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TOWARD THE DEVELOPMENT OF AN EDUCATIONAL PARADIGM FOR THE CREATION AND SUPPORT OF A JEWISH HOSPICE PROGRAM

Elias Jacob Lieberman

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of the requirements for Ordination

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Referee, Rabbi Samuel Joseph

DIGEST

From its origins as a waystation for sick and weary pilgrims in the Middle Ages, the hospice has evolved into its twentieth century permutation as both a concept and an institution with two fundamental goals: to allow the dying to live out their remaining days in a caring, pain-free environment and to help the grieving family through the process of bereavement.

This work traces the history of the hospice concept, comparing it with comparable Jewish institutions along the way, and follows hospice to its partial eclipse with the advent of the Industrial Age. The religious imperative to care for one's neighbor, which lies at the core of the hospice concept, became obscured as Western society came to view individuals not as human beings, but rather as insignificant parts in the societal machinery. At the same time, death came to be perceived as the enemy, and no longer the goal of life's pilgrimage.

Contemporary societal attitudes toward death reflect the legacy of the nineteenth century . . . death is still the enemy and is denied or trivialized on virtually every level. That hospice has reemerged in recent decades as a viable alternative to death in the hospital or "convalescent" home settings is, in large measure, a tribute to the efforts of certain individuals who never lost sight of the need to always see the person and not merely the disease afflicting that person.

From here the work turns to a study of traditional Jewish attitudes toward illness and death. The supreme importance attached to the sanctity of life manifests itself in Judaism through the reverence traditionally accorded the act of <u>bikkur cholim</u>, visiting the sick. In addition, Jewish tradition sets forth elaborate dictates concerning the impermissibility of wantonly foreshortening life as well as unnecessarily prolonging the life of one who suffers.

The hospice concept is then examined once again, this time in the light of Jewish teachings, to discover the degree to which the two are compatible. Areas in which Judaism can inform and further the goals of hospice, in a uniquely Jewish way, are then set forth.

Finally, recognizing the need to educate the Jewish community with regard to hospice and Jewish tradition, three model curricula conclude the work, demonstrating ways in which this information may be transmitted to Jewish learners who may, in turn, be inspired to effectuate a synthesis of Jewish tradition and the modern hospice.

I would like to extend heartfelt thanks to Rabbi Samuel Joseph for exemplifying the best of Buberian andragogy. His caring support went far in helping to shape this work and his encouragement was a needed tonic.

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INTRODUCTION

Mortality is, undisputably, inherent to the human condition, but the response to human finitude has varied greatly over time and across cultural boundaries. It is possible to trace, in some detail, the history of shifting perspectives on the process of death and dying, particularly with regard to societal views on how the dying person is to be treated.

In Western society it is the religious imperative to look to the welfare of others, to treat the less fortunate with the God-like attributes of compassion and gentle concern, that inspires the growth of elaborate systems of health-care. Paradoxically, these systems with their hospitals, nursing homes and convalescent facilities, often fail to meet, or even recognize, the needs of the dying . . . the need to be free from pain, to retain as much control over their lives as possible and to live fully until they die.

Recent decades have witnessed the reemergence of an institution uniquely suited to meet the needs of the dying person, the one whose life span is measured in weeks or months at best. This institution is known as hospice. It is not very surprising that hospice met with such success in recent years . . . society was ripe for an alternative to the anxiety induced by pretending that death is what happens to the next person, never oneself. This massive denial of the reality and inevitability of death manifests itself in many ways . . . in society's fascination with television violence which is "unreal" and therefore safe; in society's preoccupation with youth culture and bodily perfection. The result of this denial is that the dying often end their lives in pain and anguish because so few dare make the effort to ascertain just what the dying really need to live out their days in peace and dignity.

Such was not always the case. Medieval European history reveals the role played by the Christian hospice and its Jewish counterpart, the hekdesh. These were places where the wayfarer or pilgrim found surcease from the rigors of the road, places where the sick and dying could find a haven to regain their strength or die in the presence of compassionate caregivers.

These early hospices were, more often than not, expressions of the religious imperative alluded to above. The dying person was likened to a pilgrim on life's road and it was a moral obligation to ease that person's final journey.

Through the centuries these institutions evolved into sick-care societies, nursing orders, etc . . . all the while operating on the principle that to care for the sick and dying was to do God's work in the world.

The advent of the Industrial Age and the quantum leaps made in scientific knowledge in the nineteenth and twentieth centuries had a twofold effect: on the one hand, science made tremendous strides in diagnosing and treating disease, decreasing mortality and inreasing longevity; on the other hand, the Industrial Age reduced many to the status of the poor, sick and dispossessed . . . societal non-entities who were important only insofar as they served the societal machinery. The result was the emergence of the modern hospital, that fortress of health wherein doctors fought disease and death was the ultimate enemy, and the eclipse of the hospice concept and its paramount concern for the individual. It can only be interpreted as a healthy sign that the hospice concept has once again taken root and found acceptance. Naturally Jews ask, however, to what degree hospice addresses the concerns of Judaism for the dying as given expression in the many layers of Jewish tradition. To what extent is hospice, which has often been affiliated with the church, compatible with Jewish needs and views of the process of dying?

Jewish attitudes toward the care of the sick and the dying are conditioned by the paramount concern for the sanctity of life which God alone creates and sustains. The physician is obligated by Jewish law to heal the sick and the foreshortening of life in any way is regarded in Jewish tradition as being tantamount to murder. How, then, does one reconcile the demands of Jewish tradition with the implicit claim of hospice that the quality of life remaining to a person is more important than the quantity of life?

The reader will learn that much of Jewish tradition is written in the grey areas which lie between the black and the white of absolute dogma.

It is the author's premise that not only are Jewish tradition and hospice basically compatible, but moreover, that Judaism has much to offer the hospice concept as well as the Jew who may one day use the services of a hospice. While the halachic finepoints will need to be resolved by competent authorities, hospice is already gaining widespread acceptance among Jews of every persuasion.

This work concludes with a series of model curricula intended to set in motion the process of educating the Jewish community about hospice and ways in which hospice may come to reflect a synthesis of Jewish values and the principles of compassionate care which undergird the hospice approach to caring for the terminally ill.

CHAPTER I

THE HISTORY OF HOSPICE

It is a measure of a concept's success when a word naming that concept filters down to public awareness. The word "hospice" achieved that status in the early years of the present decade. Many hear the word but few are prepared to offer a good working definition of "hospice."

If one is to fully appreciate the history of hospice, its ramifications for 20th century Americans, and its value in the light of Jewish tradition, it is essential that a working definition of hospice be established which will serve the reader as a guide through the following sections.

The United States government, through the subcommittee on Health and the Environment of the House of Representatives, offers the following definition of hospice:

> HOSPICE: A program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another county agency such as a visiting nurse association. Originally a medieval name for a way station for pilgrims and travellers where they could be replenished, refreshed and cared for; used here as an organized program of care for people going through life's last station. The whole family is considered the unit of care and care extends through the mourning process. Emphasis is placed on symptom control and

> preparation for and support before and after death, full scope health services being provided by an organized interdisciplinary team available on a 24-hour-a-day, seven-days-a-week basis.[1]

The definition of Hospice cited above succeeds in describing the scope of the hospice concept but falls short in describing the human element which is so central to hospice. It is necessary therefore to augment this definition by stressing that, ideally, hospice is a "caring community" --a group of people who have joined together by means of a shared dedication to a common task, a group of people highly trained in various skills, particularly in the art and craft of medicine. It is a community which operates on its own principles.[2]

The etymology of the word "hospice" underscores the human interaction which lies at its core. "The latin word <u>hospes</u> means both 'host' and 'guest'. This in itself is interesting, since it focuses the spotlight on a process, an interaction between human beings, which was once perceived as simple and natural."[3]

Having established a working definition of hospice it is now necessary for the reader to view the hospice concept in its historical context in order to fully appreciate the hospice of today.

How easy it is to convince ourselves that ours is the only age in which the battle against disease and death has been waged with fervor. We are but the beneficiaries of phenomenal scientific and technological advances. An exploration of the roots of hospice reveals a longstanding attempt to deal with human suffering and the special needs of the dying.

It is impossible to say where and when hospice first began. The Roman Emperor Julian the Apostate (c. 361 C.E.) spoke of early Christian communal care for the sick and makes mention, in this connection, of a wealthy Roman matron by the name of Fabiola. Fabiola was apparently a Christian and is reported to have established a hospice-like facility wherein she lodged and fed pilgrims and nursed the sick and incurably ill. The emperor was sufficiently impressed by such good works that he bade all Roman citizens to emulate Christians in the "brotherly love they demonstrate toward the sick and the poor."[4]

Although the classical world shared much of our contemporary passion for the perfectly formed, perfectly groomed, healthy human body, it lacked a sufficiently deep appreciation of the value of <u>all</u> human life for the true hospice concept to have emerged in that period. A "true" hospice implies, of necessity, a place wherein all human life is cherished, regardless of the socio-economic status of the needy individual. Speaking of the world of the Ancient Greeks, Stoddard says, "In such a system, a glittering aristocratic superstructure may be maintained without a second thought, upon a base consisting of the labor of human slaves. In such a world as this, the basic concept of hospice is as yet unborn."[5] In ancient Rome, for example, hospitals existed for three classes of people--warriors, gladiators and slaves . . . essential cogs in the societal machinery. These "cogs" were "repaired" in valetudinaria, wooden structures based on a military camp model.

> One can easily imagine the atmosphere in the valetudinaria, as they were called: wooden barracks set on the square with small rooms and symmetrical corridors around four sides, stark and well-scrubbed. The model, both architecturally and tactically, was strictly a military one with a highly rational heirarchical division of labor. In the bare, echoing halls one could hear at all hours of the day and night the hurrying feet of the attendants, cleansing wounds, sewing them up; and of others, more highly skilled, setting bones and performing surgery. One would hear the cries of the wounded, the voices begging for water, for wine, for opium; and the consultations of the various caretakers and surgeons among themselves."[6]

The wealthy received their medical care in the privacy of their homes.

The search for a better hospice precedent leads to a 5th century B.C.E. place of healing in Epidaurus, Greece. It was a large and impressive facility which included temples, gymnasia, lavatories, treatment rooms, baths . . . even a theater where patients might experience a healthy katharsis. Part of the treatment regimen included sleeping on the abaton, the portico of the Temple of Asklepios, where a sort of dream-therapy was undertaken.

"Epidaurus was a magnificent medical happening, rather as if in our own time Dr. Freud, Dr. Jung and Elizabeth Arden had managed to collaborate with Hollywood and HEW in a vast project designed, simply, to make people feel better."[7] There was a catch, however, for at Epidaurus the hopelessly ill were not treated. The terminally ill went elsewhere to die.

It is not until many centuries later, in the Middle Ages, that one begins to finds a hospice of identifiable form and function. The Christian practice of making a devotional trip to the Holy Land meant that large numbers of wayfarers and wanderers moved through the land. The word "pilgrim" found its way into the English language from the Latin roots _per_ and _ager_ ("across" and "the field"), which, in later permutations became "peregrine," "pellegrino," "pellegrin" and eventually, "pilgrim." These wandering "field-crossers," these pilgrims, were at the mercy of strangers when, in the course of their travels, they fell ill. The ancient hospice was, therefore, a place for the wayfarer, the woman in labor, the leper _et al_, to find "hospitality" in the original sense of the word . . . protection, nurturing and refreshment.

But as Plautus (c. 205 B.C.E.) once observed, "After three days, a guest and a fish begin to stink." Sick pilgrims were often shunted from one community to the next as soon as they were sufficiently healthy to be moved.

It is in the medieval world that the hospice concept, in its pre-20th century permutations, flowered. The mandate of one 12th century English hospice was quite explicit; "If anyone in infirm health and destitute of friends should seek admission for a term until he shall recover, let him be gladly received and assigned a bed. In regard to the poor, people who are received late at night, to go forth early in the morning, let the warden take care that their feet are washed and, as far as possible, their necessities tended to."[8]

A petition by the citizens of London to Henry VIII, dated 1538, seeks the establishment of a hospice, ". . . for the ayde and comforte of the poore, sykke, blynd, aged and impotent persones . . . whereyn they may be lodged, cherished and refreshed."[9]

The medieval hospice model recognized the integrity of the healing process. Indeed, "cheryssing" was deemed as important a component as pharmacology. There was an intuitive awareness that "what happens to mind and spirit at any given time is at least as important as what happens to the body."[10]

At the core of the medieval hospice approach lay the metaphor of life-as-pilgrimage. Each individual was a wayfarer, moving from uncertain origin to uncertain destination. Christian love demanded that the pilgrim be aided in the journey from birth to death. The metaphor found concrete expression in services rendered the pilgrim travelling toward the Holy Land in spiritual quest.

The medieval mind viewed death as transition and transformation and was unburdened by modern preoccupations with "clinical" and "brain" death. When death was the ultimate mystery, those who lay at death's door were regarded as special individuals, imbued with a special holiness. To tend the sick and dying was, therefore, a particularly holy act.

The hospice of the medieval period married medical practice, such as it was, with ministry to the soul. It was well-integrated into the community, serving its needs and welcoming the stranger with an open admissons policy.[11] Its primary objectives were 1) medical management, achieved through pain relief and extant medical knowledge, 2) comfort, implying attention to basic needs for food, quiet, clean linens, massage, etc., and 3) spiritual care, conveyed through prayer and solicitude for the patient's well-being.

Many medieval hospices were to be found in the centers of towns, adjacent to the market place, facilitating easy accessibility. They often had pharmacies supplied by medicinal herb gardens, providing medicines for patients as well as townspeople.[12] As early as the 7th century C.E. opium poppies grew in the medicinal gardens of the hospice at St. Gall's Switzerland, attesting to early experimentation with pain relief. Morphine-like drugs were given with wine and alcohol to relieve suffering.[13]

Medieval hospices were to be found in other locales as well; "at monastic hermitages in wilderness areas; and in particular, at the mountain passes and river crossings that presented the greatest hazards to travellers on their way to the Holy Land. It was natural enough in those days to see death as a venture, for life itself was perceived then as a journey, a pilgrimage."[14]

The Crusades dramatically increased pilgrimage to the Holy Land and in so doing, exacerbated the need for hospice-like institutions. The Order of Hospitaller Knights of St. John had its origins in this very need.

Founded by the keeper of the Castella of Rhodes in 11th century Jerusalem, the order's haven met the needs of merchants from Amalfi who petitioned the caliph in Egypt for permission to build a way station in Jerusalem for sick and weary pilgrims. The original institution was managed by one "Brother Gerard." He and his group called themselves the "Poor Brethren of the Hospital of St. John."[15]

Eventually, the occupation of the Holy Land by the Saracens forced the order to move first to Tyre, then Acre and finally to Cyprus. There they provided pilgrim ships with protection from marauding pirates, their new military status having been sanctioned by a papal bull in 1113. The Knights Hospitaller of St. John swore vows of poverty, chastity and obedience.

In 1306 the Knights stormed Rhodes and held it for two centuries against the Moslems. It was here that they established their greatest institution for the care of the sick. At Rhodes the incurably ill were, for the first time, set apart from the other sick and were placed in eleven rooms of an upper gallery where they received special care befitting their status as persons on the final voyage of life.

After evening prayers, the terminally sick were asked by the ministering priest to join in a special prayer. This prayer, from 12th century Acre, had the sick make special intercessions to God, since Heaven was now so directly open to them:

> My Lords the sick, pray for the peace of heaven, that God may bring it to earth; pray for the kings and cardinals, for the bishops and the soldiers; pray for the Pope, and pray for all poor, weary pilgrims who are now lost at land or at sea; and pray for us who serve you here, that we may all be brought in time to the great repose.[16]

All personnel serving the hospice at Rhodes were under an oath of poverty; they could not accept gifts from the people in their charge. The knights and attendants ate plainer fare than the sick. If they were unkind or neglected to attend to the needs of the patients they were put on bread and water rations for a week and flogged on Wednesday and Saturday.[17]

The care which was to be extended to the sick and the wayfarer was explicitly stated in the incorporating statutes of the order:

> How our Lords, the Sick, Should be Received and Served: When the sick shall come . . . let him be carried to a bed and there . . . each day before the brethren go to eat, let him be refreshed with food charitably according to the ability of the house. The beds of the sick should be made as long and as broad as is most convenient for repose, and each bed should be covered with its own coverlet . . . and each bed should have its own special sheets . . . Little cradles should be made for the babies of women pilgrims born in the house . . . the Commanders of the house should serve the sick cheerfully, and should do their duty by them, and serve them without rumbling or complaining . . . .
>
> Moreover, guarding and watching them day and night . . . nine serjeants (sic) should be kept at their service who should wash their feet gently, and change their sheets . . . .[18]

Regard for the sick person *qua* person, and not as a disease, seems to have characterized the medieval hospice approach. This attitude of holistic healing finds poetic expression in the recipe for longevity set down by the 13th century Franciscan master of pharmacology, Roger Bacon: "Joyfulness, singing, the sight of human beauty, the touch of young girls, warm aromatic water, the use of spices and strengthening electuaries, and bathing on an empty stomach after getting rid of superfluities."[19]

Lest one think, at this early stage, that the Christian impulse was the sole impetus for the creation of hospice-like institutions an examination of early Jewish precursors is now in order.

Midrashically, Kaufmann Kohler points to the legends of Abraham's hospitality at the terebinths of Mamre to suggest that care of the sick and the itinerant is a concept deeply imbedded in Jewish culture.[20] "The Talmud (Baba Batra 8b) does speak of provision for the itinerant poor, and although nothing is said there of any special communal building or institution to provide for the sick, we may assume that the itinerant poor and sick were lumped together."[21]

The Jewish equivalent of the Christian pilgrim's hospice was known as the hekdesh, a Talmudic term for something dedicate to a sacred purpose, something consecrated. In Temple days the treasury and Temple property were so designated.

The term hekdesh in medieval times probably referred to community funds and, by extension, to that institution of communal charity, the hospital. One finds the term so used in southern France and Germany not later than the 15th century.[22] Kohler and others believed that Jewish hospices date from Talmudic and even pre-Christian periods for ancient synagogues often had adjoining rooms earmarked for the lodging of itinerant travellers.[23]

Whom did the hekdesh serve? Persecutions, expulsions, crusades, pilgrimages and poverty set many Jews on the road during the Middle Ages. It was this population of the poor and the dispossessed which was served by the hekdesh. "Jewry was constantly on the road and individuals frequently became sick. It was these wanderers, sick or healthy, who made the creation of the hekdesh a social necessity. It was not created for the local sick."[24]

The Jewish community assumed a religious responsibility toward the very sick. Prayers were offered in the home, synagogue and cemetery, prompted by a consciousness of the Jewish ethical obligation to care for the sick. "The community saw to it that there was a hospice for poverty-stricken patients; it subsidized the 'respectable' poor of its own community who had suffered reverses in life, and it issued a series of ordinances touching every phase of the life of the sick."[25]

The provision of physicians, surgeons, apothecaries, hospitals and bathhouses was seen to by the Jewish community council. In addition it oversaw wet-nurses and circumcisors, legislated with respect to certain foods, and acted in the face of plagues and epidemics.[26]

"Sick transients, who constituted the great mass of those provided for, were given a night's lodging in the local hospice, and, if not too sick, were dispatched to the next village on a cart or on a horse . . . . If the itinerants were too sick to move, they were kept in the local hospice and fed and given medical attention and nursing until they recovered and then they were sent on again."[27]

The <u>hekdesh</u> was frequently situated next to a cemetery, usually the only open spot of land near the crowded towns. Oftentimes they were found outside the city gates in order to keep itinerants, and their contagion, beyond the reach of the populace.[28]

No self-respecting upper or middle-class Jew would use the <u>hekdesh</u> for it suffered a reputation as a dirty place. And no itinerant of standing would be asked to use it.[29] The word <u>"hekdesh"</u>--"like Bedlam from the lunatic asylum of St. Mary of Bethlehem in London--became a synonym for dirt and misery and noise and squalor."[30] The <u>hekdesh</u>, usually a room, or at the most a series of rooms in a building, "was a 'hospital' if by this term we understand care for the sick of a most primitive character."[31]

The <u>hekdesh</u> evolved, over the course of time, into a complex of brotherhoods and guild associations which mandated to themselves responsibility for the sick and impoverished Jews of their respective communities. "In the classical form which these societies assumed in eighteenth century Germany they sought to provide, in an organized form, for spiritual care and comfort for the dying, and to bring cheer to all who lay upon the bed of sickness. They were created to relieve the physical and financial distress of the indigent sick, both local inhabitants and aliens, at home or in a hospital, and to expedite their recovery."[32]

The prototypes of these Jewish societies appear to have emerged in Spain in the fourteenth and fifteenth centuries where they were known by various appellations: _hebrot_, _confradias_, _confratrias_--but their goals were the same. Their members busied themselves with the burial of the dead, the education of the poor, the dowering of orphan brides, support of the poor and visiting and providing for the sick.[33]

It is clear that these Jewish benevolent societies patterned themselves after similar Christian institutions. "In the all-embracing public health program the Jews followed, with some modificatiions, the organization of the average large town which had a Christian tradition of medical and hospital practice going back many centuries."[34]

It is worth stressing the religious sensibilities which underlay both the establishment of such organizations and the nature of the care which they provided. "Medieval Catholicism and Judaism were in complete agreement that education, prayer and philanthropy were to be subsumed under religion."[35] The constitutions of some of these Jewish brotherhoods expressly stated the belief that people could best manifest the spiritual life in, and through, worthy organizations.* These societies served the population at large by inspiring their members to walk in the ways of their ancestors. "The real underlying inspiration for all these societies was the love and the fear of God and the desire to honor Him, that is, religion. The care of the poor and the sick and reverence for God are equated. To love and respect God demands that man help and support the sick. The Jew, who is God's peculiar treasure, must serve Him in love by carrying on this type of religious and charitable activity."[36]

The dedication to care of the sick and dying finds poignant expression in the rules of the sick-care society of Mantua in the eighteenth century. The by-laws stipulated a round-the-clock watch for seriously ill members of the society.

> Some societies permitted the watchers, who were selected by lot, to pay professional attendants to take their place. However, most members were willing to do their duty, for the care of the dying and the dead was a great virtue, a true act of mercy, because it could never be repaid by the recipient. Under no circumstances were the dying ever to be left alone, bereft of the comforting presence of a fellow Jew.[37]

A shortcoming of these societies was alluded to in the preceding quote, for health care and support was conditioned

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* In fact, many guilds and associations found their *raison d'être* in scripture, particularly Avot 1:2 ("On three things the world exists. . . Torah, service and acts of loving kindness") and Leviticus 19:18 ("You shall love your neighbor as yourself.")

upon membership in the sick-care society. It is only with the emergence of the organization known as the chevra kaddisha that care for the poor and the dispossessed was assured--at least in communities in which the organization existed. The chevra kaddisha did have subscribing members but it extended its services to local poor Jews and impoverished itinerants free of charge. "The [chevra kaddisha] provided the sick, if they were without means, with hospitalization, medicines, with medical and surgical services--occassionally even with special consultations with other physicians--with a primitive nursing service, and a system of voluntary 'visitors'."[38]

By and large, the sick-care societies and Holy Brotherhood (chevra kaddisha) were staffed and administered by adult males of the community. The exceptions to this rule, however, are worth noting. Traditionally, women played a far greater role in Christian sick-care guilds than in their Jewish counterparts. However, Jewish women were routinely enlisted to care for sick women and to prepare female corpses for burial, since it was considered inappropriate for a Jewish male to do so.

By the early eighteenth century, however, one does find separate Jewish societies of and for the care of women. In 1776, Amsterdam alone boasted two women's organizations occupied with the care of dying and dead women: The Woman's Society for Loving Kindness (Hevrah gemilut chassadim shel nashim) and the Shroud Society (Hevrah be-takri-kin).[39]

Another departure from the pattern of adult male-dominated societies was the phenomenon of "youth aid societies" which sprang into existence in the late seventeenth and early eighteen centuries. Patterned on the societies of the adults, their members were most often single, unmarried men, often teenagers. What motivation underlay the formation of these youth societies? "The members of the Vienna society were determined to set their elders a good example! 'Perhaps the married people will listen and follow after the young unmarried folk by setting aside a fixed period for religious study, by helping the poor and the sick, by helping poor brides and providing dowries for them . . . so that we may merit the speedy coming of the Messiah in our own day.'"[40]

By the dawn of the nineteenth century the Jewish brotherhoods and sick-care societies were gradually subordinated to the community structure and integrated into its administration. In much the same way, the Christian hospice concept of the medieval world, that way-station for the battered pilgrim, became eclipsed in the beginnings of the Victorian Era.

The new industrial-based economy which characterized that age ushered in a host of attitudinal changes, not least of which was a tendency to regard the poor, the unemployed and the landless as "things", expendable parts in the workings of society. These dispossessed individuals, when sick, were now likely to find themselves in work-houses, being punished for their poverty, rather than welcomed in a hospice as they might have been in earlier centuries.

English hospitals began to adopt a policy of dismissing their incurables, even when this violated the spirit and the letter of their charters. Patients received moral instruction urging them not to peacefully yield to death but to recuperate in order to regain the moral vigor whose loss led to illness in the first place--through drunkenness and idleness.[41]

Death was no longer the ultimate goal of the pilgrim's quest, but now became the ultimate enemy. Hospitals were now seen as places to repair the human "tools" of the new economic order, or as places to lock up the insane, the contagious or the orphaned . . . the new "storage bins for society's spare parts."[42]

It was a bleak era for humane sick-care but individuals and institutions did emerge who based their practice on the view of the sick person-as-person, rather than object. One finds that in 1891, in England, William Hoare of the Merchant Bankers of London, appealed through The Times for money to establish a home for the mortally ill, to be called the Hostel of God. His efforts were rewarded and the hostel still exists today under the administration of the Anglican Sisters of the Society of St. Margaret.[43]

In France, a Madame Garnier organized the Women of Calvary who founded houses for the destitute dying in Paris (1874), St. Etienne (1875), Marseilles (1881) and Rouen

(1891).[44]

Another 19th century nursing order had its roots in a 17th century tale of piracy. In approximately the year 1600, a French priest was captured by pirates and sold into slavery. His third master succumbed to the teachings of the slave-priest and converted to Christianity whereupon he freed the priest. Returning to France, the priest established a hospice for galley slaves, an orphanage and a nursing order called Filles de la Charite. The priest was Vincent de Paul and his nursing sisters were taught that "their monasteries were the houses of the sick, their cloisters the city streets."[45]

Three generations later, in Prussia, the first Protestant hospital with its own nursing order was founded under the name Kaiserwerth. It was founded upon the principles of aiding the sick, dying and destitute. The order grew, flourished and spread throughout the Continent.

In the year 1840, Elizabeth Fry, an English Quaker, visited Kaiserwerth and other hospices and was so impressed that she devoted the remainder of her life to hospital and prison reform in England. One of Fry's contemporaries and kindred spirits was Florence Nightingale who worked both with the Filles de la Charite in France and with the Kaiserwerth order in Prussia. For her work as a nurse during the Crimean War, Nightingale brought together nurses trained in both the French and the Prussian nursing orders.

Nightingale's compassion is well documented. She wrote:

> How little the sufferings of illness are understood, how little does anyone in good health imagine himself into the life of a sick person! . . . 'What can't be cured must be endured' is the very worst and most dangerous maxim for a nurse that was ever made. Patience and resignation in her are but other words for carelessness and indifference.[46]

A co-worker with Nightingale, Sister Mary Aikenhead, founded in Dublin, in the late nineteenth century, a shelter for the incurably ill. She consciously called the institution she founded a "hospice", resurrecting that "gentle and half-forgotten, medieval English name."[47]

In the United States, at the turn of the present century, Manhattan's House of Calvary was founded by Catherine McParlan and a group of Irish-Catholic laywomen. The institution still functions as Calvary Hospital.

The Hawthorne Dominicans, founded by Rose Hawthorne Lathrop in 1900, established homes for the terminally ill in Hawthorne, N.Y., New York City, Philadelphia, Fall River, Mass., Atlanta, St. Paul and Cleveland.

It was back in England, however, that the greatest progress was made in developing models of humane caring and treatment of the incurably sick. St. Luke's Hospital in Bayswater, London, was founded in 1892 by the West London Mission, an evangelical group. St. Luke's guiding force and medical superintendent was Howard Barrett, who established the hospital to serve the working and lower middle-classes who were too poor for private nursing and too proud for parish relief. It was, according to Barrett, "a home for the dying."[48]

In the early years the majority of St. Luke's patients were tuberculosis victims. Cancer was the second and heart disease the third largest cause of death among the hospital's patients. In 1896 the average male patient was 34, the average female 43 years of age; the average length of stay in the hospital was 74 days.[49]* Said Barrett, "If those we provide for were curable it would be difficult for us to carry out this leading idea . . . we aim at giving to all those who are brought to us a home of peace and comfort, and even pleasure."[50]

This discussion has traced the origins of the hospice concept from Roman and Greek antecedents through the flowering of the Christian pilgrim's hospice and the advent of sick-care societies in the Jewish communities of the Middle Ages and post-Renaissance era.

The urbanization and industrialization of the post-Enlightenment through the Victorian periods fostered fundamental changes in the way society regarded its poor, sick and incurables. The "hospice", connoting personalized care of the sick person, gave way to the "hospital", with all of its modern overtones of sterilized, impersonal treatment of the disease--and not the patient. Despite these fundamental attitudinal shifts, beacons of enlightened medical care

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* This may be contrasted with the figures from St. Christopher's Hospice of London where in 1979 the average patient was in his/her 60's and the average stay was 14 days. (HASTINGS CENTER REPORT p. 152.)

were lit, under the guidance and inspiration of individuals like Nightingale and Aikenhead, and in institutions such as the House of Calvary and St. Luke's.

The connecting thread which runs unsevered from the early hospice to the contemporary institution of the same name is the dedication to easing the lot of the dying person on life's final journey.

> Throughout the history of the hospice (or <u>hospitium</u>, 'hotel-Dieu' or 'hospitall', for these concepts were for a number of centuries interchangeable) one finds again and again the sense of life itself as a journey, a pilgrimage and a sojourn among strangers--a 'trip' as some now say--toward some future state of rest and blessedness. In a time of reexamination of material values and of renewed spiritual questing, it is no coincidence to find hospices once more appearing on the scene. At the present time, in somewhat different guise, aided by every advantage of modern medicine, psychology, and clinical pharmacology, the hospice concentrates its energies upon dying individuals, their families and friends. If they are alone in the world, the hospice community becomes their own."[51]

Best known of contemporary hospice communities, and a model for hospices throughout the world, is St. Christopher's Hospice of London. The founder of St. Christopher's, and hospice-booster extraordinaire, is Dr. Ciceley Saunders. Her early training as a nurse and her subsequent medical training in St. Joseph's Hospital in London, where she specialized in pain management, made Dr. Saunders acutely aware of the special needs of the dying.

One particular individual, a patient of Dr. Saunder's, may well be described as the spark behind the founding of St. Christopher's. He was David Tasma, a Jewish refugee from the Warsaw Ghetto. "It was through David's eyes that I was given the vision of this hospice, in the beginning. As he was dying in a busy surgical ward, we talked for many hours of what his real needs were--not simply for medical care as such, but for someone to care for him as a person, to stand by and honor him for what he was--and it was he, a refugee from the Warsaw Ghetto, who left the first 500 pounds for St. Christopher's. 'I want what is in your mind and what is in your heart', he told me. I saw then that what was needed was a place that was both a hospital and a home; and he said, 'I want to be a window in your home.'"[52]

St. Christopher's opened in 1967 and is today maintained through a combination of private contributions and subsidies from Britain's National Health Insurance. It was designed as both a haven for the terminally ill and as a teaching community wherein nurses, physicians, social workers and others might be inculcated with a respect for, and a desire to serve, the needs of the dying. As such, it has become the model <u>par</u> <u>excellence</u> for the hospice movement.

Developments within American society during the 1970's, which will be explored in greater detail further on, created a hospitable climate for the hospice concept to take root in North America.

Inspired by the work of St. Christopher's in London and aided by Dr. Saunders and her staff, a dedicated group of individuals in New Haven, Connecticut, established the first hospice in the United States in 1971--Hospice, Inc. of

New Haven. Originally it functioned to care for patients only within their homes but within a few years support for the hospice concept was sufficiently strong to finance the building of a permanent home for Hospice, Inc.

In 1976 the National Hospice Organization was formed to coordinate the activities and the struggles of the nation's fledgling hospices. Its aim was:

> to promote the principles of the Hospice concept and the program of care for the terminally ill and their families among the general public and professionals; to act as a clearing house serving the professionals involved in, committed to, and providing services within the principles of the Hospice program of care; to sponsor national symposia, conferences and workshops throughout the United States to develop and promote ideas of Hospice care; to provide technical assistance to emerging Hospice organizations and Hospices throughout the United States; to provide a mechanism for the monitoring of health programs and legislation relative to the Hospice movement and the needs of the terminally ill and their families.[53]

By 1978 there were approximately 150 groups around the United States in various stages of establishing hospices.[54] There were some thirty established hospices in England during the same period.

As of 1980, the National Hospice Organization directory listed 138 hospice organizations in the United States, and by 1982 estimates of the number of hospices ran as high as 500 to 750.[55]

The American Hospital Association, as reported in a <u>New York Times</u> article of August 18, 1983, estimates that there are 1,200 hospices in the United States. It is obvious that the hospice movement found fertile ground in the United States and has proliferated in little more than a decade.

This historical overview has traced the emergence of hospice from its ancient roots to its modern efflorescence. Later chapters will delineate approaches and practices of the hospices to which the reader has been introduced, but it is worth underscoring the components of the "old" hospice care--hospitality, "cherysshing" (sic) and a religious devotion to the infirm--which are now wedded to technology and advances in alleviating suffering to create the "new" hospice. It constitutes a happy union of compassion and knowledge.

CHAPTER II

HOSPICE: PHILOSOPHY AND PRACTICE

Preceding sections have introduced the reader to societal attitudes and conditions which allowed the hospice concept to take root. It is important that the reader now gain an understanding of the manner in which the hospice concept of caring translates into hospice philosophy and practice.

Hospice emerged to meet a spectrum of needs, some of which have been described earlier. American society distanced itself from the death experience. One academician described the situation in this way:

> Most of us will die in a ritually organized bureaucratic institution where life dribbles out, and where every effort is made to keep the patient alive until the next shift by any heroic means necessary so as to let someone else take the blame for the failure which death in the hospital represents.[1]

When death is perceived as failure, when the individual is reduced to a disease, "when the patient's body has become merely an object, a public commodity, and a pawn in our irrational war against death, then it is time to call a halt to such proceedings."[2] Hospice proponents were ready and willing to halt that dehumanizing process.

Demographic research provided another compelling reason for society to embrace hospice: American society is rapidly aging, suggesting even greater needs in the future for facilities and methods to care for the dying. Ironically, some have suggested that fatally ill children may have yet a greater need for hospice care than the elderly: ". . . because we hate to see children die even more than we hate to see adults die, and because children cannot refuse treatment, agressive life-preserving therapies seem to be practiced even more vehemently on them than adults."[3]

Others suggest that hospice has a role to play in plugging certain gaps . . . the gap between treating the disease and the person, the gap between technological research and psycho-social support, and the gap between society's denial of death and the acceptance of death by those who face it.[4]

Moreover, there is a compelling spiritual reason why society needs hospice. "The community needs the dying to make it think of eternal issues and to make it listen . . . we are debtors to those who can make us learn such things as to be gentle and to approach others with true attention and respect."[5] Assisting the dying person becomes a shared adventure, replete with dangers as well as spiritual rewards.

What approach, then, does hospice take to meet the needs of the dying? What are the fundamental principles upon which hospice operates? The National Hospice Organization provides the following statement of principles and standards:

> Dying is a normal process whether or not resulting from disease. Hospice exists neither to hasten nor to postpone death. Rather hospice seeks to affirm "life"--by providing support and care for those in the last phases of incurable disease so that they can live as fully and comfortably as possible. Hospice promotes the formation of caring communities that are sensitive to the needs of patients and their families at this time in their lives so that they may be free to obtain that degree of mental and spiritual preparation for death that is satisfactory to them."[6]

Hospice philosophy subsumes a number of elements which include:

1. A committment to allowing death with dignity.
2. A concerted effort to control pain.
3. Helping the dying person fight a sense of isolation and abandonment.
4. Involving the patient's family in the patient's care.
5. Assisting the patient in retaining control over his/her life as long as possible.
6. Giving the family of the dying person bereavement counselling and support once the patient has died.

Undergirding hospice philosophy is the belief that there is never a moment when nothing more can be done for the patient until that patient dies.[7] Hospice sees the dying person as having legitimate needs which must be reasonably met: ". . . the dying have the right to a great many things that [hospitals and nursing homes] simply cannot provide. They need life around them, spiritual and emotional comfort and support of every sort. They need 'unsanitary' things, like a favorite dog lying at the foot of the bed. They need their own clothes, their own pictures, music, food, surroundings that are familiar to them, people they know and love, people they can trust to care about them."[8]

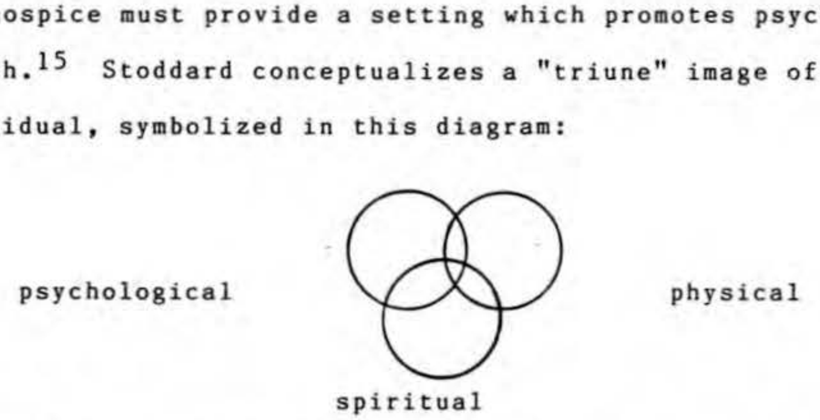
Hospice, with its emphasis on home-care when possible and for as long as is feasible, recognizes that there is such a thing as inappropriate institutionalization.[9] Hence, hospice philosophy encourages the shifting of the locus of control from the institution to the dying person.

Theodore H. Koff, in Hospice: A Caring Community, elaborates on hospice principles and lists these essential ones:

> -caregivers must respect the element of time, fulfilling needs "now" since any request may be a last request. This requires sufficient staff and a support system of family and volunteers.
>
> -the family, with the patient, is the unit of care, where "family" is defined as the circle of significant others.[10]
>
> -the individual lifestyle of the dying person should be supported as long as possible. Respect for the individual's ethnicity, cultural orientation, social and sexual preferences must be reflected in the services and program of hospice care.[11]
>
> -hospice regulations should be held to a minimum and be related to life, safety and licensing regulations. Hospice clients should enjoy the greatest flexibility and responsiveness to their needs.[12]
>
> -hospice care requires home-care services and the capability of providing institutional care.[13]

Truth-telling is fundamental to hospice philosophy. To tell or not to tell is not the question for hospice, rather, what, how and when to tell. "Hospice people believe that every patient has the right to know what is happening to his life, and that every answer given to every question must be the truth. It need not be the whole truth, but it must be the truth. And the truth must be spoken within the framework of caring."[14]

Hospitals are future-oriented, concerned with cure and release; hospice allows the patient to dwell in the present or the past. Health, for the remaining days must, therefore, be defined in psychic terms for the dying patient and hospice must provide a setting which promotes psychic health.[15] Stoddard conceptualizes a "triune" image of the individual, symbolized in this diagram:



The word "cure" connotes restoraton to full health of the physical element of the triune being. But when physical "cure" can no longer be effected, the remaining two-thirds of the triune being--the spiritual and emotional elements--become proportionately more important. The "healing" efforts of hospice philosphy and practice focus therefore on these two spheres of the triune being.[16]

In summation, the hospice philosophy describes an approach to caring for the dying person which speaks to the basic humanity and dignity of the individual. It views death and the process of dying not as an embarrassing aberration but as a stage of growth through which one can be comforted and assisted by caring persons. One may succinctly restate this philosophy in this way: "What people need when they are dying is relief from distressing symptoms, the presence of caring people, a comfortable environment, and the opportunity to live in their own unique lifestyle until death."[17]

Clearly, pain and other distressing symptoms can prevent the dying person from living fully until death. Incessant, debilitating pain and the anxiety to which it gives rise, rob the individual of the opportunities he or she might otherwise have to contemplate impending death and make plans to meet it in his or her own way. It is no surprise that dying with chronic unrelenting pain is one of the greatest fears of the dying cancer patient.[18] Accordingly, pain management and symptom control are among the highest of hospice priorities.

A patient's response to pain depends upon a combination of factors including cultural background, prior experiences with and exposure to pain, and stress induced by other factors (i.e. family conflicts, financial problems.)[19] "Chronic terminal pain can be conceived of as a vicious circle: physical pain arouses anxiety, anxiety generates depression, depression causes insomnia and insomnia, in turn, aggravates the physical pain."[20]

Apart from direct pain, there are other physiological problems with which hospice symptom control must deal:

loss of appetite, vomiting, diarrhea, shortness of breath, immobility, incontinence, skin breakdown, mood changes, insomnia, limitations in motion, fatigue, change in appearance and concentration difficulties.

Painful, distressing symptoms may have a variety of different origins. Pain may be physical, emotional, spiritual or a combination of these factors and hospice must employ varying techniques to alleviate such symptoms. Care in hospice is directed toward overcoming pain and suffering by controlling the symptoms which cause or promote distress.[21] This is achieved through medication, positioning for comfort, massage, heat, radiation therapy, chemotherapy, surgery, supportive activities and counselling.[22] The goals in pain relief are:

1. Clarifying the underlying cause of pain.
2. Preventing pain by anticipating its recurrence.
3. Erasing the memory of pain.
4. Keeping the patient alert.
5. Considering the ease of administration.[23]

The pain-control regimen of hospice involves 1) the right analgesic 2) in the least amount necessary 3) at the right time (<u>before</u> pain hits) and 4) in the most effective manner.[24]

The key to hospice's success in eliminating or controlling even the most severe chronic pain lies in its novel idea of administering pain medication continuously, as opposed to the standard hospital procedure of giving medication "as needed." Continuous dosages of analgesics, when properly titrated, prevent the return of pain and the grave anxiety which accompanies the fear that pain will return.

In England, where the modern hospice got its start,* a combination of drugs (diamorphine, commonly called "heroin", phenothiazine, alcohol, water and cherry syrup . . . to offset the bitter taste of the narcotic) became the most efficacious means of controlling pain. It is known as "Brompton's Mixture" or "Hospice Mix" and it is taken round the clock in prescribed dosages. The patient is often encouraged to keep a "pain/comfort" chart to help track and manage his or her own pain control.[25]

Unlike England, where diamorphine may be legally prescribed, the United States does not allow its use and so morphine, cocaine or methadone are often substituted in its place. Some claim that the American version is less effective while others claim its superiority to its English equivalent.

Hospice dismisses, out-of-hand, objections to the use of narcotic, potentially habit-forming drugs. Addiction is simply not an issue for those whose lives are numbered in weeks or months at best. Affording the dying person surcease from debilitating pain and allowing him or her to function alert and free of the fear of pain are the ultimate goals of the hospice approach to controlling pain.

Hospice philosophy just described translates into practice in a variety of forms, including in-patient facil-

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* See page 25, Chapter one.

ities, home-care organizations and combinations of the two. One must examine the structure of existing hospice organizations to gain an understanding of the variety of approaches employed to provide humane care for the dying.

Many communities are either too small or too saturated with existing health-care facilities for hospice to take root in them. In such communities, hospice care often takes the form of home-care: service to terminally ill patients provided by a team of hospice specialists within the patient's home. Sometimes this will involve the participation of a visiting nurse association to provide much of the care. Otherwise the hospice team is composed of the same important mix of medical professionals, social workers, clergy and volunteers as well as the patient's family.

The goal of hospice home-care is to allow the dying person to die at home, in a familiar environment, without suffering the trauma of a hospital admission. Hospice Inc., of New Haven, for example, started out with a home-care program until community support was sufficient to enable it to build an in-patient facility to complement the home-care program. During its first five years, Hospice Inc.'s home-care program allowed 56% of its patients to die at home. This contrasts dramatically with the figure of 2% nationally for those who die at home.[26]

The problem associated with moving a dying patient from a home-care situation to a hospital in the final stages of illness is that "continuity of care [is] lost on hospital admission. Techniques of comfort that had worked well in the home [are] ignored by a system geared to investigation, diagnosis and cure--but not to comfort care."[27]

Few, if any, hospices function solely as in-patient facilities without any home-care component. Some hospitals, however, have incorporated hospice-style techniques within the hospital setting. Calvary Hospital in the Bronx, New York, is one such hospital. It is a chronic disease hospital, admitting patients whose life-span is anywhere from three to six weeks. Patients are referred to Calvary from some 92 regional hospitals. Its hospice-like features include a primary physician for each patient, two constant-care units under twenty-four-hour-a-day supervision. and a recreation program. Unlike hospice, it has no home-care program and no bereavement program. The focus for Calvary Hospital is the proper medical management of the dying cancer patient. As such, it has all the traditional hospital trappings and regulations.[28]

St. Luke's Hospital in New York City began a hospice program in 1975 in which special treatment teams provided care for five to ten terminally ill patients scattered throughout the hospital. Normal hospital regulations were bent to some degree to allow for special visitations and dietary privileges for the patient. In addition, ten patients received out-patient care. While this may represent a good model of care for communities which are too small to support a hospice or for hospitals which lack the space for a separate hospice unit, it still falls short of the true hospice concept. Elements noticeably lacking include a committment to research, in-staff education and morale-boosting staff sessions.[29]

By far the most common and the most successful form of hospice is one which combines home-care with a separate in-patient facility. Hillhaven Hospice of Tucson, Arizona falls into this category. It has a home care program established through contract with the Visiting Nurse Association of Tucson. Its emphasis is on teaching the family unit to be the caregiver for the patient; it teaches such skills as administration of medication, how to change bed-linens while the patient remains in bed, proper massage, skin-care techniques and the like.

In addition, Hillhaven Hospice has a 39-bed facility for patients who have no one to provide home-care or for situations where home-care has over-taxed the family's energy and spiritual resources, necessitating the patient's transfer to the in-patient facility.[30]

St. Christopher's Hospice in London, England, the model hospice on which so many others have patterned them selves, is another combination-type hospice. In addition to its home-care program and in-patient facilities, St. Christopher's boasts a number of other features which make it an example of hospice at its best. These include four-week study courses for visitors which culminate in the student-visitor's becoming part of the ward team caring for patients; a "Pilgrim's Club" which is a support and social group for the survivors of former patients; a day-care center for children of staff which allows for interaction between the children and the dying patients; and a designation of Mondays as "Visitors' Day Off"--giving the family of the patient, and the patient as well, an oft-needed respite to "recharge their batteries" and tend to the necessary details of daily life.[31]

A 1982 study looked at twenty-four hospices which had been in operation for at least one year, having served at least 100 patients each. All offered home-care and bereavement counselling but only 41.7% of the sample had an in-patient program. Ten of the twenty-four were institutionally based, usually in a hospital.

Portraits of two divergent types of hospices emerged from this study. The first type is the independent hospice, heavily volunteer-oriented, with a variety of professional staff positions and a wide array of social/psychological services. Its funding tends to be unstable. The second type is institution based, with a greater variety of medical/nursing services and less variety of social/psychological services. It has fewer types of volunteers and paid staff. Its funding tends to be stable.[32]

A crucial component of hospice care and one which is often overlooked, is the physical design of the hospice. Does its design maximize the giving of care and minimize those elements which will remind patients and visitors of sterile, hospital facilities? A number of considerations go into the design of a hospice unit incorporating the needs of the patient, family and staff. These include:

- the need of the patient to have input into the choice of room decor (Is there ample space to display cherished pictures? Is there room for a favorite sitting chair?)
- the need for adequate noise control
- space for family members to stay overnight in close proximity to the patient
- comfortable lounges for staff, family and patients (where all three may interact, if they so choose)
- separate rooms for staff (where they may unwind or work through the variety of emotions engendered by their work)
- a kitchen for the use of the family to prepare or reheat favorite foods of the patient
- a non-denominational chapel (which, as in <u>all</u> hospice rooms, must allow access for bed-ridden patients)
- a viewing room for the corpse
- a children's play area[33]

The guiding principles in hospice physical design mandate that the design should 1) stress homelike characteristics and provide a living environment 2) recognize the low energy level of patients 3) reflect the involvement of family members 4) provide for patient privacy 5) offer staff convenience and 6) allow for patient control over his or her environment.[34]

Once decisions have been made concerning the physical design of hospice, each decision-making hospice group must establish criteria for admission reflecting both the philosophy of the group and the particular concerns and needs of the community the hospice will serve. Accordingly, admission criteria will vary from one hospice to the next.

St. Christopher's Hospice in London has a fairly simple admissions policy: the patient must be experiencing pain which is not temporary, and which is not easy to manage but is, in fact, chronic and overwhelming. The patient must have a "reasonable" life expectancy, beyond hours or days, and the patient must have family or friends within reach of the hospice.

Koff elaborates on general admission criteria within the hospice movement and sets forth the following:

1. The patient has a diagnosis of terminal illness.
2. The disease has been determined to be past the point of aggressive treatment for cure; however, palliative treatment for symptom control is acceptable.
3. The patient and the family wish to enter the hospice program.
4. General life expectancy is less than six weeks.
5. The patient's personal physician agrees to the referral and will continue to attend the patient.
6. A competent caregiver is available to the patient in the home if home-care is recommended.[35]

Once a person enters hospice, whom is he or she likely to encounter among the personnel? Mention has been made earlier of the full complement of skills brought to focus on the hospice patient. Physicians, social workers, nurses, clergy, pharmacologists, psychologists, art and music therapists, trained volunteers, etc. all bring their skills to bear on the patient's needs.

Is it possible, however, to characterize the type of person who chooses to work in hospice? Clearly, working with the dying requires both commitment and sensitivity but there are a variety of reasons why individuals choose hospice work. It may be a matter of accident or convenience; it may stem from a desire to do the "in thing" or to associate with a charismatic leader; it may be a response to an intellectual appeal (i.e. a desire for mastery over pain and death); it may involve a sense of "calling" or a previous personal experience; it may grow from the suspicion that one might some day develop a terminal illness and be in need of hospice environment.[36]

One hospice advocate reiterates this last point. "I have not yet met persons in the hospice movement who did not admit to wanting to contribute to a system which might someday conceivably support them. The motivation is deep. It is personal. And it is legitimate."[37]

Those who stick with hospice work, who find deeply felt needs fulfilled through giving, tend to describe hospice work in intensely personal, almost religious terms: "Those who do hospice work, whatever the structure of their religious or philosophical beliefs, tend to feel . . . that there is a sort of centeredness and holiness about it. Whether they are offering massage or medicine for pain, clean linens or a hand to hold and a listening heart, they sense that these are gestures of obedience to Love of a higher order. And the dying who are cared for in this way are offered, without any preaching or intellectualizing about it, a clear representation of that 'time out of time' which is celebrated by our poets and our prophets and in our liturgies."[38]

An overview of existant hospices reveals a large number which operate, in some fashion, under sectarian auspices. This is not surprising in view of the history of hospice, but it is worthwhile to raise the question of the extent to which religion manifests itself in hospice practice.

The strong connection between hospice and the Church in England is reflected in the names of hospices there: St. Joseph's, St. Christopher's, St. Ann's, St. Margaret's, St. Luke's. Some maintain that the very concept of hospice may be traced to the Gospels. A quotation from the New Testament, Luke 2:29-31, is often cited as the operative inspiration for hospice: "Lord, let they servant depart in peace."

Much of the literature on hospice stresses the consonance of Christian faith and hospice practice, but a spirit of ecumenism is distinctly manifest in most hospices. Consider, for example, this expression of the ecumenical mandate of hospice:

> To the Christian, the patient's body is, quite literally, the body of Christ. To the Jew, the patient may be the angelic messenger who in ancient Scripture was welcomed and refreshed, by God's command, in the form of a human stranger. Hindus and members of other faiths have similar beliefs; so do compassionate people who call themselves merely humanists.[39]

One encounters repeatedly in the literature the notion that the work of hospice is, in itself, a form of worship and prayer.[40] The word "religious" is used unhesitatingly, but it is broadly defined:

> [Is hospice] religious? Well yes, if you believe that a caring community is necessarily religious. But in one very fine little English hospice that I know of, two nursing sisters quit recently because they felt not enough religious ritual was being observed; and the director (who is both a physician and a deacon) asked them in astonishment, 'But aren't you in the habit of praying with your finger-tips?'[41]

Hospice proclaims a religious message insofar as it claims that death as well as life has meaning, preaching by example that human life is valued whether or not it has productive use for society.[42]

Certainly in some hospices sectarian rituals are an integral part of the care provided. At St. Joseph's Hospice, in London's East End, for example, the rhythm of daily life is that of a strongly liturgical religious order. Chapel bells ring three times a day and all work ceases for a moment of prayer. Staff meetings begin with a scriptural reading. In St. Joseph's, a Catholic hospice, the issue of euthanasia becomes irrelevant, for the duty to care for the patient is understood to mean that the dying person must be so well-cared for that he or she would never wish to be killed. St. Joseph's is an exception to the unstated rule which implicitly commands that the individual patient's own needs take precedence over any religious agenda of the institution.

While spiritual matters are not ignored by the entire hospice team, the hospice chaplain still plays a unique and sometimes pivotal role in hospice care. The presence of clergy on the hospice team helps the patient and family articulate spiritual problems which would otherwise receive only superficial treatment.[43] The chaplain is often in a privileged position to help interpret what is happening to a dying person in light of its religious implications.[44] He or she can be a "mediator and minister of reconciliation" between the patient and his or her family.[45]

The usefulness of the clergyperson to the hospice as a whole is directly proportional to the degree to which that person is integrated into the hospice team. This implies full access to medical charts for the clergyperson and participation in the treatment plan.[46] The caring cleryperson will be attentive to, and respectful of, the patient's religious needs . . . or lack thereof. The Rev. Edward Dobihal, Jr., of New Haven's Hospice, Inc., sums up this sensitivity nicely:

> We give each other space, and we don't lean on patients for any kind of conversions, either. If they want to talk about it, fine; if they don't that's their business. We let them know we are available any time, that's all."[47]

Apart from the clerygperson who is part of the hospice team by virtue of being employed by the hospice, the patient's own clergyperson can play an important role as well. He/she is in a unique position to act as an advocate for both the patient and the patient's family in a number of ways: by alerting the family to the possibility of hospice care if the physician has not; by pressuring a reluctant physician to explore the hospice option for a terminally ill person; by keeping in touch with hospice staff and providing it with the feedback which patients and their families are sometimes unwilling or unable to give.[48]

Most importantly, the patient's own clergyperson can help the patient view impending death through the understanding of his or her faith system with all of the comfort that can sometimes afford.

Clergy will often play a significant role in the bereavement counselling which is so integral a part of hospice practice. Recognizing that the process of grief often begins the moment a family member is told the patient will not recover, the clergyperson joins the social-worker or caseworker assigned to the family-unit in assessing the bereavement needs.[49]

Bereavement counselling and support assume a number of forms ranging from having someone stay with the body until funeral arrangements have been made, or planning classes for survivors on such topics as estate-taxes or living alone, to celebrating holidays with the family, a particularly difficult time for mourners. As in all phases of hospice care, bereavement care is tailored to the needs of the individual but will almost always involve periodic checkups through the first year after the death of the patient.

This concern for the survivors has a practical component as well. "Bereavement follow-up is actually preventive health-care. In the first year after the loss of a family member or other intimate, there is increased vulnerability to illness for the survivor . . . ."[50]

The reader has now moved from an examination of hospice philosophy through an overview of hospice form and function. This section would be incomplete if it did not make mention of the problems hospice faces from inception to public acceptance. Unless hospice can surmount these obstacles, its well-defined philosophy of care will serve for naught.

Without a doubt, the greatest problems facing the hospice program are issues of funding and licensure. At the time of this writing many of these issues are being resolved through legislation but the basic problem stems from the unique position hospice occupies within the health-care system. It is neither "fish nor fowl", neither hospital nor nursing-home and, as such, it does not easily fit into the licensing requirements of many communities nor into the categories of institutions providing health-care insurance and reimbursement.

The unique combination of services which are subsumed under hospice care (social work services, dental care, bereavement counselling, etc.) are not described under existing statutes and therefore hospice patients and their families sometimes experience great difficulty in obtaining reimbursement for their hospice expenses.

Some maintain that it is hospice's uniqueness which has upset the status quo of the health-care industry:

> Hospice has intruded into the spiral of health-care technology with startling impact. It has not been the newness of hospice, but rather its challenge to the humanness of health-care that has disturbed the status quo. Hospice has advocated for the quality of life, for living until death, for the absence of pain, for the

> maintenance of personal control. Hospice is being folded into a larger philosophical framework in which there is renewed recognition that emotional well-being is at least as important as physical health."[51]

In many states for a number of years, hospice was not recognized qua hospice. It was variously defined as home health-care agency, skilled nursing facility, chronic care institution, general hospital, etc. This led, in many cases, to a misunderstanding of hospice's true function on the part of the general public.

Some posit a more insidious motive in keeping hospice outside the established health-care system . . . an economic motivation of self-interest:

> While home care cuts costs for the family, it does not help keep institutional balance sheets in the black. Thus hospice poses a financial threat to a health-care system that is controlled by medical care providers--hospitals and doctors--and third-party payers--Blue Cross/Blue Shield and the various health insurance companies."[52]

Hospice philosophy was anathema to health insurance companies for under their reimbursement policies, death is not an allowable treatment objective. The multi-level care which hospice provides created problems for regimented coverage systems and reimbursement programs.[53]

Consequently, many hospices were forced to resort to affiliation with hospitals in order to qualify for third-party reimbursements. This often led to certain compromises of hospice philosophy. Hospice faced the choice of relinquishing autonomy and achieving "legitimacy" in a hospital context or going it alone depending on donations . . . usually an unfeasible route to take.

Already, shifting public attitudes towards hospice have caused changes. New standards of licensing and accreditation have granted hospice new legitimacy in the eyes of third-party reimbursers. As the hospice movement has grown, more evidence has amassed suggesting that hospice care makes good economic sense for health-care consumers. Societal changes are gradually creating the climate necessary for hospice to take its rightful place in the health-care systems pantheon. Recent congressional action, reflecting a popular mandate for hospice care, paved the way for substantial Medicare coverage of hospice services . . . a sign of long-awaited legitimation of the hospice approach.

Apart from issues of funding and licensing, which seem to be resolving themselves as the hospice movement grows, there remain other concerns. The explosive growth of the hospice movement concerns some . . . they fear the excessive fragmentation and over-specialization which have plagued American medicine to date. Some express concern that society will not sustain its new-found interest in more humane care for the dying . . . that hospices will suffer a terminal lack of support.

Others are even more cynical:

> There is no evidence that our society really wants to spend large sums on compassion--whether in caring for children and juvenile delinquents, or the aged . . . or the dying. Cancer money is designed for research to cure cancer, and the hospice people must not be allowed the illusion that it is going to be easy to change the direction of the whole health-care system with its passion for cure, for paying attention to the disease rather than the person.[54]

Hospice has made a promising start in this country but it remains to be seen how long-lasting and how deep an impact it will have on societal attitudes towards the dying person. Bear in mind that hospice care is not for everyone. It is <u>not</u> appropriate when:

1. the patient and/or the family is unable to deal with the dying process and finds hospice too threatening to be helpful.
2. the applicant may be too close to death to warrant change in the care setting or care routine.
3. the individual and family are content with current care.
4. the cost of hospice care or the limits of insurance/third-party coverage place hospice care beyond the means of the family/patient.[55]

The growth of the hospice movement clearly demonstrates that hospice is, in fact, meeting the needs of many.

CHAPTER III

DEATH IN CONTEMPORARY AMERICAN SOCIETY

The growth of the hospice movement in the United States has been almost exponential: from one hospice in 1971 to an estimated 1200 in 1983. It is clear that the public perceives hospice as meeting some very basic societal needs which heretofore went unanswered. How does one account for such widespread acceptance? One begins by examining societal attitudes toward death and the process of dying, for therein lie the reasons that hospice is flourishing today.

"In medieval times, dying persons were seen as prophetic souls, voyagers and pilgrims valuable to the community in a number of ways, not least in the opportunities they provided those around them for service and spiritual growth. It is a modern and ignorant prejudice to consider death a failure. It is a modern superstition to avoid knowledge of it, to treat it as if it were something unnatural, shameful or wrong."[1] To put it more succinctly, death was once seen as a door to the hereafter. It is now seen as a wall.[2]

The denial of death is certainly not an exclusive phenomenon of life in twentieth century America.* Many ancient myths seemingly deny mortality as a human condition by presenting death as the creation of gods who were jealous of immortal humans or by suggesting that death entered the world through human error, as in the biblical account of the Garden of Eden.[3]

The epic of Gilgamesh, for example, presents the belief that the gods reserved immortality for themselves. The epic's protagonist, Gilgamesh, wanders through the world seeking a means to overcome mortality imposed upon humankind by capricious creator-gods.[4]

Freud observed that soldiers can fight and commit acts of barbarism because they do not believe that they themselves will be killed. Everyone, in reality, displays an "unmistakabe tendency to 'shelve' death, to eliminate it from life."[5]

Bailey, in his volume Biblical Perspectives on Death, states that,

> The human dilemma is that we are caught between two worlds, the one symbolic and the other animal; we are able to transcend nature and speculate about the mysteries of the universe--able to experience awe and love, able to create value systems--and yet we are part of a body that aches, stinks and dies; we are able to soar, physically as well as mentally, among the stars, yet are destined to rot beneath the ground; we are often beautiful of form, yet constrained to bodily functions that shame us: 'gods with anuses'. This incongruity, it is said, produces a fear of death which must be repressed lest one become mad and which is the common denominator

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* The denial of death in American society has been explored in two "classics" in the field of death and dying: Ernest Becker: The Denial of Death and Jessica Mitford: The American Way of Death and Dying.

behind many, if not all, other fears and drives."[6]

This grappling with the presence of death is nowhere more acute than in American society where the triumphs of technology and the pursuit of pleasure have forced death to take a back-seat to other concerns. Society has waged war on death, on both the scientific and popular fronts. Death has been gradually expelled from common experience. One encounters it instead, graphically and violently, on television and in the movies. Even childrens' cartoons broadcast the message that death is not real, that the cartoon hero can be infinitely resurrected.

This is a future-oriented society but death inherently denies a future. "Death is seen as the destroyer of the American dream--the right to life, liberty and the pursuit of happiness."[7]

One of the consequences of the zeal with which the war against death is being waged is that society turns away from the hopelessly and incurably ill and from those who are consciously ready to die.[8] This phenomenon presents itself in the "cure" versus "care" dichotomy which pits proponents of the use of any possible means to sustain life, even if great suffering is the consequence, against those whose desire is to provide emotional support and surcease from suffering.

The death-bed scene is no longer a common or familiar experience for most Americans. The dying person's last companion is now more likely to be a machine than a human being. Nursing homes for the aged and incurably ill foster a myth of "convalescence" which society is only too eager to embrace. The Puritan notion, that the loss of individual power, vigor, and self-control is somehow disgusting, has led many to believe that death is personal surrender and therefore must be denied.[9]

In the all-out war against it, death was removed from the home to the fortress-like walls of the hospital, the domain of "specialists" and "procedures." "What was not seen, no longer heard and participated in as a normal event was now whispered about, feared and finally, ignored or repressed."[10]

This staving-off of death, its removal to the realm of doctors and technology, or cinematic "reality", has a very detrimental impact on societal attitudes toward death: " . . . all of this [aging] takes place . . . in relative secrecy. We can only really know of the deaths in our own households, or among our friends. These detached in our minds from all the rest, we take to be unnatural events, anomalies, outrages. We speak of our own dead in low voices; struck down, we say, as though visible death can only occur for cause, by disease or violence, avoidably.'"[11]

Technology confers mixed blessings. Machines and procedures can prolong life but when they do so society ignores larger questions concerning the quality of life being preserved. Generally available medical care, bolstered by technology, fails in two respects: 1) it prolongs suffering without regard for the quality of life, ignoring the dignity of the patient and enforcing the patient's isolation from family home and friends and 2) generally available care is unsuccessful--pain is not continuously controlled nor are accompanying symptoms, and no true prolongation of life, in all its aspects, is achieved.[12]

In traditional settings wherein dying persons ordinarily receive care in the last stages of illness, there is a high incidence of unwarranted and excessive use of "heroic"* means, inhumane employment of life-support systems and undue prolongation of physical life.[13]

The following passage, written by a physician about his dying mother, is a poignant example of clinical and detached care of the dying person.

> What happened was a nightmare of depersonalized institutionalization, of rote management presumably related to science and based on the team approach of subdivision of work . . . . Different nurses wandered in and out of my mother's room each hour, each shift, each day, calling for additional help over a two-way radio . . . . They were trained as part of a team "covering the floor" rather than aiding a sick human being . . . . Laboratory studies of blood and urine continued to be performed, fluids were given, oxygen was bubbled in, antibiotics were administered; the days went by but seemed to be years. The patient was seen occasionally by large groups of physicians making rounds, presumably learning the art of practicing medicine properly . . . . The chart was enlarged regularly with "progress notes." These hastily scrawled writings always dealt with laboratory data, never about the feelings of the patient or her family . . . . One report stated that occult blood had been found in the stool. Someone responded by writing in the chart that in view of this finding, sigmoidoscopic examination and a barium enema were indicated. I

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* The word "heroic" connotes unusually intensive efforts, often employing highly sophisticated equipment, to sustain life.

> suggested to the author that this conditioned reflexive act was not warranted in the case of an unconscious 80-year-old woman who wanted to die gracefully . . . .[14]

A consequence of the faith vested in medical technology is that society now perceives doctors as "priest/technicians", infallible and omniscient. One wonders whether the high rate of medical malpractice suits does not reflect a disillusionment with the medical priesthood for its failure to win the ultimate victory over death.[15] Perhaps society expects too much of its healers. Nine thorough empirical studies, described by Kastenbaum and Aisenberg, conclude that physicians have an above-average fear of death and often choose their career in order to gain more control over their death fears. Medical training encourages bravado and a desensitization toward death. If this is true, "the front line [of the war against death] would be manned by volunteers who are more intimidated by the enemy than are many of the civilians behind the lines."[16]

The difficulty which many in the healing profession share in confronting death merely exacerbates the problems experienced by the dying patient. "Terminal patients are frequently avoided by hospital personnel, thereby increasing their sense of loneliness and isolation. Physicians and nurses may avoid conversation or otherwise distract a patient when he begins to discuss death. When the patient feels that hospital personnel are uncomfortable in allowing him to discuss the taboo topic, he will gradually erect his own communication barrier. It is the conspiracy of silence that is most destructive since it leads to separate the dying from the living and offers the patient no opportunity to verbalize his feelings and thoughts, or allow his positive feelings for others to emerge."[17]

For all the denial in which society engages, the subject of death still holds a morbid fascination for many. How else can one account for society's consuming interest in accidental death, which is screamed from the newspapers and televisions in endless streams of auto accidents, accidental drownings, electrocutions and homicides? Perhaps it is a way to avoid the reality that 95% of the population will die of natural causes. "Thus we deny that death is in us all; we comfort ourselves by remaining within the child's universe of causality; we pretend that only one type of death is inevitable rather than confronting the fact that we all die."[18]

Through a combination of factors, including the disintegration of the family unit as it is presently constructed, increased mobility, advances in technology and a trivializaton of death experience through the media, Americans have become alienated from death, inordinately reticent to broach the subject on either the personal or societal levels. The "right to life" is vociferously defended, but for most Americans through the 1970's the right to die with dignity remained a low priority.

The pioneering work of a number of individuals, best known of whom is Dr. Elizabeth Kubler-Ross, went far in preparing the societal ground to accept the hospice concept. These individuals approached the phenomenon of death empirically; they questioned attitudes, interviewed the dying to determine just what were their needs, fears and desires. Works such as Kubler-Ross's On Death and Dying and Becker's The Denial of Death gained wide audiences and engendered even more research and discussion in the area which came to be called thanatology (from the Greek god of death, Thanatos), which means "the study of death."

What emerged most clearly from this body of work was the perception that the dying need to be treated as persons, not as diseases or societal pariahs. Moreover, the investigations of these researchers led to useful categorizations of the stages in the dying process and the reactions to those stages from the vantage points of both the dying individual and those close to that person.

For example, researcher Thomas Leich set forth six "fears" which he believes the dying encounter:

1. Fear of the process of dying: this includes fear of pain, anxiety, altered body image.
2. Loss of control: implying an increased dependency on others.
3. Loss of one's loved ones: concern over what will happen to them.
4. Fear reflected in those who care for the dying; the non-verbally communicated fear.
5. Isolation: the "aloneness" of dying.
6. Fear of the unknown: here faith systems are called into question.[19]

Another researcher lists the following reactions, on both the individual and institutional levels, to the process of dying:

> *Individual*:
> 1. Fear of pain, isolation, surgery, loss of job
> 2. Anger
> 3. Loss of self-esteem
> 4. Guilt . . . viewing the disease as punishment
> 5. Loss of pleasure
>
> *Institutional*: Care of the dying patient usually induces so much anxiety in health personnel that in many hospitals emphasis is placed on the routine technical aspect of physical care rather than on the development of close interpersonal relationships with patients.[20]

The work of thanatologists, physicians, social workers, psychologists, clergy *et al*, went far in demonstrating that methods of care for the dying existed, or could be developed, which were more appropriate to the needs of the dying than what was routinely offered in hospital settings. A growing awareness that death need not be a painful, terror-inducing experience helped establish a climate favorable to the hospice concept.

CHAPTER IV

JEWISH ATTITUDES TOWARDS DEATH AND DYING

An appreciation of the hospice concept from a Jewish perspective presupposes a clear understanding of attitudes towards illness, death and mourning as expressed in Jewish law and tradition. This section will afford an overview of these attitudes which will then allow for an examination of the degree to which Jewish beliefs and hospice approaches are compatible.

There is considerable discussion in the literature of Jewish tradition over the origins of pain and suffering, but regardless of whether or not pain is considered to be divine punishment, it is clearly viewed as a curse. The notion that physical pain and suffering represent some virtue is virtually absent from the tradition.[1] In fact, the Jew is enjoined to do everything possible to eliminate pain even if this necessitates violation of halacha. For example, the Shulchan Aruch mandates that one is allowed to refrain from eating and even from lighting candles on Shabbat if either action would cause discomfort to the sick person.[2]

Even the criminal walking to his execution was spared unnecessary suffering in accordance with the scriptural dictate: "Thou shalt love thy neighbor as thyself." Hence the Talmud states that the condemned criminal be drugged into insensibility before the execution so that his feelings might be spared.[3]

Moreover, the tradition views pain as a degradation of the human spirit. As Reimer points out in his volume Jewish Reflections on Death, ". . . Job found pain to be not the instrument for recapturing his faith but what almost cost him his faith and with it all that made life worth living."[4]

With respect to Jewish attitudes toward the process of dying and death itself, it will be instructive to trace the evolution of those attitudes from the biblical period to the present.*

The word death, in biblical usage, carries three connotations:

1) As a metaphor for things which detract from life, from the full potential God intended for all. These include illness, persecution, despair and non-participation in the life of the covenant community.

2) As a symbol of the "power" which stands in opposition to the created order of the universe (i.e. Deut. 30:15, 19 "life and good, death and evil . . .").

3) As biological cessation, usually the end of an individual's historical existence.[5]

Unlike other Oriental religions, wherein preoccupation with death was a central religious concern, the Bible

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* The word "biblical" here connotes the Jewish canon exclusively.

rarely deals with death as a problem:

> There is no rebellion against death, no bitterness over its sting, no preoccupation with the afterlife. In striking contrast to its two great neighboring civilizations, Egypt with its intense preoccupation with the afterlife, and Babylonia with the Epic of Gilgamesh who wanders in search of immortal life, the story of the descent of Ishtar, and the legend of Nergal and Ereshkigal, the Bible is reticent in speaking about these issues. The Hebrew Bible calls for concern for the problem of living rather than the problem of dying.[6]

The biblical canon reflects a range of attitudes towards death. It does not stress the idea that human life is so intrinsically sacred that it must be preserved at all costs. However the power of granting and sustaining life is seen as belonging solely to God and as being imparted through the act of creation. The taking of life, therefore, is understood as an act against God.[7] Ultimately the Bible is ambiguous on issues related to death <u>per se</u>.

What does the Bible reveal about the ways in which ancient Israelites coped with death? First and foremost as a coping mechanism available to them was the notion that God, the one God, establishes the limits of life. One need not, therefore, fear other deities. Individuals could pray for death, even premature death, secure in their faith that Yahweh was the lord of life and death.[8]

"And [Elijah] asked that he might die, saying, 'It is enough, now, O Lord, take away my life.'"

(1 Kings 19:4)

Death was not irrational, not an intruding enemy; rather it was part of an ordered, controlled harmonious creation. Biological life and death were not seen as separate phenomena but as two parts of life bound together as part of divine will. To accept one was to accept the other.[9]

Biblical persons, the textual evidence seems to suggest, were better able to see themselves within the larger scheme of creation than their modern counterparts. They openly acknowledged the implicit chasm which existed between themselves and God; they saw death, therefore, as natural and acceptable with an ease that most modern persons cannot.[10]

A second coping mechanism was the belief that the welfare of the group predominated over that of the individual. God's covenant and promise to the people Israel diminished the sting of death. Moses, for example, expressed no resentment about death as such . . . his remorse springs from the knowledge that he will not see the promised land. (Deut. 34:1-8, 3:23-28, Nu. 20:1-13)

A third coping mechanism was the belief that the continuity of the people insures the continuity of the memory of the deceased, whose "name" would not perish with the body.

Communal expressions affirming God's sovereignty over biological death, as well as God's presence, were a fourth means of coping with death.

One finds in the Bible opinions as to what constitutes both "good" and "bad" death. "Bad" death might include the following elements:

1. Premature death (i.e. the death of Absalom, II Sam. 18:32-33)

2. Violent death, particularly if bloodshed was involved.

3. Death leaving no heir. In spite of canonic injunctions against ancestor worship and the imposition of the concept of the impurity of corpses, heirs, especially males, were still quite important in ancient Israel.[11]

What, then, constituted "good" death? It was that death which God promised to Abraham in Genesis 15:15, to die "in a good old age." The notion is repeated in Job 5:26 "You shall come to your grave in a ripe old age, as a shock of grain comes to the threshing floor in its season."

Generally in the Bible, death at an advanced age does not give rise to questions of theodicy. "We must all die; we are like water spilt on the ground, which cannot be gathered up again." (II Samuel 14:14)

Death is sometimes a form of release in the Bible:

> Why did I not die at birth, come forth from the womb and expire? . . . For then I should have lain down and been quiet; I should have slept; then I would have been at rest . . . ."
>
> (Job 3:11-13)

Sometimes death is presented as an incentive to inquiry and spiritual growth: "So teach us to number our days that we may gain a heart of wisdom." (Psalm 90:12)

Moving from Biblical literature to the next major stage in Jewish tradition one finds that Rabbinic literature offers a rich vein to mine for developing Jewish insights into death and its attendant concerns. Of great interest to the shapers of the genre of literature was the question of the origin of death.

The basic perspective of rabbinic literature is that mortality is part and parcel of the Creator's design for humans. For example, R. Meir is quoted in Genesis Rabbah 9:5 as saying that the words in Genesis 1:31, והנה טוב מאד ("... behold, it was very good") should be interpreted to read והנה טוב מות, ("... behold, death is good").

The Tanhuma suggests that the Angel of Death was created on the first day of Creation, as an integral part of God's plan. Hence it is not the nature of man, exclusively, to die, but of _all_ life.[12] The absence of the pronouncement "it was good" during the second day of Creation led some midrashists* to suggest that the underworld for the dead was created at that point . . . further evidence for the centrality of death in God's cosmic scheme.[13]

There are other accountings in rabbinic literature for the origins of death. Some trace it to Adam and Eve's sin in the Garden of Eden. This death-as-punishment explanation (i.e. Shabbat 55a "There is no death without sin.") holds a minority status within rabbinic literature. Others maintain that death predated Adam and Eve. One finds also the belief that mortality was made part of the human experience so as to instill the fear of God.

Other sages viewed death as originating not in punishment but in the attempt to stir God's creation to serve God. Still others maintain that death was decreed to

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* scriptural exegetes

impress upon humans that they cannot be God.[14]

Once the ordained presence of death became an established fact in rabbinic literature, the sages turned their attention to causality . . . what, specifically, brings on a person's death? A number of possibilities are suggested

1. Theological cause: death is linked with sin and therefore the wicked die sooner, the righteous have extended lives. (This must have been a minority view in light of the martyrdom of so many righteous Jewish lives throughout Jewish history.)
2. "An evil (grudging) eye, the evil impulse, and hatred of one's fellow creatures" are cited as conditions which cause people to give up their lives when terminally ill and actually want to die.[15]
3. Alienation from the community, owing to personality problems, leads to loneliness and a hastened death.
4. Intrinsically dangerous situations (i.e. poor housing, adverse travelling conditions).[16]

Death is characterized in rabbinic literature, just like in the Bible, as inevitable, ubiquitous and democratic. Even Moses had to die and when the angels pleaded his case for an exemption God responded that the decree of death falls on "all men equally."[17]

Death is a significant passage for it marks the cessation of all "human" activity (i.e. spiritual and moral growth). This view is reflected in the question attributed to Rabbi Hillel:

> If I am unworthy during my lifetime, who will make me worthy after my death?"[18]

These writings stress, moreover, that death is unforeseeable and unknowable. According to Koheleth Rabbah (11:5, sec. 1) the day of one's death is one of seven things concealed from a person. The rabbis believed that knowledge of one's lifespan would hinder productive existence, encouraging a selfish and cynical attitude toward the future.[19]

> [Thus] the reality of death and the fear of it, lead man to act in positive ways, in future-oriented, life-enhancing ways--rather than succumbing to the cynicism of a Bar Kappara [who wrote above the doorway to a wedding feast to which he was inadvertently not invited: 'After all your rejoicing is death, so what is the use of rejoicing?']"[20]

In the rabbinic mind the greatest problem which death poses is that it brings to an end the sacred relationship between God and human beings which, in life, is sacralized through mitzvot. Death forecloses that intimate relationship, taking from the individual the nishmat chayyim, the breath of life, which is the distinguishing characteristic of the human being.[21]

Rabbinic literature affords rich insights into the nature of the individual's encounter with death. The circumstances of a person's demise, the where, when and how of it, were all indicative of the quality of that death. The Talmud suggests, for example, that there were 903 kinds of death created. The worst of them was death by choking and the best of them "by a kiss of God" which was likened to the gentle action of removing a hair from a saucer of milk.[22]

A person's age and mental state were also considered by the rabbis to be indicative of the quality of that person's death. The aggadists noted the varied reactions of those who faced death:

- -Absalom preferred to hang by his hair rather than face death and retribution which were spread at his feet.[23]
- -Some sages refused to die until they had been shown their place in paradise.[24]
- -Others were filled with fear and wept[25] while others greeted death with resignation.
- -The death of the righteous is met with an 'all is not lost' attitude because no righteous man dies until another is ready to take his place.[26]

There are constant references in the literature to the helplessness of the individual at birth and at death since the rabbis viewed dependence and helplessness as characterizing both terminals of life.

Interestingly, the rabbis speculated that death confers upon the individual two things never to be gained in life: the privilege of seeing the <u>Shechina</u>, the Divine Image, and having it "pass over",[27] and the knowledge of one's eternal reward.[28]

Both the time and the place of death were of significance to the rabbis. They deemed Shabbat an appropriate time to die for the day of rest symbolized the eternal rest of the soul. The end of the Day of Atonement was also an auspicious time to die since all sins are forgiven then and a person's soul would, therefore, find itself in paradise.[29]

That the place of death is equally important is illustrated in the Talmudic account of the death of R. Sheshet. The Angel of Death encountered R. Sheshet in the marketplace and required of him his life. R. Sheshet adamantly refused to comply and demanded of the Angel of Death that he accompany him home and there take away his soul.[30]

There is in this story an implicit acknowledgement of the inevitability of death; R. Sheshet protests not the decree of death but rather the degradation of dying in the marketplace, like a beast. He reacts not with fear or denial but with the demand that death respect his humanity and grant him the autonomy of choosing where and how he will die. His aggresiveness reflects the importance the rabbis attached to a dignified end to life.

Even the right to die is given consideration in rabbinic literature. In Yalkut Shimone, Mishle, 8, it is recorded that a woman came to R. Jose b. Halafta and told him that her life was no longer worth living and that she wished to die. He responded by counselling her to give up going to the synagogue--that activity which was precisely the most life-giving activity for her. Three days later she died.[31] This story implies an understanding on the part of the rabbis that there exists a need for dying to be "allowed" to let go of life, in spite of the anguish this may cause their survivors.

Halachic Considerations

Rabbinic writings present the reader with a variety of understandings of the nature of death, reflecting the diversity of the minds which shaped them. It is in halacha, however, particularly as codified in the Shulchan Aruch and refined in various responsa through the centuries, that the plethora of attitudes is reduced to guidelines and expectations.

It is imperative that one understand the sometimes confusing perspective of halachic Judaism before one can draw reasonable conclusions concerning the compatibility of hospice with Judaism. The following section will attempt to acquaint the reader with basic halachic pronouncements involving death and dying.

The first halachic concern relevant to care of the dying is the fundamental question of whether or not to tell the dying person the truth about his or her condition. J. David Bleich, an Orthodox rabbi and contemporary expositor of halacha, has much to say on this issue. Bleich maintains that while all are enjoined to tell the truth ("Distance yourself from a matter of falsehood"--Exodus 23:7), no one advocates a truthful answer to every question. A lie is warranted, Bleich asserts, if it is the price of saving a life. The Talmud teaches that "white" lies are justified if they serve to promote tranquil relationships, obviate pain, embarrassment or even mild psychic distress.[32]

The paramount obligation of the physician, says Bleich, is to do no harm to the patient and to avoid all things which have a tendency to discourage or depress the spirits of the patient. The underlying motivation behind this exercise of caution is the assertion in Jewish tradition that every moment of life is precious and sacred . . . therefore care must be taken not to foreshorten it. So one finds, for example, in the gemara to Moed Katan 26b, that a patient is not to be told of a relative's demise lest it hasten the patient's own death.

The prooftext most often cited to justify this policy of less-than-full disclosure, is the passage in II Kings 8:7-10 wherein Elisha informs the Syrian king, Ben Haddad, that the king will recover from his illness, although God has made it known otherwise to Elisha. "Following this precedent, the rabbis insisted on maintaining the patient's hopefulness not merely by withholding information of his imminent death, but by positive means to encourage confidence in his recovery."[33]

Halachically, the consideration is one of tiruf ha-da'at, i.e. acute mental anguish, which might cause or hasten death . . . a phenomenon which Bleich asserts has been empirically demonstrated. This approach of non-disclosure, or partial disclosure, contrasts markedly with church policy which encourages frankness in such matters so as to allow the dying person to do spiritual work before death.[34]

The difficulty involved in informing loved ones of the terminal nature of their illness is not explicitly addressed in halacha but it is given voice in various midrashim which suggest that even God has difficulty informing righteous individuals of their impending deaths. Midrash Tehillim 116:6 explains that the problem is so great that all of God's righteous ones asked with their own mouths to die, thereby sparing God that sorry task.

Even more poignant is the midrashic account of God asking Moses to inform his brother that Aaron will soon die. Moses resists God's importuning but ultimately relents and agrees to convey the news to Aaron. At the last moment, Aaron himself perceives his situation, sparing Moses the need to reveal the blunt truth.[35]

It is evident that halacha, explicitly and implicitly, discourages truth-telling with respect to the dying person, viewing a policy of non-disclosure as being in the best interests of the patient's health. Moreover, it underscores the deeply held belief that no one can fathom God's intentions, much less deny the possibility of miraculous recovery even in the face of the most devastating prognosis.

Some maintain that the approach of hospice, that of avoiding heroic measures and recussitative attempts for dying patients, is tantamount to euthanasia. It is important, therefore, to explore halachic conceptions of euthanasia.

The halachic approach to the dying person takes issue with the current notion that "human beings control life and death in general and their own lives in particular."[36] It is a basic tenet of Western civilization that the termination of life, outside of war, is murder . . . and generally no distinction is drawn between active and passive termination of life. The withdrawal of the support of life is considered in the same category as the killing of life.[37] Halacha adheres to this basic position.

The case against active euthanasia is forcefully stated in halacha. One cannot, in any way, hasten death . . . even for one who suffers and has no hope of cure. It is forbidden, for instance, to stop drugs or oxygen or to avoid administering treatment--even if these procedures prolong suffering. "[Thus] even if death is near and absolutely certain, the life of the patient is still of infinite and inestimable value, and shortening it in any way is no different from killing an absolutely healthy individual."[38]

Every attempt must be made to recussitate a patient and it must be continued as long as hope of success obtains. However, if the patient is merely being kept in an artficial state of life such that cessation of treatment does not bring about spontaneous breathing or heartbeat in a reasonable time, resuscitation should not continue.[39]

The fear of unnaturally foreshortening a person's life obtains to such a degree that there are halachic injunctions against moving a dying person, lest the movement bring on death. Rabbi Meir made the analogy between the dying person and a flickering lamp which may be extinguished with the slightest movement.[40]

The relevant portion in the <u>Shulcan Aruch</u> is found in Yoreh Deah 339:

> 1. One who is dying is considered a living being in all respects. We may not tie up his jaws, nor remove the pillow from under him, nor place him on sand, nor summon the town on his behalf, nor close his eyes before his soul departs. And whoever closes his eyes before death is regarded as a murderer. One may not rend garments nor make lamentation for him nor bring a coffin into the house for him before he dies.
>
> Gloss: Some say we may not dig a grave for him before he dies even though this is not done in his

> presence and he would not be aware of it. It is likewise forbidden to hasten the death of a dying man--e.g. if one has been moribund for a long time and continues to linger on, we may not remove the pillow or matress from under him or do anything overt to hasten his death. However, if there is anything external that prevents his release from his death pangs, such as a clattering noise near the patient's house, or if there is salt on his tongue, and these hinder the departure of the soul, it is permitted to remove them, for this is no direct act but only removal of a hindrance.

The dominant halachic view is that life without suffering is, in many cases, preferable to eliminating suffering by hastening death. Active euthanasia, therefore, cannot be condoned. Joseph Caro's gloss to Yoreh Deah 336:1 reads, "The Torah has granted the physician permission to heal, and, it is a religious duty. If he witholds treatment he is 'as one who sheds blood'". R. Eliezer Waldenberg states that everything possible must be done to save the patient's life, "even if the patient himself cries, 'let me be and do not give me any aid because for me death is preferable.'"[41]

Regardless of the fact that the motivations of one who terminates a life may spring from compassion and love, the Torah brands euthanasia as murder, pure and simple[42]. In the view of <u>halacha</u>, one's human perception and conclusion that continued existence is meaningless in the face of great suffering simply cannot be set against God's eternal law of life and death.

Fortunately, rabbinic literature has preserved its minority opinions, allowing for varied halachic interpretations. In the Talmud one finds the account of the death of

Judah ha-Nasi.[43] As Judah lay dying his disciples occupied themselves in fervent prayer for his recovery and in so doing, prevented the dying man's soul from departing. Judah's maidservant, witnessing the torment of her master, climbed to the roof and hurled to the courtyard below an earthen vessel. The noise of the shattering vessel disrupted the prayers of the assembled disciples and in that momentary space, when their prayers ceased for an instant, Judah ha-Nasi's soul left him.

Rabbenu Nissim of Gerondi referred to this tale in his comments on Neddarim 40a and stated that it is permissible, and even praiseworthy, to pray for the death of someone who is gravely ill and in extreme pain. He chides those who are remiss in fulfilling their obligation to visit the sick, saying of such an individual, ". . . not only does he not aid [the patient] in living but even when [the patient] would [derive] benefit from death, even that small benefit [i.e. prayer for the patient's demise] he does not bestow upon him."[44]

R. Chaim Palaggi accepts the view of R. Nissim but adds a caveat: only totally disinterested parties may take even as innocuous a step as prayer to bring about a premature end to life, since emotional involvement and subjective interest will influence those close to the patient.[45]

It is a forceful minority opinion favoring the right of the dying person to be allowed to die, and even assisted in doing so with prayer, but as Bleich points out, prayer is one thing and action quite another. The ultimate decision, from the halachic perspective, must remain God's.

Nonetheless, the question of passive euthanasia, the removal of impediments to death, remains at the heart of a very "gray" area in halacha. R. Judah b. Samuel, the Pious states, ". . . if a person is dying and someone near his house is chopping wood so that the soul cannot depart, then one should remove the [wood] chopper from there . . . ."[46] Some proponents of the right-to-die suggest that the concept of removal of impediments to death sanctions the cessation of intravenous feedings or the removal of oxygen tubes for the comatose, terminally ill patient, viewing the presence of those devices as impediments to the soul's departure.

The difficulty inherent in understanding the halachic approach to the issue of the dying person is further compounded by the halachic concept of the goses, or moribund person. The term originates in a discussion over Yoreh Deah 339:2 which deals with the question of when relatives who live a great distance from the dying person may begin mourning if they will not arrive before the time of death. The rabbis decreed that mourning begins 72 hours after the patient has been declared a goses, the clear assumption being that the patient will not survive longer than 72 hours.

Halachically, a person is labelled a goses when death is thought to be imminent. Rabbinic sources say the patient then brings up a secretion in the throat due to the narrowing of the chest.[47] Even in the state of g'sisut the person is still treated as a living person in all respects and one is forbidden to do anything which might hasten death.[48]

Bleich points out that when a person is declared a *goses* this is the one and only time when treatment may be withheld in order to allow for an unimpeded death. While the death of a *goses* may not be *hastened*, there is no longer an obligation to prolong the life of the patient in this state. As Bleich phrases it, "When a patient is, as it were, actually in the clutches of the angel of death and the death process has actually begun, there is no obligation to heal."[49]

While the presence of the secretion in the throat, alluded to above, is a necessary condition of *g'sisut*, it is not an exhaustive criterion. The onset of death is the necessary condition of *g'sisut*. However, and herein lie implications with respect to hospice care, the halachic provisions governing the care of a *goses* may not be applied to all who are terminally ill.[50]

If a person may be assumed to survive 72 hours, he or she is by definition *not* a *goses*. The *halacha* assumes axiomatically that the death process cannot last longer than 72 hours since Yoreh Deah 339:2 enjoins one to begin mourning a *goses* after that amount of time has elapsed. Bleich states the bottom line: if it is medically feasible to prolong life, the person is not a *goses* and therefore the obligation remains to preserve life as long as possible.[51]

Paradoxically, the concept of g'sisut recognizes that there comes a time when treatment and extraordinary measures are inappropriate and a person should be allowed to die . . . values which are very much in keeping with the hospice philosophy. Yet halachically, this period of grace is limited to 72 hours and one can never, with absolute certainty, state that a patient will not survive those three days.

Fred Rosner, in his book Jewish Bioethics, offers a concise summary of the Jewish attitude toward euthanasia:

> The sum total of [this] discussion of the Jewish attitude towards euthanasia seems to indicate, as expressed by Jakobovits that '. . . any form of active euthanasia is strictly prohibited and condemned as plain murder . . . anyone who kills a dying person is liable to the death penalty as a common murderer. At the same time, 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.' Jakobovits is quick to point out, however, that all the Jewish sources refer to an individual in whom death is expected to be imminent, three days or less in rabbinic references. Thus, passive euthanasia in a patient who may yet live for weeks or months may not necessarily be condoned.[52]

What does Jewish tradition teach about how to prepare for death? Significantly, there are relatively few halachot which are concerned directly with preparation for death . . . reflecting, perhaps, Judaism's "this worldly" nature. The tradition, where it does express itself on this issue, urges caution that such preparations not aggravate the patient's condition or compromise the will to live. Ordering one's temporal affairs is as important as one's reconciliation with God. This reconciliation is formalized in the deathbed confession, the vidui.[53] The vidui is explicated in the Shulchan Aruch, Yoreh Deah 338:

> When death draws near he is advised to confess. And we reassure him: "Many have confessed and then not died just as many have not confessed and then died." If he is unable to confess aloud let him confess in his heart. If he does not know what to say we instruct him to say: "May death be an expiation for all my sins." This is not done in the presence of women and children lest they cry and break his heart.

The deathbed confession must be viewed as a ceremony of passage, bearing in mind that confessions are also recited on Yom Kippur and on the wedding day by both bride and groom. As such, the vidui marks the end of one cycle and the beginning of another.[54]

Jewish tradition calls upon the dying person to settle all wordly affairs and confess before God. There is yet another tradition, which is not mandated by halacha, but which has a long history behind it--that of the ethical will.

Ideally, the ethical will, which serves as a spiritual legacy for one's heirs, is composed well in advance of death. When this has not happened the dying person may be encouraged to give thought to those values and principles he or she may wish to pass on to survivors. Sometimes this will take place near the time of death, as expressed in this account of the death of a Hassidic master:

> When the hour came for Rabbi Elimelekh to depart from the world, he placed his hands upon the foreheads of his four disciples and gave each of them a portion of his soul. To the Seer of Lublin, he gave the light of his eyes. To the Maggid of Koshnitz, he gave his heart. To Rabbi Mendel of Prustik ,he gave his mind. To the Rabbi of Apt, he gave the power of his tongue. He died on the

twenty-first of Adar, 1786.[55]

Having defined the dying person and counselled preparation for death, the halacha then turns its attention to establishing the criteria and time of death. This is today an area greatly complicated by advances in technology which allow for physiologic states of existence which were unimaginable to the shapers of the halacha . . . i.e. comas in which life is maintained with heart/lung machines. As Bleich points out, "Whether a human organism in any physiological state is to be treated as a living person or a corpse is an ethical, religious question and not a medical one. Accordingly, advances in medical science and technology have no effect upon Jewish teaching with regard to the establishment of the time of death."[56]

Jewish tradition long held that death may be assumed to coincide with the spontaneous cessation of breathing.[57]* Rashi, in the gemara to this passage, says, "At times life is not evident at the heart but is evident at the nose."[58] Hence Jewish law insists on examination of the nostrils, traditionally with a feather or mirror, for signs of respiration. However, if respiration ceases and the heart still functions, the person is alive. Thus later authorities ruled that the patien may not be declared dead unless, in addition to the total absence of respiration, the patient

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* The close connection between respiration and life is traced to specific Biblical passages, notably Gen. 7:22 and Gen. 2:6.

also "lies as an inanimate stone <u>and</u> there is no pulse whatsoever."[59]

Rosner complicates the definition of death somewhat by suggesting that death is a process which <u>begins</u> when spontaneous respiration ceases. When other functions continue, however, such as electrical activity in the brain, the person is no longer completely alive nor completely dead: death has begun but the death process is not complete until both the heart and the brain completely cease functioning. A person in this state is not fully alive and not fully dead and someone who hastens the death of such a person is guilty of murder in the eyes of <u>halacha</u>.[60]

Bleich asserts that only <u>irreversible</u> cessation of respiratory and cardiac activity constitutes death; and "brain" death, the cessation of electrical activity in the brain, is not a halachically acceptable criterion of death.[61] This assertion clearly demands that recussitative efforts be attempted when heart and respiratory activities cease in the non-<u>goses</u> patient . . . a policy greatly at odds with hospice philosophy and practice.

Once death has been ascertained, care of the body is governed by paramount concern that respect be given to what was, just moments before, a living being. The corpse is likened in the tradition to a damaged Torah scroll, which may no longer be used for ritual purposes but which is still reverenced for the holiness inherent to it.

The tradition has created guidelines for behavior once death has occurred:

1. During the final minutes of life no one in the presence of the deceased may leave, except for those who are physically ill or unable to control their emotions. It is a matter of respect to watch over the passage from this world to the next.
2. After death is ascertained, the eyes and mouth of the deceased are closed and a sheet drawn over the face.
3. Depending on local custom, rending of clothes and recitation of the blessing "The True Judge" may or may not be observed.
4. The deceased should be placed with feet facing the doorway but otherwise the corpse should not be moved.
5. A lit candle is placed near the head of the deceased.
6. Some traditions have relatives and mourners ask forgiveness of the deceased at this time.
7. Mirrors in the house are covered.
8. Psalms 23 and 91 are recited.
9. No eating, drinking, smoking or disrespectful behavior is to take place in the room with the deceased. No disparaging remarks about the deceased are to be spoken.
10. From the moment of death until burial, the deceased is not to be left alone.
11. Tradition calls for <u>taharah</u>, ritual cleansing of the body before burial.
12. All services rendered the body are to be performed, if possible, by Jews.[62]

Even beyond the moment of death, Jewish tradition is explicit in its guidance. While issues such as autopsy and burial do not impact directly on hospice care, they are nonetheless integral parts of the death and mourning process. An examination of the Jewish approach to these areas will shed more light on the issue of compatibility of Jewish tradition and the hospice concept.

The fundamental objection to autopsy in Jewish law rests upon the concept of the inviolability of the body based on Deuteronomy 21:22-23 which states that a criminal put to death shall not hang all night on a tree (a biblical sign of contempt) but should be buried.

Halachic authorities are nearly unanimous in prohibiting the performance of an autopsy on a Jew for the purpose of studying medicine. The reasons given include: desecration of the dead, the prohibition against deriving any benefit from the dead, the prohibition against delaying burial and of not burying the body or parts thereof.

Autopsy is permitted where it may clearly help save the lives of other known patients or in the case of a fatal familial illness where other family members may be helped. All parts removed from the body during the course of the autopsy must be buried together with the body itself.[63]

Dissection or organ transplants are permissible only in the case of choleh lifaneinu, literally "a sick one before us" . . . i.e. a clear and present danger. Hence Jewish law does not permit the storage of human organs in organ banks.[64]

With respect to burial, Jewish tradition prescribes in great detail the necessary steps. The overriding concern is that of rendering the respect and honor due the dead. So great is the mitzvah of accompanying the dead to their final resting place that even a priest who suffers ritual contamination by burying the corpse of an unknown pauper is considered to have earned eternal reward for his action.[65]

Even more explicit in its message is the midrash which relates that while the Israelites gathered gold and silver from their Egyptian neighbors prior to the Exodus, Moses was searching out Joseph's bones, in order to re-inter them in the land of Israel. As his reward for so selfless a deed, Moses is buried by none other than God.[66]

Burial of the dead is considered by the tradition to be the greatest of <u>mitzvot</u>, for the one who performs the burial expects no recompense in this world. It is a selfless act which symbolically states that the tragedy of death may be overcome through such affirming acts of kindness . . . acts which aid and comfort the bereaved and so become life-giving.

Equally strong in the tradition is the call for burials which do not exceed appropriate costs. The Talmud states that prior to the example set by Rabban Gamliel, who left orders that he be buried in simple linen shrouds, those for whom the expense of a burial was too burdensome would simply leave the corpse somewhere and flee.[67]

The final significant element which the tradition mandates is that burial take place as quickly as possible, preferrably the next day, except where Shabbat or holy days intervene. This haste is dictated by scripture (Deut. 21:

22-23) and reinforced by the insights of modern psychology which suggests that the mourning process and full recovery from grief cannot begin until the dead are removed from the presence of the mourners*

Beyond burial lies mourning. Jewish tradition recognizes, as do hospice psychologists, that the process of mourning often begins in <u>advance</u> of death. Consider the <u>midrash</u> which suggests that God began mourning the destruction of the Earth seven days <u>before</u> the Flood.[68] This suggests the very real and very human preparations which those who are about to lose someone undertake . . . breaking bonds, saying farewells, letting go.

Elsewhere in rabbinic literature is found the belief that God mourns just as people do. In fact, God even inquires of the angels precisely how humans mourn and having learned, God pledges to do likewise.[69] This is a conception of God which sees God as a participant in the affairs of humans.

> God is deeply affected by Man's suffering. He mourns the dead just as the bereaved do, imitating man in performing those acts which symbolize mourning. The image of the mourning God conveys to man the message that his life and death do not go unnoticed. God is present even at the moment of greatest sorrow . . . even at that moment when man would sooner curse God than praise Him. God is present and takes his place among the mourners.[70]

For the Jewish mourner, contact with death brings with it an awareness of ultimates . . . the end of life, the

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* For a fuller treatment of Jewish burial traditions the reader is urged to consult Lamm's <u>The Jewish Way in Death and Mourning</u>.

frailty of human beings, the omnipresence of God. The mourner must return to life, and contact with the sacred, only by degrees prescribed by the mourning ritual.[71] The mourner moves from the realm of spiritual impurity back to the land of the living in a series of regulated and ritualized steps.

The traditional rites the mourner undertakes--foregoing shaving and cutting of the hair, sitting on low stools, rending garments--represent non-living, the subjugation of the preoccupation with the self which characterizes so much of life. The mourner does not work during the initial seven day mourning period for work is that which sustains life and thereby joins the individual to the community of the living.

Slowly the mourner reintegrates into the community within the framework of a mourning ritual which passes from seven days to thirty to eleven months of mourning activities which become less restrictive with the passage of time.

The tradition clearly views mourning as the appropriate response to bereavement. But it also recognizes that there can be such a thing as excessive mourning. The <u>Shulchan</u> <u>Aruch</u> states:

> One should not grieve too much for the dead, and whoever grieves excessively is really grieving for someone else. The Torah has set limits for every stage of grief and we may not add to them: three days of weeping, seven for lamenting, and thirty for abstaining from laundered garments and from cutting the hair . . . and no more.[72]

The rabbis concluded that grief and mourning should have their limits, that too much is destructive. While not to mourn is impossible, the Talmud warns that too much mourning is also impossible because it would work a hardship on the community.[73]*

For the person facing death and, in many instances, for that person's survivors, the question of life after death may hold tremendous significance. While Judaism as a whole has placed far greater emphasis on the nature of this world and human actions therein, and while liberal Judaism has downplayed or sidestepped the question of life beyond death, there are clear statements within Jewish tradition attesting to an afterlife. Insofar as a presentation of these beliefs may provide comfort for dying Jews, it will be instructive to touch upon them here.

Some biblical scholars maintain that the concept of the afterlife arises from the desire of the ancient covenant community to maintain that covenantal relationship with God into eternity.[74] The Book of Ecclesiastes comes closest of all the biblical writings to presenting mortality as a problem to which others propose an afterlife as a solution. "Wisdom", so highly regarded by the author of Ecclesiastes, prevents only metaphoric, not biologic death. Comfort from the harsh reality of death is to be found only in the present moment; "There is nothing better for a man than that he should eat and drink and find enjoyment in his toil."

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* This assertion is made with respect to mourning the destruction of the Temple but its ramifications for those mourning their dead are obviously parallel.

(Ecclesiastes 2:24a)

By the time the Mishnah is codified, around the early third century of the Common Era, belief in the afterlife is already fundamental to Judaism. The Mishnah states, in Sanhedrin 10:1, that anyone who claims that resurrection of the dead is without biblical warrant is excluded from the reward of the olam ha-ba, the "world to come."[75] Maimonides includes belief in corporeal resurrection as one of his thirteen fundamental principles of faith.

Although many Jews in contemporary society have no clearly-formed or deeply-held beliefs in life beyond death, it is probably safe to say that all speculate about the possibility . . . particularly when they or their loved ones face death. How curious it is that this preoccupation with the status of the soul beyond death is not counterbalanced by a curiosity about the soul before birth. Reflecting on the tendency of many to reject outright the concept of an afterlife, Abraham Joshua Heschel wrote, "A soul does not grow out of nothing. Does it, then, perish and dissolve in nothing?"[76]

In recent years, owing largely to advances in the field of medical technology which have allowed for the recussitation of individuals whose heart and respiration had stopped, there has been a growing body of anecdotal material describing what is now called "life after life" experiences. A number of phenomena are reported to characterize these experiences and are corroborated by many of the individuals who were clinically "dead" and then restored to life. These include:

1. Ineffability of the experience
2. Hearing news of one's own demise
3. Feelings of peace and quiet
4. Auditory sensations, both pleasant and unpleasant
5. Feelings of passing through a dark tunnel
6. Out-of-body sensations
7. Meeting others
8. Meeting the "Being of Light"
9. Review of one's life
10. Coming back
11. Telling others of the experience
12. Great effect on lives afterwards
13. New views of death[77]

In a fascinating and suggestive article, David S. Shapiro compared these phenomena with at-death phenomena described in traditional Jewish literature. A few examples will suffice to demonstrate that herein lies a valuable tool to communicate to the dying Jew the notion that 1) belief in the afterlife is not incompatible with Jewish tradition and 2) that traditional Jewish beliefs are, in some measure, validated by the evidence Moody and others have amassed on "life after life."

Example: Moody reports auditory sensations at death, both pleasant and unpleasant.

Yoma 20a states that the noise of the soul leaving the body reverberates throughout the world.

Example: Moody reports out-of-body sensations.

In Shabbat 153a Rav tells R. Samuel bar Shilat that he (Rav) will be standing listening to Samuel's eulogy.

Berachot 19a and Shabbat 152b suggest that the dead hear conversations held in their presence.

Example: Moody reports a radiant light, sometimes perceived as "divine" light.

> Psalm 97:11 "Light is sown for the righteous."
>
> The Sifra to Leviticus 1:1 states, "While man cannot see the glory of God during his lifetime, he can see it at the time of death."[78]

This section has attempted to familiarize the reader with basic attitudes towards death, and its attendant behaviors and rituals, as expressed in Jewish tradition. It is meant to serve as a refracting lens through which the hospice concept, elucidated in earlier chapters, may be evaluated from a Jewish perspective.

It should already be clear to the reader that much of what Judaism has to say about appropriate care for the sick and dying is fully in accord with the motivating principles of hospice care. There are, however, possible points of contention which need to be explored--in particular, the "gray" area of Judaism's view of passive euthanasia. Can the mandate to heal-at-all-costs, as expressed in Jewish tradition, ever yield to the needs of the individual when "healing" is no longer a possibility? Is "not acting", by rejecting heroic measures for a terminally ill patient, the same as "acting" and therefore deemed the equivalent of murder in Jewish tradition?

These are the sorts of questions which the next section addresses in trying to propose a hospice concept informed by Jewish values and traditions.

The reader has seen that hospice is concerned with the quality, and not the quantity, of time left to a dying person. Its philosophy is succinctly captured by Edmund Pellegrino:

> The act of dying must be both human and humane. To be human it must be understood, consciously assimilated and given a personal quality and shape by the dying person himself. To be humane, all who assist, aid and collaborate in the act must provide what is necessary to make the last act a truly human one--to relieve pain, listen, provide those things which have meaning for the dying person, and permit him or her to make the major decisions on how, when and under what conditions to die.[79]

This hospice philosophy of care which is both "human and humane" reflects values shared by peoples of many faiths and cultural orientations. It has been the author's intent to focus on a specific faith/culture, that of Judaism, to ascertain the degree to which Judaism's view of the death process is compatible with that of hospice.

Basically, Jewish tradition maintains that every moment of life is sacred and it therefore follows that it is a violation of God's will to foreshorten it in any way. Judaism mandates that every possible attempt be made to heal the sick person, disregarding the possibility that in so doing one might violate God's wishes for that person. But hospice deals with patients for whom "healing", in the normative medical sense of the word, is no longer possible. "Cure". in the sense of recovery to full vitality, is no longer relevant.

Here Judaism operates in a vaguely defined way. Some maintain that the halachic mandate is to <u>heal</u>, not to sustain life that cannot be healed.[80] And, as Dr. Cicely Saunders points out, "Healing a person does not always mean curing a disease. Sometimes healing means learning to care for others, finding new wholeness as a family--being reconciled. Or it can mean easing the pain of dying or allowing someone to die when the time comes.[81]

Others approach the reluctance of Jewish tradition to allow a dying person to slip into death without attempting rescussitation, by reworking traditional halachic concepts. Rabbi Solomon Freehof, for example, redefines the concept of the goses, arguing that this state of moribundity be extended from 72 hours, to twelve months prior to death.[82]

Precisely because the question of what to do for the dying person elicits such varied responses in Jewish tradition, it becomes clear that there can be no fundamental objection to hospice from the Jewish perspective. The most troublesome area, potentially, is that of Judaism's view of passive euthanasia. Even here, however, Jewish law and its interpreters are not of one opinion as to which actions foreshorten life and which actions merely allow for unimpeded death.

Contemporary Judaism in North America takes many forms . . . from halachic to a-halachic. Jews will ultimately make their own choices, with the guidance, hopefully, of the tradition or an interpreter of halacha. Those who lead their lives within a halachic framework should seek counsel with a rabbi before choosing hospice for themselves or their loved ones. Other Jews may opt for hospice with the assurance that Jewish tradition stands firmly behind the respect for the totality of a human being which hospice represents.

Thus the basic question of the compatibility of Jewish tradition with the hospice concept is resolved. But there is more involved, however, than merely acknowledging that Judaism finds hospice acceptable. There remains the larger question, one of great significance to Jews, of how Judaism can inform hospice . . . what specifically does Judaism teach and affirm which might increase the effectiveness of hospice in general and allow for the possibility of a specifically "Jewish" hospice?

There are a number of areas in which Jewish tradition speaks directly to issues which hospice confronts. The very basic concept of visiting the sick and being available to them is known in Judaism as <u>bikkur</u> <u>cholim</u> and it is seen not merely as an unpleasant task, but as a religious obligation. The imperative to visit the sick is codified in the <u>Shulchan</u> <u>Aruch</u> in this way:

> 1. It is a religious duty to visit the sick. Relatives and close friends enter the sickroom at once, others after three days. If the illness is serious, both groups may enter at once.
> 2. Even a distinguished person visits a humble one.
> 3. One who visits the sick should not sit upon the bed, chair or stool, but rather in front of the patient, for the Divine Presence rests above a sick person. (Gloss: this applies only to a patient who lies upon the ground.
> 4. Do not visit the sick during the first three hours of the day and the last three hours. In the morning the patient is stronger and therefore the visitor will not pray for his welfare; in the evening the patient is weaker and the visitor will think it is useless to pray.
>
> 7. A sick person should be advised to look over his

> affairs. He should be assured that this is only a precaution and it does not mean he is about to die.
> 8. One should not visit those for whom a visit will cause discomfort or embarrassment. If the patient is so ill that conversation is a strain, he should not be visited, but instead, one should stand in the antechamber and inquire about him and offer whatever household or nursing help he may need, and sympathize with him and pray for him.[83]

So highly regarded is the act of bikkur cholim that near-miraculous powers are attributed to its performance. One Talmudic passage states the belief that one who visits a sick person removes 1/60 of the patient's illness. One might think, therefore, that a steady stream of sixty visitors would completely cure the person but the statement goes on to say that each visitor removes 1/60 of the illness which remained after the previous visitor's departure. And even to accomplish this much, the sages add, the visitor must love the patient as much as him or herself.[84]

A Hassidic tale reinforces the belief in the efficacy of visiting the sick and tending to their physical and spiritual needs:

> 'Yid' heard that his friend, the preacher of Kozenitz, lay incurably ill. The 'Yid' sent two of his disciples to sing for the preacher. They arrived on Friday and sang the Shabbat hymns. With each song, the dying man, who told his friends he had no desire to live, felt in himself a force strongly re-awakening. He exclaimed, 'Blessed be my friend the 'Yid'--he knew I've walked in all spheres of life except music and sent his singers to remind me I've still a task in my earthly life: to explore the realm of music.'[85]

These aggadic and folkloristic examples underscore the significant place bikkur cholim occupies in the realm of ethical Jewish behavior. It legitimates, from the core of Jewish tradition, the fundamental practice inherent in hospice care . . . giving of oneself to the dying person.

Judaism also teaches that there is no virtue to be found in suffering. In fact, one may even violate halacha in order to alleviate the suffering of a sick person.* Pain, from the perspective of Jewish tradition, represents not an uplifting spiritual test, but rather the degradation of the human spirit. Job, whose suffering almost destroyed his faith, remains a potent symbol of this viewpoint. Hence Jewish tradition is in full accord with the hospice approach to managing pain and alleviating suffering of all kinds.

The literature on hospice conveys the ideals for which hospice strives--death in the setting of the home, with family and loved ones nearby. It does not address sufficiently, in the opinion of this writer, to the need for death preparation which is essential to promote the gentle death which hospice espouses. This is an instance where the concerns of Jewish tradition may provide guidance in the hospice setting. Jewish tradition enumerates the steps the dying person should take in order to prepare for death. These include the ordering of worldly affairs, confession before God, reconciliation with family and friends and, if possible, the drafting of an ethical will to serve as a spiritual legacy for the survivors.

Clearly, not every Jew, much less every hospice patient, will be desirous of fulfilling these steps. None-

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* If, for instance, the Shabbat lights will disturb a patient's rest, they need not be lit. (Orech Hayyim 273:7)

theless they represent pieces of the death process which may serve to minimize the trauma of death for both the dying person and those whom death leaves behind.

For the dying person struggling to fashion a means of coping with death, Jewish tradition offers numerous paradigms for ways to confront death. Here midrash, scriptural exegesis, stands out as a valuable aid to the dying person. For example, Elizabeth Kubler-Ross is noted for her "stages" theory of the death process, positing that every person moves through a series of stages as death approaches, including denial, anger, bargaining, resignation and acceptance. While many question the sequence, or even the applicability of the concept for all people, Jewish tradition, through midrash, substantiates Kubbler-Ross's basic contention. In the collection of midrash on the Book of Deuteronomy, one finds the account of the death of Moses. Commenting on this midrash Rabbi Sol Goodman writes:

> At different times in the dialogue with God Moses refused to take his death seriously. At another point he begged for an annulment of the decree. He railed against God that it was not fair that this should be his reward, and later attempted to bargain with God for extra life, if only as a bird or animal. When he realized that nothing could save him from death, he accepted his fate. However, he refused to allow the Angel of Death to take his soul. God had to do it, symbolically indicating that he had not vanquished Moses.[86]

The sensitive rabbi or teacher will see this midrash as a perfect tool to initiate counselling with a dying person who might otherwise be too uncomfortable verbalizing feelings about incipient death. It is a perfect example of Jewish tradition plugging into a hospice context and thereby enriching it.

Other midrashim address other issues: informing the dying person (God uses Moses to tell Aaron, see page 73), the right-to-die (Judah ha-Nasi's maidservant, see page 75), the right to choose the circumstances of one's death (R. Sheshet's marketplace confrontation with the Angel of Death, see page 69), grief and relief (Aaron expresses relief that his sons died and were therefore spared leprosy . . .),[87] meaning in death (Beruriah's viewing her dead children as pledges redeemed by God).[88]

Even the question of the nature of the life worth living is placed under midrashic scrutiny:

> The aggadists were aware that death did not mean just the cessation of bodily function. They knew that existence could only be called life when it was enhanced by 'blessing'--life-affirming activities. Otherwise, it could not be considered life at all, and one in such circumstances could only consider himself--and be considered--dead. The same idea is expressed in the Aboth de Rabbi Nathan (ch. 25) where included among those whose life is 'no life at all--is one who is dependent for his sustenance upon another, and one whose body is racked by suffering.'[89]

Rabbis and students of Jewish literature should be able to mine both traditional and contemporary sources for relevant passages. The challenge then becomes to use the materials to meet the needs of the dying person. The rabbi may be in the unique position of serving as the vehicle of expression for the dying Jewish patient and may help legitimate the emotions expressed by relating them to the tradition at large.[90]

Significantly, appeal to the tradition may facilitate decision-making for the dying person, or the family, by suggesting an authority more substantive than their own logic which, understandably, may be impaired by emotion. Thus, for example, midrashim stressing the notion that there is an appropriate time to die may very well "permit" family members to let go of their loved one and allow that person to die.

Most hospices are extremely sensitive to the needs of family and friends in the time just after the patient dies. Time and space are given for the mourners to remain with the body and work through their initial reactions.

Jewish tradition calls for certain at-death rituals which emphasize the respect due God's creation which has just passed from one state of being to another. So, for example, halacha dictates that the body is never to be left alone until it is interred. It might possibly be a source of comfort to a mourner to know that someone remained with the deceased at all times up until burial.

The recitation by the survivors, at the moment of death, of the blessing praising God as the "True Judge" is another tradition which, for some, will help put death in a proper perspective.

Speaking of the mourning process, Glen Davidson cites research done by Parkes and Bowlby which sets forth four stages of healthy mourning: 1) numbness 2) yearning for the deceased person 3) disorganization and 4) reorganization.[91] Jewish tradition speaks most eloquently on the subject of mourning, and its rituals give shape to a time-tested grief-therapy. Each of the phases Davidson lists is addressed by some aspect of the Jewish mourning ritual.

The numbness is dealt with graphically when mourners are encouraged to throw dirt onto the lowered casket. The ugly finality of that sound is very often enough to bring about an end to the numbness, to the sense of unreality which many mourners feel, precipitating a stage of intense yearning for the deceased.

This, too, is reflected in the tradition which states that grief reaches its peak three days after the death of the loved one since the soul of the departed is believed to hover over the grave for that length of time, hoping to be restored to the body.[92]

Disorganization and despair are addressed in the tradition by surrounding the mourner with a supportive community. Normal obligations, such as prayer, are not incumbent upon the mourner until the period of disorganization wanes. Reorganization follows as the mourning ritual moves the mourner back from the realm of the dead and inactivity, and into the world of life and activity.

The Jewish approach to bereavement can only complement the bereavement follow-up which is an integral part of hospice work.

It is highly unlikely, given the variegated nature of the North American Jewish community today, that there will emerge a need for an exclusively Jewish hospice. There are, however, many major metropolitan areas with sizeable Jewish populations which do have hospices. To the extent that these hospices are sensitized to the potential needs of their Jewish patients as they face death, and to the degree to which the respective Jewish communities accept the responsibility and the challenge of using Jewish tradition to help Jews in their dying, then the caring and reverence for life which lie at the very core of both Judaism and hospice will be actualized for the benefit of all.

CHAPTER V

MODEL CURRICULA

What we call the beginning is often the end
And to make an end is to make a beginning.
T.S. Elliot

Preceeding chapters have presented the reader with information necessary to answer certain questions: what is hospice? How did it begin? What is its philosophy? How does it work? How does Jewish tradition regard the sick and dying person? How does Judaism view hospice? Are the two compatible?

To conclude that Judaism and hospice <u>are</u> compatible and that, indeed, Judaism can inform hospice philosophy and practice in valuable ways, is to make an end of this work. With poet T.S. Elliot's quote in mind, however, it is necessary that this "end" be transformed into a potential "beginning" by means of model educational curricula which shape information about hospice and Judaism into tools for making informed choices about death and dying within a Jewish framework.

Clearly, the subject of death and dying, and the role of hospice in it, is of potential interest for every

Jew, regardless of age, because no one is immune to the impact of death. Admittedly, not all will have cause to consider hospice care--some because they are still too young and healthy, others because death will come suddenly and unexpectedly or it will arrive gently, in old age, sparing the individual the trial of a protracted terminal illness. But for so many people the spectre of confronting their own terminal illness, or that of someone close to them, looms uncomfortably large.

It was Pascal who quipped, "Since men could not do away with death, they decided not to think about it."[1] One recognizes a certain amount of bitter truth in Pascal's observation reflected in contemporary societal concerns . . . the pursuit of perpetual youth and the "body beautiful", the on-going love-affair with material culture. Death is perceived and shrugged off as what happens on television, or to the next person, rather than as a fundamental condition of existence. And so the dying are quietly shunted aside into "convalescent" homes, or riddled with intravenous tubes in hospitals where death represents the ultimate failure.

And yet, in spite of the colossal amount of energy this society expends on ignoring the reality of death, a concept as significant as hospice has taken root and flourished in a relatively short time span. This augurs well for the possibility that many individuals are desirous of hearing the message hospice speaks: the act of dying need not be a painful, lonely experience.

Since this work examines hospice from a Jewish perspective, it is natural that the model curricula which follow are addressed primarily to a Jewish audience. What is the nature of this target audience? Clearly, education about Judaism and hospice could be targeted for virtually any age group, for the fundamental issues of life, death and compassion transcend concerns of age. For the sake of these models, however, a specific group was targeted in two of the three curricula: adults above the age of thirty-five.

It is more than likely that any individual approaching middle-aged will have already faced, or may expect to face in the not-too-distant future, 1) the death of a parent 2) the death of a contemporary 3) the possibility of his or her own death. These factors may make the midde age person more acutely aware than a younger person of the need to fashion a personal perspective on death and dying, informed by the voice of Jewish tradition as well as that of society at large.

What is the intended scope of these curricula? Specific areas which will be addressed within the curricula include:

-Death and dying in the secular world (including an examination of current health-care models)

-Death and dying within Jewish tradition.

-The hospice concept: origins, philosophy, practice, advantages, limitations.

-A Jewish perspective on hospice:
  1. how hospice fits into Jewish tradition
  2. ways in which Judaism can inform hospice

What can the learner experiencing these curricula hope to gain or accomplish? The learner will:

- gain an understanding of the ways in which Judaism approaches death and dying and the degree to which these approaches are in consonance with contemporary secular society.
- gain an understanding of the hospice concept . . . its history, philosophy and limitations
- be able to make an informed choice concerning hospice if, and when, necessary. The learner will recognize that utilization of the services hospice provides is congruent with Jewish tradition
- understand that Jewish tradition has significant contributions to make to the hospice concept.

It is important that the philosophy of education which gives shape to these curricula be articulated at this point. In the field of death and dying there are no experts; there _are_ experienced voices and sources of information toward which the learner may turn in hopes of assembling discrete pieces of the larger picture. It should be clearly understood by both the curricula implementers and the learners that the educational process is a shared one.

The adult learner is best served by being presented with information which will be processed and assimilated within the context of that particular individual's own experiences and needs of the moment.

The "teacher" of the material is by no means to be perceived as the final arbiter, the decider of the "rightness" of any given approach to death and dying. Rather, the "teacher" is best perceived as the conduit through which information is channeled to the learner and as a codialoguer in the exchange of ideas and feelings which lies at the core of these curricula.

The "teacher" should try to tap that reservoir of experience which characterizes the adult learner and must stand ready to help the learner translate that experience into resources for learning. Here techniques such as role-playing or case-work may prove particularly valuable.

Moreover, the "teacher" can help the learner articulate his or her "need to know" about death and dying. Their "readiness to learn" is already manifest by their participation in the group but many may approach the subject of death and dying not yet fully aware of that "need to know" more about the subject.*

Essentially, the curriculum experience is to be a guided dialogue in which personal expression of thoughts and feelings generated through exposure to the material covered is as integral a part of the curriculum as any other. This goal may be best achieved through a structured sharing of thoughts and feelings which will be articulated in the curricula designs which follow.

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* The reader is encouraged to read Malcolm Knowles' comparison of pedagogy and andragogy in <u>Faith Development in the Adult Life Cycle</u> (Kenneth Stokes, ed., N.Y.: W.H. Sadier, 1982)

Regardless of the subject and the enthusiasm it inspires, it is highly unlikely that any given topic will attract all the potential learners to a given educational program. The nature of current Jewish education, for both adults and younger learners, is such that it is but one of many spheres competing for the time and attention of contemporary Jews.

It is for this reason that this section presents three model curricula for teaching about Judaism's view of death, dying and hospice within a Jewish context. An adult learner may well be inclined to attend an all-day conference but not a weekend retreat; some may be interested in a more in-depth exposure to the subject matter, such as a retreat might provide. Precisely because the needs of the adult learner vary from individual to individual, several curricular modalities should be utilized to address those needs.

Ideally, the adult learner will experience many curricular modalities in order to fully comprehend all of the ramifications of the subject. Insofar as reality frequently draws up short of the ideal, each curriculum model, in and of itself, must address the following goals. The learner will:

1. gain an understanding of the ways in which Judaism approaches death and dying and the degree to which these approaches are in consonance with the approaches of contemporary society.

2. gain an appreciation of the hospice concept . . . its history, philosophy and limitations.
3. be able to make an informed choice concerning hospice if, and when, necessary. The learner will recognize that the utilization of the services hospice provides is congruent with Jewish tradition.
4. recognize that Jewish tradition has significant contributions to make to the hospice concept.

The reader will note that the third curriculum is addressed to younger learners . . . junior and senior high school age students in the temple religious school program. It is the author's belief that while the adult learner may well derive the most benefit from an encounter with Jewish views on death, dying and hospice, younger students may also resonate to the issues raised in the curriculum, thus preparing the ground for a growing appreciation of the subject as they mature. This will allow, hopefully, for a greater degree of sensitivity on the part of these young people when they interface with the older adults round about them who may be dying or grieving.

CURRICULUM MODEL #1 All-day Workshop

Format: All-day workshop

Setting: Temple

Timing: 8:30 - 5:30

Age of learners: Adults, twenty-five and older

Overall/long-term goals: (see page 107)

Short-term goals: The learner will emerge from the workshop with an appreciation of-

1. how death and dying are viewed in contemporary society
2. how Judaism views death and dying
3. what hospice is and how it began
4. how Judaism relates to the hospice concept

Objectives for the wokshop:

A. Death and dying in contemporary society
The learner will be able to-

A-1 cite an example of death-denying behavior in contemporary society

A-2 identify institutions which further the death-denying tendencies in society.

A-3 infer the consequences of death-denying behavior in contemporary society (i.e.--focus on "youth" cult, glorification of the body, more protracted bereavement)

A-4 assess the degree to which he/she engages in death-denying behavior

B. Judaism and death and dying
the learner will be able to-

B-1 define the words hekdesh, goses, aninut, avelut, shivah

B-2 identify the basic principle which governs the Jewish approach to the dying person (The dying person is, until death, to be considered and treated as a living person.)

B-3 explain the fundamental Jewish objections to autopsy

B-4 illustrate the ways in which traditional Jewish mourning practices are in consonance with contemporary psychological views on mourning and grief

B-5 articulate the significance of <u>bikkur cholim</u> in Jewish tradition

B-6 judge the degree to which the Jewish view of death and dying coincides with his/her own views

C. Hospice: what it is and how it began
The learner will be able to-

C-1 define the word "hospice" and state two concepts inherent to hospice philosophy

C-2 describe the hospice approach to pain control

C-3 identify the basic positions which constitute a hospice staff

C-4 differentiate between hospice "home-care" and hospice "in-patient" care

C-5 predict the implications of hospice care for his/her own life

D. How Judaism relates to the hospice concept
The learner will be able to-

D-1 identify at least one area where Jewish tradition may stand in conflict with hospice philosphy

D-2 compare the Jewish view of pain and suffering to the hospice view of the same

D-3 illustrate the ways in which Jewish mourning practices support the hospice approach to bereavement

D-4 explain the implications of Rabbi Elliot Dorf's statement that "the halachic mandate is to heal, not to sustain life that cannot be healed."[2]

D-5 evaluate his/her own needs for Jewish support and tradition if facing a terminal illness as a hospice patient

Key concepts:

A. Death and dying in contemporary society:

denial of death, trivialization of death, "cure vs. care", heroic measures, thanatology

B. Judaism and death and dying

goses, aninut, avelut, shivah, hekdesh, midrash, ethical will, bikkur cholim, theodicy, halacha, Shulchan Aruch, truth-telling.

C. Hospice: what it is and how it began

death with dignity, home-care, in-patient care, symptom control, waystation for pilgrims, humaneness, living until death

D. Judaism and hospice

theodicy, sanctity of life, preparation for death, bereavement support, bikkur cholim

Strategies/Schedule:

8:30-8:45	Registration, payment of fees for materials and lunch. Distribution of name-tags and assignment to reference groups, arbitrarily determined, of 5-6 people. Each group designates a reporter to record group comments, reactions.
8:45-9:00	Coffee, tea and pastries available.
8:45-9:00	Welcome and introduction by program leader, addressing the intent of the workshop and explaining the schedule for the day.

A. Death and Dying in contemporary society (Objectives A-1 through A-4)

9:00-9:45 Presentation by psychologist or sociologist (20 minutes)
Response by panel members (physician, rabbi, minister, mortician . . . 15 minutes)
General questions and answers (10 minutes)

9:45-10:45 Reference group discussion (30 minutes)
Sample questions for groups:
- At what age and under what circumstances did you first become aware of death?
- How would you characterize your own attitude toward death?
- How do you see your attitudes toward death shaped by society?

10:15-10:30 Coffee break (15 minutes)

B. Judaism and death and dying (Objectives B-1 through B-6)

10:30-11:15 Presentation by rabbi (20-25 minutes)
Questions and clarifications (15-20 minutes)

11:15-12:00 Reference group discussion (45 minutes)
Sample questions for groups:
- To what degree does Jewish tradition impact on your life?
- What aspects of the Jewish view of death and dying are troubling to you? Which are meaningful?
- If you were dying, or close to someone who was, would you be inclined to turn to Jewish tradition for support? A rabbi?
- What are your reactions to the concept of the *goses*?

12:00-12:45 Lunch (with seating according to reference groups to facilitate further discussion and sharing)

C. Hospice: what it is and how it began (Objectives C-1 though C-5)

1:00-2:30 Presentation by hospice representative on history of hospice (20-30 minutes)
Film: "The Dignity of Death" (about St. Christopher's Hospice in London . . . 30 minutes)

Responses by panel of hospital administrator, psychologist, and hospice administrator (20 minutes)

Questions and answers (10 minutes)

2:30-3:00 Reference groups
Sample questions for groups:
- Have you experienced the terminal illness of someone close to you? Can you share the experience with the group?
- If you yourself were terminally ill, what issues would you want to decide about your care?
- What is your greatest fear concerning terminal illness? Does hospice seem to address that fear?
- When, in your view, would hospice be inappropriate?
- Would you feel comfortable utilizing a hospice run under sectarian, non-Jewish auspices?

3:00-3:15 Coffee break (15 minutes)

D. Judaism and hospice (Objectives D-1 through D-5)

3:15-4:00 Presentation by rabbi (20-25 minutes)
Questions and answers (15-20 minutes)

4:00-4:30 Reference groups (30 minutes)
Sample questions for groups:

- In what areas of your life does Judaism currently influence your decisions and actions?
- If you or a loved one needed hospice, would Judaism's view of hospice affect your decision?
- How do you think you would react, as a dying patient, to your rabbi's attempts to help you confront death through traditional Jewish teachings?
- Do you feel a need to die among other Jews?
- Is there a need for a "Jewish" hospice?

4:30-4:50 Time designated to fill out evaluative questionnaire for use of workshop conveners. (20 minutes)

4:50-5:20 Entire group reconvenes. Reference group reporters share key responses from each of the four parts of the workshop . . . a chance to hear the variety of reactions to the material covered. (30 minutes)

5:20-5:30 Closing remarks by program leader.

Resources:

People: rabbi, psychologist, sociologist, mortician, physician, hospice and hospital administrators, hospice volunteers, interested laypeople to act as reference group leaders

Print: to be included in information packets given to all participants

- -pages 1-15, reproduced from Sandol Stoddard's The Hospice Movement: A Better Way to Care for the Dying, Vintage Books, N.Y., 1978.
- -relevant excerpts from Mittford's American Way of Death.
- -relevant passages, in Hebrew and English, from Yoreh Deah sections of Shulchan Aruch
- -article, "Rabbinic Involvement in the Hospice Movement", Journal of Reform Judaism, 28:41-6, Summer, 1981.
- -article, "Death Experiences in Rabbinic Literature", S. Shapero, Judaism, Winter, 1979.
- -article, New York Times, August 18, 1983, "Medicare Rate Set for Hospice Care of Terminally Ill."
- -pamphlet, "Facts About Hospice", Hospice of Cincinnati, Inc.
- -pamphlet, "A Hospice Guide for Care of Jewish Patients and Families", Jewish Hospice Commission of the Jewish Federation Council of Greater Los Angeles, 1983.

Media: Film, "Dignity of Death", ABC News, 1973.

CURRICULUM MODEL #2 Weekend retreat

Format: Weekend retreat for several area congregations (approx. 75-100 people)

Setting: Camp or retreat center

Timing: Friday evening to Sunday afternoon

Age of learners: Adults, twenty-five and older

Overall/long-term goals: (see page 107)

Short-term goals: The learner will emerge from the weekend retreat with a knowledge and an appreciation of a variety of approaches to death and dying:

1) the societal model
2) the model of Jewish tradition
3) the hospice model
4) the model of a hospice approach informed by Jewish values and tradition

Objectives for the retreat: (The reader should note at this point that the lists of objectives which follow represent far too many objectives to be achieved in one weekend retreat. It is possible that more than one retreat may be necessary or desirable to do jutice to the subject, in which case the retreat leaders may choose from among these objectives)

A. The societal model of death and dying

The learner will be able to-

A-1 identify those institutions which interface with the dying

A-2 identify death-denying behaviors in society

A-3 relate examples of ways in which media trivialize or render unreal the death experience

A-4 articulate the degree to which he/she engages in death-denying behaviors and attitudes

A-5 create a fantasy society and describe its approach to death and dying

A-6 express his/her greatest fears about dying

A-7 paraphrase Freud's understanding of the fear of death

B. The Jewish model of death and dying
The learner will be able to-

B-1 identify significant sources of information about the Jewish view of death and dying

B-2 define the term "theodicy"

B-3 identify the necessary criteria of death in Jewish tradition

B-4 interpret a meaning from the <u>midrash</u> concerning R. Sheshet and the Angel of Death

B-5 explain the conept of <u>g'sisut</u>

B-6 draft an outline for an ethical will

B-7 cite an act of <u>bikkur</u> <u>cholim</u> which had spiritual implications for the person who experienced it

B-8 describe the major elements of a traditional Jewish funeral

B-9 relate Jewish funeral rituals to contemporary psychological understandings of grief and mourning

B-10 compare his/her own views of death and dying to the dictates of Jewish tradition

B-11 respond to either the majority or minority voices within Jewish tradition regarding the "right to die"

C. The hospice model of death and dying
The learner will be able to-

C-1 briefly recount the origins of hospice and describe Jewish parallels

C-2 describe the hospice approach to symptom control and explain how it differs from standard hospital practice

C-3 be aware of the humanitarian concerns which undergird hospice philosophy

C-4 relate how religion impacts upon the day-to-day functioning of the typical hospice

C-5 describe the components of a hospice staff

C-6 explain why some health-care institutions feel threatened by the hospice concept

C-7 relate the services which hospice provides to his/her anticipated needs with respect to the process of dying

C-8 suggest possible reasons why the hospice movement has grown so rapidly in the past decade

C-9 imagine situations wherein hospice would <u>not</u> be an appropriate choice for a dying person

C-10 decide for himself/herself if hospice is an appropriate place for a terminally ill child

D. Hospice informed by Jewish values and tradition
The learner will be able to-

D-1 identify areas where Jewish tradition may stand opposed to hospice philosophy and practice

D-2 infer the significance of <u>bikkur</u> <u>cholim</u> to hospice care

D-3 identify elements of Jewish tradition which would lend themselves to use in counselling the dying Jewish patient

D-4 reflect on ways in which Jewish tradition might have eased the death transition of someone known to the learner

D-5 compare and contrast the Jewish view of pain and suffering with hospice's view of the same

D-6 imagine specific ways in which an

existing hospice could become more "Jewish" (meet the specfically Jewish needs of patients and their families)

D-7 decide if traditional Jewish mourning practices obviate the need for hospice bereavement counselling

D-8 examine the concept of g'sisut from both a traditional and a liberal perspective and evaluate its significance for hospice care

D-9 identify that literary work in which Jewish law concerning death and dying is codified

D-10 relate the midrash of R. Sheshet and the Angel of Death to the hospice concept

Key concepts:

A. Societal model of death and dying:

denial of death, death with dignity, "cure vs. care", thanatology, life-after-life, heroic measures, trivialization of death

B. Jewish model of death and dying:

goses, aninut, avelut, shivah, ethical will, bikkur cholim, theodicy, halacha, truth-telling, euthanasia: active & passive, chevra kaddisha

C. Hospice model of death and dying:

death with dignity, life-as-pilgrimge, symptom control, waystation for pilgrims, living until death, home-care, in-patient care, bereavement counseling

D. Hospice model informed by Jewish values and tradition:

theodicy, sanctity of life, preparation for death, hekdesh, bereavement support, bikkur cholim, welcoming the stranger

Strategies/schedule:

Friday evening: Arrive at retreat center, register, receive
5:00-600 accommodation assignment

6:15-6:45 *Kabbalat Shabbat* service

6:45-7:30 Dinner

7:45-10.00 Introduction to schedule for weekend
Evening program: Societal model of death and dying (Objectives A-1 through A-7)

> Psychologist and sociologist give overview presentation of the topic, followed by a viewing of the film "Tell Me A Riddle", which concerns the relationship between an elderly husband and wife, one of whom is contending with a terminal illness.

10:00-? Opportunity for journal work. (Blank journal books will be provided to each participant. They will be numbered but otherwise not identified. Hopefully, at the end of the retreat, they will be collected, edited for significant responses and reproduced for all who attended the retreat. A name/number master list will facilitate the return of the journals to their authors.)

Careful thought should be given to providing space conducive to journal work. A lodge with a fireplace would be a possibility. Background music can aid the flow of expression if appropriately chosen. Not everyone will wish to do the journal work. There should be plenty of literature available on death, dying, hospice, etc., so those people can immerse themselves in the topic. Discussion groups are another alternative for non-journal writers.

Teaser questions for journal work:

- What sort of emotional impact did the film you saw this evening have on you?
- Was there a character with whom you particularly identified? Why?
- Did the film bring to the surface any fears?
- How "typical" was the fashion in which this couple faced death and loss?

-What motivated you to attend this retreat?

-What goals have you set for yourself this weekend?

-What conceivably could stand in the way of your achieving those goals?

-Draw a continuum line for yourself with one end labelled "Accepting of Death", the other end labelled "Denying of death". Where would you place yourself along the continuum? Have you been different places along the line in your life? Where do you expect to find yourself ten years from now? 20 years? 30 years?

Saturday
morning

8:15-9:00 Communal breakfast

9:00-9:45 Shabbat morning service

9:45-11:30 Study groups of fifteen people divide off for exploration of Jewish views on death and dying. Five group leaders required (ideally Jewish educators, rabbis). Launching point for each group should be that week's Torah portion if possible.

Study materials:
- relevant biblical passages
- rabbinic materials (<u>midrash</u>)
- passages from <u>Shulchan Aruch</u>

Leaders should guide the discussion through the levels of Jewish history, touching on the evolving perspective on death and dying. Each group will not necessarily cover the same exact material but the key concepts (see above) will be examined in each group. Leave ample time for questions, discussion. (Objectives B-1 through B-7, B-11)

11:30-12:15 Private time for journal work

-What new things did you learn about the Jewish perspective on death and dying?

-Which <u>midrash</u> spoke most directly to you? Why?

-Describe an act of <u>bikkur cholim</u> in which you took part, either as recipient or visitor.

-How does the Jewish view of euthanasia fit into your own beliefs? Autopsy?

-Have you ever attended a traditional Jewish funeral? How did you react to the various ritual aspects of the ceremony?

-To what extent do you view death as a Jew? . . . to what extent as a member of society-at-large?

12:15-1:00 Lunch

1:15-2:30 Time for creative expression.
Have available for use a variety of materials: paints, collage materials, musical instruments, sketchpads, markers, clay, face-paints, instant cameras. Encourage participants, as individuals, to take the time to create something, anything, which emerges from their response to the material they are studying. Poems, paintings, photos, songs, sculputures . . . anything and everything is valid. Encourage participants to share the results with others during the free time scheduled later in the afternoon.

2:30-3:45 Viewing of videotape "A Plain Pine Box" Which concerns a congregation's attempts to form its own <u>chevra kaddisha</u>

Break up into groups for discussion/role-play

Role-play situation: A congregant's sole remaining parent is terminally ill. The imminent death has been expected and the congregant seems well prepared for the parent's death. The parent is, by now, in a coma and has never indicated what type of funeral he/she would want. The congregant comes to speak to:

-a funeral director of a Jewish funeral home . . . who is a knowledgeable, caring and respected person in the community

-the chairperson of the congregation's <u>chevra kaddisha</u>

Have individuals play these roles, counseling the survivor about funeral arrangements.

Allow for group discussion:

- What needs and whose needs does the funeral address?
- Should tradition have a veto or a vote in death and dying situations?
- Whose wishes should be respected?

(Objectives B-8 through B-10)

3:45-4:15 <u>S'udah</u> <u>sh'lishit</u>: coffee, tea, munchies. An opportunity to socialize with the whole group

4:15-5:30 Free time for journal work, rest, New Games, etc.

5:45-6:45 Dinner

Saturday evening:

7:15-8:45 Program: Hospice history, philosophy, practice (Objectives C-1 through C-10)

Lecture/discussion by hospice representative, hospice volunteers, individuals who have used hospice services. This section should include information on the financial ramifications of hospice.

8:45-9:00 <u>Havdallah</u> ceremony

9:00-10:00 Dramatized readings of accounts of hospice patients, staff, families . . . culled from various books on hospice, Kubler-Ross interviews with patients. Presented by pre-selected and prepared retreat participants

10:00-? Free time for journal work

- What is your greatest fear concerning your own death?

- When would hospice be an appropriate choice for a dying person?

- Is hospice an appropriate place for a terminally ill child?

- What skills could you bring to a hospice as a staff member or volunteer?

- Do you agree with the sentiment expressed in the Book of Ecclesiastes that "there is a time to be born and a time to die"? Who is to decide when it is time to die?

-Under what conditions would you place yourself, or have others place you, in a hospice?

-Describe your ideal death.

Sunday
morning:

8:30-9:15 Breakfast

9:30-10:15 <u>Shacharit</u> service

10:15-11:00 Program: Hospice informed by Judaism
(Objectives D-1 through D-10)

Group divides into five smaller groups. Each group has as its task the exploration of connections and/or disjunctions between Judaism and hospice in one of the following areas:

1) <u>bikkur cholim</u>
2) symptom control
3) euthanasia
4) preparation for death
5) bereavement

Each group will need both a Jewish resource person (rabbi, educator) and a hospice resource person (staff or hospice volunteer) to answer questions and provide clarifications. Each group will draft a summary report of its conclusions.

11:00-12:30 Entire goup reconvenes to hear summary reports

12:30-1:30 Lunch

1:45-2:30 Wrap-up session led by retreat leader to tie together loose ends, answer questions. Evaluation forms to be filled out by all participants, journals collected, information/resource packets distributed which include bibliographic information on each of the four death and dying models explored during the retreat, information on local hospice groups as well as the "caring community" concept of congregational life.

2:30 Departure.

Resources:

People: rabbi(s), Jewish educator(s), psychologist, sociologist, hospice worker(s)/volunteer(s), funeral director, hospital administrator

Print: (see CURRICULUM MODEL #1)

Media: Film, "Tell Me A Riddle" (available for rental, possibly as a videocassette)

Videocassette "A Plain Pine Box"

CURRICULUM MODEL #3 Religious school

Format: A five-lesson unit for use in religious school (high school)

Setting: Congregational religious school

Timing: Five lessons spread over five class sessions

Age of learners: Ninth grade and up

Overall/long term goals: (see page 107)

Short term goals: This unit on death and dying, hospice and Judaism presupposes that the student will have some basic knowledge of Jewish attitudes towards death and mourning. The student will emerge from this unit with an appreciation of a relatively new approach to confronting death, namely the hospice movement, as well as an appreciation of the ways in which the hospice concept dovetails with Jewish concerns for the dying.

Lesson one: Death and dying in contemporary society

Objectives: The learner will be able to:

A-1 give examples of ways in which death is trivialized in the media

A-2 identify institutions whose mandate it is to deal wih the dying

A-3 create a fantasy society and articulate its approach to death and dying

Strategies:

A-1 One week prior to the first lesson, the class is given the following assignment by the teacher: Before we meet next week I want each of you to do *one* of the following things-

1) watch three hours of prime time television, picking the shows at random, and at least one local nightly newscast
2) read, cover to cover, a newsmagazine such as Time or Newsweek
3) watch one hour of children's cartoons.

As you watch the program, or read the

magazine, keep a notepad nearby and jot down whenever someone dies, is killed, or a reference is made to death. Be as precise as possible so you will be able to recall what you observed when you return to class next week.

When the class comes together the following week, the teacher leads a round-robin discussion of what the students observed. A chart on the board may be helpful:

Death at advanced age	Violent death	Natural death	Unexplained death	Premature death

Other categories may be added. It is likely that many, if not most, of the deaths reported will be violent or premature deaths (t.v. violence, airplane crashes, natural disasters, etc.)

How do students perceive this presentation of death? The teacher is to use these "statistics" to help students discover that society has a skewed view of death: it is either something which happens unexpectedly, and to someone else, or it is a taboo subject, not to be discussed in detail. Ask students to reflect on other ways in which death is trivialized or covered over in society (i.e. emphasis on youth culture, search for the perfect body, etc.)

A-2 Have students divide into groups of 5-10 people for a role-play exercise.

Role-play cast: Middle-aged man (husband
Middle-aged woman (wife)
Elderly parent, dying of cancer

The elderly parent has reached a stage where the husband and wife need assistance in providing care for the parent. They discuss their options. (hospital, home-care with nurses, nursing home). They then consult with the dying parent, inquiring of his/her needs as a dying person.

Students should discuss the pros and cons of the options which emerge from the role-play. Personal experiences with health care facilities can be shared here. The teacher should help clarify distinctions between health care facilities such as hospitals and nursing homes, saving mention of hospice for another session.

A-3 Have the class read Rabbi David Polish's - "Topsy-Turvy World" (see appendix to thesis) which describes a distant planet where values are totally reversed . . . charities raise money for armaments and governments devote their resources to human welfare.

Ask the students to describe their own "Topsy-Turvy World" for the dying, addressing the most common fears of the dying person: pain, dependency, loneliness. The teacher should copy down on the board the ideas which emerge from this exercise for later comparison when hospice is discussed. To what extent does hospice meet the description of the fantasy worlds?

Closure: Points to be reiterated/stressed-

1. Death is often alluded to in the media but from a skewed perspective . . . death is violent or capricious, and rarely portrayed as our natural end. This media treatment reflects society's inability to confront death which, in turn, reflects our personal difficulties with death.
2. Certain institutions have traditionally dealt with dying people, answering some needs and ignoring many more.
3. The needs of the dying can be ascertained and addressed, if only by beginning at the fantasy level and imagining an ideal response to the needs of the dying.

Lesson two: Death and dying in Judaism

Objectives: The learner will be able to:

B-1 articulate the importance of bikkur cholim

B-2 differentiate between "passive euthanasia" and "removing impediments to death" (see Yoreh Deah 339 and reference to the death of Judah ha-Nasi, Ketuboth 104a)

B-3 explain the contemporary significance of the <u>midrash</u> concerning R. Sheshet and the Angel of Death (Moed Katan 28a)

<u>Strategies</u>:

B-1 Read, with the class, the relevant portion of the <u>Shulchan Aruch</u>, Yoreh Deah 335, which mandates <u>bikkur cholim</u> as a religious responsibility. Discuss the implications of <u>bikkur cholim</u>. Can it really help a person recover? Relate the talmudic assertion that one who visits a sick person removes 1/60 of that person's illness (Nedarim 39b). What good can it do a terminally ill person? Of what benefit is it to the one who visits? Ask students to relate personal experiences.

Share the Chassidic story of "Yid" and his friend, the preacher of Kozenitz (see p. 95). What is the message of the story? How would you convince a dying friend that life still held meaning? What could you, personally, offer that person?

B-2 Ask a physician and a rabbi to present the concepts of "passive euthanasia" and "removing impediments to death" . . . the medical view and the traditional Jewish view. Allow time for questions.
Present the <u>midrash</u> of the death of Judah ha-Nasi. Ask the students, as well as the rabbi and physician, to place themselves on the following continuum line:

would allow Judah ha-Nasi's students to pray uninterrupted	would have done as Judah ha-Nasi's servant did

Ask each person to explain his/her reasons for their place along the continuum.

Ask students to role-play the roles of Judah ha-Nasi's servant and one of Judah's disciples who was praying that his master not die.

B-3 Have the class divide into groups of three to five people. Ask each group to briefy study the Moed Katan passage relating the story of R. Sheshet and the Angel of Death. Ask each group to write a dialogue between the two and then present it to the rest of the class.

- How does the Angel of Death make its case?
- On what grounds does R. Sheshet refuse to die in the marketplace?
- Does the story have contemporary relevance? Why? Why not?
- What would R. Sheshet's options be today if faced with death?

The teacher may want to distribute copies of Danny Siegel's retelling of this midrash (see thesis appendix)

Have the class draw, sculpt, create in collage, poetry or song, the encounter between R. Sheshet and the Angel of Death

Lesson three: Hospice Background and Philosophy

Objectives: The learner will be able to:

C-1 briefly recount the origins of hospice in medeival Europe as well as Jewish counterparts to the early hospice

C-2 relate ways in which hospice philosophy differs from the hospital philosophy of care

C-3 identify the needs of the dying person which hospice directly addresses

C-4 decide if he/she would want a dying loved-one to use a hospice

Strategies:

C-1 The teacher will lead the student on a guided fanatsy: they are to imagine themselves to be travelling Christian pilgrims in the Middle Ages. The teacher should use elaborate imagery to set the mood. The teacher then introduces the elements of sickness, poverty, being a stranger far from home. Where does the pilgrim turn? The teacher now introduces the medieval hospice.

Second guided image: a medieval Jew, forced from home by Crusader mobs, illness or poverty. Sick and on the road, where can you turn for comfort? Teacher now introduces the concept of the hekdesh and communal sick-care organizations in Jewish communities.

The teacher then makes the transition to the modern hospital, focusing on the shift in human values exacerbated by the Industrial Age. The film "The Elephant Man" may provide a useful touchstone for discussion about the development of the modern hospital and the "death-as-the-enemy" mentality as well as the loss of the distinction between the person and the disease afflicting that person

C-2 & C-3 The teacher presents students with a list of patient regulations from both a hospital and a hospice. Ask students to study the rules and infer policy for the respective institution from the rules.

- What do the rules say about the way the institution perceives the patient and the patient's needs?
- What about the needs of the patient's family?
- Whom do the rules serve? Protect?

The teacher can reinforce the concept that in hospitals, death represents the ultimate failure of science and medicine while in hospice, death is the goal.

Ask the students to prepare a list of what <u>they</u> feel the dying need and/or fear. Compare those lists to the fears listed on page 59.

Point by point, the teacher should explain how hospice addresses those fears and needs.

C-4 An exercise may be introduced here to sensitize the students to the nature of the interaction between the dying and those who care for them. The success of this exercise will depend significantly upon the maturity of the group and the teacher should use great discretion before going ahead with this exercise.

Have the students pair off and sit facing one another. Alternately, one student will role-play a dying patient who no longer has use of his/her body. Speech, for this person, is no longer possible and only the face retains any mobility. The other student role-plays a caregiver whose duty it is to feed the other some food (yoghurt or pudding may be used) with all of the devotion he/she can bring to the task. The students then reverse roles.

After the exercise allow the students time to process and discuss their reactions to the exercise:
- -How did you feel as the helpless patient?
- -What did you think your caregiver was feeling?
- -How did you feel as caregiver?
- -What did you imagine the "patient" was thinking?
- -To what extent are you able to differentiate between your "self" and your body? In other words, if you lost the use of your body, as in this role-play situation, to what extent would you still be "you"?

Lesson four: Hospice practice

Objectives: The learner will be able to:

D-1 identify hospice staff positions and functions

D-2 relate hospice's physical layout to hospice philosophy

Strategies:

D-1 & D-2 Ideally, this fourth lesson would entail a field-trip to a hospice, to meet with patients if possible, but more realistically, to meet with volunteer staff who could relate hospice practice and show the facility to the students. During this lesson the student would also be exposed to the "other half" of hospice care, that is, home care. Volunteers would describe their duties as home care workers and share relevant anecdotal material.

In the absence of a hospice to visit, a film such as "The Dignity of Death" (ABC News, 1973) can be used to introduce the student to the ways in which hospice functions.

Based on students' understanding of hospice philosophy and the needs of dying patients, have the students design a "blueprint" for a hospice "in-patient" facility. What have they included? Why? What has been excluded? Why? How does the design differ from that of a convalescent home? A hospital? How would students decorate various parts of the hospice? Would they ask for patient input in the designs? Family input?

Arrange a "debate" between a "hospital pharmacologist" (student) and a "hospice pharmacologist" (another student) over the merits of their respective approaches to pain and symptom control. (This will require prior research by the students.)

Discussion questions:
- -Is hospice an appropriate place/concept for dying children?
- -When is hospice inappropriate?
- -Why might hospitals and nursing homes feel threatened by the hospice concept?

Lesson five: Judaism and hospice

Objectives: The learner will be able to:

E-1 suggest ways in which hospice might better meet the needs of Jewish patients

E-2 relate the midrash of R. Sheshet and the Angel of Death to the hospice concept

E-3 explain how midrash can be a valuable tool in death preparation

E-4 explain how traditional Jewish mourning practices can augment the bereavement support which hospice provides

Strategies:

E-1 Students will create a "guide for hospice workers to the needs of Jewish patients" (the pamphlet published by the Jewish Hospice Commission of Los Angeles might be used to evaluate student efforts . . . see appendix)

What areas did the students focus on? What was missed? How might the Jewish community (i.e. Jewish professionals and organizations) better serve Jewish hospice patients?

E-2 Students must decide if R. Sheshet, were he alive today, would opt for hospice. Ask students to take sides and debate the issue.

E-3 Use this excerpt from Stephen Levine's book to discuss "appropriate" death preparation. What constitutes appropriate "Jewish" help for the dying?

Some time ago we received a letter from a woman in New York city who said she was thinking of going over to the Brooklyn Convalescent Hospital, in which her mother was dying, to sit by her bed and read her The Tibetan Book of the Dead. I called that day to tell her she might be making an error of judgement. Consider the likely reaction of an eighty-five-year-old Jewish woman in considerable pain and fear, dying in a strange environment, who has to lie there and hear that when she dies she is going to confront swirling lights and thunderous roars coming from harukas and demons in circumstances she has perhaps never confronted in life. Death is frightening enough but to put it in terms so unfamiliar would cause her yet more anxiety and fear. The Tibetan Book of the Dead was intended for Tibetan monks, not for old Jewish ladies dying in Brooklyn. Since we do not share this same conditioning in life, why expect the mind to project such conditioning after dropping the body? Instead we suggested she sing old Yiddish love songs to her mother.[3]

Students will examine a number of midrashim (see pp. 97-99, and decide how each might be used in counselling hospice patients. The teacher can point out parallels between certain midrashim and contemporary thanatology research (i.e. the death of Moses and Kubler Ross's stages of dying; or a comparison of rabbinic observations on death and reported after-death experiences in contemporary society)

E-4 Ask students to imagine that a close friend of theirs has just died after a six-month bout with leukemia; or a close friend has just lost a parent after a long illness. How can they, as friends and as Jews, help the surviving family with their grief and bereavement? (Stress the importance in

Jewish tradition of the supportive community which provides the mourners' meal, forms the minyan, etc.)

Curricula Bibliographies

Death and Dying in Contemporary Society

PRINT

Becker, Ernest. The Denial of Death. New York: Free Press, 1973.

A modern classic and best-seller which examines the phenomenon of the fear of death and ways in which society as a whole denies the reality of death.

Grollman, Earl, ed. Concerning Death: A Practical Guide For The Living. Boston: Beacon Press, 1974.

A collection of essays written by various authors dealing with issues confronting the bereaved.

Jury, M.; Jury, D. Gramp. New York: Grossman, 1976

A moving testimony, in words and pictures, to the way in which one family helped a family member to die with dignity, in his own home.

Kubler-Ross, Elizabeth. On Death and Dying. New York: Macmillan, 1972.
________. Questions and Answers On Death and Dying. New York: Macmillan, 1972.
Two works by the influential, and controversial, thanatologist who did pioneering work in understanding the needs of the dying person.

Levine, Stephen. Who Dies?: An Investigation of Conscious Living and Conscious Dying. Garden City, N.Y. Anchor Books, 1982.

A "new age" poet and meditation teacher leads the reader on an extended exploration of the spiritual aspects of coming to terms with death. Includes meditation exercises.

Ring, Kenneth. Life at Death: A scientific investigation of the near-death experience.

New York: Coward, McCann & Geoghegan, 1980.

A thorough scientific study which examines the phenomenon of people who report after-death experiences. Compelling and thought-provoking material, but quite detailed.

Simpson, Michel A., ed. Dying, death and grief; a critically annotated bibliography and source book of thanatology and terminal care. New York: Plenum Press, 1979.

NON-PRINT

Film

"How Could I Not Be Among You?" Thomas Reichman, Eccentric Circle Cinema Workshop, Box 1481, Evanston, Ill. 60204. 30 minutes, color. 1970.

The film is a visual accompaniment to the poetry of Ted Rosenthal, a 30-year old leukemia victim. It is a song of dying whose message is "live and love while you can."

"Death: Coping With Loss." Audio-Visual Library, P.O. Box 1986, Indianapolis, In. 46206. 16 mm. 19 minutes.

Interviews with a doctor, rabbi, minister, psychiatrist, funeral director, parents who have lost a child through death, brothers and sisters and a widow who describe their reactions and what they have learned as a result of the experience.

"Though I Walk Through The Valley." Audio-Visual Library. (See above for address.)

Story of the last months of a terminal cancer victim, Tony Brower. Told in a straightforward, unsentimental style, it is a film of hope, with only moments of despair.

Judaism and Death and Dying

PRINT

Bleich, J. David. *Judaism and Healing: Halakhic Perspectves.* New York: Ktav Publishing House, Inc., 1981.

A contemporary Orthodox expositor of *halacha* looks at issues relevant to the concerns of hospice, i.e. death and dying, from a modern Orthodox perspective.

Jacob, Walter, ed. *American Reform Responsa*. New York: Central Conference of American Rabbis, 1983.

A compilation of respona from a liberal Jewish perspective. Contains a number of responsa relevant to issues of death and dying.

Jakobovits, Emmanuel. *Jewish Medical Ethics*. New York: Bloch Publishing Co., 1975.

Another contemporary Orthodox halachist examines issues of death and dying from the perspective of traditional Judaism.

Lamm, Maurice. *The Jewish Way in Death and Mourning*. New York: Jonathan David, 1969.

A lucid explanation of traditional death, burial and mourning rituals by a modern Orthodox rabbi who publicly supports the hospice concept.

Marcus, Audrey Friedman; Bissell, Sherry; Lipschutz, Karen. *Death, Burial and Mourning in the Jewish Tradition*. Denver: Alternatives in Religious Education, 1976.

A mini-course, with leader's guide, geared to grades 5-12.

Marcus, Jacob Rader. *Communal Sick-Care in the German Ghetto*. Cincinnati: Hebrew Union College Press, 1978.

Marcus sheds considerable light on Jewish counterparts to the medieval Christian hospice and traces the evolution of Jewish care for the sick and dying through the Middle Ages to the Emancipation.

NON-PRINT

Audiocassettes

First Jewish Hospice Institute (April-May 1983). Available from the Jewish Hospice Commissin of the Jewish Federation Council of Greater Los Angeles, Los Angeles, California.

1. "The Jewish Perspective: Grief and Mourning." Herman Feifel, Ph.D. & Rabbi Maurice Lamm, D.D.
2. "The Jewish Perspective: The Death System" Rabbi Maurice Lamm, D.D.
3. "The Jewish Perspective: The Dying Patient". Rabbi Elliot Dorf, Ph.D.
4. "Death and Dying in Contemporary America" Herman Feifel, Ph.D.
5. "Introduction to Hospice Care for Volunteers". Claire Tehan, M.A. & Robert Taub, M.D.

A series of tapes from a conference sponsored by the Jewish Hospice Commission of Greater Los Angeles. They provide a good overview of issues relating to Judaism and death and dying.

Films

"The Day Grandpa Died." Available from Media Project, 65 William Street, Wellesley, Mass. 02181. 11 minutes, color.

A young Jewish boy's reaction to the death of his beloved grandfather. Recommended for age 10 and up and for counsellor training.

Hospice: History, Philosophy and Practice

PRINT

Davidson, Glen W. The Hospice: Development and Administration. Washington: Hemisphere Publishing Corp., 1973.

A thorough, albeit somewhat dry, treatment of hospice philosophy and practice. Contains a useful filmography and annotated bibliography.

Hamilton, Michael; Reid, Helen, editors. A Hospice Handbook: A New Way to Care for the Dying. Grand Rapids: Eerdmans Publishing Co., 1980.

An anthology of articles concerning the needs of the dying, the response of hospice to those needs and the elements of hospice organization. Includes a helpful filmography.

Koff, Theodore H. Hospice: A Caring Community. Cambridge, Mass.: Winthrop Publishers, Inc., 1980.

Lucid and well-written introduction to hospice. It contains particularly good explanations of hospice administration, funding and licensure.

Stoddard, Sandol. The Hospice Movement: A Better Way to Care for the Dying. New York: Vintage Books, 1978.

By far the most readable, and moving, introduction to hospice history, philosophy and practice. It contains much anecdotal material and useful appendices.

NON-PRINT

Films

"Hospice: Care for the Living and Dying." National Council of Churches, TV Film Library, Rm. 860, 475 Riverside Drive, New York, N.Y. 10027. 30 minutes. B&W.

A look at New Haven's Hospice, Inc. when it was being established. Interviews with the president of Hospice, Inc. and its medical director about dealing medically and spiritually with the terminally ill and their families.

"Death." Arthur Barron, Filmakers Library, Inc., 290 West End Ave., New York, N.Y. 10023. 40 minutes, B&W, 1968.

A documentary produced originally for educational television presenting the problems of caring for the dying cancer patient in Calvary Hospital in the Bronx. It is an honest portrayal of death as it has usually been accomplished by patients everywhere and, as such, it stands in stark contrast to the goals of hospice care.

"The Dignity of Death." ABC News, 1973.

A rather comprehensive look at St. Christopher's Hospice in London, the model on which so many hospices have been based, in less than 30 minutes.

Judaism and Hospice

PRINT

Very little material has appeared, to date, concerning the relationship between Judaism and hospice specifically. The reader is referred to the bibliographies for "Judaism and Death and Dying" and "Hospice: History, Philosophy and Practice."

Jewish Hospice Commission of the Jewish Federation Council of Greater Los Angeles. A Hospice Guide For Care of Jewish Patients and Families. 1983

Intended to inform hospice workers how to better serve the needs of Jewish patients. Includes a useful bibliography.

Moss, Steven A. "Rabbinic Involvement in the Hospice Movement." Journal of Reform Judaism, 28:41-46, Summer, 1981.

The author argues for rabbinic support of, and participation in, hospice programs. He sees the hospice mandate deeply rooted in the Jewish view of life and death.

NON-PRINT

Audiocassettes

See "Audiocassettes" in bibliography for "Judaism and Death and Dying."

CHAPTER NOTES

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1. Sandol Stoddard, Hospice Movement: A Better Way to Care for the Dying (New York: Vintage Books, 1978), p. 218

2. Ibid., p. 219ff.

3. Ibid., p. 2

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6. Ibid., p. 22

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8. Paul M. DuBois, The Hospice Way of Death (New York: Human Sciences Press, 1980), p. 60.

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10. Ibid., p. 47.

11. DuBois, p. 61

12. Ibid.

13. Stoddard, p. 153.

14. Ibid., p. 9.

15. Ibid., p. 37.

16. Ibid.

17. Ibid.

18. Ibid., p. 13.

19. Ibid., p. 45.

20. Jacob Rader Marcus, Communal Sick-care in the German Ghetto (Cincinnati: Hebrew Union College Press, 1978), p 163.

21. Ibid.

22. Ibid., p. 162.

23. Ibid.

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25. Ibid., p. 6.

26. Ibid., p. 7.

27. Ibid., p. 8.

28. Ibid., p. 177.

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31. Ibid., p. 165.

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33. Ibid., p. 61.

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35. Ibid., p. 72.

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39. Ibid., p. 138.

30. Ibid., p. 152.

41. Stoddard, p. 82.

42. Ibid.

43. Theordore H. Koff, Hospice: A Caring Community (Cambridge: Winthrop Publishers, 1980), p. 10.

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45. Stoddard, p. 85.

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48. "St. Luke's House: A Turn-of-the-Century Hospice," The Hastings Center Report, (April, 1982), p.12.

49. Ibid.

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51. Stoddard, p. 13.

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53. Koff, p. 14.

54. Ibid., p. 12.

55. Robert W. Buckingham and Dale Lupu, "A Comparative Study of Hospice Services in the United States," American Journal of Public Health, Vol. 72, No. 5, 1982, p. 455.

Notes to Chapter II

1. Parker Rossman, Hospice: Creating New Models of Care for the Terminally Ill (New York: Association Press, 1977), p. 193.

2. Stoddard, p. 24.

3. DuBois, p. 29.

4. Kenneth B. Wentzel, To Those Who Need It Most, Hospice Means Hope (Boston: Charles River Books, 1981), p. 11.

5. Stoddard, p. 5.

6. Koff, p. 15.

7. Glen W. Davidson, The Hospice: Development and Administration (Washington: Hemisphere Publishing Corp., 1978), p. 44.

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9. Koff, p. 16.

10. Ibid., pp. 31-32.

11. Ibid., p. 69.

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13. Ibid., p. 77.

14. Wentzel, p. 31.

15. Rossman, p. 78.

16. Stoddard, p. 233.

17. Koff, p. 94

18. Ibid., p.45

19. Ibid.

20. Michael P. Hamilton and Helen F. Reid, A Hospice Handbook: A New Way to Care for the Dying (Grand Rapids: Eerdmans, 1979), p. 77.

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APPENDICES

FACTS

about hospice

hospice
of
cincinnati,
inc

Hospice of Cincinnati, Inc.
2710 Reading Road
Cincinnati, Ohio 45206
(513) 559-3100

P.R. 7/83

WHAT DOES HOSPICE MEAN?

The word "hospice" is a Medieval term that means "waystation," a place for travelers to obtain refreshment and care. Originating in Europe, they provided care to the wounded, the sick and the dying. The word "hospital" comes from the word "hospice." Today, hospice refers not only to a place, but to a concept and program of providing care (and support to those persons and their families) who are in the last phases of a terminal illness.

WHAT IS THE HOSPICE PHILOSOPHY?

It is that a dying patient be allowed to "live until death" in an environment of choice, surrounded by familiar persons.

WHAT ARE THE GOALS OF HOSPICE?

The goals are:

1) To express reverence for human life, not by prolonging the terminal illness of patients, but by assisting them to live fully, to preserve mental alertness, and to experience the support of family and a caring community.
2) To provide an alternative hospital environment for those persons whose illness is beyond curative efforts.
3) To focus the efforts of an interdisciplinary team of specially trained staff and volunteers in order to provide the patient and family with physical, emotional and spiritual support that continues into the bereavement period.

WHO GIVES HOSPICE CARE?

An interdisciplinary team of registered nurses, physicians, social workers, home health aides, trained volunteers and clergy provides personalized care to patients and support to their families.

WHAT KIND OF CARE DOES HOSPICE OFFER?

There are two components to Hospice care — home care and inpatient care. Patients may utilize either one or both parts, whichever is appropriate.

WHAT DOES HOME CARE MEAN?

The focus of the Home Care Program is on teaching families how to care for a seriously ill patient at home, and providing support and relief in that care through the use of home health aides, trained volunteers, social work services, clergy and skilled nursing care and supervision. Under the direction of the patient's personal physician, care is provided on an intermittent basis; it is not intended to replace the primary caregiver in the home. A 24-hour 7-days-a-week phone service links the patient and family with one of the Home Care nurses should problems and/or questions arise.

TELL ME MORE ABOUT THE INPATIENT UNIT

The 18-bed Inpatient Unit provides a home-like atmosphere for patients whose medical condition warrants hospitalization. Patients are discharged when they no longer require the acute medical care of a hospital. Admission is made through the patient's physician.

WHAT IS THE DIFFERENCE BETWEEN THE INPATIENT UNIT AND A REGULAR HOSPITAL?

Hospitals focus on treating and curing disease. Hospice focuses on treating the symptoms of the diseases which have gone beyond the expectations of being cured. Hospice specializes in pain control, teaching and supporting not only the patient but also the family throughout the patient's illness. By offering both home care and inpatient care, Hospice can follow the patient more closely and provide a continuity of service for the terminally ill patient that has been unavailable in the community until now. Visiting hours are more flexible and children of all ages are allowed to visit. The number of patients cared for by each nurse is limited so that patients receive the individualized care they require.

WHO IS ELIGIBLE?

Any patient with a limited life expectancy whose disease is not responding to curative treatment is eligible. The patient's personal physician must consent to Hospice care.

To be eligible for home care, the patients must reside in either Hamilton or Clermont Counties, be able to be cared for in their home, and identify a responsible person who can be taught to care for the patients unless they are able to care for themselves.

To be eligible for inpatient care, there must be a physician-documented medical condition which necessitates inpatient care. There are no residency requirements.

WHAT ABOUT COSTS?

Hospice services are not free but every effort will be made to find third party reimbursement for services. Many home care services are covered by Medicare, Medicaid and Blue Cross and the Major Medical component of many insurance carriers. Inpatient care is considered acute care hospitalization. The Hospice team will work with patient/family in exploring all financial resources.

FOR FURTHER INFORMATION WRITE
HOSPICE OF CINCINNATI, INC.
2710 READING ROAD
CINCINNATI, OHIO·45206
OR PHONE 513-559-2100.

a way of living
that makes the
time
left
special

hospice
of
cincinnati,
inc.

Bethesda
Foundation of Cincinnati
619 Oak Street
Cincinnati, OH 45206

Hospice

a way of living that makes the time left special

Providing specialized care and emotional support for persons with a terminal illness and their families is the goal of Hospice of Cincinnati, Inc

The Hospice philosophy emphasizes a reverence for the quality of human life by assisting the terminally ill patient in living as fully as possible Patients and families are members of the decision-making team which gives them the opportunity to maintain control and make choices concerning their care

Through a coordinated program that includes both inpatient and home care services, Hospice offers personalized care for individuals with a limited life expectancy whose disease is not responding to curative treatment. By providing these two integrated programs, Hospice is able to insure a continuity between the care provided at home and that provided in the Inpatient Unit

Patients are usually referred first to the Hospice Home Care Program and then they enter the 18-bed Inpatient Unit, adjacent to Bethesda Oak Hospital, as their medical condition warrants. Home care services are limited to residents of Hamilton and Clermont Counties while the Inpatient Unit has no geographic restrictions

Home Care enables patients to remain within the family circle and among the familiar comforts of home for a longer period of time The Home Care Registered Nurses in cooperation with the patient's personal physician, visit their patients at home on a regular basis and coordinate the various services that the patient may require. They provide skilled nursing care along with instruction to the family and/or friends in how to care for a seriously ill patient at home. Other services available through the Hospice interdisciplinary team include home health aides, trained volunteers, social workers and clergy

A 24-hour, 7-day-a-week phone service links the patient and family with one of the Home Care nurses at all times should problems and/or questions arise If a problem cannot be dealt with over the phone, a home visit is made

Hospice exists in the hope and belief that, by providing a caring community, sensitive to the unique needs of each patient and family, patients may continue to live as fully and as comfortably as possible

Chairman's Message

The original idea of a hospice was to provide shelter and refuge for weary travelers Today, Hospice of Cincinnati, Inc provides emotional shelter and refuge for the weariest of travelers, the terminally ill and their families Started in 1979, Hospice has served more patients and families each year In 1982, Hospice served 266 inpatients and made 2,050 home care visits

Often a terminal illness puts a strain on the financial resources of patients and their families Unfortunately, not all of our patients have Medicare, Medicaid, Blue Cross or other private insurance and often assistance is needed to help meet the costs of Hospice care

Following the death of a loved one, many family members have said that the Hospice experience was truly a positive period of good feelings. You can help others receive care from Hospice by making a donation in memory or in honor of someone you care about, or by including Hospice of Cincinnati in your estate plan

Help share the unique program called Hospice of Cincinnati

James M Leahy
Chairman
Hospice Advisory Board

The Dying Person's Bill of Rights

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness, however changing its focus may be.

I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions concerning my case.

I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to die in peace and dignity.

I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.

I have the right to discuss and enlarge my religious and/or spiritual experiences, regardless of what they may mean to others.

I have the right to expect that the sanctity of the human body will be respected after my death.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

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Prepared by the Southwestern Michigan Inservice Education Council.

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California

DIRECTIVE TO PHYSICIANS

Directive made this __________ day of __________ (month, year).

I ____________, being of sound mind, willfully, and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

1. If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.
2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.
3. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.
4. I have been diagnosed at least 14 days ago as having a terminal condition by __________, M.D., whose address is ____________, and whose telephone number is ___________. I understand that if I have not filled in the physician's name and address, it shall be presumed that I did not have a terminal condition when I made out this directive.
5. This directive shall have no force or effect five years from the date filled in above.
6. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed ______________________________

City, County and State of Residence ______________________________

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness ________________________ Witness ________________________

DECLARATION

Declaration made this ________ day of ______ (month, year).
I, ________________________, being of sound mind, willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed ________________________

City, County and State of Residence ________________________

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness ________________________

Witness ________________________

THE VIABILITY OF PEDIATRIC HOSPICES: A CASE STUDY

DOTTIE C. WILSON
Hospice Development Group, ELM Services, Inc.,
Rockville, Md.

This paper identifies the special characteristics needed by hospices caring for terminally ill children. It is based on a feasibility study conducted in 1979 for a pediatric hospital in New York City. From the analysis of statistical data and confidential interviews with health care professionals in the hospital and in the community, the study concludes that the needs of terminally ill children and their families are not being met currently and that the hospice is as appropriate for children as for adults. Three major differences in emphasis are noted, however. First, support of the family suffering the death of a child is of prime importance, because the grief is devastating and long lasting and because the number of family members affected is usually large. Second, the hospice emphasis on home care is even more imperative for children than for adults as it more significantly benefits both child and family; home care can be facilitated through supplementary care components such as day care. Third, there is a major need for both professional and public education in caring for terminally ill children and their families and in coping with childhood death. The author concludes that further research is needed in all aspects of pediatric terminal care.

St. Mary's Hospital for Children, Bayside, New York, is an Episcopalian skilled nursing facility founded in 1870 and located at its present site since 1950. It is the only special purpose extended care facility for children in the New York City metropolitan area. St. Mary's became interested in establishing a pediatric hospice as a new program for its facility and commissioned ELM Services, Inc. to carry out a feasibility study of the

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proposed project. ELM Services is a health care consulting consortium, specializing in cancer programs, hospice, long-term care, hospital planning, and association management. Its hospice consulting is conducted through its Hospice Development Group.

The study was conducted in the autumn of 1979, employing the following methodologies:

- Literature search on pediatric terminal care.
- Consultation with experts in the field, including Dr. Cicely Saunders, St. Christopher's Hospice; Dr. Ida Martinson, University of Minnesota; members of the pediatric research staff of Children's Hospital, Washington, D.C.; and others.
- Confidential interviews with key personnel of the hospital, including key members of the medical staff and a representative cross section of administrative and nursing staff and educators. Interviews with medical community leaders, including leading pediatric physicians and deans or faculty members of three medical schools. Canvassing of the other hospices in the area concerning their pediatric admission policies.
- Two planning sessions, one with hospital staff and the other with community representatives, including social workers, hospital discharge planners, and home care representatives.
- Collection and analysis of statistical and demographic data, including the New York City Health Department records of pediatric deaths and the HSA Health Systems Plan.
- Foundation searches to identify funding possibilities.
- Analyses to determine the financial implications of the proposed hospice and evaluations of referral patterns and potential patient load.

The principles of hospice care as they relate to terminally ill children (aged 0-16) were compared with those relating to adults. In general they were found to be consistent but with variable emphases in certain aspects. Nine areas of comparison were identified.

(1) A hospice approach is as beneficial for terminally ill children and their families as for terminally ill adults and their families. Quotations from staff members interviewed during the study included the following:

> Children are not afraid of dying—parents instill fear into them.
>
> A hospice is needed so that death is not hidden away. It is now so difficult for the family and the child.

As for adult patients, a hospice program was determined to be beneficial when symptoms (physical, emotional, interpersonal, financial, spiritual) are out of control for the child or the family. As in all hospices the goal is to meet the needs and wishes of the patient and family.

(2) All care components associated with an adult hospice are equally appropriate for a pediatric hospice: home care, inpatient care, bereavement, and education, as well as day care and night care and outpatient services.

(3) A pediatric hospice needs to place more emphasis on support of the family than does an adult hospice. The parent-parent interrelationship is key. Fischoff and O'Brien have pointed out that

> Parents experience the death of their child in a way that is different from the death of their parents, brother, or sister. Becoming a parent is a unique event. The parents feel the loss of their child as if they have lost a part of themselves, which, indeed, they have. . . . The search for a "reason" why the child died and a search for the meaning of life and death, the absolute and the mystery, is present during the mourning process. Parents seek consolation, meaning, and faith from any source that is available. However, many parents mourn the loss of their child in isolation and solitude. (1, p. 140)

The death of a baby is shattering. The death of a child with whom the parents have become acquainted and for whom long-range plans have been made can be even more traumatic. In this situation, the relationship between the parents is often at stake. Studies have shown that a large number of parents separate following the death of their child (70 percent in one study, 90 percent in another), whereas with support that percentage can be significantly reduced (to 7 percent in one study) (2).

In the pediatric hospice, the "family" can mean a broader group than the immediate family and close friends found in adult hospice programs. Here, the family may include the grandparents and siblings, as well as aunts, uncles, cousins, friends, and schoolmates.

Pediatric hospices need to be able to support the bereaved in their grieving and to let them know when it is all right to stop grieving. Group sessions with families of children who are dying (or who have died) of the same disease are effective. The families of hospice home care, inpatient care, and day or night care patients are included in the hospice support program. It may be feasible to extend outreach support activities to any family in the community that has suffered or is suffering the loss of a child, whether or not the child was admitted to the hospice.

(4) Emphasis on medical and nursing care, pain and symptom control, attention to detail, and continual reassessment are as necessary in a pediatric as in an adult hospice. The period of time established by professional opinion as appropriate for hospice care may be shorter for the child with terminal cancer, however. Calman has offered one explanation for this finding.

> Inevitably, the decision that a child has reached a terminal state is made more reluctantly. There is a tendency to "treat till the last" in the hope that something will work; consequently the time during which symptomatic care only is given may be relatively short. (3, p. 42)

(5) Pediatric hospices need to place even more emphasis than do adult hospices on the home as the most desirable location for both patient and family. When there is a family to care for the child and there is a hospice home care program to teach and support, home care is appropriate, with or without other children in the home (4). The benefits of maintaining the terminally ill child at home are many:

- The child feels more secure.
- The family has more control, both in making decisions and giving comfort.

- The family is kept together; family members are near whenever the patient needs them and are not deprived of the patient's presence during his or her remaining lifetime.
- The family members may make a better adjustment after the death if they have fulfilled the child's wish to be at home. Feelings of guilt are often allayed if parents feel they have gone through the experience together.
- The cost of care is greatly reduced (to perhaps one-fourth the cost of acute care).

(6) Pediatric hospices, even more than adult hospices, should examine the possibility of supplementing home care with day care or night care, either in an inpatient hospice unit or other location. When a patient being cared for at home cannot be cared for full time at home, because parents are working and other care givers are not available at home, a center for day care or night care may be provided through the inpatient hospice unit or satellite center. Day care and night care provide a short-term facility for respite care for the family and serve as an alternative to inpatient care. If the center is in the inpatient unit, the existing trained unit staff may be utilized, with associated cost savings.

(7) Experience has shown that the inpatient backup of choice for home care pediatric patients is a pediatric acute care ward that is familiar to the patient. Other inpatient alternatives are special inpatient hospice units in hospitals or in skilled nursing facilities.

The hospice staff members differed in their interviews as to the merits of the various alternatives:

> I can't see having all those different age groups together.
>
> There should be a separate building, and a separate entrance—perhaps not even on hospital property—so the other children would not find out it was there.
>
> Hospice children would need to be on a ward by themselves, but they can't be isolated. They have to be stimulated by involvement with everyone else.

Inpatient care is appropriate when (a) pain and symptom management is out of control at home; (b) respite care is needed by the family for a limited period; (c) care is needed for a longer period because home care is not appropriate at the time (perhaps because of the illness of another family member); or (d) home care is not possible because there is no home available or no primary care person in the home who can care for the child adequately.

(8) Pediatric hospices should emphasize even more than do adult hospices ongoing professional and public education about the needs of terminally ill children and their families and the hospice alternative. This increased emphasis is needed because of the devastating effect of the death of a child on the whole community.

There are several major target groups for this type of education:

The community, so that people can face the idea of such deaths and support their neighbors. Knowledge of the existence of a pediatric hospice program will increase referrals.

The medical profession, particularly pediatricians and oncologists, so that they can better understand the needs of their patients and families, can better manage pain and other symptoms, and can refer appropriate patients to the hospice.

Discharge planners and others (in addition to physicians) who refer patients, so that they are aware of the hospice concept and the many hospice modalities available for appropriate referrals.

The community's institutions—schools, churches, service organizations, emergency squads, and so on—to increase knowledge and support.

Funding agencies, both private and public, so that funds may be available to continue this work.

Students in medicine, nursing, social work, pastoral care, and other disciplines, so that they will better understand needs and resources for terminal care and may later improve their professional approach to these patients and families.

The patients and families themselves, in the details of care and in understanding of the situation and their reactions to it.

The hospice staff and volunteers, in all areas.

(9) Pediatric hospices, like adult hospices, need to emphasize evaluation of their program and research on patient and family needs, details of care, and hospice organization. Particularly because of the paucity of data on terminally ill children and the appropriateness of hospices for them, demographic and other research results will make a major contribution to pediatric knowledge.

Based on this feasibility study and on ELM's experience with adult hospices, the following seven recommendations were made:

1. Develop a pediatric hospice program cautiously and with careful attention to detail. The need for careful planning is highlighted by data that show that the patient load is small. In addition, pediatric hospices are new; what few there are have tended to develop into chronic care services rather than hospices.
2. Become a pediatric hospice resource center and develop educational materials. This is a particularly urgent need at this early stage of pediatric hospice development.
3. Establish a solid referral base. This is especially crucial in light of the projected small patient load. The very existence of the program depends on referrals and the education of the referrers, particularly the physicians. Initiate a major effort as quickly as possible to establish a solid referral base, beginning with the major referring hospitals in the area. As the average length of stay in a pediatric hospice is not known conclusively, viability depends on adequate referrals for both inpatient and home care.
4. Determine criteria and responsibility for admissions to the program. The program administrators must be fully aware of both the diseases and conditions of the patients it will accept.

5. Establish staff selection criteria, training, and support systems. These must be planned carefully.
6. Utilize existing home care programs, if possible, and provide hospice care training to their staffs. Explore the utilization of home health agencies and of the home care programs of the major referring hospitals in the area. The pediatric hospice needs to assume responsibility for training such staff in hospice care and may need to provide, on occasion, assistance in staff recruitment and selection.
7. Provide a wide variety of care and support modalities and resources to meet the diverse needs of this target population. Attention must be paid to the variety of diseases and their side effects, the variety of needs of children related to age, the variety in family size (siblings, grandparents) and consequently of those suffering loss.

All this means that pediatric hospice staff need to be innovative and open and creative, and that the hospice needs to be a supportive, well-planned, professional organization. The development of a pediatric hospice represents a major challenge in a new field.

Much more needs to be learned about the care of terminally ill children and their families. Research is needed first to define more clearly the hospice-eligible pediatric patient and the appropriate time of referral and length of stay and second to evaluate the effect of a terminally ill child's age, level of cognition, and ability to communicate needs on the provision of care. Only then can the needs of these patients and their families be addressed successfully.

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Rabbinic Involvement in the Hospice Movement

Steven A. Moss

ALONG WITH "changing attitudes toward health care in general and toward the care of the dying in particular,"[1] the concept of health care known as hospice has grown and developed. Hospice care is a grass roots movement whose impact is being felt all across the country. Local community groups, hospitals, and medical centers are calling for a hospice system of health care which will provide the caring environment so sadly lacking for the terminally ill, an environment in which they can die with "dignity" as a whole human being.

As rabbinic leaders who need to be in tune with new developments in our communities which affect the well-being of those we serve in our congregations, we should be familiar with the concept of hospice care.

But, I believe, our involvement in hospice should go beyond the level of "useful information" to that of actual support and personal participation. The very nature of hospice care is spiritual and religious, and, I feel, deeply rooted in the Jewish view of life and death.

What Is a Hospice?

"The term 'hospice' derives from a medieval word for a place of shelter for travelers on difficult journeys."[2] Just as is the case with its related words—*hospitium*, "hotel-Dieu," or hospital—the connotation of "hospice" is hospitality, as it "offered an open door of welcome not only to the sick and dying, but the hungry wayfarer, the woman in labor, the needy orphan, or the leper with his bell."[3] The hospice was, for much of its pre-modern

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STEVEN A. MOSS is Rabbi of B'nai Israel Reform Temple in Oakdale, Long Island, N.Y. He is also the Chairman of the CCAR's Subcommittee on Grief and Terminal Illness.

history, a way station for pilgrims. As such, literally hundreds of them were located throughout Europe during the Middle Ages—in cities, in monastic hermitages in unpopulated areas, in mountain passes and river crossings, in any place that "presented the greatest hazards to travelers on their way to the Holy Land."[4]

The medieval hospice laid the framework from which developed the hospital. But down through the centuries, alongside the development of the hospital, the hospice remained a separate institution whose dedicated work turned specifically to the care of the terminally ill, who were considered pilgrims on a "spiritual" journey from one world to the next.

The current use of the term "hospice" began in the United Kingdom, "where many hospices have been established in the last ten years, most notably St. Christopher's Hospice."[5] There are various hospice models in use at the present time both in Europe and in America. Some are hospital-based, where there is a hospice unit in a local general hospital, containing only an in-patient component, which sometimes may be combined with an out-patient home care service. Other hospices have only an out-patient service, composed of a mobile medical oncology and nursing service which visits patients and families in their homes. The third model is the St. Christopher one, on which the New Haven, Connecticut hospice was based. This type of hospice has its own separate building with both in- and out-patient services.

The basic focus of the hospice is to meet the needs of the dying, and these include, in the words of Craven and Wald,

> relief from the distressing symptoms of their disease, the securing of a caring environment, sustained expert care, and the assurance they and their families won't be abandoned.[6]

Such needs are met by a program directed by a physician and which includes an interdisciplinary team of doctor, nurse, social worker, chaplain, etc., providing psychological, sociological, and spiritual services. The hospice is concerned with physical symptom control, that is, with the quality of living. When possible and desired by patient and family, the dying process and death occur at home, with the supportive team present and available. Whether the patient chooses to die at home, or is cared for in a hospice unit or an in-hospital hospice unit, that team is present at all times. In the unit, visiting hours are open with no age limitations. The patient's young children are frequent visitors, enhancing the atmosphere of the unit with their joy of living.

The patient is encouraged to bring any items which would create a "home-like" feeling in the hospice unit. The hospice patient is not considered the usual hospital case number, but is a distinct human being who is encouraged to live with wholeness and meaningfulness and to die with the same.

One of the most important aspects of hospice care is in the area of pain control. "Pain control, it turns out, is not so much a matter of what is in the medicine as it is how and when it is administered."[7] Medications are given when needed and not according to some arbitrary schedule which does not meet the patient's needs. The various medications are administered with the individual patient in mind, using those drugs which will make him as symptom-free as possible, in order to live as humanly as possible. And sometimes in the control of pain, or in the lessening of fear or anxiety, the things that can truly bring healing to the dying are:

> Gentle massage, a soft-pillow placed just so, a subtle change in diet, a tempting drink, or time taken simply to be present, quietly caring and listening, recognizing the person as a unique and valued individual . . .[8]

Bereavement care is an essential part of hospice care because as one cares for the dying, one must care for the living survivors. The hospice team lets the survivors know that even after the patient's death, they can turn to a team of professionals who knew that patient, and who can offer their support and love.

Hospice enables the dying to feel like a whole person and to die with the dignity of a human being in the highest sense of the term.

> Nothing that is human is excluded from the premises, or from the consciousness, of hospice life. Beauty here is not a matter of tidy appearances, logical proprieties, or even of physical prowess. Rather, it pertains to those exchanges between people living and dying, who value one another as vessels of a purer and more lasting force.[9]

Judaism and the Dying

It is undeniable that the institution of the modern hospice has its roots in Christianity's medieval history. But the Jewish community throughout its history has also had institutions for the care of the ill and terminally ill. The basic religious and spiritual dimensions of hospice care are an integral part of Jewish thought.

The term *Gemilut Chasadim* has been a "fundamental social virtue encompassing duties of sympathetic consideration toward one's fellowman"[10] with both religious and spiritual meanings for daily life. In Av. 1:2, Simeon the Just declares, "By three things is the world upheld: by the Torah, by service, and by deeds of loving-kindness [*Gemilut Chasadim*] . . . " "If the moral order was to survive, 'loving-kindness' had to be practiced: societies had to be created to take care of the sick, and the dying, and to bury the dead."[11] In Talmud Pei-a 1:1 it is said that the rewards of these social virtues (including welcoming the stranger, visiting the sick, and consoling the bereaved) are so great that they are enjoyed in both this world and the world to come. This guide for behavior toward our fellow human beings was such an integral part of the Jew's thinking and his societal actions, that it became a reading included in the opening section of the daily prayer service.

These religious ideals became the inspiration for the Jew's care for members of his society. The understanding that "the care of the poor and the sick and reverence for God are equated . . . "[12] became the *raison d'être* for societal institutions such as the hospice, the hospital, and the Holy Brotherhood (the *Chevra Kadisha*).

As far back as the hospitality shown by Abraham to the three strangers who visited him on their way to Sodom and Gomorrah, the above societal values can be seen operating within biblical and later rabbinic Jewish society. But it was with the Middle Ages that the Jewish hospital, called the *Hekdesh*, came to be. The term *Hekdesh*, originally meaning the Jerusalem Temple's treasury, reflected the financial support necessary for the running of a societal hospital. Marcus, in his pioneering work *Communal Sick-Care in the German Ghetto*, traces the concept of hospice care in both Jewish and Christian circles to the first century. He presents detailed comparisons between the two communities' hospices and hospitals down through the time of the Middle Ages:

> Had the Jews of medieval Europe been a large group invested with more economic and political rights, they no doubt would have developed along similar lines.[13]

Based upon its own funds and resources, the Jewish community in the Middle Ages did develop institutions to care for the poor, the sick and dying:

> The community saw to it that there was a hospice for poverty-stricken transients; it subsidized the 'respectable' poor of its own community who suffered reverses in life, and it issued a series of ordinances touching every phase of the life of its sick.[14]

The community cared for its sick and dying with all of the means avilable to it.

During the Middle Ages the Jewish community also cared spiritually for its sick and dying. During this time liturgical handbooks such as *Ma-avar Yabok* and *Seifer Hachayim* were developed. These were handbooks outlining religious and spiritual care of the sick, dying, dead, and bereaved. The genuine respect shown to the dying, even to the *goses*, who is in the last phase of the dying process, was a very important part of Jewish law and behavior. Such actions on the part of every Jew were so important that in *Ma-avar Yabok* it is written that the deeds of *Gemilut Chasadim* with the living and the dead are equivalent to the worthiness (*zechut*) of the patriarchal fathers. No matter at what stage along the living-dying continuum an individual might have been, that person was treated as a whole person, as a child of God worthy of the love and care of the community.

The Rabbi of Today and Hospice

The ideals and practices of the Jewish community, as described in the previous section, embody the basic philosophy of the modern hospice. The hospice of today makes real the dictum of Simeon the Just in that it takes the inspiration of the Torah's ideals and puts them into service toward one's fellow human beings by the acts of loving-kindness. Therefore, we—as rabbis and religious leaders—should be involved in the hospice movement both because of our Jewish values and because of our historical commitment to Jewish societal institutions.

At the end of this article I include a bibliography for those readers who wish to pursue in more detail the philosophy and history of the hospice movement. It is my hope that more rabbis will become involved in community hospice development in this country and that they will serve hospices as community chaplains.

I have been involved with dying persons through my chaplaincy work. I recall vividly a nineteen-year-old who was dying of leukemia. I received an emergency call to visit him. He had been in the hospital for three and one-half weeks with no rabbi's visit. When I walked into the room, the family asked if I had come to perform "last rites." A rabbi should not be a stranger to dying and to the dying process, but should be a part of that process through his or her presence and care. Our positive participation in the hospice movement will show our care for the dying and their families in the Jewish and non-Jewish communities.

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See also the various publications and reprints of the Hospice Institute, 765 Prospect St., New Haven, Conn. 06511.

NOTES

[1] William M. Markel and Virginia B. Sinon, *The Hospice Concept* (New York: American Cancer Society, 1978), p. 3.

[2] *Ibid.*

[3] Sandol Stoddard, *The Hospice Movement* (New York: Vintage Books, 1978), p. 9.

[4] *Ibid.*

[5] Markel, *loc cit.*

[6] John Craven and Florence S. Wald, "Hospice Care for the Dying Patient," *American Journal of Nursing*, Vol. 75, No. 10 (October 1975), p. 1816.

[7] Stoddard, *op cit.*, p. 64.

[8] *Ibid.*, p. 65.

[9] *Ibid.*, p. 48.

[10] Geoffrey Wigoder, ed., *Encyclopedic Dictionary of Judaica* (Jerusalem: Keter Publ. Co., 1974), p. 207.

[11] Jacob K. Marcus, *Communal Sick-Care in the German Ghetto* (Cincinnati: Hebrew Union College Press, 1978), p. 92.

[12] *Ibid.*, p. 91.

[13] *Ibid.*, p. 168.

[14] *Ibid.*, p. 6.

JEWISH HOSPICE
COMMISSION

A Hospice Guide For Care Of Jewish Patients And Families

JEWISH FEDERATION COUNCIL
OF GREATER LOS ANGELES

The Jewish Hospice Commission is grateful to the Jewish Community Foundation for funding this Hospice Guide. Particular thanks and words of praise are reserved for Rabbi Maurice Lamm, Chairman of the Jewish Hospice Commission, whose dedication, insights and wise counsel have provided inspiration and leadership. In addition, the Jewish Hospice Commission wishes to express its gratitude to Marilyn Friedman, Chairperson of the Council on Jewish Life, and to Jerry Weber, Director of the Council on Jewish Life. A listing on the following pages of the men and women responsible for the growth and development of this literature is a token expression of appreciation for leadership. There are many in the Jewish community of greater Los Angeles whose efforts and suggestions have guided us in our efforts and who have helped make this document possible. They deserve our thanks.

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PREAMBLE

The Jewish Hospice Commission was formed to serve existing hospices in their care for Jewish patients and families. To accomplish this mission, the Commission is active in generating religious materials, training courses, and in stimulating community interest in needs of the dying and their families. This booklet is designed to inform members of the helping professions about Jewish values and conduct, and to develop application of Jewish religious values to clinical care.

I. INTRODUCTION

DEATH, DYING AND LIFE AFTER DEATH

Death is the crisis of life. As there is meaning to life, there is meaning to death; as there is a Jewish way of life, there is a Jewish way of death -- attitudes and observances uniquely Jewish that relate to the dying and to the dead.

The Jewish tradition teaches that life has infinite value, and thus even the fraction of life left to the dying person is of infinite worth. While one may inform the patient of the seriousness of his * condition, one must always inject an element of hope. Perhaps it is only the hope of ameliorating pain; or the possible extension of life's duration by virtue of today's medical sophistication; or some divine miracle; or the immortality of the patient's cherished values; or the simple assurance that even now, time is measured not only by the clock but by its quality and meaning. Regard for the dignity of the individual requires that we strive to have family and friends accompany the patient until the very last possible moment.

Even after physical death, the body is considered holy because it has housed the sacred image of God, much as the holy scroll of the Torah retains its sanctity even after it is impaired. The body, therefore, should not be disturbed or touched unnecessarily until it has been removed and the burial process initiated. Jewish tradition has developed specific religious practices which express this respect for the dead.

Judaism has spoken historically of a life after death and this belief is held by many Jews.[1] If the soul is immortal, then death is only a night that lies between two days -- the day of life on earth and the day of eternal life in the world to come. This outlook has served as both a consolation and a hope for the dying person.

*This document utilizes the pronoun "he" to denote "he" and/or "she."

II. THE RESPONSIBILITY TO LIVE AND TO KEEP ALIVE

Judaism emphasizes that life is to be lived as fully as possible. This includes maintaining personal health, fostering relationships with family and friends, and contributing to the welfare of society.

One cannot accomplish these goals by pretending that realities do not exist. Consequently, while endeavoring to enhance the quality of life, a dying patient should make appropriate arrangements for the protection of those near and dear to him after death.

As emphasized earlier, neither patient nor physician should abandon hope. Relinquishing hope and effort may deprive the patient of the will to live and ministrations that could improve life. The model for this principle is reflected in the procedure for death-bed confessional in traditional Jewish practice. The confessional prayer (Vidui) is couched in the conditional rather than absolute mood. Rather than declare, "I am about to die and I confess my sins," the patient prays first for recovery, then, "If I am not to recover, I confess, etc." The conditional tone is prescribed to avoid despair and to buttress the patient's will to live.[2]

Similarly, Jewish medical ethics stress the duty to treat the person and not just the disease, and provide the effort, skill and facility to palliate, enhance, and not shorten life.

III. THE RELATIONSHIP BEWEEN PATIENT AND HELPING PROFESSIONAL

A. THE OBLIGATION TO HEAL

Judaism affirms that we inhabit a body that belongs to God. In consequence, we are responsible for its care through prevention and cure. The physician's efforts to cure are not perceived as a denial of God's prerogatives, but rather as a duty.

B. TELLING THE TRUTH

The following principles apply:

1. The better informed a patient is, the easier it becomes for him to cope with reality. People tend to do better when they are oriented to reality rather than fantasy.
2. The patient has a legal and ethical right to know the truth. Patients who want to know will usually ask direct questions. Such questions should be answered directly and honestly. When possible, answers can include hope for improvement, even if the improvement relates only to symptoms.[3]
3. Respect denial. Patients who do not wish to know will usually not ask questions. We should be prudent in providing unrequested information. Some patients may deny the reality of their situation in order to protect emotional integrity. This must be respected. According to Jewish law, it is permissible to withhold facts about a patient s condition (or that of a close friend or relative), or even to bend them, if that will contribute to the welfare of the patient.[4]

4. Needs of the patient are primary. Decisions as to sharing information about the patient's condition with family should be determined in this context.

C. EUTHANASIA

Judaism distinguishes between actively inducing death (active euthanasia) and allowing nature to take its course (passive euthanasia). All means of active euthanasia are prohibited. Passive euthanasia is more complicated. At some point in life -- usually characterized by debility, pain, and suffering, there is an awareness of approaching death with cure judged unlikely. Even at this stage, certain Orthodox authorities strenuously oppose any relaxation of energies to extend life. Nevertheless, some Orthodox rabbis and most Conservative and Reform rabbis, maintain that heroic measures are not required to prolong the life of a hopelessly sick patient (goses). The sacred obligation of the physician is then to make the patient as comfortable as possible.

D. ORGAN DONATION

Because Judaism views the body as God's property, we do not have the right to disfigure it without a good reason. One such reason is to help an ill patient through the use of a dead person's organs. This is not considered to be dishonorable to the integrity of the dead. Judaism requires that the donor be dead and that the practitioner approach the issue with reverence. Jewish authorities differ as to exact determination of the moment of death.

E. TREATMENT OF THE DEAD BODY

After death has been certified, the eyes and mouth of the dead person should be closed, if possible, by children, relatives or friends. A sheet is also drawn over the face.[5] Some Jewish families require that a rabbi be called who, in turn, will notify the funeral director to care for the body. From the moment of death until burial, the deceased should preferably not be left alone.[6] Customarily burial takes place as soon as possible after death. Cremation is forbidden by traditional religious law.[7]

IV. THE FAMILY

While the physician is required by Judaism to provide pertinent drugs to relieve pain, the most immediate human support to ameliorate suffering can be the family, with whom the patient has shared hopes, experienced tragedies and joys, and who represent the embodiment of his extension beyond death. In a situation of terminal illness, the family -- far from being an adversarial or obstructive presence -- can be a source of warmth, meaning, and love, and can strengthen the patient's will to live. Tending the sick is not merely a social responsibility but a religious obligation which alleviates anxiety and reaffirms the worth of life.

Traditionally, the family provides three levels of care:

1. Physical. This ranges from such basic functions as bed-changing and household work to relieving the patient from financial arrangements, insurance matters, etc.
2. Psychological. This involves reenforcing the patient's confidence in being able to deal with his perilous situation, providing companionship to relieve the desperate loneliness of serious illness, and, most important, cheering the patient. "Cheering" in Jewish tradition means humanizing the frequently prevailing antiseptic environment in which patients too often find themselves.
3. Spiritual. This means enabling the patient to perform religious rites, and encourages the patient to "talk to God" informally and in private as he sees fit. During serious illness, many Jewish patients desire to observe Jewish religious practices. This should be honored.

V. CULTURAL TRADITIONS AND VALUES

Jewish cultural traditions and values provide a source of spiritual comfort and order, and a continuation of the rhythm of life for the terminally ill Jewish patient and his family. Integration of one's Jewish heritage as life ebbs tends to promote the patient's well-being and to alleviate disorientation.

A. PRAYER

A significant facet of Judaism which can help maintain a patient's spirit is prayer. For those Jews who are not familiar with the Hebrew prayerbook, books of prayer are readily available in English and other languages. There are some collections specifically designed for the sick. Many Jews will also wish to use the traditional garb of Jewish prayer, i.e. the tallit (prayer shawl) and tefillin (phylacteries).

B. JEWISH DIETARY LAWS

Only certain categories of food and beverages are consumed by traditional Jews. The following are some prominent features of the laws governing ritually fit (kosher) food: pork and shellfish are prohibited, and separation of meat and dairy in both the preparation and eating of food is required. Adherence to the dietary laws is of overriding importance for a religious Jew in hospital as in home.[8] The Jewish belief is that dietary rules (kashrut) are biblical injunctions which foster holiness before God.[9]

C. CELEBRATION OF HOLIDAYS

The Sabbath period, from sunset Friday to sundown Saturday, is the fulcrum of a practicing Jew's existence and is generally a source of strength, refreshment, and cheer.[10] Observing the day by lighting candles, drinking sacramental wine, and eating *challah* (twisted bread) may be of primary importance for the person in hospital or home. The Jewish calendar includes *Rosh Hashanah* (Jewish New Year), two days which are marked by the blowing of the *Shofar* (ram's horn); *Yom Kippur* (Day of Atonement), a day of fasting and prayer, which also includes commemoration of the dead with the lighting of the *Yahrzeit* (memorial) candle; *Sukkot* (Tabernacles), which is marked by a prayer over nature's bounty, symbolized by the palm and citron; *Passover*, the holiday of *matzot* (unleavened bread) and the avoidance of bread products; and *Shavuot* (Pentecost), which celebrates the ancient spring harvest and the giving of the Torah at Mt. Sinai. Minor festivals are Chanukkah, marked by lighting eight candles, starting with one and increasing every night; and *Purim*, which is highlighted by the reading of the Scroll of Esther (*Megillah*). Holidays are based on a lunar calendar and corresponding dates in our solar calendar can vary from year to year. Each holiday has its own coloration and observances.

D. VISITING THE SICK

In order to lift up a patient's spirit, Jewish law requires that friends, as well as family, visit the sick to reassure them of their continuing worth as individuals and to reenforce their feelings of being integral members of the community. Judaism considers such visits to be important for the patient, but they are permissible only if the patient welcomes them. In the case of a dying person, tradition asks that a person not be left alone.[11]

E. JEWISH ETHICAL WILL

The Jewish religion has created a channel that can be helpful in enabling many dying persons to confront their death. An ethical will can assist them in sharing with their families what is most important to them.[12] An ethical will is a document which a dying pérson prepares in which he tries to articulate those matters that are most important in his life and wishes to pass on to family or friends. Just as we commonly leave a will to dispose of material possessions, it is appropriate that we leave a will to pass on a spiritual legacy. The ethical will can take any form. There are no legal requirements for the will from the perspective of Jewish law.

VI. GRIEF

The Jewish tradition recognizes that the ache and pain of death does not end with physical death. It views expression of grief not as a sign of weakness or self-indulgence, but as a deep human psychological need which all persons possess. In this context, it provides a number of avenues for grief work to occur through various laws, rites, and time sequences. Notable among these are: a mourning period of seven days by the bereaved after burial (*Shivah*); the observance of a period of thirty days after the funeral (*Shloshim*), during which mourners resume normal activity but avoid places of entertainment and continue to recite certain prayers; and the recitation of the *Kaddish* prayer daily during the first eleven months after death.

Judaism accepts varying coping and defense reactions which demonstrate grief but attempts to prevent them from becoming self-defeating or pathological by channeling them into controlled forms of expression.

An example of this is the custom of *Kriah*, where the mourner tears a section of his jacket, dress, or tie to symbolically represent the laceration in his heart. Despite prescribed rites, Judaism offers some latitude to differing sub-ethnic groups, such as *Ashkenazim* (European influenced) as against *Sephardim* (Mediterranean Sea basin and Near East outlook), in permitting variations in the form and style of mourning.

A major orientation of the Jewish response to death is to provide emotional and social support for the survivor. Jewish rituals of mourning mandate strong communal participation, such as a *chevra kaddisha* society, whose members devote themselves to preparing the dead body for burial, and a meal of consolation provided by neighbors for the immediate family on their return from the burial ceremony. These observances serve to reduce feelings of abandonment and loss on the part of the bereaved. They also afford a channel whereby the community can indicate feelings of shared loss. Additionally, they contribute to quickening repair of the breach which has occurred in the social fabric.

Judaism frowns on excessive grief. Hence, it limits the essential mourning period to the first year after death. Despite this, there still is provision for further grief catharsis in an annual memorial observance (*Yahrzeit*) each year on the anniversary of the person's death, as well as the saying of *Yizkor*, a remembrance prayer, four times during the year on holy days.

Judaism is a faith that embraces all of life, and views death as a part of life. As this faith leads us through moments of joy, so does it guide us through the anguish of grief, bidding us to turn our gaze from the night of darkness to the daylight of life.[13]

NOTES

1. There are four major movements in Judaism with varying attitudes toward religious observances. They are Orthodox, Conservative, Reform, and Reconstructionist.

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4. Caro, Joseph. Shulhan Arukh. Yoreh Deah 337. See also: "BaCH" (Joel Sirkes) to "Tur" [Arba'ah Turim, by Jacob ben Asher. (Vilna: 1900)] Yoreh Deah 337; Gersonides (Levi ben Gershom) to II Kings 8:10 [In: Mikraot Gedolot. (New York: Pardes, 1951)].

5. Lamm, Maurice The Jewish Way in Death and Mourning. (New York: Jonathan David Publishing Co., 1969) p.4.

6. Lamm, p.5.

7. Lamm, pp. 56-57. See also: Theodore H. Gaster. The Holy and the Profane. (New York: William Morrow and Co., 1980) pp. 142-148.

8. Siegel, Richard, Michael Strassfeld, Sharon Strassfeld, editors. The Jewish Catalog. (Philadelphia: Jewish Publication Society of America, 1973) pp. 18-19. See also: Hayim Halevy Donin, To Be a Jew. (New York: Basic Books, 1972) pp. 97-120.

   Note: Kosher frozen prepared meals are available for use in in-patient facilities without a kosher kitchen. Kosher "Meals-On-Wheels" are available in certain urban areas for patients in their homes. Contact the Board of Rabbis of Southern California for further information. [Board of Rabbis of Southern California, 6505 Wilshire Boulevard, Los Angeles, California, 90048, (213) 852-1234].

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***

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A TOPSY-TURVY WORLD

THERE IS a world out in space which is an exact duplicate of our own. It is populated with men and women like ourselves. They live in countries like our own. They conduct business and raise families. They live under various economies and governments. and are divided into different national, religious and racial groups. They differ in only one respect. In each country there is a pathological obsession with human welfare. As a result, over sixty percent of the national budgets are devoted to a compulsive and hysterical desire toward sheltering life from the normal ravages of human existence which we accept more stoically. Billions of dollars are spent by governments on the conquest of disease. Over the years, nations have poured their resources into medical research and today no cancer, no vascular disease, no kidney ailments, no degenerative disease exists. Unheard of sums are spent by governments on housing. They have so tortured their fiscal policies that slums and blight are unheard of. They are so over-protective of their children that they overpay teachers, and training schools for teachers have to turn candidates away. The perverseness of these conditions reaches its greatest height in their legislation against all private charities in behalf of human welfare. The outlawing of private charity has, of course, stifled the philanthropic instincts of the people.

There is only one exception to this restriction against private benevolence. Since the national budgets are so swollen with welfare appropriations, there is little left for national defense. It therefore becomes necessary for private citizens to raise money for armaments. Thousands of private organizations exist for this purpose alone. There are clubs to buy guns through raffles. People stand with tin cups on street corners to collect coins for the purchase of hand grenades. Drives are conducted to acquire tanks. There are tag-days for military aircraft. Cousin clubs sponsor dances to buy uniforms. The national governments simply neglect the problem of defense and let the burden fall on private agencies. But the inadequacy of this system is apparent to all. People are grumbling that under such a policy there will never be a war.

-Rabbi David Polish, Beth Emet Temple, Evanston, Ill.

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RAV SHESHET AND THE ANGEL

Mo'ed Katan 28a

"In the street like an animal?
You would take me here
among the shops and flies?
How dare you!"
Thus did Sheshet scream defiance
at Death.
"Come home with me!
Let me die in my bed
like a Mensch!"

Was it the cry, or
was it because no one
had said such things
to the Angel before?
Whichever it was,
Death followed Rav Sheshet
to his home
and waited for his family
to gather his last words.
Then,
and only then,
did he dare
to take his soul.

Between Dust and Dance
by Danny Siegel
Department of Youth Activities
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