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Implementing Empathy

at the End-of-Life

by

Rabbi Dr. Maurice Lamm

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Jewish Ethics
and the
Care of End-of-Life Patients

A Collection of Rabbinical, Bioethical, Philosophical & Juristic Opinions

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The National Institute for Jewish Hospice

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Relieving the Suffering

There are two sentences freighted with the most tragic overtones known to man: "We have done everything we can. Now you're in God's hands." There words trigger a hail of emotion, from anger to fear to jealousy to guilt, that rip open the innards of those who care but are helpless. From this moment until the advent of death, the terminal patient and his family experience the most painful and critical hours of their lives.

What follows are the bases for managing the terminally ill Jew, and then a number of real-life strategies of care, emanating from the Jewish understanding of regesh, feeling, which caregivers could use.

Dying is the juncture between time and eternity. It is twilight, not day, not night, when the sun sinks beyond the horizon. Curiously, it is precisely at the end of the day when the deep colors of day and night blend and swirl in broad strokes on the brush-painted sky. It is like the twilight of the trees in the fall, when the leaves burst with a palette of colors, bringing together the greens and yellows of summer and winter. In physical nature, twilight squeezes out the most brilliant and memorable of scenes, but in human nature, twilight is most often a gray, bleak mist that is swallowed up by the onrushing blackness.

Ideally, this should not be so. After the initial trauma, the dying should experience a stillness, a serenity, a coming-together of all of the events of life, a bottom line that makes everything add up, peace that until now they never knew. No longer the relentless pressure to "make it," the drive to posses more and more. No more reputation to earn; no impossible goals to reach; no petty power to be acquired; no glorious models to imitate; nobody to impress; no more games to play. Terminal patients know at last that the

bitch-goddess of success makes a mockery of sincere striving. Finally, too finally, they can become detached from everything that is not truly an extension of their own self. They can love whoever they wish to love; no more ulterior motives. They are left with their mind and their soul and their memories and their faith and their values; and only with real friends and family. It may be the first time they can afford to live in purity, and in total honesty with their private self.

Yet these times may become intolerable – when the ticking of the clock is too loud, when family members are confused, erupting in anger at no one, blabbering incessantly but to no point, pouring sweetness-without-substance over a sick relative; when the patient does not know what to think, what to say, what to do, what is proper, mentally transfixed by questions without answers: "Why me? What now? Who will take care?"

The individual has no experience in dealing with such matters. Until a generation ago, death usually came too quickly for the victim to ruminate, and that is why, according to Jewish law, the definition of dying is a process that takes at the most three days. Today, when people die from degenerative diseases, the process of dying is often extended for six months or more. Because people spend more time with the dying, they have more time to be frightened; the mystery becomes greater, the emotional complexities overwhelming. The dying person, like most people, is used to being in the company of family or friends at every major step of life. Now death will terminate all relationships with everyone. This is the great fear. The end-of-life patient will let go of the offering hands all around, and will proceed to the precipice of life slowly and alone.

It is not only that individuals have not dealt with this matter in any creative, significant way. The community has not even put the management of dying on its agenda.

patient. The giving may exalt love to a level that was hitherto unimaginable.

The art of loving is most strained when you love someone who is approaching death. Done properly, love can rise to its most intense level at precisely this moment; feelings can become more authentic that at any other time in life; the capacity of giving and for sheer goodness can be unimaginable, and their effect can physically lengthen a person's life and make the last moments beautiful. These last expressions of love plumb our deepest personal resources.

A friend of mine, Jack Goldberg, was trying to impel his wife, Mary, to take more medicine in her dying days. He said to her, "Mary, I'm not giving you poison." Mary looked at him and said, "Jack, I never thought you were capable of caring for me so much. Even if you gave me poison, from you I would take it as medicine."

It is twilight. As the sun falls behind the horizon, human life, like nature, can produce a burst of color – the color of meaningfulness, of hope and love.

The Jewish community, which deals successfully with the daytime concerns of youth movements and old-age homes and family services and hospitals, and also with the night-time concerns of cemetery and free burial and conferences on grief, has never dealt with twilight. But dying is the crisis of life. One can die in fulfillment and with meaning; or in misery – filled with hate and jealousy. The confrontation with death is the greatest test of personality and of culture. May we abandon our people at this crossroads?

Just as a Torah scroll, used for holy purposes, retains its holiness even when it becomes religiously unqualified, so we humans, having been created with the sanctity of Gods image, retain our dignity even in death when the image disintegrates. Human remains possess the same holiness that characterizes a disqualified Torah scroll. Thus one may not dishonor a corpse, just as one may not dishonor the scroll. In dying, as even in death, man retains the integrity of having been created in Gods image.

In fact, this Torah view of human worth is the basis of social work. The Western religions, derived philosophically from a Jewish base, hold that all people – especially those who are sick and infirm, or to young to take care of themselves – are the objects of social work practice.

This idea translates itself onto practical behavioral application in Jewish law. For example, the Torah mandates speedy burial because it compares a dead human being to a king's wayward twin brother who is being hanged. When people pass by, they say: "There hangs the king." the brother's hanging reflects upon the dignity of the king. In much the same way, the rabbis reasoned, if we unnecessarily leave a human corpse to lie unburied, shame accrues to the King of Kings; man's image is Gods "twin." So too the performing of a routine

autopsy, except when needed to save life, runs counter to Jewish law, which says that not only the soul but the body of the person that contained the image of God is not to be unnecessarily disturbed.

Moreover, dying must be confronted as a new reality. Franz Borkenau classified cultures as death-defying, death-escaping, or death-denying.

The Egyptian culture, against which the Israelites rebelled, built society around the glorification of death, symbolized for ages by the pyramids.

America has a death-denying culture. In an era of possible nuclear holocaust and of the graphic nightly portrayal of bloodshed on television, this is comically absurd. We deny death by diversion, stupefaction, a closing of the eyes, wishful thinking. We repress our fear of death by developing the art of embalming – beroughing the dead to make them look alive; by having family sit separate from friends in the mortuary, by masking graves with green mates and consigning the burial to hired diggers. Indeed, we gladly consign the dying to specialists: the physician, the charge nurse, the private nurse, the rabbi, the convalescent home operator, and finally, the mortician. Someone else is always there to handle the terrible reality. "We can't bear to see it," we say in self-indulging compassion.

But by history and by theology, Judaism is death-defying. Of all the forms of ritual impurity, the most severe defilement is caused by contact with a dead body. Contrarily, holiness is identified with life. We refer to a "God of life," and we are unable to accept a "dead god," whether it be Adonis or Jesus. Through the centuries the Jew has followed Dylan Thomas's prescription, "Rage, rage against the dying of the light," and our survival relates directly to this.

Not only does Judaism defy death, but, as a

scenes fly by as we focus on another era. The content of this episodic recall is triggered by soft words from sympathetic eager-to-listen relatives and friends., It is a vacation from the constant bad news of the current situation – vacations, celebrations, heroic achievements, incidents that stirred pride, weddings and births and grandchildren, a Bar or Bat Mitzva, long-dead relatives, another country, a happier time. One of the qualities of the human brain is that, even though the senses are fading, it has the ability to soar back to old scenes for instantaneous recall.

This iconic replay of life's repertoire can transform a patient's mood more humanely than mind-altering drugs. The God-given capacity to forget events too horrific to deal with can now be abetted by the God-given function of remembering.

Love

Since time is now limited, life becomes ever more precious, and the relationship between the family and the dying person should be intensified in depth and quality. This should be a period when loved ones sustain and cherish the patient. Perhaps the relationship has been strained for many years, that there were dissonances and bickering, and therefore that the expression of love now suddenly demonstrated is felt to be hypocrisy. But now life is new and love can begin anew. Rabbi Eliyahu Dessler, the twentieth century's greatest Jewish ethicist, asks: Which come first – giving or loving? The common answer is that one gives to a person whom one already loves. But the reverse is also true. One loves the person to whom one has given. The more parents give to a child in need, the more the love grows.

At a time of terminal illness, that family should give of themselves. They should hug and stroke and touch the

Setting one's house in order. The time of dying is a time to make arrangements for one's family, and for dealing with one's own personal attitudes and status and relationships. The patriarch Jacob was blessed with illness, the rabbis say, in order that he might prepare for death. The prophet Isaiah tells King Hezekiah: "Set thy house in order, for thou shalt die, not live."

Reminiscence

Virtually all terminally ill people prefer to doe at home rather then in an institutional setting, even a caring, free-standing hospice. This is not only because of the personal care and the presence of family members, but also because the home surroundings are familiar and is a source of security at a time of fearful uncertainty.

This universal sentiment is the origin of a number of traditions. Among them is that in the last hours of life the dying should be surrounded by a minyan of people, akin to the quorum required for public prayer. Death is a moment of sanctity, as is a prayer service. But it also an awareness that the ambience of friends and relatives makes for warmth and a great relief from the fear of loneliness.

The terminally ill desperately desire what they know they cannot achieve, life, getting out of bed, back to the old days. Reminiscence is really episodic recall. We change the ambience of those who are sick and enable their minds, even if only for a short time, to fly away from their troubles to an earlier, healthier time.

Neuroscientists hold that the human mind is like a tape-recorder, stacked with an infinite number of dormant memories. Recalling these long-forgotten memories is like digging up subcortical imprints of remote events. With the collaboration of the patient, we rewind the tape, and the

consequence of the sin of Adam, it literally refuses to consider death a natural phenomenon. It is, as Adin Steinsaltz terms it, "the disease of death." Man is to do battle against the "spirit of defilement," which, in fact, is a lifelong battle against death, considered to be the worst defect of this world. The climactic last phrase of the traditional funeral service is *bila hamavet la-netzach*, "May God swallow death forever." In the end of time, man will be victorious; death will be defeated. *Herpat amo*, "the shame of His people will He remove from this earth." This is not only a fond wish, it has become a mandate to Jews to struggle, when feasible, against the end which inevitably will engulf us all. This philosophy informs the obstinate Jewish refusal to give up on life even against the most insurmountable medical odds. It explains the profound reluctance to pull plugs and stop treatments.

But we must live our daily lives before the realization of that ideality for which we strive. The reality that in the end we will face death mandates our confrontation with the process of dying. The traditional Jew is expected to prepare for death. He often sewed his own shrouds, purchased a burial plot while he was in the blossom of life, wrote a will, arranged his funeral, and handled his own death as the necessary though ever-present evil that it is. Man must accept death after defying it to the last. But repressing the reality of death is an un-Jewish attitude, and our elaborate attempts to deny it are a religious absurdity.

In this sense, we are called upon to confront the reality of dying. In Jewish law, even such mundane matters as concluding a business contract and formulating a last will were guided by different, more binding and efficacious standards during these fateful days. This is a new reality, requiring new attitudes. It is not life as usual, and it is not the resignation of death. Hospice is effective to the degree

that it looks upon the process of dying as a new stage of existence and uses different norms with which to realize our humanity.

Dying is not primarily a scientific event. Judaism makes a clear distinction between *bios* and *humanum*: physicality and humanity. It is important to determine at what point before birth the fetus goes from *bios* to *humanum*, from a simple physical organism to a fully developed human being; and at dying, at what point the *humanum* returns to *bios*, when one loses one's distinctive sanctity as a human being and becomes a vegetating organism. Jewish law, for this reason, extends a person's *humanum* well beyond the conscious state until the last breath of existence as a person.

Judaism forcefully and legally affirms that a human being may never be treated solely as *bios*, even during the terminal process of dying. Man is not primarily a fact. Dying is not primarily a scientific event, it is a human one. During this period, the person has to be treated more humanely, more sensitively, not less.

The care given a dying person is a demonstration of whether the caregiver's emphasis is on *bios* or on *humanum*, Jewish law or feeling. Judaism long ago established that it is concerned not primarily with sickness, but with the sick person. The Midrash says that even when there are only a few minutes left to life, we should advise the dying person, "Eat this, drink that," notwithstanding that it cannot possibly make any difference. A deep concern for the prevention of human pain and suffering was uppermost in the rabbis' minds. Even when dealing with the angst of ordinary healthy people, all religious requirements are exempted in the face of pain. The Hebrew word for "doctor," *rofeh*, derives from the Hebrew word *rapeh*, which means "to ease" or "to assuage."

tested and turned and injected; they are cried over and spoken behind and prayed for. The Jewish tradition provides form specific activities which give them a sense of power - thought to be managed, projects to be executed which can excite the mind and spark one's imagination to think creatively, even during this time of smallness.

Ethical wills. In order to give them some initiative, terminal patients should be encouraged to write an ethical will. This is an ancient Jewish device. People should leave their families not only an estate but also a heritage. Sometimes parents have not been able to communicate effectively with a child or grandchild. This affords them the opportunity to leave their loved ones a sense of their purpose of life, their values and beliefs, in a format that will be treasured after death.

Oral history. Another application of empathy which is of clear value at this time is leaving behind the legacy of an oral history. By speaking into a tape-recorder to be transcribed later, they can give an account of their youth and education, of their beliefs and dreams. A mate, child, or nurse can assist by asking pertinent questions and guiding the conversation. Describing one's life in this way invokes good feelings, both in recalling pleasant memories during the days of recording the personal history, and then in giving children a gift volume describing their family roots. It is little short of an intimation of immortality.

Charity. The Jewish sages said that "Charity rescues from death." Obviously the sages were not speaking of magic. They meant that it saves the dying from the feeling of death. Distributing charity, no matter who the recipient or what the amount, and deliberating on who should receive it, may give a person a feeling of strength and a sense of being alive.

a. He should not have brought a squad of interns when he was to tell a person that she is going to die. Does anything more critically deserve privacy than this event?

b. He should not have stood next to her bed, he should have sat down. First, because a person lying down feels more vulnerable when somebody stands over her. Second, because he looks like he has to get out of there fast, and can't afford time to stay.

c. He de-hoped her by saying nothing could be done.

She had the pain and the scar and nothing was done? He never mentioned that other treatments could be tried.

2. How could the resident have en-hoped her?

a. Without lying, he could have said that some of the tumor was removed, though not all of it.

b. That further therapy would be required to attempt to deal with the remainder.

c. He could have said that miracles happen every day and that she might be one of them.

d. He could have told her that researchers are coming up with new medications, and who could tell whether she would she could be lucky enough to get a working remedy.

e. Also he could have used the old medical escape, "It's in God's hands. I pray that He will help you."

Would he have saved her life? Ultimately no. Would she have lived longer? The lady died too soon of evident heartbreak. Hope might have enabled her to live while she was dying.

Power

Dying patients find themselves in a passive condition. They are powerless to initiate significant actions or make significant decisions. They are

Hospitals, which treat *bios* exclusively, characteristically do not relate to a sense of shame on the part of the patient, to the need for privacy, personal delicacy, the need for warmth. The hospice, which emphasizes the *humanum* component and treats not only the illness but the patient, provides a team of psychologists, clergy, social workers, doctors and nurses, but mainly family and volunteers, because it has a primary concern for human comfort and for the prevention and control of suffering.

The difference between an emphasis on bios and humanum is tellingly illustrated in the style of informing patients of their terminality. One can announce it in a direct and accurate clinical diagnosis. But with an emphasis on the *humanum*, the telling can be a gradual self-revelation, a sort of Socratic self-understanding. After all, the shortest distance between two points is not necessarily a straight line when the straight line deals with a personal cataclysm, the upsetting of the whole natural order. If the patient chooses to deny the validity of the medical conclusion, Judaism tells us to respect his denial. Helmut Thielicke quotes a Japanese doctor who said, "There are lies that express profound human love." Truth we should tell, but the superior value is not truth but humanity. In all cases the old-folk wisdom obtains: "Be a mentsch" (Yiddish for "humane").

The care of the terminally ill, then, must embody certain fundamental principles: that we are created in the image of God and retain our integrity no matter who or in what condition we are; that a person's humanity should elicit from us sensitivity and delicacy; that defying death is an ideality and a hope, but the reality of our situation requires that we struggle to preserve life and, failing that, we struggle to preserve humanity, so long as we live. We

were created as human beings; we must nurture that creation by being human.

Strategies for Implementing Empathy

These underlying attitudes of the Jewish religion are expressed in specific strategies that ameliorate the agony attendant on a dying situation. If it is the true religion we believe it to be, Judaism must translate its moral axioms into policies of healthy behavior; virtually into a medicine-bag of attitudes which can make the twilight meaningful. These attitudes inform the Jewish component in hospice care. The Jewish part deals not only with Jewish law of medical-cure ethics, but with the Jewish law of care ethics. As there is a Jewish way of living, so too there is a Jewish way of dying – and of caring for the dying. The rich Jewish heritage, which thorough the centuries has experienced man in the zenith of his growth and the nadir of his decline, has designed helping strategies for coping with the problems of the severely ill.

Loneliness

That the dying are lonely is of course understandable. The shock has thrown them back on their own resources. They will travel the road to their ultimate destiny wholly alone, without any company.

But they are lonely for two other reasons as well. The dying have already begun mourning themselves, their own death, the world that will go on without their presence, without their direction. In Hebrew, the word for "mourner" is avel, which means "one who withdraws." The family withdraw and become mourners (*aveilim)*, after the dying patient's death, but the patient begins now to withdraw in mourning for himself.

The dying are alone not only because of their own psychological state, but because others cause them to suffer a pariah syndrome; they are figuratively placed

was admitted to the hospital with a lesion in the right lung. She was not in pain, and was affable and very cheerful and helpful to the health personnel on the floor. She was transferred to surgery for an open thoracotomy, and was found to have squamous cell carcinoma that had metastasized and was inoperable. Then a section was removed for biopsy and the incision was closed.

She had to be informed of the terrible news. The resident entered the room with a gaggle of interns behind him, stood at the bed, looked down at her and had this conversation with her.

> *Resident:* Well, it's cancer and we really couldn't resect it, so we just opened and closed.
> *Patient:* Opened and closed?
> Resident: Yes, well, it couldn't be removed, so we just closed. It was useless.
> *Patient:* Opened and closed?
> Resident nodded.
> *Patient:* Opened and closed?
> Resident nodded again.
> *Patient:* You mean you just left the cancer there?
> *Resident:* Yes.

The patient died that night. The autopsy showed no actual cause of death, just the cancer, which had been there for many months. Dr. Levine writes in the *Western Journal of Medicine* that she believes the patient simply died of despair, the removal of Esperanto, HOPE, all hope had been squeezed out of her.

Comment:

1. The resident de-hoped the patient. He did it with body language, with unthinking and callous disregard.

conversation. But what can one hope for? Pessimists are fond of saying that from the moment of birth one proceeds every day closer to death. Helmut Thielicke observes that this is not quite true. He makes an analogy with walking. Every step we take seems to be a falling, and yet at the very last moment, before we really fall, we stretch forth our other leg and straighten up again. After a series of fallings and risings, we find that we have progress through these ups and downs. But dying is, after all, the time of the final falling. What straightening up can come?

What rising sun can be expected from the twilight? Yet hope we must. One can hope for less pain, for the future happiness of children, for the family's continuation of the values one has spent a lifetime instilling. While there should be an intelligent awareness of hope's limitations in this situation, a sincere expression of hope is required by the tradition. In fact, Jews believe that death may be the beginning of exaltation. a reunion of the divine image with the divine source of being, as Abraham J. Heschel says:

> Death is not sensed as a defeat but as a summation, an arrival, a conclusion. Our ultimate hope has no specific content, our hope is God. We trust that He will not desert those that trust in Him. The meaning as well as mode of being which man hopes to attain beyond the threshold of dying, remains an impenetrable mystery, yet it is the thought of being in God's knowing that may be both at the root and the symbol of the ultimate hope.

Here follows an illustrative case history:

> Dr. Alexandra Levine at the University of Southern California (USC) Medical School reports on an experience as a medical student. A 55-year-old-woman

outside the social pale. If death is a terminus of relationships, then dying is its prelude, and relationships now begin to be strained and to alter. It is like a candle flame about to be extinguished that flickers and sputters before it dies. Among the flickerings in personal relationships are the friends and relatives who shy away from the severely ill because they do not know what to say, how to express their genuine feelings of remorse. The patient, amputated from the living body politic, becomes passive, abandoned, and disconnected precisely when what is needed is connectedness to overcome the forbidding loneliness of dying.

Judaism addresses itself to this problem through the religious requirement of bikkur holim, "visiting the sick." The sick visitation is not merely a practice of social etiquette, but the fulfillment of a religious obligation.

Unfortunately, the structure and content of this important function is very often not properly focused. It is simply an exercise in undiscerning sweetness – important, but not crucially helpful. We pay scant attention to what the tradition demands from this religious institution and how psychological findings can enrich it.

Visits should be frequent but of short duration, in keeping with the patient's fatigue threshold. We are not to hover over the bed, not to stand, bit to sit on the patient's level. The patient is constantly looking up at doctors and nurses and visitors and made to feel like an object "over" whom people work. We must never leave without praying on the patient's presence. We must never leave without expressing hope (as described below).

The very presence of people is a therapeutic process and considered a very great mitzvah ("obligation"). It reassures the patient of his continuing worth as an individual and reinforces the feeling of being an integral member of the family and community. Traditionally, in

fact, a minyan of ten Jews (the minimum number for a public service) was gathered to be present at the expected moment of life's expiration.

Apology

Jewish tradition understands that, in order to achieve a degree of inner peace, end-of-life patients need the process of *mehillah*, the asking of forgiveness from those they may have wronged. It is wiping the slate clean, an unburdening of the accumulated baggage of a lifetime. Indeed, they also need a *mehillah* of another kind. Even though death is not an act of will on their part, many patients feel a need to apologize, and seek "permission," for leaving their families and for the pain they cause by dying. The need may not be expressed openly, and in response it may require only a look of recognition, a holding of hands; but it should not be mocked or ignored.

Prayer

Maimonides rules that no *bikkur holim* visit is complete without prayer for the sick person. Prayer is considered a gift, not an obligation, and it can be a great comfort to many patients. There is a formal prayer, recited from the prayerbook three times daily in the traditional manner.

There is also informal prayer, which can be recited in any language, in any posture, at any time. This prayer may ask for an extension of life or for remission from pain. It also may be used to vent anger and complaint, even to ask for a rapid death. Prayer is especially valuable at this time because it allows for the articulation of hopes and fears in an accepted and elevated manner, and because it is offered as a communication from one who is powerless to the Almighty. Even those who do not customarily pray or even believe in God are often moved to do so in such conditions. "Pray for me" is a phrase often heard in hospital corridors. "Pray for yourself" is equally valid and even more helpful.

Curiously, the Code of Jewish Law suggest that whereas prayers recited in the synagogue or outside the room should be in Hebrew, the prayer in the patient's room may be recited in any language the patient understands. Prayer, in this sense, serves the twofold purpose of petitioning God and comforting the sick. It is also entirely proper to recite a prayer for the sick in the synagogue before an open Torah scroll. The prayer is called Mi she-Berakh ("He who Blesses).

Traditionally, over the centuries, the last syllables uttered by Jews as life nears its end are the words of a confessional prayer called Viddui ("Confession"). It is a cumulative apology to God for the misdeeds of a lifetime. The Sages considered it extremely valuable as an expiation for all sins. It is brief and moving. Great care should be taken to introduce this prayer delicately, assuring the patient that many have recited this prayer and survived. If it might traumatize the patient, it should not be recited.

An abbreviated form of the confession is as follows: *Teheyai mitati kapparah al kol avonotai* ("May my death be an atonement for all my sins"):

> I acknowledge unto Thee, O Lord my God and God of my fathers, that both my cure and my death are in Thy hand. May it be Thy will to grant me a perfect healing. Yet, if Thou has decreed that I should die, may my death expiate all the sins which I have committed before Thee, and grant me a portion in the Garden of Eden and cause me to merit the life of the World to Come, which is reserved for the righteous. Hear, O Israel, the Lord our God, the Lord is One.

Hope

What hope is possible for the dying? Yet, in the midst of this apparently hopeless situation, one is mandated by the Jewish tradition to inject hope into every visit, every