within the movement, Daniel Gordis, is a frequent contributor to the discussion of bioethics within the Conservative movement. In an article titled "Wanted – The Ethical in Jewish Bio-Ethics," he decries what he sees as "the problems with halakhic

formalism.”⁵⁹ He sees a trend in bioethics away from the secularism of the nineteen-seventies to one of “religious ultra-conservatism.” Those who choose to operate somewhere between the two extremes, and I assume he includes himself and Conservative Judaism, “...must demonstrate that religious traditions can offer a sophisticated but sensitive perspective which might otherwise be absent from debates on crucial social issues.”⁶⁰ This perspective is an important one. The Jewish tradition and indeed, other religious traditions do have something to say concerning life and death issues. Decisions based upon medical criteria alone lack an important element. Decisions based upon economic criteria alone fall short of protecting those who face the crucial end-of-life decision-making process. Yet Gordis says:

Halakhic formalism, the process of seeking some ‘precedent’ (no matter how remote) in order to make a positive statement about a halakhic response to a certain issue, may ultimately prove devastatingly problematic. Traditional *Halakha* certainly doesn’t speak about abortion. It might have something to say about transplants, or, at least, when we can take a vital organ from a donor. But *Halakha* could surely not have anticipated the dilemmas posed by surrogate motherhood or organ transplants from non-humans. To pretend to find any precedent for this type of issue destroys the meaning of the original case, and in many instances, stresses a non-essential trait which the cases share in common at the expense of never addressing the new ethical agenda at hand... Another danger of the approach to text that mandates that every case must be answered by means of precedent is that the search for such a precedent will often lead to unnecessarily and unacceptably conservative results.⁶¹

Those who attempt to address these issues from within the context of the Reform movement in Judaism would argue that this is precisely why the second generation leaders of the Reform movement abandoned *Halakha* as the determinant of proper conduct and instead sought to establish the ideals of the movement and the guiding principles for behavior upon prophetic notions of justice, mercy, etc. In any case, I think

that Rabbi Gordis has portrayed the tension that describes the Conservative movement. Any religious system that attempts to ground itself in *Halakha* while at the same time address contemporary issues in a meaningful and timely fashion, will have tension in the application of fundamental principles to concrete cases.

Gordis makes one other point that should be obvious to anyone seeking to reason through a solution to a concrete problem not dealt with in the halakhic tradition. The rabbis mention those criteria for establishing the death of a person that they could in fact measure. Thus, they relied upon observation of heartbeat and breathing to make the determination. But, as he argues, had they been privileged to be able to measure a person's brain stem activity, see the results of an electrocardiogram, or have the prediction and detection devices that we have today, they would have in all likelihood, set such tests as the standard rather than cessation of respiration or heartbeat. He says that "...in our insistence on the significance of life, we sometimes foreclose the possibility of affording someone else a second lease on his own life."⁶² By this, he seems to indicate that the position that every moment of life is as sacred as any other, can lead to the maintenance of a person on life-support beyond an appropriate time when the organs of that individual could be used to extend the life of a potential organ recipient.

Gordis gives us further indication of the Conservative approach to bioethical questions. Citing the work done by his colleague, Elliot Dorff mentioned above, he says: "he makes an invaluable contribution to the literature by demonstrating that (a) seriousness about halakhic issues need not always result in restrictive positions, and that (b) in combing the rabbinic tradition for guidance, we may legitimately make use of aggadic (non-legal) as well as halakhic sources."⁶³

If we were to summarize the approach to end-of-life questions of the Conservative movement as it has been summarized by Elliot Dorff and Daniel Gordis, we would conclude that the movement looks to traditional sources of Halakha for guidance, but that it does not feel compelled to base every position on an analogy from those sources to the issues of today. Second, we would conclude that the sanctity of life is paramount, but that *pikuach nefesh* does not necessitate the prolonging of the life of a person who is terminally ill and in pain. The Conservative movement would also allow a person to refuse life-saving treatment, in some instances including CPR. Finally, we would conclude that the Conservative movement uses an approach to these end-of-life questions that relies on Halakha as a resource – an important resource – for solving them, while not being bound to the halakhic formalism characteristic of Orthodox approaches to the same questions. Reasoning by analogy is acceptable if it helps find a workable and humane solution to a problem. But the Halakha must not be a mechanism that allows inhumane conclusions concerning treatment options and bioethical issues for the sake of upholding the reasoning process itself.⁶⁴

Reform Jewish Approaches

Reform Jewish approaches to bioethical questions give a greater weight to the autonomy principle than any of the other movements within Judaism. As noted above, members of the liberal wing within Judaism who adhere to a polydox philosophy would elevate the autonomy principle to the highest place within a hierarchy of applicable principles. Rabbi Terry Bard, a bioethicist at Boston's Beth Israel Medical Center, has

noted that the approach taken by the liberal streams of Judaism has broad appeal in the American Jewish community that *Halakha* does not have.⁶⁵ This reflects both the diversity of the American Jewish community and the broad support for liberty interests within that community because of its history and because the liberty principle is so ingrained within the American value system. Rabbi Bard says:

Like most other periods in Jewish history, *halakhic* arguments by the scholarly class did not always address the thinking and concerns of the *hoi polloi*; scholarly conclusions and decisions were frequently denied or ignored by Jews... in the arena of medical ethics decisions, especially for most Jews today, the role of *halakhic* discourse represents but one model among many that Jews use for ethical decision making. Hence, it is prudent to distinguish between Jewish medical ethics and medical ethics decisions by Jews... In today's pluralistic American Jewish community which by and large accepts the notion of autonomous decision making and rejects the role of authoritarian *Halakha*, structured rabbinic reasoning on medical ethics issues usually achieves only supportive power at best.⁶⁶

Rabbi Bard does not reject the necessity of looking to *Halakha* for guidance. Rather, he asserts that given the centrality of autonomy within the American Jewish community, *Halakha* can be but one factor to be considered in making medical ethical choices.

Perhaps a selection from a resolution proposed by the Union of American Hebrew Congregations Bio-Ethics Committee would summarize the Reform approach to end-of-life and resuscitation decisions best. I quote at length:

WHEREAS, Jewish tradition affirms the sanctity of life, as well as the precept that every means must be undertaken to preserve life, and also affirms that when there is no hope for a patient and death is certain, the patient being "goses" – that is, terminally ill where death is irreversible – impediments to death may be removed enabling a patient to be permitted to die in dignity and in peace, and

WHEREAS, Recent scientific developments now make it possible to artificially prolong the lives of people whose deaths would be imminent unless they receive certain medical treatment and procedures...the application of such treatment and procedures has resulted in many thousands of patients being kept

alive with a minimum quality of life after they have become (1) incompetent, and are (2) either terminally ill or in a persistent vegetative state, with no chance of recovery...

RESOLVED, The UAHC reaffirms the ethical, moral, and legal right of each individual in accordance with Reform tradition to make his or her own health care decisions, and *that such right survives incompetency*. [Emphasis mine].⁶⁷

In short, the Reform approach to such questions respects the autonomy of the individual while respecting what our tradition has to say about the subject. The Reform approach recognizes the importance of rights to an individual in a modern society. Autonomy and freedom of choice are basic values in Reform Judaism. While the resolution affirms autonomy and rights, it does not ignore what our tradition has to say about life and death, *pikuach nefesh*, and the duties that Judaism imposes upon its adherents. Rather, the resolution directs the individual making a choice to respect both the rights of the individual **and** the values that are the foundation of Jewish bioethics. In the same Program Guide that contains the quotation above, it says in reference to whether the Harvard Medical School Criteria for brain death should apply in these terminal medical cases:

We are satisfied that these criteria comply with our concern that life has ended. Therefore, when circulation and respiration only continue through mechanical means, as established by the above-mentioned tests, then the suffering of the patient and his/her family may be permitted to cease, as no 'natural independent life' functions have been sustained. We would permit a physician in good conscience [that is acting in the 'best interest of the patient – acting in a utilitarian fashion] to cease treatment and to remove life giving support systems.⁶⁸

Life, as a principle is valued, while autonomy is protected.

A Personal Approach

It is fitting that I should move from a discussion of a Reform approach to bioethical questions to stating one particular Reform approach to these issues – my own approach. At the beginning of this thesis, I recounted the factors that had influenced my decision to write a thesis concerning bioethics and end-of-life issues. Some of those factors included my experience working in a Clinical Pastoral Education Program, a reading of the book, How We Die, by Sherwin Nuland, and wrestling with questions and concerns that I had about death and dying issues. As I have researched the materials for this thesis and have interviewed the many people whose stories are told here or that only appear here as background, I have sought to develop my own personal religious, ethical framework for confronting end-of-life issues. The exercise has not been in vain.

At the core of my personal framework of bioethics is the Reform Judaism that I cherish dearly. The Reform philosophy with its emphasis on “choice” speaks to me of truth. The values that form its core, are values that have been a part of me throughout my life. The prophetic principles that are the heart and soul of our tradition, are guideposts for my own behavior. If “justice, justice” we must pursue, then there can be no better place to exercise it than in the arena of bioethical choices. Justice is at the heart of my own personal ethical philosophy. Every act that I engage in for the sake of *tikkun olam* is done out of a sense of justice. Yet it has been difficult to develop an ethical framework out of the principal classical theories because justice often conflicts with other values that I hold dear and that are essential to Reform Judaism. I have nonetheless attempted to do so.

In the previous chapter we surveyed different ethical theories that have evolved from within philosophy. We started with a discussion of utilitarian theories with their emphasis on results and consequences. We considered the notion of “best interest,” “paternalism,” “beneficence,” and “nonmaleficence” and showed how they form a part of a theory that is based upon utilitarian ethics. I also presented criticisms of utilitarian theories because of the difficulty they face in making sure that every factor that could influence a decision had been considered and given proper weight in the burden – benefit analysis that lies at the heart of such a system. As I said, how can one ever account for every possible factor, and can we ignore the role that God, chance, or luck might play in such decisions?

When we looked at duty-based theories, the so-called *deontological* theories, we pointed out the weaknesses of theories that rigidly state that an act may be wrong in every instance. Killing another in cold blood is wrong, and yet, most moral systems have made exceptions for killing in times of war and for self-defense. I suggested, following others, that we might focus on rights instead of duties and still work within the deontological framework. A system based upon rights is formulated on the same respect principle that a theory focused upon duties is based upon. It still is focused upon the notion that we won’t lie to another because we don’t want to be lied to. Likewise, there can be no rational basis for treating individuals in similar circumstances in different ways. Finally, a rights-based theory will place informed consent and autonomy at the center of all decisions.

In formulating my own ethical framework, I have been concerned primarily with an emphasis on autonomy and rights, and with two potential pitfalls with such an

approach. First, I have been concerned with the question of where to set a boundary or limit on personal autonomy. While I see autonomy as an important principle in liberal Judaism and in bioethics, I am concerned that there may be an ethical slippery slope, if autonomy becomes the exclusive value or principle governing decision-making. While I am willing to say that an individual has complete freedom to predetermine resuscitation treatment choices based upon informed consent, autonomy, and the respect principle, in general, I am not willing to extend that autonomy to a decision that permits the individual to terminate his life by committing suicide or having a physician assist them in committing suicide. There are limits placed upon individual autonomy by virtue of the individual's place in society and based upon society's interest in upholding the value of life. One's autonomy may not transgress the societal interest in life.

The second concern I have with basing my ethical framework on the concept of individual rights or patient's rights is the fact that the role of duties within the traditional Jewish ethics is too strong and central to ignore. My own ethical framework would have to consider the traditional duties that Judaism has established in the bioethical area. Thus, I see my personal liberal Jewish framework as still imposing, (1) a duty on the part of the doctor to heal, (2) a duty on the patient to seek healing, and (3) a duty on all involved to respect the principle of *pikuach nefesh*. If the duties are clearly formulated with the focus of saving life, analysis of particular cases becomes clearer, if not easier. These duties become clearer if one considers what the tradition teaches us about the person who is a *goses*. These duties are clearer, still, if one keeps in mind the traditional notion of "not hastening death, but also not prolonging dying." Finally, if those involved in the treatment of the sick remember that pain is literally a disease, to be treated like any

other disease, and that tradition permits treatments that relieve pain even if they shorten a person's life, more emphasis will be placed upon palliative care for the terminally ill than on whether "life" itself is something that is to be prolonged at any cost.

In considering the issues surrounding CPR and Do Not Resuscitate orders, except for some authorities in the Orthodox branch of Judaism, a person will be permitted to refuse resuscitative therapy, if she is in an arrest situation, by either an express refusal at the time or by an advance care directive. Autonomy and the respect principle require this, and my system would encourage the autonomous choice to be respected. Beyond the standard documents that are available for execution to indicate treatment choices in advance, there are documents provided by Jewish organizations that may better help to preserve Jewish ideals and values.⁶⁹

I would now like to discuss briefly the role of the clergy in end-of-life decisions. This role is distinct from the one that a secular bioethicist might play. Fred Rosner has written: "Many terminal patients lack religious faith, yet they desperately need emotional support; but by whom? The busy physician? The busy nurse?... The emotional support and reassurance to the dying patient are usually provided by the family and clergy where appropriate, in addition to the medical team."⁷⁰ While the religious ethicist may focus on principles, values, and guidelines, the clergy person will consider those but also work within the particular religious tradition to insure that the religious framework of the patient/family is considered when the ethical decisions are being made. A religious bioethicist might do the same, but the clergy person is perhaps better able to draw upon the religious tradition to provide guidance to the patient and family as opposed to balancing the interests of those involved or analyzing the ethical dilemmas from a purely

ethical vantagepoint. In addition, the clergy person may draw upon the religious tradition to make sure that the moral framework of the patient has been considered. He or she will draw upon that tradition to provide comfort and care for the patient and the patient's family once a decision has been reached. Isaiah, the prophet has said: "Comfort, comfort, my people."⁷¹ At the time of death no greater duty can be imposed upon us. May we be up to the task.

CHAPTER FOUR NOTES

¹ Macklin, Ruth. Mortal Choices: Bioethics in Today's World. (New York: Pantheon Books, 1987), 18.

² Beyond the question of avoiding "paternalism" the broader question of the physician's role in the healing process is in flux. One may read in articles in the medical journals a wide range of perspectives on questions of physicians' rights and duties. In the case mentioned here, the physician was concerned that someone would question her judgment on Monday morning. The physician seems to be placed in a position with respect to the patient's care that crosses traditional, definable medical boundaries. Fred Rosner asks: "Ultimately, to whom is the physician responsible? To himself? To the patient? To Society? Or to God?" Fred Rosner, Modern Medicine and Jewish Ethics, p. 221. At least part of the physician's concern with whether her judgment would be questioned is due to the ambivalence about to whom responsibility is owed in these situations.

³ Shimon Glick, in a paper delivered at the Louis Feinberg lecture series in Cincinnati, Ohio in 1994, noted that there was developing a consensus in bioethics circles that the four major bioethical principles that have emerged over the past two decades are beneficence, nonmaleficence, autonomy, and justice. He says that, in practice, autonomy often dominates the other three principles. Shimon Glick, "Trends in Medical Ethics in a Pluralistic Society: A Jewish Perspective." The Seventeenth Annual Rabbi Louis Feinberg Memorial Lecture in Judaic Studies, Judaic Studies program, University of Cincinnati, April 25, 1994, p. 8-9.

⁴ Freedman, Benjamin. Duty and Healing: Foundations of a Jewish Bioethic. URL: <http://www.mcgill.ca:80/CTRG/bfreed>. (1997): p. 6.

⁵ Marty, Martin E. "A Protestant Approach to Mortal Choices." A Time to be Born and A Time to Die: The Ethics of Choice. Barry S. Kogan, ed. (New York: Aldine De Gruyter, 1989): 245.

⁶ Ibid., 249.

⁷ Ibid., 249-50.

⁸ Ibid., 250.

⁹ For example, consider the following scenario described by Marty: "Even with hermeneutical awareness, the politics of pluralism make the act of "being guided" complicated. A simple scene suggests this. A Seventh-Day Adventist is "brain dead." At the head of the bed is his pastor, who announces that the patient is ready for eternity; that nothing in the teaching of the Adventists, nothing in the family understanding, nothing in the expressed will of the patient, demands continuing life-support. At the foot of the bed is an Orthodox Jewish physician, whose Jewish concept of the physician's covenant and whose understanding of Hippocrates does not permit him to be an agent, however passively, of the patient's death. At the side of the bed (or down the corridor) is the staff ethicist, whose understandings are informed by Aristotle, Kant, Mill and Rawls, and who must negotiate on the basis of "secular rationality" in an aspiration toward a universal language. All this occurs in a Catholic hospital, and its policies have to be taken into consideration. In the next room is another patient in similar circumstances, but

other traditions are present. Ibid.251. During interviews for this thesis I spoke with ethicists at Catholic hospitals who spoke of the difficulty of trying to accommodate the choices of patients and family members who did not share the Catholic framework for ethical decision-making. Of course, one of the moral critical areas involved decisions about the termination of a pregnancy or those decisions that might be considered "euthanasia."

¹⁰ Ibid., 254.

¹¹ The American Friends Service Committee. Who Shall Live? Man's Control over Birth and Death. A report prepared for the American friends Service Committee by a Working Party of the same. (New York: Hill and Wang, 1970): 70.

¹² McCormick, Richard A., S.J., "A Catholic Approach to Mortal Choices." A Time to be Born and A Time to Die: The Ethics of Choice. Barry S. Kogan, ed. (New York: Aldine De Gruyter, 1989): 233-37.

¹³ Ibid.,235.

¹⁴ Ibid., 235.

¹⁵ Schüller, Bruno, S.J., "The Double Effect in Catholic Thought: A Reevaluation," in Doing Evil to Achieve Good. Richard A. McCormick, S.J. and Paul Ramsey, editors. (Lanham, MD: University Press of America, Inc., 1985): 165-192.

¹⁶ Ibid., 167.

¹⁷ Ibid., 174.

¹⁸ Porat, Joan. "Ancient answers guide Jewish ethicists through modern medical revolution." *The American Israelite*. Thursday, January 15, 1998: 17. The brain stem death criteria decision is particularly interesting because the traditional rabbinic definition defined death as cessation of spontaneous respiration. Since modern medicine has allowed continued maintenance of a heartbeat after natural respiration has ceased and artificial maintenance of respiration through ventilators, drugs, etc., a new definition became necessary for the situation where the heart was being used for organ transplantation. In such cases, the heartbeat must be maintained up to the time of removal from the body of the deceased until it is placed into the body of the donee. The Chief Rabbinate based its reasoning on the following criteria: If one is brain dead and must be maintained on a ventilator to sustain respiration, he is viewed as having been decapitated. Further, the Orthodox rabbis reasoned that forcing oxygen into the lungs of a patient is not equivalent to respiration.

¹⁹ Ibid. Further, even though the Chief rabbinate may have approved a certain procedure on *halakhic* grounds, there may still be other Orthodox rabbis who have reviewed the issue using *halakhic* guidelines and have decided not to approve such procedures. In the case of the brain death criteria, the Chief Rabbinate put in strict guidelines to avoid abuses of the criteria. A detailed protocol has been established that the transplant surgeons must follow. In addition, a representative from the office of the Chief Rabbinate must be involved in the determination of the patient's death.

²⁰ The term, *Talmud*, refers to the collection of rabbinic commentary on the Mishnah that is the collection of Oral law gathered by Rabbi Judah the Prince about the year 200 of the Common Era. There are two collections of the Talmudic material- one from Babylonia, and one from the Land of Israel. In the Talmud, the materials are presented with a certain structure. First, the Mishnah is given. Then a discussion of the

meaning of that Mishnah, called *the Gemara*, is presented. Thus, the first Mishnah of the Babylonian Talmud raises the question at what time the *Shema* may be recited in the evening. The Gemara, which presents different rabbinic positions on the question, follows in the Talmudic text. It is important to note that the Gemara presents the different teachings intact, but rarely decides which of those presented is the "correct" one. One of the great aspects of presenting the Gemara is to reflect the dynamic process that the rabbis used to discover the will of God.

²¹ There are two sets of Talmud within Judaism. The first is that which was created in the academies of Babylon, called the Babylonian Talmud or the Talmud Bavli. Many of the Jews went to Babylon after the destruction of Jerusalem by the Romans in the year 70 CE. The other Talmud, called the Yerushalmi, was created within the land of Israel by those who remained within the land. Each of the two Talmuds relies upon the same method of recording discussions and deriving Halakhah.

²² The term *Ashkenazi* denotes the Jewish communities principally of Germany and central and eastern Europe. The term *Sephardi* represents the Jewish communities from the areas of Spain, Portugal, North Africa, the Near East generally. In Israel there are two chief rabbis, one representing each of the two communities.

²³ Some of these materials are listed in the Bibliography.

²⁴ Talmud Bavli, *Sanhedrin* 74a.

²⁵ Talmud Bavli, *Yoma* 85a.

²⁶ *Scholendorf v. Society of New York Hospital*, 211 N.Y. 125, 129-30, 105 N.E. 2nd 92, 93 (1914).

²⁷ Bleich, Rabbi J. David. "The Moral Obligations of the Physician in Rabbinic Tradition." *Doctor's Decisions: Ethical Conflicts in Medical Practice*. (Oxford: Oxford University Press, 1989): 219.

²⁸ David J. Garrow, "Letting the Public Decide About Assisted Suicide," *The New York Times*, sec. 4, (Sunday, June 29, 1997): 4. Reporting on the findings of a new Gallup poll that showed that fifty-seven percent of Americans supported the right to physician-assisted suicide.

²⁹ A review of the opinions in the cases decided by the Supreme Court indicates how much the attitudes are in flux. Although the decisions were unanimous in both of the cases the justices did not join in one opinion. Several of the justices issued their own decisions describing their own rationale for coming to the conclusion that they reached. See *Vacco v. the Attorney General of the State of New York* No. 95-1858, and *Washington et al. v. Glucksberg et al.* No. 96-110. Decided June 26, 1997.

³⁰ Talmud Bavli, *Avodah Zarah* 27b, also see *Tosafot* in the same place.

³¹ Benjamin Freedman, 5.

³² See Semahot 1.1, Maimonides' *Mishneh Torah, Hilchot Avel* 4.5, and *Shulkhan Arukh, Yoreh Deah* 339.1

³³ The tractates are Pesachim, Yevamot, Nazir, Gittin, Keddushin, Bava Batra, Sanhedrin, and Aruchin. A full listing of the relevant passages is contained in Appendix C, attached.

³⁴ Thus we read in Maimonides' *Mishneh Torah, Hilchot Avel* 4:5: "One who is in a dying condition is regarded as a living person in all respects. It is not permitted to bind his jaws, to stop up the organs of the lower extremities, or to place metallic or

cooling vessels upon his navel in order to prevent swelling. He is not to be rubbed, washed, or put upon sand or salt until he expires. He who touches him is guilty of shedding his blood. To what may he be compared? To a flickering flame, which is extinguished as soon as one touches it. Whoever closes the eyes of the dying while the soul is about to depart is shedding blood. One should wait a while; perhaps he is only in a swoon."

³⁵ Quoted in: Weiner, Rabbi Yaakov. Ye Shall Surely Heal, Medical Ethics From a Halachic Perspective. (Jerusalem: Jerusalem Center for Research, 1995): 27-28. This quote not only commands our attention for pointing to the difficulty of precisely determining when the soul leaves the body, but also in distinguishing between nutrition (feeding) and hydration (providing drink) for the dying patient. Much of the discussion in Jewish sources has dealt with the ramifications of withdrawing nutrition and hydration of patients at the end of life. The AMA Council on Ethical and Judicial Affairs issued a statement concerning its policy on withdrawal of nutrition and hydration for terminally ill or permanently comatose patients. There are specific criteria to be followed, but the interesting point for our discussion is that the AMA suggests a "benefits vs. burdens" approach to determining whether a treatment should be started or continued.

³⁶ Rabbi Moses Isserles on *Shulkhan Arukh, Yoreh Deah*, 339.1. Jacob ben Samuel in his responsa, *Beit Yaakov*, no. 59, extends this as follows: "it is forbidden to hinder the departure of the soul by the use of medicines." Quoted by Fred Rosner M.D., Modern Medicine and Jewish Ethics, 2nd ed., (Hoboken, NJ: Ktav Publishing House, Yeshiva University Press, 1991): 207. It should be noted that not all Orthodox authorities agree with the statement in *Beit Yaakov*. J. David Bleich also states that one may be permitted to refrain from taking an action when the death is imminent, and that the distinction between refraining from doing an act versus doing an affirmative act applies only in the situation of a *goses*.

³⁷ Jakobovitz, Immanuel. "The Dying and Their Treatment in Jewish law: Preparation for Death and Euthanasia," Jewish Medical Ethics, (New York, Bloch Publishing, 1959): 123.

³⁸ Waldenberg, Rabbi Eliezer Judah. Responsa *Tzitz Eliezer*, (Jerusalem, 1977) vol. 13, no. 89. Reported in Fred Rosner, Modern Medicine and Jewish Ethics, 2nd ed., (Hoboken, NJ: Ktav Publishing House, Yeshiva University Press, 1991): 209.

³⁹ Sinclair, Dr. David, Hebrew University. In: UAHC Committee on Bio-ethics, Program Guide VI: "Voluntary Active Euthanasia-Assisted Suicide." (Philadelphia: 1993): 26-27.

⁴⁰ Ibid.

⁴¹ Dorff, Elliot. "End-Stage Medical Care: A Halakic Approach," Conservative Judaism. Vol. XLIII, No. 3, Spring 1991. Quoted by Rabbi Richard Address in Program Guide VI: Voluntary Active Euthanasia-Assisted Suicide, (UAHC Committee on Bio-Ethics, Summer 1993): 11.

⁴² In an article titled "Is There Patient Autonomy in Halachah?" Rabbi Zev Schostak discusses the nature of traditional *Halacha* and whether it is in fact rigid. He says: Jewish law has been accused by ethicists and reform-minded secularists of being paternalistic. In their opinion, patient autonomy in *halachah* is non-existent. As a result, 'patients are treated as if they are not capable of making decisions about medical

problems: they are too ignorant medically speaking, and such knowledge as they have, is too partial in both senses of the word.' Thus, they are unlikely to understand the situation even if it is explained to them so that they are likely to make worse decisions than the doctors would. These critics claim that Jewish law substitutes the judgment of the rabbi and/or the doctor for that of the patient, thus violating his right of self-determination. As we have seen, *halachah* generally recognizes and supports the concept of patient autonomy." Schostak, Rabbi Zev. "Is There Patient Autonomy in Halachah?" Assia: A Journal of Jewish Medical Ethics and Halacha, Vol. II, No. 2 May 1995, 26-7.

Unfortunately to an outsider to the halakhic system this "autonomy" appears to be limited to specific procedures and decisions that have been made in certain areas rather than being a broad policy of personal autonomy. One may argue whether such a case-by-case approach, dependant upon the input of a rabbi or other halakhic guidance, is consistent with a modern view of patient's rights or personal autonomy.

⁴³ Washofsky, Mark. "Nancy Cruzan and the 'Right to Die': A Jewish Perspective," Midwest Medical Ethics (Fall 1990): 6.

⁴⁴ Talmud Bavli, *Ketubot* 104.

⁴⁵ Schostak, Rabbi Zev. "Is There Patient Autonomy in Halachah?" Assia: A Journal of Jewish Medical Ethics and Halacha, Vol. II, No. 2 May 1995, 24.

⁴⁶ Shulevitz, Rabbi Marion. "Whose Life Is It Anyway?" *Spiritual/Religious Values and Clinical Ethics in Long-term Care*, The Jewish Chaplain, Vol. 2, No. 1 Spring 5757/1997. (Whippany, NJ: The National Association of Jewish Chaplains, 1997): 12. The author cites an article by Rabbi Avram Reisner, "A Halakhic Ethic of care for the Terminally Ill," appearing in *Conservative Judaism*, vol. 43, #3, pp. 54-5 that cites Arukh Hashulchan, Yoreh Deah, 339:1.

⁴⁷ *Polydoxy* is a philosophy of Judaism that places the autonomy of the individual Jew above any other principle in Judaism. Thus, one Jew can not bind another nor forbid any act to any other autonomous Jew. For a fuller discussion see Alvin J. Reines, *Polydoxy: Explorations in a Philosophy of Liberal Religion*, (Buffalo, NY: Prometheus Books, 1987). See particularly chapters one, two and three.

⁴⁸ Shulevitz, Rabbi Marion. "Whose Life Is It Anyway?", 13.

⁴⁹ Schostak, Rabbi Zev. "Jewish ethical guidelines for resuscitation and artificial nutrition and hydration of the dying elderly," Journal of Medical Ethics, (London: The Institute of Medical Ethics, 1994; 20: 93.

⁵⁰ Ibid.

⁵¹ Ibid., 94.

⁵² Ibid., 95.

⁵³ Ibid., 95. Quoting Paul Ramsey, "On (Only) Caring for the Dying," in Ethical Issues in Death and Dying, Robert F. Weir, ed., (New York: Columbia University Press, 1977), 192.

⁵⁴ Ibid., 95.

⁵⁵ Ibid., 95.

⁵⁶ Porat, Joan. "Ancient answers guide Jewish ethicists through modern medical revolution." *The American Israelite*. Thursday, January 15, 1998: 17.

⁵⁷ Ibid.

⁵⁸ See Maimonides' commentary to Mishnah Nedarim 6:8.

⁵⁹ Gordis, Daniel H., "Wanted – The Ethical in Jewish Bio-Ethics." Judaism: A Quarterly Journal, (Issue no. 149, Vol. 38, No. 1, Winter 1989): 28.

⁶⁰ Ibid., 28-29.

⁶¹ Ibid., 29-30.

⁶² Ibid., 31. Query: Would he require the older man in the example set forth above to give up the respirator so that the younger man with a better prognosis could live?

⁶³ Ibid., 32. Gordis gives an example of such use of aggadic materials by recounting the story of the death of R. Haninah b. Teradyon at the hands of the Romans. The details of the story may be found in the Babylonian Talmud, Tractate, Avodah Zarah 18a. In short, the story tells us that the Romans put tufts of wet wool on Rabbi Haninah's chest to prolong his suffering as they burn him to death. One of the executioners offers to remove the wool tufts and to increase the heat of the fire if R. Haninah agrees to see that he gets a share in the world to come. Haninah agrees, the executioner removes the tufts and turns up the heat, and leaps into the fire. Haninah dies and by agreeing to the removal of the tufts and the increased fire, he hastens his death. Yet in the story a voice from Heaven says that he and the "compassionate" executioner both were admitted to the world to come. Thus, the aggadic story is told to reason that in some circumstances it may be permitted to hasten death. In this specific instance that condition is in order to end R. Haninah's suffering. The same reasoning is used in other places as we have seen to permit the giving of high levels of painkillers to relieve suffering even though the use of the medication may shorten the patient's life.

⁶⁴ In a statement by Ismar Schorch, the Chancellor of the Jewish Theological Seminary of the Conservative movement given February 8, 1995, he says of the role of *Halakha* within Conservative Judaism:

"The sixth core value [of Conservative Judaism] is the governance of Jewish life by *Halakha*, which expresses the fundamental thrust of Judaism to concretize ethics and theology into daily practice. The native language of Judaism has always been the medium of deeds. Conservative Jews are rabbinic and not biblical Jews. They avow the sanctity of the Oral Torah erected by Rabbinic Judaism alongside the Written Torah as complementary and vital to deepen, enrich and transform it. Even if in their individual lives they may often fall short on observance, they generally do not ask of their rabbinic leadership to dismantle wholesale the entire halakhic system in order to translate personal behavior into public policy. Imbued with devotion to *klal yisrael* and a pervasive respect for tradition, they are more inclined to sacrifice personal autonomy for a reasonable degree of consensus and uniformity in communal life.

Collectively, the injunctions of Jewish law articulate Judaism's deep-seated sense of covenant, a partnership with the divine to finish the task of creation. Individually, the mitzvot accomplish different ends. Some serve to harness and focus human energy by forging a regimen made up of boundaries, standards and rituals. To indulge in everything we are able to do, does not necessarily enhance human happiness or well-being. Some mitzvot provide the definitions and norms

for the formation of community, while others still generate respites of holiness in which the feeling of God's nearness pervades and overwhelms...

The challenge, however, has not induced Conservative Judaism to assert blithely that the Halakha is immutable. Its historical sense is simply too keen. The halakhic system, historically considered, evinces a constant pattern of responsiveness, change and variety. Conservative Judaism did not read that record as *carte blanche* for a radical revision or even rejection of the system, but rather as warrant for valid adjustment where absolutely necessary. The result is a body of Conservative law sensitive to human need, halakhic integrity and the worldwide character of the Jewish community. Due deliberation generally avoided the adoption of positions which turned out to be ill advised and unacceptable.

Nevertheless, what is critical for the present crisis is the reaffirmation of Halakha as a bulwark against syncretism, the overwhelming of Judaism by American society, not by coercion but seduction. Judaism is not a quilt of random patches onto which anything might be sewn. Its extraordinary individuality is marked by integrity and coherence. The supreme function of Halakha (and Hebrew, for that matter) is to replace external barriers with internal ones, to create the private space in which Jews can cultivate their separate identities while participating in the open society that engulfs them. *Copyright 1996-97 Jewish Theological Seminary. Comments to webmaster@jtsa.edu.*

⁶⁵ Bard, Rabbi Terry. "Jewish Medical Ethics; Medical Ethics and Jews," The Jewish Chaplain, Vol. 2, No. 1 Spring 5757/1997. (Whippany, NJ: The National Association of Jewish Chaplains, 1997): 16.

⁶⁶ Ibid., 16.

⁶⁷ Draft of a proposed resolution to be considered by the UAHC, dated 12/17/90. Reproduced in Program/Case Study IV, Winter, 1991, UAHC Committee on Bio-Ethics, at p. 19. By including language that speaks to the rights surviving incompetency, the resolution indicates that the Reform Movement supports and encourages the use of Advance Care Directives that allow for decision-making after the author of the documents has become incompetent to make the decisions herself.

⁶⁸ Ibid., 5. Walter Jacob, for the Responsa Committee of the UAHC.

⁶⁹ See Appendix D attached.

⁷⁰ Rosner, Fred. Modern Medicine and Jewish Ethics, 2nd ed., (Hoboken, NJ: Ktav Publishing House, Yeshiva University Press, 1991): 22.

⁷¹ Isaiah 40:1.

CHAPTER FIVE

AN ETHICAL FRAMEWORK AND CONCLUSIONS

The Maharal of Prague in *Be'er HaGolah*, *Be'er Aleph*, Page 19 says:

The rabbis are called *ba'alei asufot*, "members [sic] of collections," for it is impossible that all the wise will agree, because everything has more than one aspect. For even if some thing is ritually unclean, it is impossible that it would not have some aspect of being clean... Therefore, the rabbis are called "members of collections" because when they sit together and study Torah, even though they differ in their wisdom, they contain all the different opinions... For just as God is the Creator of all, and from Him came the complex world that has contradictory things in which one is the opposite of the other, similarly everything has different aspects, and therefore both he who pronounces something unclean and he who pronounces it clean has studied Torah, for God has created all and He has created this thing which has two aspects.¹

Likewise, with the matter of end of life questions and decisions, those who are placed in the position of providing guidance for people facing decisions concerning treatment of a dying patient, loved one, or of oneself, may come to different conclusions. What is important to recognize is that each may be based upon a sound tradition and upon a differing interpretation of that tradition. If the decision is made based upon information and informed consent that is buttressed by a religious tradition, the choices made will have a "truth" of their own.

Throughout this thesis, I have sought to present different problems that arise with the implementation of Do Not Resuscitate Orders and different approaches to dealing with those problems. We have briefly examined the role that a secular bioethicist

might play in helping resolve those problems. We have also looked at how a religious framework can give guidance to those facing difficult decisions concerning these orders and other end-of-life decisions. Throughout the research and interviews, certain problems kept recurring. In many cases the patients' families felt that the medical care providers did not really care for their input or that the doctors did not provide the necessary information to allow the patient or the proxy decision-maker to make a good treatment choice. The second recurring problem was that people spoke of a fear of being put on "life-support" and being kept alive beyond the time that their life had meaning. A third problem was that people were concerned that they would be in a great deal of pain, and that perhaps refusing resuscitative therapy would be the easiest solution to the dilemmas that arose.

In some instances, when conflict arose over treatment options, the conflict was resolved by the physician making a treatment decision and relying upon a carefully crafted explanation to prevent any further questioning or conflict. There is still a very strong tendency on the part of some physicians towards paternalistic decision-making. To be sure, it is cloaked in terms of medical expertise, but it still exists more than it should, if we are to respect the autonomy and informed choice of the patient.

I do not wish to portray physicians as uncaring or only concerned with their own skins. Quite the contrary. During the interviews that I conducted and in the literature that I read, I saw nothing but compassion, concern, and caring for people in difficult situations. The medical personnel involved in these decisions are struggling to balance their own values and concerns with those imposed by a demanding profession, a client base that increasingly doesn't trust them, and a governmental albatross that changes in

complexity and size from day to day. Those physicians who acted in a paternalistic way often did so not out of malice or any other negative motive. Rather, they were trying to practice this difficult art in demanding situations where they had to make spur-of-the-moment decisions.

What I found to be true of doctors I also found to be true of other members of the health care team, including those who served on bioethics committees. I also saw these people struggle with different ways to convey information to the patients and their families and to provide clear choices. In some instances I saw institutions attempt to institute policies, guidelines, and procedures that would ensure quality care for the patient. Some of these did better than others at these efforts. Whether they were successful or not, the attempt was greatly appreciated by families, patients, and staff. Those who viewed the process as a good thing and a necessary part of good health care seemed to have greater success with their policies than those who viewed the process as a means to keep in compliance with medical boards and accreditation committees. Many of them sought to develop a framework and a process for dealing with these issues and sought to use past experience as a teaching tool for new protocols and procedures. I will now look at the way I developed my own model for dealing with these issues.

Development of A Framework for Dealing with Bioethical Dilemmas

Many things became apparent as I worked from my initial thesis proposal through research and into the writing phase. One of the first things I discovered was that the

development of a framework for working through ethical dilemmas would probably prove to be the biggest challenge. Developing such a framework is not necessarily difficult because of the concepts involved. Ethical theories and medical facts can be explained and understood if the time is taken to do so and the parties involved speak clearly and consistently about the issues to be faced. The difficulty comes from the nature of the task itself. In these situations each patient is an individual with his or her own clinical facts, family relationships, and different access to medical facilities, and his own value system. The medical care providers also do not operate in a vacuum. Whether we care to admit it or not, doctors and nurses have feelings, bring values to the treatment setting, and these sometimes conflict with those of the patient or family or other medical personnel.

Any model for making treatment decisions faces the challenge that there can be no "one size fits all" approach to bioethical decisions. This is correct. Yet there can be a framework that is applied in a realistic and flexible way to ensure that the proper questions are asked and the relevant factors are considered. The conclusions are not preordained. Rather, the process of information gathering and analysis will be uniform while the conclusions will differ from case to case.

Terry Perlin has suggested a model for dealing with the ethical dilemmas and questions that people face in making health care decisions. His approach is well reasoned and treats all involved with dignity and compassion. This bioethicist is a bright light in the field of bioethics, and it is doubtful that he could ever make a decision that did not promote understanding and compassion for all involved. His approach uses the acronym

"PRACTICE" to symbolize all the various factors and parties that should be involved in these decisions. This is his practice model:

PRACTICE MODEL

A tool for analyzing and evaluating difficult ethical dilemmas in health care.

P: Patient (medical and psychological facts)

R: Relationships

A: Advocacy (rights and duties)

C: Conflicts

T: Treatment or non-treatment options

I: Interests (of the various parties)

C: Consequences (short and long term)

E: Ethical principles at stake²

This model serves as a useful framework for analyzing factors and the role of the appropriate parties involved in treatment decisions. One criticism that I have of this model is that it depends greatly upon a utilitarian approach to bioethics. As I stated in chapter three, I do not favor such an approach because of the shortcomings that I see with utilitarianism or consequentialism. Under the model suggested by Dr. Perlin, the various

elements are used to gather information necessary to make treatment decisions. For example, one will list the medical factors involved with the patient's condition and make a determination of the patient's mental health- whether she appears to be depressed or despondent. Next, the person doing the ethical analysis will make a list of all of the relationships involved in the case. The rights and duties of the respective parties will be noted. An assessment of any actual or potential conflicts among the parties will be made. Each of the remaining elements will be examined and information will be gathered for each of them. This information will be shared by all of the parties to assist them in arriving at the proper course of medical treatment for the patient.

If the goal of the process of information gathering and the examination of the relevant factors is to give the people involved in the decision-making process sufficient information to make a decision based upon informed consent and justice for the patient, Dr. Perlin's model seems to be useful. However, there appears to be some downsides to the model. The PRACTICE model appears to require a balancing between the elements of the model and a balancing that must be done within the elements, themselves. For example within the category of relationships, which relationships are paramount? Does the relationship between the patient and doctor outweigh that between the patient and spouse or family? What about the relationships between the different medical care providers? What about the relationship between the patient and God? Each relationship has importance. Which relationship should take precedence over others? Can this be determined as a general rule?

A second criticism of the model is that it contains elements of utilitarianism and elements of a deontological approach to the ethical questions. Can one use both

approaches? Under the advocacy element, one is required to consider the rights and duties of the parties, a clearly deontological approach. What if one treatment decision results from this approach and another results from the analysis under the "Interests" element? What if the analysis under a rights and duties approach results in a different conclusion than the analysis based upon consequences? Who resolves the conflict and how?

Any framework that attempts to set forth a mechanism for resolving conflicts and questions will have weaknesses or pitfalls. What one seeks to do in creating such a model is to offer a means for making decisions that provides clarity and consistency for those who attempt to utilize it.³ A formal model and mechanism helps provide clarity and consistency in the institutional setting. Yet the danger is that a formal approach may become rigid and removed from the patient and others directly affected by the workings of the model. Terry Bard says that when he was helping establish the Ethics Advisory Group at Boston's Beth Israel Hospital, the parties involved in establishing the group kept three criteria in mind. First, everyone agreed that "... (1) all decision making must be kept at the bedside, (2) any ethical program should not have the status of a formal hospital standing committee with its normal bureaucratic structure, and (3) any such group would not be making ethical decisions on behalf of the hospital."⁴ The model that I am proposing will attempt to keep the decision-making "at the bedside." This means that the decisions will be made by the patient and his family in consultation with the attending physicians and bioethicists, where necessary, rather than by a committee removed from the view of the patient and the family.

I cannot attempt to judge whether the model that I have arrived at has any better potential to help resolve the bioethical issues raised than other models that have been proposed. What I do hope is that the elements of the model cause those involved to give kavod, honor or respect, to those who are in the process of dying, that it keeps the value of life as the highest principle, and that all of those who struggle with these ever increasing and ever more difficult decisions can find a way to ease the decision-making process. In that spirit I have given my model the acronym: KAVOD. Here are its elements:

K: Knowledge

A: Autonomy

V: Values

O: Options

D: Duties

The model I suggest here contains all of the various elements of the liberal approach to these questions that I outlined in chapter four. Further, since I base my personal philosophy upon a theory of duties, and ground those duties within a deontological and Jewish framework, the underlying principle of Kavod seems to make sense within a religious context. Since modern formulations of Kant's categorical imperative are often couched in terms of "the respect principle," the use of a model incorporating these elements seems doubly appropriate. The order of the elements does

not suggest their relative importance, but rather provides a convenient way to remember them.

The first element, knowledge, contains several aspects. First, the assumption is that the medical care providers have the latest medical training and knowledge concerning the medical aspects of the case that they confront. Second, they will have knowledge of the patient's medical and personal history, her family situation, and the particular moral values that the patient brings with himself to the care setting. The patient is responsible for providing this knowledge, and if unable to do so, a person close to the patient must do so.

The patient, or a proxy decision-maker, must be given sufficient knowledge to give informed consent to any proposed treatment. Thus, the options must be discussed with him or her with clarity, in simple language, and as free of paternalistic bias as possible. Medical conditions, treatment options, with any prognosis must be clearly conveyed to the patient in order to increase his knowledge of his own condition. If such information would cause harm to the patient, such information may be withheld, but this loophole should be used very infrequently. The medical staff must take the time to give this information to the patient and make sure that the patient clearly understands what is being said.

Only with such knowledge can a patient make a free and informed choice as to treatment options. Only with as complete information as can be given in the situation can the patient make a truly autonomous choice about the path to pursue. At the heart of my philosophy is a healthy respect for personal autonomy. This principle lies at the heart of the American enterprise and the heart of Reform Judaism. This autonomy should be

allowed to be exercised with complete freedom except for the situation of euthanasia and physician-assisted suicide. Drawing the limit of autonomy at this point is consistent with principles that value life, rights, and the duty to respect a person as a member of society above autonomy. The state does have an interest in preventing killing, and the duty of the physician to heal is too critical to the physician-patient relationship for the physician to become the agent of a premature death.

At the heart of my philosophy and the bioethical framework that I have proposed is a set of core values. Most of these values coincide with widely held societal values, but I may place one value above another as I just mentioned in dealing with autonomy. By placing the element of "values" within the framework, I deliberately emphasize the role that they play in the decision-making process, while providing flexibility when the values of the parties in a particular situation do not coincide. What should happen in such circumstances is that all of the values are placed on the table and are considered when the decisions are made. The element is so critical that this is why I believe a bioethicist should have a role in the process whenever possible. Furthermore, in a society whose members often hold particular religious beliefs, I feel that a chaplain should also be involved in order to ensure that the particular values of the patient's moral or religious system are given the proper place in the discussion. Values are the only thing that can keep technology from removing any remaining decision-making capacity from the patient, because "technology" itself may become a value. As Velv William Greene said earlier, "...just because we can do something doesn't mean that we should do something."⁵

Technology has provided the patient and the medical caregivers with many treatment options that we did not have a mere twenty or thirty years ago. Hence, the element of "options" within my framework introduces a dimension of flexibility into the decision-making process that is necessary in order to deal with diverse medical conditions and expanding medical technology. Medical options must be based upon sound science and medicine and must provide realistic and reliable alternatives to the patient. In providing these options, the physicians must consider the medical circumstances of the patient and the patient's advance directive if it has been given. The physician must base her decisions upon clear and consistent information and knowledge. Treatment options should be offered if the proposed procedures are not medically futile. The cost of the options should not be the determinant as to whether a procedure is done or not.

The final element of my framework for dealing with the bioethical issues at the end-of-life comes straight from the Jewish tradition as well as Kantian philosophy. That element is the concept of duty. We noted in the previous chapter, that Jewish tradition does not speak of rights with regard to healing. Instead the physician has a duty to heal. The patient has a duty to seek healing. The members of the patient's family have a duty to attend to the patient. The patient and all involved have a duty to respect life and to engage in *pikuach nefesh*. The patient has a duty to protect his own health because of it being a gift from God. Thus, the respective duties of the parties must be carefully evaluated and considered when treatment decisions are made in order to avoid conflict that harms the patient.

With a framework centered on duties, some of the conflicts that arise and could arise under a system that seeks to consider rights AND duties, and that seeks to balance interests AND consequences may be avoided. If each of the elements of the model are considered and put in their proper places, the result of such a process of gathering information and examining options will be the kavod that a person deserves by virtue of her or his humanity. Treatment choices will be made based upon a sense of duty and kavod. Pain will be relieved when possible, and death will be confronted rather than shunted aside to be ignored until it is too late. Kavod will be given to the health care providers as well. They will be respected for their diligence in pursuing treatment and healing, and they will be able to avoid decisions that are based upon paternalism.

If one follows my model, gathers the information about the patient, his values, his medical condition, outlines the available treatment options, and makes a careful assessment of the duties of each of the parties involved in the decision, will one correct answer be the result of the process? That answer must be "no." Neither this model, nor any other, can magically provide a correct answer to every treatment question. Ethical analysis and bioethical theory are not designed to do that. Ruth Macklin has stated that there is never **one** correct answer to moral dilemmas. She says: "...[T]hat is the nature of philosophical inquiry. Philosophy doesn't supply answers to multiple-choice questions. It cannot offer a 'how-to' guide to ethical quandaries."⁶ All that a model for dealing with bioethical dilemmas can hope to provide is understanding. If each of the parties understands the medical facts of the case, if each understands the duties owed to the respective parties, if each of the treatment options is understood with the expected results from each of the options, then the model will be successful.

What Questions Should Be Asked in These Settings?

Since so much of my model for dealing with bioethical issues is based upon the value of knowledge, questions form an integral part of that process. Questions form the basis for rational decision-making on the part of the medical staff and the patient. In the ideal situation the patient should feel encouraged to ask the medical care providers any question that comes to mind concerning treatment, prognosis, and the implications of particular choices. Ideally, the doctors attending a particular patient should ask the patient enough questions to be able to suggest treatment options based upon an understanding of the patient's family circumstances, the patient's value system, and address potential concerns that the patient might have.

For his part, the patient should ask, what are all of the options that I have to treat my particular medical conditions? What are the consequences if I refuse treatment? Are the proposed treatments experimental? Are any proposed procedures risky or otherwise life threatening? Will this possible treatment serve to alleviate pain? How will my refusal to accept a treatment be viewed by the medical staff? There is also a very important question that deals with the specific issue of resuscitation therapy and agreeing to a "Do Not Resuscitate Order". Will the level of care provided to me decrease as the result of my agreeing to a DNR or because I have signed advance care directives? In this instance, the patient must be assured that the cessation of treatment or the refusal to start certain treatments does not constitute medical abandonment. Such abandonment has been witnessed in certain settings and is a clear violation of the physician's duty to heal.

For their part, the medical care providers must ask many questions to make their own decisions concerning treatment options. Such questions should seek to confirm that the patient's apparent consent to treatment is, in fact, actual consent and that the patient's consent is based upon knowledge. Furthermore, the questions that the medical staff ask must attempt to determine the values and moral framework of the patient. Questions of this sort should include: Do you understand all of the medical terms that I have used? Do you understand the choices that I am giving you? Do you understand what will likely happen if you choose alternative A or if you choose alternative B? General questions concerning the patient's beliefs, background, etc. should be asked in order to give the doctor a better understanding of the whole person that he or she is treating instead of just symptoms, diseases, or complaints.

What Procedures Should Be Followed?

The answers to the aforementioned question depend upon the model used to work through the ethical decisions. If one accepts the standard approach of most modern American healthcare facilities, one will concentrate on the process of gathering information, consulting with family, patient, medical staff, and perhaps a bioethicist or a chaplain to determine what is in the best interest of the patient. Benjamin Freedman, as noted in the preceding chapter, has suggested that a Jewish approach to these situations would focus less on procedures and more on what is the right decision. This is true from a traditional Jewish perspective and may have its place in a modern secular setting as well.

However, because there is little agreement on the basic framework, and even less agreement on what policies and procedures should be followed, it is difficult to see how those involved would be able to agree on the correctness of a decision. So what procedures should be followed? In non-emergency situations, I would argue that a model such as I have outlined should be followed. Information should be exchanged in a non-hurried fashion. Family members as well as the patient should be involved in giving and gathering information. Members of the medical staff from different disciplines should be consulted. A bioethicist should carefully analyze the process and the results of the information gathering stage to confirm that the values of the patient are understood, that all of the parties understand their respective duties, and that when conflicts occur, a mediation process is available to deal with the conflicts.

A chaplain should also be involved in the consultations. Sometimes this should be the patient's personal clergy person, and sometimes the input of the staff chaplain may be helpful. In either case, the clergy person will focus on those values that come from the patient's religious tradition that may have a considerable impact on the decision-making process of the patient and the ultimate decision itself. Such values may be involved even if the person does not consider himself religious.

In non-emergency situations, there should be a "cooling-off period" before decisions made are carried into effect. Perhaps a twenty-four hour period of time can be instituted in order to give the patient, the doctor, and all concerned a chance to consider the implications of the decision once it is made. After the treatment has been implemented, the results of the treatment should be evaluated, and a determination should be made as to whether the decision was the correct one, whether treatment should be

continued or discontinued, and whether there has been a change in any of the factors that were involved in the initial decision that would necessitate a new decision.

What Approaches to These Questions Are Illegitimate?

In developing a model for dealing with difficult bioethical issues, I evaluated different ethical theories, reviewed medical journals, bioethics literature, and interviewed individuals involved in making treatment choices. The questions that are faced are difficult at best, and it is difficult to feel good about the results in many instances. If the reader will recall the case of the patient in the permanently unconscious state in chapter two, the only avenue for resolving the conflict proved to be the possibility of saving another life through organ donation. The input of caring and qualified pastoral care and social workers was also an important factor. Through all of the cases and situations that I heard about or read about, the one approach to these questions that I resented more than any other was the paternalistic approach. This occurred when otherwise dedicated medical staff decided what was in the best interest of the patient and that they alone should determine what the proper course of treatment should be. This type of assumption caused more conflict than any other approach that I saw used.

Invariably, a patient died who probably shouldn't have died, a patient was kept alive who should have been allowed to die, or the feelings and concerns of the patient or family were trampled on because someone did not take the time to discuss the elements of the case as they should have been discussed. I will admit that utilitarian approaches do not appeal to me. I still believe that one can never include every factor in the ethical

analysis. There are others who feel as strongly that utilitarian approaches resolve issues better than duty-based theories. But paternalistic decision-making takes neither the utilitarian approach nor the duty based approach seriously. Instead, we see the medical caregiver choose for him or herself what is appropriate under the circumstances of a particular case. Investing one individual with this much power over the life of another is fraught with danger. If a committee has difficulty in deciding what to do in particular circumstances, how can one person who may care too much about the case or not care at all about the case make an appropriate decision for another, no matter how good his or her intentions are or how well they have been trained?

What other approaches to these issues are illegitimate? I consider any approach that uses a cost vs. benefits approach as the principal factor to be used in determining who gets a treatment and who doesn't as being seriously flawed. Justice requires that we treat all individuals equally who are in similar circumstances. Those circumstances may legitimately include medical conditions and their prognoses. But, they may not include whether an individual can pay for the treatment. Race, gender, sex, and social class also are inappropriate factors for bioethical decision-making.

Recommendations

Given the weaknesses of the paternalistic approach to decision-making, I would recommend that all medical care facilities and personnel adopt a systematic approach to dealing with resuscitation questions in particular and end-of-life questions in general

based upon my model suggested above or by one developed to fit the peculiarities of the particular facility. Second, any guidelines or policies adopted to foster communication and informed decision-making in these settings should have a built-in mechanism to ensure that the policy is applied on a case-by-case basis considering all relevant factors and that such policies do not discriminate against females, the elderly, the poor, or other groups based upon a status other than the medical condition that brings the patient to the facility.

Beyond developing a model for confronting treatment decisions, health care facilities should have regular, on-going training to maintain high standards of ethical conduct for those who care for others.

Conclusions

Cardiopulmonary resuscitation has been an incredible medical advance. There are literally thousands and thousands of people alive today who would not be alive but for the development of this medical procedure. Yet, the advance of medical life-saving procedures has placed a considerable burden on those forced to make decisions for themselves or for others. The kavod principle demands that we consider carefully how medical technology is created and how it is used. We must ensure that we do not lose our humanity in order to extend an abstract concept known as "life." We can ensure that the tremendously difficult choices that we make at the end of life are done with compassion, authenticity, justice, and love if we base those decisions on the respect principle and a strong moral framework. It is my hope that this undertaking will help that process along.

What I Learned in the Process of Doing This Thesis.

Any endeavor undertaken for the purpose of learning is worthwhile. I have learned more in writing this thesis than I expected at the outset. As I look at the project that I proposed in January 1997, I can only shake my head in amazement that I could have ever have hoped to accomplish what I set out to do. It did not take very long in the research and interview phases of the thesis for me to discover that the scope of the project was more than one person could achieve in many, many years of research. And yet, I have learned throughout the process – even if on a reduced scale. Prior to this project, my exposure to the medical questions presented consisted of one night working in an emergency room with a hospital corpsman in the late nineteen-sixties and ten weeks of a hospital chaplaincy program. Neither of these experiences prepared me for the anguish and conflict that I was forced to confront as I interviewed people who had had to deal with resuscitation questions and other end-of-life issues.

By listening to the stories that all of those involved told, by listening to medical personnel who cared deeply for their patients, by being permitted to visit places within peoples' hearts where they felt most vulnerable and afraid, I was able to learn the importance of providing support to all involved in these decisions. And beyond listening for a story, I was forced to apply the theoretical knowledge that I had gained in philosophy courses, theology that I had learned in theology courses, and the skills in human relations that were unrefined up to now to real situations involving real people.

I recall one story told to me by a hospice care worker who spoke of a case that she had been assigned. The patient was an unrepentant, alcohol-abusing, spouse and child-abusing family man, who on top of these faults, was also an unwavering racist. "Tom" had been estranged from his adult children, and had buried a wife whom he did not miss. He had not been to a religious institution throughout his adult life. And now that he had terminal pancreatic cancer, he saw no reason to change. When the hospice care social worker first met the patient, she asked, as a matter of course, if he would like to see a chaplain. Tom cursed the idea in particular and all chaplains in general. He informed the social worker that he had no use for God, Jesus, chaplains, reverends, heaven or hell. He KNEW that he was going to hell, and if the cancer killed him tomorrow, that would be just fine. The social worker noted in his chart that no chaplain should be sent to Tom's house.

A few weeks later Tom wound up in the hospital. Again, he told the hospice care worker that he did not care to see his family, a chaplain, or anyone else who would get in the way of his death and subsequent dispatch to hell. On the second day of his hospitalization, a minister from one of the local African-American churches was visiting a congregant in the hospital, and happened to pass Tom's room. As he walked past the door he waved. Tom did not wave back although he was looking straight at the minister. Not one to be ignored, the minister turned around, knocked on Tom's door, and proceeded to ask if he could come in. Tom let out a stream of invective and called the man every negative name that he could think of. Instead of getting his back up, or responding in kind, the clergyman merely let Tom rant – which he did for a half-hour or so. At the end of the tirade, Tom was exhausted. He looked the minister in the eye,

waved his hand to dismiss the man, and then turned on his side away from the door.

Without a word, the man left.

A few days later, the minister returned to the hospital to visit his parishioner, and after doing so, he stopped in Tom's room. This time, Tom's tirade lasted only fifteen minutes. As he finished the clergyman looked at him and said: "I have listened to you speak of things from your heart, but I have not heard you express any feelings about your pain, your loneliness, or the life you are leaving behind. Would you care to tell me about your childhood?"

Tom let out with another tirade, then after a few minutes, he began to cry. He told the minister that he knew there was no chance that he could be forgiven for the evil that he had done in his life. The clergyman again let Tom carry on in this fashion for a while. Then he told Tom that it was never too late, and that he would pray with him as long as Tom would like. They did so, and over the next two weeks, the racist barrier that Tom had erected during his life came down. Further, the minister was able to bring about reconciliation between Tom and his adult children. Tom executed legal documents giving his house to his two children, asked for and received their forgiveness for the things that he had done to them in their lives.

A week later, Tom died. This recalcitrant, alcohol-abusing, racist, child-and spouse-abuser died at peace. His funeral was conducted by a black man – a minister from an African-American church to which Tom had never belonged. A new friend who had taken the time to let a scared old man vent about life and good and bad, had reached him, gotten beyond the barriers and enabled a process of reconciliation to happen between Tom and his family. Did Tom live longer because of this man's intervention?

Probably not, but he did achieve a peace that had eluded him. He did make peace with his children. And God was in that place.

It is hard to say when it is someone's time to die. It is never easy to accept the loss that death represents. Yet death, just as life, presents us the opportunity to learn and to grow. As I heard the stories, as I listened to the physicians, I learned that life cannot be measured by its quality or the cost of maintaining it. I learned that the "saving of a life" can mean more than the act of restoring breathing or heartbeat. A life can be saved *for* something.

In the opening paragraphs of this essay I mentioned how the description of dying that Sherwin Nuland gives in his book, How We Die, left me begging for answers to the questions at the end-of-life beyond a description of the clinical process of death. My research and interviews helped me fill in some of the missing pieces of the puzzle that is life and death.

Along the way, I also learned that a thesis, a book, or a year of investigation of this subject has "scratched the itch," but I also learned that I will not complete my quest for enlightenment or understanding in this area at this time – if ever. I anticipate continuing the struggle for answers to these questions for many years to come. Technology will demand it. The rabbinate will also require a continuing search and reexamination of these issues. The answers won't be easy or immutable. But I look forward to searching for them.

My father, may his memory be for a blessing, was a simple man. Rumor had it that he had graduated from the "third grade at Salisbury Elementary." Other rumors had it that he, in fact, finished the eighth grade at the one-room country schoolhouse that he

attended. The truth will never be known. In any case he became a well-read and self-educated man. His simple folk wisdom may contain the best statement yet on death and dying that I've come across. He used to wander through the house singing a song whose words went like this:

I'll eat when I'm hungry,
I'll drink when I'm dry.

If a tree don't fall on me,
I'll live 'til I die.

I love you, Pop.

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GLOSSARY

Medical Terms

Advance care directives - In an advance care directive, a person may predetermine which medical procedures will be used should the patient be unable to make treatment choices due to incapacity. The two principal types of advance care directives are the living will and the durable power of attorney for healthcare.

Arrhythmia - Arrhythmia is a term that describes changes in the regular rhythm of the heartbeat. There are different types of arrhythmias including skipped beats and other irregular patterns of heartbeat. The less serious forms may be treated with medication. Other types of arrhythmias are more serious. In tachycardia, for example, the heart races, beating up to 240 times per minute, for anywhere from seconds to days. The rapid beating can cause fainting. In atrial arrhythmia, the heart begins beating in a fast but irregular pattern known as fibrillation. (From *Microsoft® Encarta® 98 Encyclopedia*. © 1993-1997 Microsoft Corporation. All rights reserved).

Brain death - (1) the loss of all reflexes, (2) the lack of any response to vigorous external stimuli, and (3) the absence of electrical brain activity as measured by an electroencephalogram over a predetermined, fixed period of time.

Cardiac arrest - A cardiac arrest is a condition in which the heart goes into ventricular fibrillation. This condition occurs when there is an accelerated beating of the ventricles of the heart. This irregular rhythm of the heartbeat prevents the heart muscle from effectively circulating the blood through the heart. A defibrillator, (a device for providing an electric shock to the heart), may be used.

Cardiopulmonary Resuscitation - Cardiopulmonary resuscitation (CPR), involves closed-chest compression of the heart muscle as well as breathing air into the lungs of a person who has suffered cardiac or respiratory arrest. **Advanced** CPR usually involves three types of treatments: (1). Drugs that are normally given intravenously. The appropriate drugs are chosen to restore a heartbeat and to regulate the rhythm; (2). Electric shock, that is often necessary to restart the heart; (3). Endotracheal intubation and mechanical ventilation for artificial respiration.

Do Not Resuscitate Order - A DNR order is a written medical order that instructs the medical staff that resuscitative measures, including CPR, should not be instituted should the patient go into cardiac or respiratory failure.

Euthanasia - This term from the Greek meaning "good death," is used to describe the act of assisting a person in the act of hastening the time of their death. Active euthanasia is the term used to denote an affirmative act taken to hasten the death, such as giving a lethal dose of a medication or using a "suicide machine" such as that used by Dr. Jack Kevorkian. Passive euthanasia consists of **not** doing something to prevent death. Voluntary euthanasia is the term used to describe the case in which the patient, herself, requests assistance in dying. Non-voluntary euthanasia is the case in which the patient does not seek assistance in dying but rather, someone else decides that the person should die and takes steps to end that person's life.

Hospice - Hospice is an organization whose purpose and function is to provide palliative (or painkilling) care to terminally ill patients. The term includes both facilities where patients may be admitted to spend their last days of life or to care given to terminal patients in their own home, the hospital, or in a long-term care facility.

Medical futility - Medical futility is a term describing a medical situation in which medical treatment offers no conceivable medical benefit to the patient and the potential for some possible harm. In the context of CPR, futility means that the resuscitation procedures have no chance of restoring a heartbeat or restoring unassisted breathing.

Palliative care - Palliative care describes the broad range of medical treatments that may be used to reduce or eliminate certain types of pain through the use of drugs, nerve blockade, or other means. Such treatment is essential in the treatment of patients in the terminal stages of lingering, painful diseases or conditions.

Persistent vegetative state - A persistent vegetative state is a condition of permanent unconsciousness in which the patient has no ability to communicate or interact with others and has no contact with her external environment.

Thoracic surgery - This type of surgery involves the opening of the chest cavity for treatment of conditions and diseases of the heart and lungs.

Ventricular fibrillation - See *Arrhythmia* and *cardiac arrest* above.

Philosophic Terms

Autonomy - The autonomy principle in ethics states that persons should be able to make or consent to rules for themselves. An autonomous individual is both free from external control and in control of his or her own affairs through the exercise of reason and deliberation. Autonomy is most often expressed through such terms as "liberty," "right to privacy," "freedom of will," "free will," and "choice."

Beneficence - The principle that denotes doing an act that results in the greatest amount of good (or the least amount of harm), for the greatest number of people. Stated in other terms, beneficence requires a person to refrain from causing harm to another and to act to promote the good.

Bioethics - Bioethics is the term used to describe the application of ethical theory and morality in the area of biomedicine.

Deontological - Deontological theories are those that regard particular acts as right or wrong independent of the consequences of the acts.

Informed consent - Informed consent means that an autonomous individual makes a decision free of outside rules and based upon knowledge to allow another to act in a way that directly affects himself.

Futility - Futility is the principle that holds that a certain act cannot have a positive consequence in a particular instance.

Justice - Justice is the ethical principle that requires good to be distributed among individuals in similar circumstances in a similar or equal manner.

Maleficence - Maleficence is acting in a manner that will intentionally cause harm to another.

Morality - The sum of all human action whether good or bad. Two subcategories of morality are actions that are *moral* and those that are *immoral*.

Nonmaleficence - Nonmaleficence is the ethical principle that requires one to refrain from intentionally doing harm.

Paternalism - Paternalism encompasses an agent performing an act on or for another without that person's consent. The agent may intend good consequences and be acting free of any maleficence. The act may still be wrong in that the autonomy of the individual acted upon has been ignored or violated.

Utilitarianism - Utilitarianism is a term used to categorize ethical theories that look to results or consequences of actions to determine whether an act is moral or not. These results or consequences are defined in terms of some non-moral good or combination of goods that are to be maximized in order to be preferable over other alternatives.

Jewish Terms

Code - Codes are collections of the *Halakha*, or Jewish law, that may be consulted by a Jew who has a question on a specific issue. The chief codes in the Jewish tradition are the *Tur*, the *Mishneh Torah*, and the *Shulchan Aruch*.

Goses - A *goses* is a person who is literally in his last days of living. More technically, the term refers to someone manifests a death rattle in the course of breathing and who is likely to expire within thirty-six hours.

Halakhah - *Halakha* is a Hebrew word meaning "the way one should walk," that is, the one way in which one should conduct oneself. It has come to be understood as the divine law, revealed to Moses and transmitted from generation to generation down to the present. The term includes the written law contained in the Torah (the first five books of the Hebrew Bible), and the oral law that has been handed down in the Talmud, Codes of Jewish Law, and rabbinic responsa.

Mitzvot - *Mitzvot* are commandments or duties imposed upon Jews. *Mitzvot* may be affirmative acts that a Jew must do or negative *mitzvot*, or things that one must refrain from doing. The *mitzvot* are contained in the oral and the written law.

Pikuach nefesh - *Pikuach nefesh* means the saving of a life.

Responsa - *Responsa* are authoritative rabbinic replies to questions on points of Jewish law dealing with specific issues. Through the process of *she'elah* and *teshuvah* (question and answer), specific questions could be sent to respected rabbinic authorities, known as *poskim*, who would consult the wealth of rabbinic sources from the Talmud to the Codes and determine the proper action to be taken. This body of *ad hoc* Jewish legal opinion is known as *Responsa*.

Talmud - The term, *Talmud*, refers to the collection of oral law gathered by Rabbi Judah the Prince about the year 200 of the Common Era, called the *Mishnah*, and the rabbinic commentary on the *Mishnah*, called *Gemara*. The two elements, *Mishnah* and *Gemara*, together comprise the *Talmud*. There are two collections of the Talmudic material- one from Babylonia, (called the *Talmud Bavli*), and one from the Land of Israel, (called the *Talmud Yerushalmi*).

Terefah - In the traditional meaning, the term was used to denote an animal with a fatal organic defect that may not be eaten even if slaughtered in an appropriate fashion according to the dietary laws. An animal was *terefah* if it would die of the disease or defect within twelve months. However, the term also has a usage in the context of the laws on murder. Maimonides, known as the RAMBAM (1138-1204), laid out the definition of *terefah* in the context of someone who killed a person suffering from a fatal organic defect that was incurable by a physician, and whether the murderer could be subject to capital punishment. Under Rambam's scenario one could argue that the person with the defect was dead already and thus the killer could not be held liable for his death.

APPENDIX A

The Cammer Study Questions and Results (Chapter Two)

Cammer Paris, Barbara E., MD; Victor G. Carrion, MD; James S. Meditch, Jr., MD; Carol F. Capello, M.Ed.; Michael N. Mulvihill, DrPH, "Roadblocks to Do-Not-Resuscitate Orders: A Study in Policy Implementation," Archives of Internal Medicine, Vol. 153, (July 26, 1993): 1689-1695. The study interviewed physicians at two large New York medical centers. Several "problems" were given to the physicians, and they were asked to rate them in the order of their prevalence in the clinical setting. The rankings went from a scale of 5 to 0, with "5" being "common" and "0" being "rare." A list of seventeen questions were asked about implementation of DNR orders, and three questions about demographics were asked. The questions were as follows:

A. For questions 1 through 5, assume the patient is competent (i.e., has capacity to decide for himself/herself):

| Common | | | | | Rare | N/A |
|--------|---|---|---|--|------|-----|
| 5 | 4 | 3 | 2 | | 1 | 0 |

1. Patient does not want DNR status.
2. Patient gives verbal consent but does not want to sign the DNR form.
3. Private attending physician does not discuss DNR status with patient.
4. House staff is too busy to discuss DNR status with patient before patient arrests.
5. House staff does not discuss DNR with patient because house staff does not feel comfortable with the issue.

B. For questions 6 through 9, assume the patient may be either competent or incompetent:

6. Difference of opinion between attending physician and house staff regarding DNR status.
7. Failure of communication between attending physician and house staff regarding DNR status.
8. Attending physician fails to write order, even though the patient has given verbal consent.
9. House staff is too busy to complete DNR form before patient

arrests.

C. For questions 10 through 14, assume the patient is incompetent, has no previous DNR status, and his/her wishes are unknown. The "surrogate" is the person selected to make a decision regarding resuscitation on behalf of the patient:

10. Failure of surrogate to agree to DNR status.
11. Surrogate agrees verbally but refuses to sign DNR forms.
12. Failure to contact surrogate before patient arrests.
13. Uncertainty about who is the proper surrogate.
14. Difference in opinion between potential surrogates concerning the patient's DNR status.

D. For questions 15 and 16, please consider the patient who previously consented to a DNR order but who returns to the hospital with a new problem and is incapable of making a decision:

15. The surrogate objects to the DNR order.
16. Difference in opinion between attending physician and house staff regarding patient's capacity.

E. For questions 17 and 18, consider the situation of an incompetent patient whose surrogate agrees to DNR status and a witness is needed:

17. A witness is unavailable.
18. Witness does not agree to sign the DNR form.

Demographic Data

1. Were you ever instructed as to how to discuss DNR status with a patient or surrogate?
2. If yes, at what level of training were you instructed about discussing DNR status with patients or surrogates?

- A. Medical School
- B. House Staff
- C. Attending physician
- D. Other _____

3. Please complete the following:

Age: _____
Gender: Male Female
Marital Status: Unmarried Married Divorced Widowed
Position: PGY-1 PGY-2 PGY-3 PGY-4
 Fellow Attending

If attending, years in practice _____

(Note: PGY- refers to "post-graduate year" and denotes the years that used to be referred to as "residencies" following medical school).

The questions asked were ranked in the following order by attending physicians:

12,14,13,3,10,5,1,7,4,11,15,8,6,9,16,2,18,17,

and by house staff:

3,10,12,14,13,7,1,6,8,15,11,16,5,4,2,9,17,18.

It is interesting to note that with both populations, attending physicians and house staff, the same five situations ranked at the top with both groups, although the placement within the top five disagreed between the samples. It is important to note that four of the top five involved issues involving surrogate decision-makers. The fifth most frequent situation encountered was that the doctor does not discuss DNR with the patient. The implication of the ranking is that failure to communicate and/or a lack of communication with a surrogate are often implicated in DNR problems. According to the authors of the study, one of the results of this lack of communication is that the implementation of DNR orders may be applied inappropriately but also that DNR orders are implemented later than they should be. The authors conclude on the basis of their study that policies may need to be reassessed and reformulated to facilitate DNR implementation.

APPENDIX B
LANDMARK CASES IN BIOETHICS

U.S. Supreme Court

CRUZAN v. DIRECTOR, MDH, 497 U.S. 261 (1990)

497 U.S. 261

CRUZAN, BY HER PARENTS AND CO-GUARDIANS CRUZAN ET UX.

v.

DIRECTOR, MISSOURI DEPARTMENT OF HEALTH, ET AL.
CERTIORARI TO THE SUPREME COURT OF MISSOURI
No. 88-1503.

Argued December 6, 1989

Decided June 25, 1990

Petitioner Nancy Cruzan is incompetent, having sustained severe injuries in an automobile accident, and now lies in a Missouri state hospital in what is referred to as a persistent vegetative state: generally, a condition in which a person exhibits motor reflexes but evinces no indications of significant cognitive function. The State is bearing the cost of her care. Hospital employees refused, without court approval, to honor the request of Cruzan's parents, copetitioners here, to terminate her artificial nutrition and hydration, since that would result in death. A state trial court authorized the termination, finding that a person in Cruzan's condition has a fundamental right under the State and Federal Constitutions to direct or refuse the withdrawal of death-prolonging procedures, and that Cruzan's expression to a former housemate that she would not wish to continue her life if sick or injured unless she could live at least halfway normally suggested that she would not wish to continue on with her nutrition and hydration. The State Supreme Court reversed. While recognizing a right to refuse treatment embodied in the common-law doctrine of informed consent, the court questioned its applicability in this case. It also declined to read into the State Constitution a broad right to privacy that would support an unrestricted right to refuse treatment and expressed doubt that the Federal Constitution embodied such a right. The court then decided that the State Living Will statute embodied a state policy strongly favoring the preservation of life, and that Cruzan's statements to her housemate were unreliable for the purpose of determining her intent. It rejected the argument that her parents were entitled to order the termination of her medical treatment, concluding that no person can assume that choice for an incompetent in the absence of the formalities required by the Living Will statute or clear and convincing evidence of the patient's wishes.

Held:

1. The United States Constitution does not forbid Missouri to require that evidence of an incompetent's wishes as to the withdrawal of life-sustaining treatment be proved by clear and convincing evidence. Pp. 269-285. [497 U.S. 261, 262]

SUPERINTENDENT OF BELCHERTOWN STATE SCHOOL et al.

v.

Joseph SAIKEWICZ.

Supreme Judicial Court of Massachusetts,
Hampshire.

Argued July 2, 1976.

Decided Nov. 28, 1977.

Mass., 370 N.E.2d 417

Superintendent of Belchertown State School, facility of Department of Mental health, and staff attorney at school petitioned Probate Court for appointment of guardian of resident of school and simultaneously filed motion for immediate appointment of guardian ad litem with authority to make necessary decisions concerning care and treatment of resident, who was suffering with acute myeloblastic monocytic leukemia. After appointing guardian ad litem, the Probate Court, Hampshire County, Jekanowski, J., agreed with guardian's recommendation that not treating resident would be in resident's best interests, and questions concerning such decision were reported to the Appeals Court. After granting a request for direct review the Supreme Judicial Court, Liacos, J., held that:

(1) in appropriate circumstances, a person has a general right to refuse medical treatment for a terminal illness; (2) such general right to refuse medical treatment extended to the case of mentally incompetent patient; (3) in applying "substituted judgment doctrine" to determine whether chemotherapy treatment would be administered to patient, where it was to ascertaining competent person's actual interests and preferences, deciding what decision would be made by incompetent person if he were competent, taking into account present and future incompetency of individuals one of the factors which would necessarily have turned to the decision-making process of the competent person, and (4)

evidence supported determination that incompetent patient, if competent, would have elected not to take chemotherapy.

Ordered accordingly.

In the Matter of John STORAR.

**Charles S. SOPER, as Director of
Newark Developmental Center, et
al., Appellants,**

V.

Dorothy STORAR, Respondent.

**In the Matter of Philip K. EICHNER, On Behalf of Joseph C. Fox,
Respondent,**

V.

**Denis DILLON, as District Attorney of
Nassau County, Appellant**

Court of Appeals of New York.

52 N.Y.2d 363, 420 N.E. 2d, 64

March 31, 1981.

In first suit, hospital appealed from order of the Supreme Court, Appellate Division, 78 A.D.2d 1013, 434 N.Y.S.2d 46, which affirmed denial of hospital's application to continue blood transfusions to a mentally retarded and terminally ill adult cancer patient by the Supreme Court, Monroe County, 433 N.Y.S.2d 388. In second suit, the District Attorney appealed from decision of the Supreme Court, Appellate Division, 73 A.D.2d 431, 426 N.Y.S.2d 517, which affirmed an order of the Supreme Court, Special Term, 102 Misc.2d 184, 423 N.Y.S.2d 580, authorizing guardian of 83-year-old terminally ill patient to terminate patient's respirator. Following consolidation of both appeals, the Court of Appeals, Wachtler, J., held that: (1) where 83-year old patient, prior to becoming incompetent due to illness, consistently expressed his views and concluded not to have his life prolonged by medical means if there were no hope of recovery, court properly approved discontinuance of patient's respirator, on which he was being maintained in a permanent vegetative state with no reasonable chance of recovering, at the request of the patient's guardian; and (2) application by guardian of a terminally ill,

profoundly retarded adult cancer patient for permission to discontinue blood transfusions, which did not involve excessive pain and were necessary to compensate for blood loss which was related to his disease, should have been denied, in light of the fact that the patient was functioning at his usual level of mental and physical activity with the blood transfusions, whereas such level would not have been possible if the transfusions had been discontinued.

Order as to first case reversed; as to second case, modified with directions.

Jones, J., dissented in part and filed opinion.

Fuchsberg, J., dissented.

In the Matter of Claire C. CONROY
Supreme Court of New Jersey.

Argued March 19, 1984.

Decided Jan. 17, 1985.

98 N.J. 321

Guardian of incompetent nursing home patient sought permission to remove nasogastric feeding tube, the primary conduit for nutrients, from the patient, an 84-year-old bedridden woman with serious and irreversible physical and mental impairments and a limited life expectancy. The application was opposed by the patient's guardian ad litem. The Superior Court, Chancery Division, Essex County, 188 N.J.Super. 523, 457 A.2d 1232, granted permission and guardian appealed. The Superior Court, Appellate Division, 190 N.J.Super. 453, 464 A.2d 303, reversed. The Supreme Court, Schreiber, J., held that: (1) death of the patient did not moot the case because it presented a substantial issue capable of repetition while evading review; (2) competent adult generally has the right to refuse medical treatment and does not lose that right upon incompetency; (3) surrogate decision maker for incompetent may direct the withdrawal or withholding of life-sustaining treatment under certain circumstances if certain procedures are followed; (4) notification must be given to office of the ombudsman for the institutionalized elderly; (5) there must be a determination that incompetent nursing home patient is incompetent to make the decision in question; and (6) evidence in the instant case did not meet any of the three tests for termination of life sustaining treatment.

Reversed.

Handler, J., filed an opinion concurring in part and dissenting in part.

In the Matter of Karen QUINLAN An Alleged Incompetent.

Supreme Court of New Jersey Argued Jan. 26, 1976.

Decided March 31, 1976.

Father sought to be appointed guardian of person and property of his old daughter who was in a persistent vegetative state and sought the express power of authorizing the discontinuance of all extraordinary procedures for sustaining daughter's vital processes. The Superior Court, Chancery Division, 137 N.J. Super. 227, 348 A.2d 801, denied authorization for termination of the life-supporting apparatus and withheld letters of guardianship over the person of the incompetent, and father appealed and the Attorney General cross-appealed. The Supreme Court, Hughes, C. J., held that a decision by daughter to permit a noncognitive, vegetative existence to terminate by natural forces was a valuable incident of her right to privacy which could be asserted on her behalf by her guardian; that the state of the pertinent medical standards practices which guided the attending physicians who held opinion that removal from the respirator would not conform to medical practices, standards and traditions was not such as would justify court in deeming itself bound or controlled thereby in responding to case for declaratory relief; and that upon the concurrence of guardian and family, should the attending physicians conclude there was no reasonable possibility of daughter's ever emerging from her comatose condition to a cognitive, sapient and that the life-support apparatus should be discontinued, physicians should consult with hospital ethics committee and if committee should agree with physicians' prognosis, the life-support systems may be withdrawn and said action shall be without civil or criminal liability therefor, on the part of any participant, whether guardian, physician, hospital or others.

Modified and remanded.

APPENDIX C

Instances of the Term "Goses" in the Talmud

The Talmud Bavli, the Babylonian Talmud, contains several references to the term *goses*. These are contained in eight different tractates. A listing of the instances may help those who would choose to examine the issue further.

1. Talmud Bavli, *Pesachim* 70b
2. Talmud Bavli, *Pesachim* 98a
3. Talmud Bavli, *Yevamot* 120b
4. Talmud Bavli, *Nazir* 43a
5. Talmud Bavli, *Gittin* 28a
6. Talmud Bavli, *Kiddushin* 78b
7. Talmud Bavli, *Bava Batra* 127b
8. Talmud Bavli, *Sanhedrin* 78a
9. Talmud Bavli, *Arakhin* 4a
10. Talmud Bavli, *Arakhin* 5b
11. Talmud Bavli, *Arakhin* 18a

(For the citations in Hebrew, see attached reprinted from Bar Ilan University Bar Mitzvah Edition, Classic Texts on CD-ROM, Copyrighted with no date given.)

1. תלמוד בבלי מסכת פסחים דף ע עמוד ב
2. תלמוד בבלי מסכת פסחים דף צח עמוד א
3. תלמוד בבלי מסכת יבמות דף קכ עמוד ב
4. תלמוד בבלי מסכת נזיר דף מג עמוד א
5. תלמוד בבלי מסכת נזיר דף מג עמוד א
6. תלמוד בבלי מסכת נזיר דף מג עמוד א
7. תלמוד בבלי מסכת נזיר דף מג עמוד א
8. תלמוד בבלי מסכת נזיר דף מג עמוד א
9. תלמוד בבלי מסכת גיטין דף כח עמוד א
10. תלמוד בבלי מסכת קידושין דף עח עמוד ב
11. תלמוד בבלי מסכת בבא בתרא דף קכז עמוד ב
12. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
13. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
14. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
15. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
16. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
17. תלמוד בבלי מסכת סנהדרין דף עח עמוד א
18. תלמוד בבלי מסכת ערכין דף ד עמוד א
19. תלמוד בבלי מסכת ערכין דף ד עמוד ב
20. תלמוד בבלי מסכת ערכין דף ו עמוד ב
21. תלמוד בבלי מסכת ערכין דף ו עמוד ב
22. תלמוד בבלי מסכת ערכין דף יח עמוד א

*** Please treat this sacred text with respect ***

APPENDIX D

EXAMPLES OF ADVANCE CARE DIRECTIVES

Documents Prepared by the Ohio State Bar Association and the Ohio State Medical Association:

- 1. State of Ohio Living Will Declaration.**
- 2. State of Ohio Durable Power of Attorney for Health Care.**

Documents and Information provided by the National Institute for Jewish Hospice:

- 1. Jewish Living Will.**
- 2. Jewish Living Will, Health Care Proxy - Durable Power of Attorney.**
- 3. Optional Additional Medical Directives.**
- 4. Appointment of a Health Care Agent/ Advance Directive. (This document provides a section for organ donation consent.)**



STATE OF OHIO
LIVING WILL DECLARATION



I, _____, presently residing at _____, Ohio,
(the "Declarant"), being of sound mind and not under or subject to duress, fraud or undue influence, intending to create a Living Will Declaration under Chapter 2133 of the Ohio Revised Code, as amended from time to time, do voluntarily make known my desire that my dying shall not be artificially prolonged. If I am unable to give directions regarding the use of life-sustaining treatment when I am in a terminal condition or a permanently unconscious state, it is my intention that this Living Will Declaration shall be honored by my family and physicians as the final expression of my legal right to refuse medical or surgical treatment. I am a competent adult who understands and accepts the consequences of such refusal and the purpose and effect of this document.

In the event I am in a terminal condition, I do hereby declare and direct that my attending physician shall:

1. administer no life-sustaining treatment;
2. withdraw such treatment if such treatment has commenced; and
3. permit me to die naturally and provide me with only that care necessary to make me comfortable and to relieve my pain but not to postpone my death.

In the event I am in a permanently unconscious state, I do hereby declare and direct that my attending physician shall:

1. administer no life-sustaining treatment, except for the provision of artificially or technologically supplied nutrition or hydration unless, in the following paragraph, I have authorized its withholding or withdrawal;
2. withdraw such treatment if such treatment has commenced; and,
3. permit me to die naturally and provide me with only that care necessary to make me comfortable and to relieve my pain but not to postpone my death.

☐ IN ADDITION, IF I HAVE MARKED THE FOREGOING BOX AND HAVE PLACED MY INITIALS ON THE LINE ADJACENT TO IT, I AUTHORIZE MY ATTENDING PHYSICIAN TO WITHHOLD, OR IN THE EVENT THAT TREATMENT HAS ALREADY COMMENCED, TO WITHDRAW, THE PROVISION OF ARTIFICIALLY OR TECHNOLOGICALLY SUPPLIED NUTRITION AND HYDRATION, IF I AM IN A PERMANENTLY UNCONSCIOUS STATE AND IF MY ATTENDING PHYSICIAN AND AT LEAST ONE OTHER PHYSICIAN WHO HAS EXAMINED ME DETERMINE, TO A REASONABLE DEGREE OF MEDICAL CERTAINTY AND IN ACCORDANCE WITH REASONABLE MEDICAL STANDARDS, THAT SUCH NUTRITION OR HYDRATION WILL NOT OR NO LONGER WILL SERVE TO PROVIDE COMFORT TO ME OR ALLEVIATE MY PAIN.

In the event my attending physician determines that life-sustaining treatment should be withheld or withdrawn, he or she shall make a good faith effort and use reasonable diligence to notify one of the persons named below in the following order of priority:

1. _____
(Name) (Relationship)

presently residing at _____ Phone: _____

2. _____
(Name) (Relationship)

presently residing at _____ Phone: _____

For purposes of this Living Will Declaration:

(A) "Life-sustaining treatment" means any medical procedure, treatment, intervention, or other measure including artificially or technologically supplied nutrition and hydration that, when administered, will serve principally to prolong the process of dying.

(B) "TERMINAL CONDITION" MEANS AN IRREVERSIBLE, INCURABLE, AND UNTREATABLE CONDITION CAUSED BY DISEASE, ILLNESS, OR INJURY TO WHICH, TO A REASONABLE DEGREE OF MEDICAL CERTAINTY AS DETERMINED IN ACCORDANCE WITH REASONABLE MEDICAL STANDARDS BY MY ATTENDING PHYSICIAN AND ONE OTHER PHYSICIAN WHO HAS EXAMINED ME, BOTH OF THE FOLLOWING APPLY:

(1) THERE CAN BE NO RECOVERY, AND

(2) DEATH IS LIKELY TO OCCUR WITHIN A RELATIVELY SHORT TIME IF LIFE-SUSTAINING TREATMENT IS NOT ADMINISTERED.

(C) "PERMANENTLY UNCONSCIOUS STATE" MEANS A STATE OF PERMANENT UNCONSCIOUSNESS THAT, TO A REASONABLE DEGREE OF MEDICAL CERTAINTY AS DETERMINED IN ACCORDANCE WITH REASONABLE MEDICAL STANDARDS BY MY ATTENDING PHYSICIAN AND ONE OTHER PHYSICIAN WHO HAS EXAMINED ME, IS CHARACTERIZED BY BOTH OF THE FOLLOWING:

(1) I AM IRREVERSIBLY UNAWARE OF MYSELF AND MY ENVIRONMENT, AND

(2) THERE IS A TOTAL LOSS OF CEREBRAL CORTICAL FUNCTIONING, RESULTING IN MY HAVING NO CAPACITY TO EXPERIENCE PAIN OR SUFFERING.

I understand the purpose and effect of this document and sign my name to this Living Will Declaration after careful deliberation on _____ at _____, Ohio.
(Date) (City)

DECLARANT

THIS LIVING WILL DECLARATION WILL NOT BE VALID UNLESS IT IS EITHER (1) SIGNED BY TWO ELIGIBLE WITNESSES AS DEFINED BELOW WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC.

I attest that the Declarant signed or acknowledged this Living Will Declaration in my presence, and that the Declarant appears to be of sound mind and not under or subject to duress, fraud or undue influence. I further attest that I am not the attending physician of the Declarant, I am not the administrator of a nursing home in which the Declarant is receiving care, and that I am an adult not related to the Declarant by blood, marriage or adoption.

Signature: _____ Residence Address: _____
Print Name: _____
Date: _____

Signature: _____ Residence Address: _____
Print Name: _____
Date: _____

OR

ACKNOWLEDGEMENT

State of Ohio
County of _____ ss:

On this the _____ day of _____, 19 _____, before me, the undersigned Notary Public, personally appeared _____, known to me or satisfactorily proven to be the person whose name is subscribed to the above Living Will Declaration as the Declarant, and acknowledged that (s)he executed the same for the purposes expressed therein. I attest that the Declarant appears to be of sound mind and not under or subject to duress, fraud or undue influence.

My Commission
Expires: _____

Notary Public
D-4



The Ohio State
Bar Association

STATE OF OHIO DURABLE POWER OF ATTORNEY FOR HEALTH CARE



1. DESIGNATION OF ATTORNEY-IN-FACT.

I, _____, presently residing at _____, Ohio,

(the "Principal") being of sound mind and not under or subject to duress, fraud or undue influence, intending to

create a Durable Power of Attorney for Health Care under Chapter 1337 of the Ohio Revised Code, as

amended from time to time, do hereby designate and appoint: _____
(Name) (Relationship)

presently residing at _____ Phone _____

as my attorney-in-fact who shall act as my agent to make health care decisions for me as authorized in this document.

2. **GENERAL STATEMENT OF AUTHORITY GRANTED.** I hereby grant to my agent full power and authority to make all health care decisions for me to the same extent that I could make such decisions for myself if I had the capacity to do so, at any time during which I do not have the capacity to make informed health care decisions for myself. Such agent shall have the authority to give, to withdraw or to refuse to give informed consent to any medical or nursing procedure, treatment, intervention or other measure used to maintain, diagnose or treat my physical or mental condition. In exercising this authority, my agent shall make health care decisions that are consistent with my desires as stated in this document or otherwise made known to my agent by me or, if I have not made my desires known, that are, in the judgment of my agent, in my best interests.

3. **ADDITIONAL AUTHORITIES OF AGENT.** Where necessary or desirable to implement the health care decisions that my agent is authorized to make pursuant to this document, my agent has the power and authority to do any and all of the following:

- (a) If I am in a terminal condition, to give, to withdraw or to refuse to give informed consent to life-sustaining treatment, including the provision of artificially or technologically supplied nutrition or hydration;
- (b) If I am in a permanently unconscious state, to give, to withdraw or to refuse to give informed consent to life-sustaining treatment; provided, however, my agent is not authorized to refuse or direct the withdrawal of artificially or technologically supplied nutrition or hydration unless I have specifically authorized such refusal or withdrawal in Paragraph 4;
- (c) To request, review, and receive any information, verbal or written, regarding my physical or mental health, including, but not limited to, all of my medical and health care facility records;
- (d) To execute on my behalf any releases or other documents that may be required in order to obtain this information;
- (e) To consent to the further disclosure of this information if necessary;
- (f) To select, employ, and discharge health care personnel, such as physicians, nurses, therapists and other medical professionals, including individuals and services providing home health care, as my agent shall determine to be appropriate;
- (g) To select and contract with any medical or health care facility on my behalf, including, but not limited to, hospitals, nursing homes, assisted residence facilities, and the like; and
- (h) To execute on my behalf any or all of the following:
 - (1) Documents that are written consents to medical treatment, Do Not Resuscitate orders, or other similar orders;
 - (2) Documents that are written requests that I be transferred to another facility, written requests to be discharged against medical advice, or other similar requests; and
 - (3) Any other document necessary or desirable to implement health care decisions that my agent is authorized to make pursuant to this document.

4. **WITHDRAWAL OF NUTRITION AND HYDRATION WHEN IN A PERMANENTLY UNCONSCIOUS STATE.**

☐ IF I HAVE MARKED THE FOREGOING BOX AND HAVE PLACED MY INITIALS ON THE LINE ADJACENT TO IT, MY AGENT MAY REFUSE, OR IN THE EVENT TREATMENT HAS ALREADY COMMENCED, WITHDRAW INFORMED CONSENT TO THE PROVISION OF ARTIFICIALLY OR TECHNOLOGICALLY SUPPLIED NUTRITION AND HYDRATION IF I AM IN A PERMANENTLY UNCONSCIOUS STATE AND IF MY ATTENDING PHYSICIAN AND AT LEAST ONE OTHER PHYSICIAN WHO HAS EXAMINED ME DETERMINE, TO A REASONABLE DEGREE OF MEDICAL CERTAINTY AND IN ACCORDANCE WITH REASONABLE MEDICAL STANDARDS, THAT SUCH NUTRITION OR HYDRATION WILL NOT OR NO LONGER WILL SERVE TO PROVIDE COMFORT TO ME OR ALLEVIATE MY PAIN.

5. **DESIGNATION OF ALTERNATE AGENT.** Because I wish that an agent shall be available to exercise the authorities granted hereunder at all times, I further designate each of the following individuals to succeed to such authorities and to serve under this instrument, in the order named, if at any time the agent first named (or any alternate designee) is not readily available or is unwilling or unable to serve or to continue to serve:

First Alternate Agent: _____
(Name) (Relationship)

presently residing at _____ Phone: _____

Second Alternate Agent: _____
(Name) (Relationship)

presently residing at _____ Phone: _____

Each alternate shall have and exercise all of the authority conferred above.

6. **NO EXPIRATION DATE.** This Durable Power of Attorney for Health Care shall not be affected by my disability or by lapse of time. This Durable Power of Attorney for Health Care shall have no expiration date.

7. **SEVERABILITY.** Any invalid or unenforceable power, authority or provision of this instrument shall not affect any other power, authority or provision or the appointment of my agent to make health care decisions.

8. **PRIOR DESIGNATIONS REVOKED.** I hereby revoke any prior Durable Power of Attorney for Health Care executed by me under Chapter 1337 of the Ohio Revised Code.

I understand the purpose and effect of this document and sign my name to this Durable Power of Attorney for Health Care after careful deliberation on _____ at _____, Ohio.
(Date) (City)

Principal

THIS DURABLE POWER OF ATTORNEY FOR HEALTH CARE WILL NOT BE VALID UNLESS IT IS EITHER (1) SIGNED BY TWO ELIGIBLE WITNESSES AS DEFINED BELOW WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE OR (2) ACKNOWLEDGED BEFORE A NOTARY PUBLIC.

I attest that the principal signed or acknowledged this Durable Power of Attorney for Health Care in my presence, that the principal appears to be of sound mind and not under or subject to duress, fraud, or undue influence. I further attest that I am not the agent designated in this document, I am not the attending physician of the principal, I am not the administrator of a nursing home in which the principal is receiving care, and that I am an adult not related to the principal by blood, marriage or adoption.

Signature: _____ Residence Address: _____

Print Name: _____

Date: _____

Signature: _____ Residence Address: _____

Print Name: _____

Date: _____

OR

ACKNOWLEDGEMENT

State of Ohio
County of _____ ss:

On this the _____ day of _____, 19 _____, before me, the undersigned Notary Public, personally appeared _____, known to me or satisfactorily proven to be the person whose name is subscribed to the above Durable Power of Attorney for Health Care as the principal, and acknowledged that (s)he executed the same for the purposes expressed therein. I attest that the principal appears to be of sound mind and not under or subject to duress, fraud or undue influence.

My Commission

Expires: _____

Notary Public

NOTE: YOU MAY WISH TO GIVE EXECUTED COPIES OF THIS DURABLE POWER OF ATTORNEY FOR HEALTH CARE TO THE AGENT NAMED IN THIS DOCUMENT, EACH ALTERNATE AGENT, AND TO YOUR LAWYER, YOUR PERSONAL PHYSICIAN AND MEMBERS OF YOUR FAMILY.



NATIONAL INSTITUTE
FOR JEWISH HOSPICE

THE NATIONAL INSTITUTE FOR JEWISH HOSPICE

Jewish Living Will



NATIONAL INSTITUTE
FOR JEWISH HOSPICE

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Developed by the National Institute For Jewish Hospice

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This Living Will is distributed as a public service at no charge.
Contributions are encouraged from those who benefit from its contents.

Note: The National Institute for Jewish Hospice urges you to consult your attorney
for your specific needs in your specific state, as there are numerous variations in the law.

Why A Standard Living Will?

We can now be kept alive beyond "our years."

Just a few decades ago we did not have the technology to keep a person alive beyond his natural physical ability to stay alive. Today, resuscitators, respirators, heart-lung machines and other exotic instruments yet to be developed can resuscitate and keep one alive, under certain conditions. These advances give us options previous generations never had. To exercise the options we now have, we need to make some difficult decisions in advance, and then communicate them to a responsible person. We give this person the authority to decide for us should we become incapable of doing so for ourselves.

Do you want to be kept alive under all conditions?

Some do. Then that decision needs to be made known. Otherwise a nephew, doctor, or a friend will offer their own advice, regardless of what you might have thought best. That happens simply because others do not know what you would have wanted under those conditions, and you may not physically be able to communicate with them adequately.

Some do not, under certain conditions. Which conditions? You must determine now, while you are able, if, and exactly when, you want no further medical intervention — only passive palliative care to keep you pain-free and symptom-free — but not medical intervention to try to heal you.

You need to state your wishes *in writing* so they have the legal power to be enforced, and so that there is no doubt as to your wishes. Therefore, you need to write them in a legal document acceptable to the state in which you reside.

What Exactly Is A Standard Living Will?

It is simply a will which deals not with the disposition of property but with the disposition of your physical health. It is popularly referred to as a "Living Will." The person you ask to enforce your wishes — the executor of your health document, or "Living Will" — is called your Health Care Proxy, or Agent, or Attorney.

We strongly advise you to give that person a document, a directive in advance, approved by your attorney, signed and witnessed. In it, you state your wishes about the extent of medical care you want if you become unable to decide for yourself. If and when that time comes, your proxy will present the document to your physicians. It will be enforceable under the laws of your state. (It is imperative to consult your attorney to determine how this must be modified to be legally binding in your state.) Everyone concerned will then follow your wishes in these matters.

The National Institute For Jewish Hospice (NIJH) Living Will contains two types of advance documents.

A. Health Care Proxy Or Durable Power Of Attorney

There are two similar legal terms for your proxy. One is called "Health Care Proxy," the other is called "Durable Power of Attorney." Because some states, such as California, accept only a Durable Power of Attorney, you must consult your attorney to be certain which term is legally acceptable in your state.

You appoint one person whom you trust, or as many alternates as you like, whether relative, friend or professional consultant. You then give him/her or them the legal authority to carry out your wishes if you are unable to communicate them yourself.

In order to avoid quarreling amongst proxies, many attorneys suggest you appoint only one person as proxy. In addition, you should provide an alternate, in case that person cannot be reached or for some reason is not able to decide.

Your "proxy" acts for you, as though you yourself were deciding; he/she is your substitute in discussions with your physicians. Your proxy needs to know what you want done or withheld and therefore you need to inform your proxy of your wishes. You should review this document *every* year in order to keep up with the latest medical procedures and possibly also to change your proxy.

B. The Advance Medical Directive

This document spells out your specific medical treatment preferences. In it you describe which treatments you wish to accept or refuse, and the circumstances in which you want your wishes implemented.

While the *Health Care Proxy or Durable Power of Attorney* provides general guidelines on a personal level; the *Medical Directive* provides detailed guidelines in writing.

The standard health care proxy is required. The more detailed portion of the document, the *Advance Medical Directive*, is optional — you may fill it out or leave it blank.

Why A "Jewish" Living Will?

During our lifetimes we undoubtedly have concerned ourselves with God, with other Jews, with the State of Israel, with the fate of all our people. Many Jews have kept the traditions of Judaism — some more, others less. Others may be secularists, yet deeply worried about the fate of Judaism and the Jewish people.

Since we celebrate the passages of our life cycle as Jews, the final passage from this world to the next should be sanctified in a Jewish manner. If we have been sensitive to the traditions of our people during the turning points of our lifetime, we surely should not abandon that faith during the final transition of life.

But, whether we consider ourselves religious or not, our passing from life should reflect our being Jewish. This is something on which Orthodox, Conservative, Reform, Reconstructionist, and notable secularist Jews agree.

Judaism has specific teachings about confronting death. Virtually all rabbis agree:

- Life is sacred. The first imperative of life is to live. We must do everything possible to stay alive in virtually all circumstances.
- Crises may come which make some people feel that the quality of life is too terrible to bear; that it would be a blessing if God were to take our life, as long as we do not bring about our own deaths. Jewish tradition has a great deal to teach Jewish people regarding these matters. For example:
- Active euthanasia — aggressively taking our own life — is suicide, and forbidden by Jewish law.
- Passive euthanasia — not interfering in the natural process, includes not initiating heroic or invasive procedures, such as cardio-pulmonary resuscitation — may be acceptable under a variety of medical conditions.
- All rabbis generally agree to *withholding* life support. Orthodox rabbis do not generally permit *withdrawing* life support after it has been initiated. Most Conservative and Reform rabbis generally permit not only *withholding*, but also *withdrawing* life support. All the above generalities depend on the specific medical circumstances.

- At what point these passive procedures may be acceptable is a matter of profound Jewish concern, and the subject of Jewish medical ethics. This takes into consideration whether a person is terminally ill; whether there is pain; whether the medical situation is reversible; and what will be the state of a person's life if he or she remains alive.

What Distinguishes the Jewish Living Will?

A Living Will means:

Deciding on life and death issues while you are living, thinking, feeling, believing. It requires consulting your physician, attorney, and your trusted advisors, to learn the law of your state, the state of medicine, and the views of those near and dear to you.

A "Jewish" Living Will means — all the above plus:

Before writing a Living Will, look deeply into your soul. Then consult the traditions of Judaism, which have coped with the crises of human beings in every condition, and helped people cope in every sick bed, throughout history.

Seek careful guidance from your rabbi. Often, because rabbis change pulpits, it is wise to refer to "The rabbi who will be affiliated with a designated synagogue or rabbinical seminary."

That person should help you or your proxy decide on such weighty matters in the context of Jewish law — the sanctity of your life; the value of living; under which conditions you should be allowed to be taken back by God; how a Jew should confront issues such as life and death, and what Jewish medical ethics has to say about them; the meaning and the limits of suffering; the understanding of the term "quality of life;" how to balance your needs with those of the loved ones whom you are giving authority to take care of you.

In order to integrate this Jewish component into these important deliberations, the *NIJH Jewish Living Will* provides space for the inclusion of the name of a specific rabbi or trusted person.

Also, the *NIJH Jewish Living Will* includes optional additional instructions called "Advance Medical Directive" which refer to the Jewish component, and upon which it is for you to decide. The "Advance Medical Directive" need not be included in the *Jewish Living Will*. That is for you to determine.

Note: The National Institute for Jewish Hospice urges you to consult your attorney for your specific needs in your specific state, as there are numerous variations in the law.

Jewish Living Will Health Care Proxy - Durable Power Of Attorney

My Name Is: _____

My Address is: _____

I declare that, if I become incapable of giving informed consent to health care decisions, I designate and appoint the following agent to be my Health Care Proxy, with Durable Power of Attorney, to make health care decisions in my stead, including the right to consent, refuse to consent, or withdraw consent, to any procedure for any physical or mental condition. I direct that such decisions shall be made in accordance with my wishes as expressed herein. Or, if I have not specified directives that apply to my medical circumstance, I request that the decision be made by my proxy.

Name Of Proxy: _____

Address of Proxy: _____

Day Telephone _____ Night Telephone _____

In the event this person is unavailable, unwilling or unable to act as my proxy, I hereby designate and appoint an alternate agent, with durable power of attorney, to act in my behalf in exactly the same manner:

First Alternate Agent

Name of Alternate Proxy: _____

Address of Alternate Proxy: _____

Day Telephone _____ Night Telephone _____

Second Alternate Agent

Name of Alternate Proxy: _____

Address of Alternate Proxy: _____

Day Telephone _____ Night Telephone _____

In the event none of the aforementioned parties is available, willing, or able to perform these duties, I direct those who provide my health care, such as my family, all physicians, nursing home officials, hospitals and other health care providers, to follow the medical directives contained herein.

continued on other side

Health Care Proxy - Durable Power Of Attorney (continued)

If, for any reason whatsoever, the State in which I am residing when these decisions must be made in my behalf, considers this document not legally effective, I declare to those responsible for me that my wishes expressed in this document are incontrovertible evidence of my desires regarding all health care decisions.

This proxy and durable power of attorney and this medical directive shall remain in force as long as the state law permits, or unless and until I revoke them explicitly.

This request is made after careful consideration. I hope all who care for me will feel morally bound to follow its mandate. I recognize that this appears to place a heavy responsibility upon the proxies, but it is with the intention of relieving you of such responsibility and of placing it upon myself in accordance with my wishes that this statement is made.

No participant in the making of this directive or in its being carried into effect, who acts in good faith, whether it be a health care professional, member of my family, friend, or any other person, shall be held responsible in any way — morally, ethically, legally, professionally, socially, or otherwise — for complying with my directions.

I am Jewish and it is my sincere desire, and I hereby direct, that all health care decisions made for me shall be made in accordance with Jewish tradition. In order to effectuate my wishes, if any question arises as to the requirements of Jewish tradition, I direct my agent to consult with Rabbi

Name: _____

Address: _____ Telephone: _____

or, in his absence, a rabbinic authority associated with the following Institution:

Name of Institution: _____

Address of Institution: _____

_____ Telephone: _____

Or, if both the above are unavailable or unwilling, consult:

Name: _____ Telephone: _____

Address: _____

Note: The National Institute for Jewish Hospice urges you to consult your attorney for your specific needs in your specific state, as there are numerous variations in the law.

Optional Additional Instructions
Advance Medical Directive

The following detailed determinations, subject to the aforementioned rabbi's advice, shall guide those who are responsible for my health care:

I. If I am terminally ill, as determined by my attending physician and a consulting physician:

And I have severe brain damage that makes me unable to recognize people or to communicate in any fashion; then I direct:

That all forms of life-sustaining medical treatments, i.e., cardiopulmonary resuscitation, respirators, and major surgery, or other invasive procedures, shall be withheld ____ or continued ____;

that all pain medication shall be administered to me, even if that would dull my awareness and shorten my life. Yes ____ No ____.

II. If I am *not* terminally ill:

But I am in a "persistent vegetative state," meaning that I have lost all upper brain function, leaving me legally alive, but permanently unconscious, no matter what is done; then I direct:

that all forms of life-sustaining medical treatments, i.e., cardiopulmonary resuscitation, respirators, and major surgery, or other invasive procedures, shall be withheld ____ or continued ____;

that all pain medication shall be administered to me, even if that would dull my awareness and shorten my life. Yes ____ No ____.

III. If I am *not* terminally ill:

But I have brain damage that will make me unable to recognize people or to communicate with them on a *meaningful* level, although I may live like this for some time; then I direct:

that all forms of life-sustaining medical treatments, i.e., cardiopulmonary resuscitation, respirators, and major surgery, or other invasive procedures, shall be withheld ____ or continued ____;

that all pain medication shall be administered to me, even if that would dull my awareness and shorten my life. Yes ____ No ____.

IV. If I am *not* terminally ill:

But I am in a lengthy coma, with a very small likelihood of recovery, and a larger likelihood of dying; then I direct:

that all forms of life-sustaining medical treatments, i.e., cardiopulmonary resuscitation, respirators, and major surgery, or other invasive procedures, shall be withheld ____ or continued ____;

that all pain medication shall be administered to me, even if that would dull my awareness and shorten my life. Yes ____ No ____.

continued on other side

Advance Medical Directive - Optional Additional Instructions (continued)

I realize that the aforementioned cases are only an indication of feelings and do not necessarily cover all medical exigencies. Further, medical science and technology may have advanced far beyond current procedures as of this date and I may not be aware of them and their implications. Therefore, if I find myself in circumstances other than those above, or those similar to them, then I direct:

That my Health Care Proxy make that determination in the spirit of the above decisions and on his/her recognizance, and:

If any question arises as to the requirements of Jewish law, I direct my agent to consult with the rabbi or institution listed on page six.

I make these instructions being of sound mind and being more than eighteen years of age, and understanding fully the consequences of my express decisions.

Date: _____

Signature: _____

Address: _____

Declaration of Witnesses

I declare that the person who signed this document is personally known to me and appears to be of sound mind and is acting out of his/her own free will. He/she signed (or asked another to sign for him/her) this document in my presence.

Witness No. 1

Signature: _____ Address: _____

Date: _____

Witness No. 2

Signature: _____ Address: _____

Date: _____

Note: Once again, the National Institute for Jewish Hospice urges you to consult your attorney for your specific needs in your specific state, as there are numerous variations in the law.

Appointment of a Health Care Agent / Advanced Directive

I. GENERAL

(1) I _____
appoint _____
(name, home address & telephone number)
as my health care agent to make health care decisions for me if I am unable to do so. If he/she
cannot or will not serve, I appoint _____
(name, home address & telephone number)
as my agent.

I direct that my agent, family and doctors be guided by the specific directions given below.

I know that these directions do not cover all possibilities. In cases not described below, my
agent shall make health care decisions for me after consulting with my doctors. However, I
direct that in all cases food and liquids be given.

(2) Concurrence of an Orthodox rabbi. Prior to my agent making a decision about my health
care, in any case not covered by these directions one of the following rabbis shall be consulted.
The Rabbi's decision shall govern my agent and my doctors.

(a) _____
(name, home address & telephone number)

(b) _____
(name, home address & telephone number)

(c) _____
(name, home address & telephone number)

(d) If none of these Rabbis is available, my agent shall consult with the Bio-ethics Commission
of the Rabbinical Council of America (212) 807-7888, or an Orthodox Rabbi designated by it.

II. SPECIFIC INSTRUCTIONS

1. If I am in an irreversible coma or a persistent vegetative state and, in the opinion of my
doctor and at least two other doctors, have no known hope of regaining awareness and
higher mental functions, then my wishes are:

Cardiopulmonary Resuscitation: at the point of death, using drugs and electric shock to keep the
heart beating.

I want _____ I do not want _____

Mechanical Breathing: breathing by machine

I want _____ I do not want _____

Major Surgery: such as removing the gall bladder or part of the intestines.

I want _____ I do not want _____

Kidney Dialysis: cleaning the blood by machine or by fluid passed through the belly.

I want _____ I do not want _____

Chemotherapy: using drugs to fight cancer.

I want _____ I do not want _____

Invasive Diagnostic Tests: such as using a flexible tube to look into the stomach.

I want _____ I do not want _____

Blood or Blood Products: such as giving transfusions.

I want _____ I do not want _____

Antibiotics and simple diagnostic tests should be administered.

2. If I am in a coma and in the opinion of my doctor and at least two other doctors, have a small possibility of recovering fully, a slightly greater possibility of living with permanent brain damage, and a much larger possibility of dying, then my wishes would be:

Cardiopulmonary Resuscitation: at the point of death, using drugs and electric shock to keep the heart beating.

I want _____ I do not want _____

Mechanical Breathing: breathing by machine

I want _____ I do not want _____

Major Surgery: such as removing the gall bladder or part of the intestines.

I want _____ I do not want _____

Kidney Dialysis: cleaning the blood by machine or by fluid passed through the belly.

I want _____ I do not want _____

Chemotherapy: using drugs to fight cancer.

I want _____ I do not want _____

Invasive Diagnostic Tests: such as using a flexible tube to look into the stomach.

I want _____ I do not want _____

Blood or blood products, antibiotics, simple diagnostic tests, such as blood tests or x-rays, and, pain medication, even if it dulls consciousness and indirectly shortens my life, should be provided.

3. If I have brain damage that in the opinion of my doctor and at least two other doctors cannot be reversed and which makes me unable to recognize people or to communicate in any way, and I also have a terminal illness, such as incurable cancer, that will likely cause my death, then my wishes are:

Cardiopulmonary Resuscitation: at the point of death, using drugs and electric shock to keep the heart beating.

I want _____ I do not want _____

Mechanical Breathing: breathing by machine

I want _____ I do not want _____

Major Surgery: such as removing the gall bladder or part of the intestines.

I want _____ I do not want _____

Kidney Dialysis: cleaning the blood by machine or by fluid passed through the belly.

I want _____ I do not want _____

Chemotherapy: using drugs to fight cancer.

I want _____ I do not want _____

Invasive Diagnostic Tests: such as using a flexible tube to look into the stomach.

I want _____ I do not want _____

Blood or Blood Products: such as giving transfusions.

I want _____ I do not want _____

Antibiotics: using drugs to fight infection.

I want _____ I do not want _____

Simple Diagnostic Tests: such as performing blood tests or x-rays.

I want _____ I do not want _____

Pain Medications, even if they dull consciousness and indirectly shorten my life.

I want _____ I do not want _____

4. If I have brain damage that in the opinion of my doctor and at least two other doctors cannot be reversed and that makes me unable to recognize people or to communicate in any fashion, but I have no terminal illness, and I can live in this condition for a long time, then my wishes are:

Cardiopulmonary Resuscitation: at the point of death, using drugs and electric shock to keep the heart beating.

I want _____ I do not want _____

Mechanical Breathing: breathing by machine

I want _____ I do not want _____

Major Surgery: such as removing the gall bladder or part of the intestines.

I want _____ I do not want _____

Kidney Dialysis: cleaning the blood by machine or by fluid passed through the belly.

I want _____ I do not want _____

Chemotherapy: using drugs to fight cancer.

I want _____ I do not want _____

Invasive Diagnostic Tests: such as using a flexible tube to look into the stomach.

I want _____ I do not want _____

Blood or blood products, antibiotics, simple diagnostic tests, such as blood tests or x-rays, pain medication, even if it dulls consciousness and indirectly shortens my life, should be provided.

I want _____ I do not want _____

III. ORGAN DONATION

Upon my death I wish to donate life-saving organs such as my cornea(s), kidney(s), heart, lung(s), liver and pancreas for the sole purpose of transplantation. In all cases, concurrence of an Orthodox rabbi is necessary before my organs are taken for transplantation. If no orthodox rabbi is available, my agent or treating physician shall consult with the Bio-ethics Commission of the Rabbinical Council of America at (212) 807-7888.

IV. MY MEDICAL DIRECTIVE

This Medical Directive expresses my wishes regarding medical treatments in the event that I am unable to communicate them directly. I make this Directive, being 18 years or more of age, of sound mind, and understand the effects of signing this document.

Signed _____ Date _____

V. WITNESESS' SIGNATURES

Each of us believes that the person making this advance directive is of sound mind, that he/she signed or acknowledged this advance directive in our presence, and that he/she appears not to be acting under pressure, duress, fraud, or undue influence. Neither of us is related to the person making this advance directive by blood, marriage or adoption, nor, to the best of our knowledge, are either of us named in his/her will. Nor are we a person appointed in this advance directive, a health care provider or an employee of a health care provider who is now, or has been in the past, responsible for the care of the person making this advance directive.

Witness _____ Date _____

Address _____

Witness _____ Date _____

Address _____

Developed & published by the Commission on Medical Ethics of the Rabbinical Council of America 1225 Seventh Ave., NY 10001 (212) 807-7888 Fax (212) 757-8452

APPENDIX E

A SAMPLE RESUSCITATION DECISION GUIDE PREPARED BY THE ALLMA FOUNDATION

(See the attached facsimile copy)

Resuscitation Discussion Guide*

Based on a study of patients' experiences with resuscitation discussions, funded by the Allina Foundation.

Before you start: note that: Most patients want to talk about resuscitation and may already have clear opinions about their resuscitation choice.

When: Preferably when healthy and/or soon after a serious diagnosis

Where: Private, quiet, preferably outpatient setting

Who else is present: Family, friend, spiritual counselor, other professional or no one, as patient requests

How to start:

- "With each of my patients, I always try to discuss their desires about resuscitation..." and/or
- "To follow your wishes, I need to know how you want me to take care of you..." and/or
- "Let's talk about your goals for treatment, what you want us to do and why..."

Include medical information:

- Summarize medical condition
- Describe medical scenarios when the patient may have a cardiac or respiratory arrest**
- Describe resuscitation procedures, including definitions, as the patient is capable of understanding***
- Describe statistics on outcomes of CPR if patient desires them****

Solicit factors that are important to the patient:

- Life philosophy
- Experience with difficult end-of-life decisions for family/friends
- Religious beliefs
- Level of ability to function independently pre- and post-resuscitation
- Cultural influences, e.g., mistrust of health care systems

Personalize the DNR order:

- Recognize that the patient may elect to specify the resuscitation procedures to be used, e.g., "I want you to try to restart my heart with one shock, but if it does not work, then stop."
- Recognize that patients may have conditional situations, e.g., stroke, where they would limit the application of CPR or the length of prolonged therapy they would want, e.g., mechanical ventilation
- Describe possible DNR order recisions, e.g., surgery

Reassure and repeat:

- Reassure that the decision can be changed at any time and does not preclude other kinds of treatment or attention
- Verify resuscitation decisions at each change in level of care, (acute, long term, and home) because of patient tendency to forget*****
- Repeat appropriately as condition changes

***Note:** This counseling guide is for use with persons with intact decision making capacity who can:

- understand treatment benefits/risks
- make a treatment decision
- communicate that decision

****Patient scenario examples —**

Hospital — "You have severe emphysema and your lungs are failing. At some time, we may have to decide whether to use a breathing machine. We will be able to keep you comfortable without the breathing machine or we could use a breathing machine and comfort measures to prolong your life."

Nursing home — "You are in your nursing home, and your heart stops. A nurse finds you, what should she do? Should she perform resuscitation measures?"

*****Description of resuscitation procedures**

CPR (cardiopulmonary resuscitation) — If the heart or lungs stop, manual pressure to the chest, artificial breathing, drugs through IVs, and electric shock to the chest may restore heart functions.

Mechanical respiration — If the lungs do not work adequately, a machine called a respirator can take over breathing and provide oxygen through a tube down the throat.

In either case, transfer to an intensive care unit and prolonged inpatient care will be required.

******Resuscitation survival statistics**

These statistics are significantly affected by the patients' underlying conditions, e.g., survival is lower with cancer, sepsis, renal failure, etc. These statistics do not apply to patients who develop dysrhythmias while being monitored for otherwise uncomplicated myocardial infarction.

In-hospital arrests 6-15% survival to discharge from hospital



Long term care arrests 1-2% survival to discharge from hospital



Out-of-institution arrests 4-38% studies report variable survival to discharge from hospital



********* Many patients fail to recall these discussions. Provide a written summary of the discussion and decision and document in the institutional record.

CNS

For information call D. Gay Moldow, BSN, MSW at 612-725-2042

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