



BIO-ETHICS

UAHC COMMITTEE

Program Guide VIII

The Role of Pain and Suffering in Decision Making

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Developed by

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Reflections on Pain and Suffering: A Personal Letter²

Carol Baron
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...Anyway, for a lay person to address the issue of *pain and suffering* is quite intimidating because it is next to impossible to know how much pain and suffering another human being can endure.

In addition, there's a big difference between chronic pain that one can accommodate (whether through bio-feedback, medication, or appliance), and the pain and suffering of a terminal condition. Chronic pain that one finds a way to tolerate, while it causes a certain amount of suffering, if one *knows* this is the pain that will be with you as you go about the mechanics of life, one can almost learn to *tune out* that level of suffering. It's when there is pain, and it's connected with a degenerative condition where one *can't* go about one's life on almost *any* level, that the issue of suffering, or how much suffering one should have to endure, really gets *down and dirty*. Then it becomes a matter of the pain of the illness, the suffering and pain of your declining physical capabilities, suffering the pain of dependency (which for some is the *greatest* pain of all), and suffering the pain of knowing there's no recovery possible.

Now, who are *we* to say what anyone else should be forced to bear? The person who has the pain, the person who is doing the suffering, *they* are the ones who force us to confront the issue.

When there is a loving family to whom the dying person can appeal for whatever their wishes might be, that person is most fortunate, despite the misfortune of their illness, because in most cases, they know that their family has their (the patient's) best interests at heart. It's when these poor souls who are alone in the world have to depend on care-givers who, either because of their *own* religious beliefs, or their work load, or their callousness (or worse), it's *then* that the question of "who's in charge here?" comes into play.

I can only speak from personal experience. Both my mom *and* my dad, within a year of each other, at age 60 (only one year older than I am right now), died of cancer. Both were given chemotherapy and radiation following surgery. Both suffered awful, terrible, horrible, possible endings. And both of them, within a few days of the end, said, "enough already." It was *their* wish; it was *their* decision; it was *their* pain; it was *their* suffering. Now, my brother and I wanted to keep them with us for a few days longer, a few weeks longer, a few months longer, a few years longer. But we loved our parents, and respected *their* wishes. As a matter of fact, I'd go so far as to say that *we joined them* in that wish, for the pain and suffering to be over. If they had asked *us* to do it for them, what *wouldn't* we have done for them? Out of compassion, out of feeling, out of love.

I only hope that, if circumstances ever place my family in that same position, that when I say to them, "enough already," they'll hear me and know what I mean. To that end, I've prepared a living will, and trust them and whoever else is involved, to follow my wishes for *myself*.

The tears are on my cheek now, as I write and as I recall the sadness and pain of my mom and dad at the end of their lives, and I can only think of the phrase from our prayer books that says, "open unto us the gates of mercy." Rabbi Address, I'm only an interior designer, not a writer of fine prose or poetry. I hope my own small experiences can be put together with others' to give you some points of reflection as respected and esteemed counselors. We all look to *you* for, I suppose, a certain measure of approval, but for sure, for a large measure of guidance.

² Excerpted from personal correspondence between Rabbi Address and the author.

Is Death the Appropriate Treatment for Pain?

Ilena J. Blicher, MD³
Glendale CA

It is difficult to explore the issue of pain and suffering in the context of end of life decision making without the specter of assisted suicide looming into the picture. There have been numerous articles in the press and programs on television looking at the experience in the Netherlands, the cases surrounding Dr. Kevorkian, or the ballot initiatives in several states. In Oregon, such an initiative passed but the courts have intervened and put that issue on hold. It is an issue that will be continued to be raised until there has been significantly greater discussion of and some resolution of reasons behind it.

For most of us, the ideal death would occur at an advanced age, we would still be functioning, have minimal discomfort, live in a warm caring environment and finally die rapidly without a prolonged illness preceding that moment. Our greatest fear is that we will die alone, in unremitting pain.

As I began the process of preparing to write this article, my mother died. As with anyone who has experienced the death of a parent, the loss that is felt is tremendous. I, or rather she, was blessed in that she had almost the ideal death. She was almost 90, alert, active, interested in reading and people, lived in a retirement apartment near her daughter. Although she had suffered a small stroke two years before, the only residual left was her having to use a walker. When she died it was sudden and unexpected (at least for me). She collapsed and died within a few seconds. There was no attempt at resuscitation as my mother years before had signed an advance directive specifying that she did not want any attempts at resuscitation. Each time she heard of an elderly person being resuscitated she would vehemently remind all of us that she would not allow that to be done to her.

For too many people, death is not rapid. It is a prolonged process taking days, weeks, or months during which time the person may be in pain or suffering. The former, pain, is easier to deal with; the latter, suffering, may not be. The two terms are not synonymous; though we tend to interchange them too frequently, they are very different.

As a physician who specializes in neurology and as a member of several bioethics committees, I am in a position to see many patients who are slowly dying with diseases that have no treatment and may involve a great degree of discomfort if not significant pain. Some patients in spite of any pain they may experience seem to handle the situation in which they find themselves; they cherish whatever time they have. Others despair every second even if there is no pain involved; their suffering outweighs everything else.

Many people are swayed by the argument that we should end a person's pain and suffering with assisted suicide. Some because they have witnessed in the past a loved one die a painful death or because of their own fears of dying alone and in pain. The anecdotal stories of terminal patients not receiving sufficient analgesics to suppress their pain continue. Unfortunately, some of the anecdotal stories are true. There has been, however, a major change in the medical community in the past few years in the treatment of pain. Hospital and hospice bioethics committees are looking at the issues surrounding the treatment of pain and are actively developing protocols for pain management.

Last spring (1995) in Santa Monica California, a weekend bioethics seminar was held on this issue. Newer ways of treating pain are evolving, both in medication types available and in other modalities. Oral

³ Dr. Blicher maintains a private practice in neurology in Glendale, CA. She serves on medical and bioethics committees at three hospitals in southern California, as well as a joint bioethics committee of the Los Angeles County Medical Association and the LA County Bar Association.

medications, transdermal patches, intravenous medications, nerve blocks, transcutaneous stimulation are but some of the modalities available.

Physicians are no longer worried about the old bugaboos of treating severe pain with sufficient medications. It was not only frowned upon to "overprescribe," but in fact physicians were liable to prosecution from law enforcement agencies if it was felt they were overprescribing narcotics medications. Both the federal and state guidelines have been updated with the realization that treatment protocols depend upon the disease being treated, not simply the amount of medication being used.

Pain can be difficult to measure. What is minor pain to one individual may be severe to another. Is all pain unbearable? If it were, most families would have only one child and patients with shingles or cluster headaches would have a high suicide rate. We are able to tolerate the pain of a broken bone, headache, backache, or any of the numerous other common processes that cause pain because we know that the length of time the pain exists is limited. Even if there is no analgesia available we somehow bear it. It is when the pain is unrelenting and without obvious chance of treatment that we begin to despair. The patient with ongoing neuritic pain, the patient with metastatic cancer to bone as examples. The answer is not to end their lives but to conscientiously explore and utilize the medications and treatments available to mute their pain. In the case of terminal patients it is widely accepted to utilize sufficient analgesia for comfort even if as a side effect level of consciousness or respirations decrease unless the patient has instructed us not to use this degree of medication.

It is far easier today to treat an individual's pain than it is to treat their suffering. As I have previously suggested the two terms are not interchangeable. It is markedly more difficult to treat the suffering of an individual who feels alone, abandoned, dependent on others than it is to treat whatever physical pain may be present. The reasons for their suffering may be multitudinous and not always related to their medical problem.

As a physician I am obligated to treat my patients in the most appropriate way for their disease entity. At times this also means not treating if that is the patient's wish. It is important for each of us to decide how far do we want treatment to proceed, recognizing that even if we had previously decided one way, we have the option of modifying that. Do you wish to be kept on life support systems? If so, are there any limitations? Do you wish to be treated with medications, procedures? Do you want feeding tubes? The issue is not what your decision will be but that you enter into a thoughtful discussion of it with your family and physician. It is very difficult for family members to try to make these decisions if you are unable to and have not given them any insight into your desires.

Should pain itself be a factor in end of life decision making? I'm not sure it should be other than to ensure appropriate and sufficient treatment of pain if indeed we are now at a point of time when this is possible. What, however, do we do with the patient whose pain is unrelenting and is resistant to all we have available? That is the dilemma. It may be that as we continue to better treat pain there will be fewer and fewer patients in that category, and we can then approach how we deal with that patient in a more logical fashion.

The Role of Pain and Suffering as a Foundation for Decision Making

Michael H. Levy, MD, PhD⁴
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"If I have to live like this, I don't want to live." The lament of a terminally ill patient, a scorned lover, a bankrupt broker, or a constrained adolescent, these words express unbearable pain and suffering that challenges the listener to provide an appropriate response. Pain and suffering are common human experiences that require and affect many decisions. Intractable pain and suffering can compromise a person's autonomy by impairing decision making capacity and can modify the balance of benefit and burden that determines ethical beneficence. The optimal response to pain and suffering requires an understanding of the difference between pain and suffering and an awareness of available interventions to mitigate their intensity and/or facilitate their relief.

The human capacity to feel physical pain is essential for continued existence in a dangerous world. Typically, people try to avoid pain or, once experienced, seek help for its palliation. Some pains are accepted or even desired as enrichments of the human experience. Examples of such pains include natural childbirth and the "no pain, no gain" of physical conditioning. In general, however, excessive physical pain is considered unhealthy and counterproductive to rational decision making.

In his book, *The Nature of Suffering and the Goals of Medicine*, Cassell describes suffering as existential plight which he defines as severe distress associated with events that threaten the intactness of the person. Not all physical pain causes suffering. Physical pain can lead to or be aggravated by psychological, social, spiritual, or financial pain. In Cassell's model, physical pain causes suffering when the intensity of the pain is overwhelming, the source of pain is unknown, and the expected duration of the pain is endless. Patients with such pain feel out of control and perceive their pain as a threat to their continued existence as a person. Cassell defines personhood as the conglomeration of a person's personality, character, past, family, culture, roles, relationships, performance, behaviors, unconscious, body, secret life, hopes, and faith. Unrelieved suffering can destroy enough of the person so as to block or impair decision making capacity. The treatment of suffering itself demands many important decisions regarding the initiation, withholding, or withdrawal of life-prolonging or comfort-producing therapies. The anticipation of persistent suffering can diminish the intrinsic benefit or increase the potential burdens of decisions not directly related to the person's suffering or its therapy.

As with pain, some people may actually attribute a positive value to suffering. Such persons believe that suffering is the best means for self-transcendence or for enhanced understanding of the suffering of others. The obedient and the righteous choose to suffer some losses of personhood to gain their desired state of virtuosity. For most people, however, suffering is a negative experience that impairs decision making and demands its own set of therapeutic decisions. Except for martyrs, ascetics, and zealots, excessive suffering is dysfunctional to personal growth and burdensome to the friends and family of the sufferer. Unrelieved, continuous suffering is a common cause for psychological depression which reduces both quality of life and quality of decision making.

To optimize the role of pain and suffering as foundations for decision making they must be effectively relieved through skilled, individualized assessment and treatment. Reversible sources of pain and suffering must be identified and effectively treated. Most physical pains can be relieved by currently available medications, therapies, and procedures. No person should live or die with unbearable pain due to inadequate caregiver expertise. Barriers within the health care delivery system and within the patient/family must be overcome to assure optimal relief of pain. Insufficient priority, inadequate education, persistent myths and misconceptions, and restricted access to pain relief interventions must be

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corrected. Palliative therapy must be individualized to minimize treatment-related burdens and treatment-induced impairment of decision making capacity. The sufferer's life story must be heard and carefully analyzed to identify threats to personal integrity that can be mitigated.

In their *New Guide to Rational Living*, Ellis and Harper offer three basic approaches to minimize suffering. One can get out of the situation causing suffering, change the situation, or change the affective response to the situation. No person should endure pain and suffering for lack of clinical expertise. When the source of suffering cannot be avoided or reduced, sufferers can cognitively reframe their situation to reduce its impact on their personhood. An example of this approach is being thankful for having shared in the life of a loved one who has just died rather than remaining saddened by the loss of future sharing. People can also change their affective response to their situation by finding meaning in their suffering as delineated by Victor Frankl in his book, *Man's Search for Meaning*. By exercising the human freedom to choose one's attitude to a given set of circumstances, individuals can grow beyond their suffering and, thereby, overcome it.

The lament, "If I have to live like this, I don't want to live," is not a request for assistance in dying, but help in living. The listener must help the sufferer to identify the source of his or her pain and suffering. Beyond its diagnostic importance, the act of listening to the person's story validates the suffering and initiates its relief. Helpers should assure that sufferers have been offered appropriate interventions to palliate their suffering and minimize its distortion of their capacity to make decisions that are truly in their best interest. At the very least, sufferers should be accompanied on their life journey so that, if they must truly live "like this," they do not have to do so alone.

Suggested Readings

Cassell EJ: *The Nature of Suffering and the goals of Medicine*. New York: Oxford University Press, 1991.

Ellis A, Harper RA: *New Guide to Rational Living*. Hollywood: Wilshire Books, 1975.

Frankl VE: *Man's Search for Meaning*. New York: Pocket Books, 1963.

Jacox J, Carr DB, Payne R, et al: *Management of Cancer Pain*. Clinical Practice Guideline No. 9 AHCPR Publication No. 94-0592. Rockville, MD: Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, Public Health Service, March 1994.

Pain and Suffering in the Jewish Tradition

Rabbi Steven Moss⁵
Oakdale, NY

A number of years ago I walked into a patient's room while making my rounds as a chaplain in a cancer center. As I approached the woman's bed, I could not help but notice the difficulty she was having breathing. Each breath came after great exertion and each was accompanied by a deep sigh.

I introduced myself to her, sat down by her bed, and took her hand. While looking up at me, she pleaded, "Rabbi, could you please take my life. I can no longer stand this terrible pain and suffering."

I replied, "If I could take your life I would. I see the suffering you are experiencing. Unfortunately, I cannot do this because society will not allow me." I then asked her if she wanted to say the *shema* with me. Its words would act as a prayer for the peace that she yearned for, and as a sort of mantra which would hopefully allow her to find respite from her pain.

I have often reflected upon this visit. I have wondered if society will ever allow an "Exit House" to be part of our community in which a Dr. Kevorkian will end the pain and suffering of his patients when asked to do so. As a Jew, I have returned to our sources to discover what our tradition instructs our community regarding the alleviation of the physical tribulations people will go through during the end stages of catastrophic illness.

As to the alleviation of pain through medication, Jewish tradition is quite clear. J. David Bleich writes, "Elimination of pain is certainly a legitimate and laudable goal. According to some authorities it is encompassed within the general obligation to heal...everything possible should be done to alleviate treatment of pain even to a degree which at present is not common medical practice."⁶

Even the sanctity of Shabbat can be broken to end a person's pain, as R. Marinus in Kethuboth 60a teaches that a man suffering from chest pain can suck the milk of an animal on Shabbat, which although an act usually forbidden is allowed, as it can alleviate the man's pain.

Regarding the question as to the termination of life because of the oppressiveness of pain and suffering, the tradition seems to be equally specific. "Life with suffering is regarded as being, in many cases, preferable to the cessation of life and with it elimination of suffering...Life accompanied by pain is thus viewed as preferable to death. It is this sentiment which is reflected in the words of the Psalmist, 'The Lord has indeed chastened me, but he has not left me to die.' (Psalm 118:18)"⁷

The tradition seems to view the acceptance of suffering as being a good unto itself. "This confident assertion arises from the belief, which is so essential in Scripture, that suffering is in the control of God. Its effect in the rabbinic period was that suffering could be accepted as 'a good thing'."⁸ This view has as its basis Psalm 94, verse 12, where it is written, "Blessed is the man upon whom You place sufferings...."

The acceptance of suffering becomes part of a process of repentance by which the person's soul goes through a process of purification. "It is not surprising that R. Akiba was one of several rabbis to whom was

⁵ Rabbi Moss is the spiritual leader of B'Nai Israel Reform Temple, 67 Oakdale-Bohemia Rd. in Oakdale, NY.

⁶ J. David Bleich, *Judaism and Healing*. New York: KTAV, 1981, p. 137.

⁷ *Ibid.*, pp. 135-136.

⁸ John Bowker, *Problems of Suffering in the Religions of the World*. Cambridge: Cambridge University Press, 1970, p. 34.

In the Presence of Sanctity's Symmetry: A Reflection

Rabbi Cary Kozberg¹⁶
Columbus, OH

"Cast me not off in the time of old age; forsake me not when my strength fails me."¹⁷

I like to observe visitors who enter our nursing home. If they are new—that is, if the person they are visiting has not been a resident for a long time, or if they are relatively unfamiliar with the home itself—these words from the Psalmist may well resonate within them in a most powerful way. Sometimes if they are aware enough, if they are honest enough, they may be able to articulate not the fear and apprehension they feel when they visit, but also their sometimes overpowering sense of helplessness.

But even when feelings remain unexpressed, one only has to look into their eyes in order to know that they see themselves walking into "the valley of the shadow of Death," and that they *do* fear evil. So stark is the "otherness" of this place, that the comfort of the Rod and Staff is neither readily apparent nor readily felt. Indeed, this is a place where failing physical strength and diminishing mental capacity are acknowledged realities for residents, and terrifying possibilities for visitors. For the uninitiated, a nursing home is a place where the Angel of Death is ubiquitous and unrelenting. Thus, understandably, it is a place to be avoided.

And of all the areas in such a facility, no area seems to broadcast this message as does a Total Care Unit. Visit a Total Care Unit on any given day, at any given hour, and you will be visiting a foreign land, another world where the language is different, as are the rules of communication and socialization. Dementia brought on by advanced Alzheimer's Disease, organic brain syndrome, or stroke have made cognition and the capacity to reason impossible for its citizens. In this place grunting, bleating, and even blank stares may substitute for more "normal" speech; screaming and yelling may replace more familiar forms of articulation. What is deemed nonsensical conversation and mere gibberish by us rational folks are, in this world, part of the standard *lingua franca*.

I work in this world every day. Indeed, by choice my office is located at its entrance. When our new building neared completion, I had to decide between a smaller office in the Administrative Wing (the real world), or a somewhat more spacious office near this other, foreboding world. At the time, I opted for space over reality, and told myself that the sounds emanating from this other world would not disturb me, nor would they have any effect on my work.

How wrong I was! Having left my door open the first day I moved in, I quickly discovered that the screaming, the grunting, the bleating, and the gibberish were like the ever-present odor of incontinence—a natural, unavoidable part of the environment to be expected, and thus, to which one must become accustomed.

Yet, as I have learned since that day, they are not only natural, unavoidable, and expected. In a curious but very significant way, they are actually necessary. Whenever I hear them, they evoke this passage from the traditional *siddur*:

They (the Heavenly Beings) all perform with awe the will of their Creator...with pure speech and sacred melody they all exclaim in unison and with reverence: Holy, holy, holy, is the Lord of Hosts; the whole world is full of His glory.

Tradition teaches us that when a person recites this prayer, he/she proclaims God's sanctity in the world, as did the angels in Isaiah's prophetic vision. Thus, between the earthly and heavenly praises, a

¹⁶ Rabbi Kozberg is Director of Rabbinical/Pastoral Services at Wexner Heritage Village in Columbus OH.

¹⁷ Psalm 71:9.

symmetry of sanctity is created. Just as angels were created to continually praise God, so human beings were created also to praise God. That is our purpose for living; that is what ultimately gives human life meaning. Moreover, we also learn that praise of God is more beloved when it is offered as the result of free will—a gift bestowed upon human beings, and not angels.

But, alas, this is a gift that many of the residents on a Total Care Unit have lost. Having lost the ability to make free, rational choices, and having sustained other cognitive impairments (some able to make only unintelligible sounds or remain in a dumb stupor), they seem not just “little lower than the angels,” but tragically much, much lower. As we look upon their frail conditions and listen to their chatter or their silence, they indeed appear to be lost, wasted, useless, bereft of dignity and any meaningful quality of life.

Yet such observations, while perhaps shared by many, nevertheless do not reflect “facts.” The adjectives do not reflect “truth,” but are instead subjective descriptions, interpretations of our own choosing. In truth, they are conclusions we infer from a certain hermeneutic which itself views human life and its value from a certain perspective. And although that perspective may be widely popular in secular literature, it is not one shared by our Tradition. We can choose to interpret differently, as the passage from the *siddur* invites us to do.

Our Tradition teaches that the value of human life in all of its forms ultimately is grounded, not in notions of usefulness or cognitive ability, but rather in the belief that human life is *unconditionally* holy. What is valued is not life’s relative quality, but its unconditional sanctity. Human life in all of its forms is valued because it is holy; it is sacred because it is not only given by God, but also *sustained* by God. Moreover, as every human creature is brought into this world by the Creator and sustained in whatever way by the Creator, every human creature that yet breathes has a purpose—to praise the Creator in its own mysterious way—regardless of cognitive ability or apparent “usefulness to society,” even regardless of our own self-confident (but very limited) ability to understand, or concur, with this purpose.

Those who reside on Total Care Units, who are afflicted with dementia, who remain in a state of persistent unconsciousness are no longer vibrant, active individuals. There are those who conclude that these people have no “quality of life” and, therefore, should be treated as if they were “dead.” So says the hermeneutic of our secular culture. But a Jewish hermeneutic teaches otherwise: if they still breathe, they automatically praise God, as the prayer book declares elsewhere: “The breath of *every* living thing will bless your name.” And if they breathe, they cannot yet be dead, as it is written, “The dead cannot praise the Lord” (Psalms 115:17).

Perhaps such people, not vibrant and active, but not yet dead, are in a place “in between.” If this is so, perhaps we would do well to remember what Buber taught—that the spaces in between are precisely where one may encounter holiness. If we are open to perceiving not only sanctity which is manifest, but also sanctity which is concealed, if we can attune our ears to listening for the Divine issuing from everything, we may learn to hear the grunts and the screams not only as the sounds of suffering and abandonment in a seemingly “God-forsaken” place, but also as cacophonies which are mysteriously sacred in and of themselves. Reverberating in a corner of the world which is avoided by most, we may come to perceive these sounds as those of sanctification—offered by creatures who, like their celestial counterparts, have no choice in the matter, who now automatically praise the Holy One in a unique purity that comes from their afflictions. If the whole world *is* full of God’s glory, then even a Total Care Unit filled with helplessness and death, cannot be “God-forsaken.” The sounds that emanate are the melody to the lyrics of this testimony.

We humans not only revere that which is holy and sacred—we also avoid it. That which is sacred is often experienced not only with awe, but also with fear. (The Hebrew word *yirah*, as in *yirat Shamayim*, fear of Heaven, connotes both awe and fear.) Such is the nature of the numinous: so mysteriously filled with divinity, it is also taboo; so sacred it is too risky to encounter. Yet as theologian Sam Keen has written in *Fire in the Belly: On Being a Man*,

In the life of the spirit, paradox is the rule...opposites coincide, the diseased parts form a graceful whole...In considering the whole and holiness of life, we must at once hold before our eyes visions of horror and wonder, cruelty and kindness...both/and, not either/or.

To the extent we can understand this, to the extent we can affirm that our own feelings in the presence of the severely impaired and the terminally ill, come not only from a palpable fear in the presence of frailty and decline, but also from a deeper *yirah* in the presence of an undiscernable and ineffable sanctity, we may discover anew, even amidst horror/wonder, the presence of the Holy One in our broken world. If we do, may we then better succeed in helping to glue the broken pieces back together, and ultimately redeem them.

Section II—Study Pieces

1. **When Will Adequate Pain Treatment Be The Norm?**
C. Stratton Hill, Jr., MD
Editorial
JAMA, December 21, 1995—Vol. 274, No. 23.
2. **Exploring Human Suffering: Why the Reluctance?**
Timothy E. Quill
Bioethics Forum, Spring 1994.
3. **Excerpt from Quality and the Sanctity of Life in the Talmud and the Midrash**
Moshe D. Tendler and Fred Rosner
Tradition, Vol. 28 No. 1, Fall 1993.
4. **Excerpt from Comfort Care (Chapter 4)**
Timothy E. Quill, MD
Death and Dignity: Making Choices and Taking Charge
New York: WW Norton, 1993.
5. **Drugs to Relieve Pain**
Walter Jacob
Questions and Reform Jewish Answers—New American Reform Responsa, New York, 1992,
#151.
6. **Relieving Pain of a Dying Patient**
Solomon B. Freehof
American Reform Responsa. Vol. LXXXV, 1975, No. 76.
7. **Resources to Help Dispel Myths About Pain Management**
New York State Task Force on Life and the Law.
8. **Compassionate and Comfort Care Decisions at the End of Life**
UAHC Resolution.

care providers; however, if a valid health care provider-patient relationship exists, the strategies just mentioned should not threaten it.

Achieving adequate pain control must go beyond educating health care professionals and become an issue in monitoring the quality of patient care. If adequate pain relief using these methods still does not become the norm, patients must be empowered to demand adequate relief, regardless of the cause of the pain or the methods required to achieve relief. In all situations, relief of pain, either acute or chronic, must be the standard for success.

²⁶ Perry S, Heidrich G. Management of pain during debridement: a survey of US burn units. *Pain*. 1982, 13: 267-280.

Exploring Human Suffering: Why the Reluctance?²⁷

Timothy E. Quill²⁸
Bioethics Forum, Spring 1994

Medical clinicians seem reluctant to explore their patients' suffering with the same intensity and caring that they apply to their patients' underlying biological problems. In this essay, I speculate about reasons for this reluctance beginning with a story of extreme suffering told to me by a long-time patient.

Bill²⁹

Bill was a physically fit, energetic man in his mid-seventies who still worked part-time when he wasn't playing tennis or golf. He lived life fully and was a joy to be with because of his thoughtfulness, sensitivity and wit. His first encounter with serious illness came when he suddenly lost the vision in the center of both his eyes from a disease called macular degeneration. He became legally blind and was unable to read, drive, or enjoy sports that required fine hand-eye coordination. Though he was devastated by this loss, he began to adjust and develop new skills to get around his deficit.

Several months later Bill was found to have cancer in his throat. Because the cancer had already spread to the lymph glands in his neck, Bill was not a candidate for operative treatment. Instead, he was offered radiation treatment which he was told had a good chance of controlling the disease. To take advantage of this chance, he would have to tolerate a sore mouth, difficulty swallowing, and perhaps temporary hearing trouble. With little hesitation or questioning, he began radiation treatment.

The reality of the radiation treatment was unfortunately harder than he imagined. He permanently lost most of his hearing and could not swallow any solid foods. Though the tumor shrank, the hearing loss and the inability to eat solid foods persisted. He adjusted as well as he could to these severe losses, though his energy and joy of life never fully returned.

Over the subsequent eighteen months, Bill lost weight, had constant headaches and walking short distances left him exhausted. His cancer began to grow rapidly making it difficult to swallow liquids. It had also spread to his sinuses and his brain. Large amounts of drainage from his nose forced him to wear a pad under it to keep himself dry. Bill found the drainage from his nose and mouth to be humiliating, a constant reminder of his physical degradation. This once active, joyful, proud man was now legally blind and severely hearing impaired. Copious quantities of mucus drained constantly from his nose, and he was unable to swallow most of his own secretions. After two years of progressive loss and misery, it would only get worse.

A long-time patient of mine, who was a retired nurse and a former hospice worker as well as a Hemlock Society member, was also a close friend of Bill and his wife. As a friend of the family with special knowledge and experience, she was called on for advice because of Bill's rapidly deteriorating condition. Bill's wife confided, with tears streaming down her face, that he was now thinking about

²⁷ For many reasons health care professionals, patients, their families and society are often challenged by suffering. This essay suggests why clinicians, in particular, are unwilling to journey into suffering with their patients and proposes how they might overcome these barriers.

²⁸ Timothy E. Quill, MD, is associate chief of medicine and associate professor of medicine and psychiatry at The Genesee Hospital, University of Rochester, Rochester, NY.

²⁹ This story was initially presented in Timothy E. Quill, *Death and Dignity: Making Choices and Taking Charge*. New York: WW Norton, 1993, pp 117-120.

Excerpt from *Quality and the Sanctity of Life in the Talmud and the Mishnah*

Moshe D. Tendler and Fred Rosner
Tradition, Vol. 28, No. 1, Fall 1993³²

Physical Pain

Intractable pain is described in the Talmud in several cases. In each instance, death is the preferred outcome and either the removal of an impediment to death or the withholding of a life-prolonging measure to allow death to occur naturally is not only sanctioned but praised. One case concerns Rabbi Yehuda haNasi, known as Rebbe, the compiler of the Mishna. When he fell deathly ill, his handmaid ascended the roof and prayed for his recovery as follows:

The immortals [i.e., angels] desire Rebbe [to join them] and the mortals [i.e., the Rabbis] desire Rebbe [to remain with them]; may it be the will [of God] that the mortals overpower the immortals (Bava Metsia 85a).

She saw how often he resorted to the privy because he suffered from acute and painful intestinal disease. She observed him painfully taking off his phylacteries whenever he went to the privy and putting them on again when he returned. As a result she prayed: "May it be the will [of God] that the immortals overpower the mortals."

But the Rabbis incessantly continued their prayers for heavenly mercy for Rebbe's recovery. She, therefore, interrupted the prayer service by throwing an urn to the ground. The noise startled the Rabbis who momentarily ceased praying and the soul of Rebbe departed to its eternal rest (Ketobot 104a).

Another quality of life case involving intractable pain is that recorded in the Talmud as follows:

One of Rabbi Akiva's disciples fell sick and none of his fellow students visited him. So Rabbi Akiva himself entered [his house] to visit him and provided necessary care. "My master, you have revived me," said the disciple. [Straight away] Rabbi Akiva went forth and lectured: He who does not visit the sick is like one who sheds blood (Nedarim 40a).

Rabbi Nissim Gerondi, known as Ran (1320-1380), states in his talmudic commentary that "none visited him" and, therefore, none prayed on his behalf either that he recover or die. What the Talmud means, continues Ran, is that sometimes it is appropriate to pray that a patient die, particularly if the patient is undergoing great suffering and has an incurable disease or condition. He then cites the case of Rebbe and his handmaid as an example of severe suffering where it is to the patient's benefit that one pray for their death.

Perhaps the most famous talmudic case of severe physical pain and suffering is the story of Rabbi Hanina ben Teradion who was martyred because he refused to abide by the Roman decree not to study and teach Torah. According to the Talmud (Avoda Zara 18a), he was wrapped in the Torah scroll, and bundles of branches placed around him and set on fire. The story continues as follows:

They then brought tufts of wool, which they had soaked in water, and placed them over his heart, so that he should not expire quickly... His disciples called out, "Rabbi, what seest thou?" He answered them, "The parchments are being burnt but the letters of the Torah are soaring on high." "Open then

³² pp. 22-27.

thy mouth" [said they] "so that the fire enter into thee" [and put an end to the agony]. He replied, "Let him who gave me [my soul] take it away, but no one should injure oneself." The executioner then said to him, "Rabbi, if I raise the flame and take away the tufts of wool from over thy heart, will thou cause me to enter into the life to come?" "Yes," he replied.

Several lessons are derived from this narrative. First, the removal of an impediment to death, i.e., the tufts of wool, is permitted to allow nature to take its course. Second, it is forbidden to hasten one's death, i.e., by opening the mouth to let the flames enter. Third, there was great concern voiced about the intractable pain the Rabbi was suffering—an important quality of life issue.

Increasing the flame presents a serious challenge to the unanimity of halakhic opinion that active euthanasia is never condoned. This view was affirmed by Rabbi Hanina who refused to open his mouth and breath in the flames. One of us (MDT) has suggested that, as an extra measure of cruelty not mandated by the Emperor or Governor, the Executioner had placed the wads of wet wool and had lowered the flame. "Burning at the stake" had a formal protocol which was not followed by the cruel Executioner. Restoring the flame to its original intensity is not considered an act of hastening death but merely the removal of the extra measure of cruel torture introduced by the Executioner.

Mental Anguish

Judaism is not only concerned with physical pain but also with psychological or emotional pain. Mental anguish is just as significant as intractable physical pain. Mental and physical suffering are recognized as being of equal importance in Jewish legal thought. A woman who has had two post partum psychoses is allowed to use contraception since another pregnancy would be a serious threat to her mental health.³³ Even abortion is sanctioned for serious maternal psychiatric disease that may lead to suicide.³⁴

In the area of death and dying, Judaism is concerned with psychological trauma. A classic example of this concern is the talmudic story of the great righteous Sage Honi the Circle-Drawer who slept for seventy years. When he awoke and identified himself, no one would believe him. When he came to the house of study and told the rabbinic scholars who he was, they did not believe him nor give him the honor due to him although they recognized his great mastery of Torah Law. This hurt him greatly and he prayed for death and was granted his wish. Raba commented: Hence the maxim, "Either companionship or death" (Taanit 23a). Honi had no terminal illness but suffered from severe mental anguish and psychological pain. By divine intervention his suffering was ended and his wish for relief by death was granted.

Another example of concern for psychological pain is recorded in the Midrash.³⁵ A very old woman came to Rabbi Yose ben Halaftha saying that she was so old that life had no more meaning. She complained of loss of appetite and lack of desire to live and she asked to be taken from this world. He said to her, "How did you reach such a ripe old age?" She replied, "I go to synagogue services every morning to pray, I allow nothing to interfere with that daily activity." He said, "Absent yourself from the synagogue for three consecutive days." She complied with the Rabbi's suggestion. On the third day she took ill and died. The Midrash is a proper source for halakhic directives when unopposed by talmudic sources.³⁶

³³ R. Moshe Feinstein, Responsa *Iggerot Moshe, Even Haezer*, part 1, no. 65.

³⁴ R. Nathan Friedman, Responsa *Nester Mata'ai*, part 1, no. 8.

³⁵ *Proverbs Rabba* 8.

³⁶ The great talmudic authority Rabbenu Tam (1100-1171), head of the French School of Tosofists, cites in two places (*Berakhot* 48a, s.v. velvet hikhata and *Sefer haYashar*, no. 619) that the Midrash is the source of practical Jewish law (halakha lemaase) if it is unopposed by any talmudic reference.

Excerpt from Comfort Care: A Humane Alternative

Timothy E. Quill, MD

from *Death and Dignity: Making Choices and Taking Charge*, Ch. 4.

New York: WW Norton, 1993³⁹

Comfort care is a humane approach to the medical treatment of incurably ill patients that embodies a set of principles, values, and techniques that are quite distinct from traditional medical care. Comfort care focuses its energy more on the patient's quality of life, personal meaning, and symptom alleviation than on prolonging life or treating disease. Given the dual directives of the Hippocratic Oath, comfort care clearly dedicates itself to alleviating patient suffering. The terms "comfort care," "hospice care," and "palliative care" are used interchangeably to capture this approach and philosophy. Comfort care is generally discussed and initiated under two circumstances: (1) when traditional medical treatments of a patient's disease are no longer effective; or (2) when the burdens of the patient's illness outweigh the benefits of continued aggressive medical treatment.

Although a comfort-care philosophy can be implemented in any clinical setting, it is most commonly associated with formal hospice programs. A hospice program is the institutional expression of comfort care, sometimes in the form of a residential facility devoted to the care of the dying, and other times in a formal program designed to provide comfort-care services in the patient's own home. Formal hospice programs began in England in the late 1960s with the founding of St. Christopher's Hospice in London. Initially they emphasized inpatient care of the terminally ill—patients were admitted to a residential facility, where they received comfort care from an attentive, multidisciplinary team of caregivers until they died. Hospice programs have proliferated in the last twenty years, both in the United Kingdom and in the United States, and they now provide a wide range of residential and home-based services. In the United States, the emphasis has been on providing comfort care in the patient's own home.

My own involvement was as a medical director of a Medicare-certified hospice program in Rochester, New York, where a wide range of health-care services and social supports could be provided, using a comfort-oriented philosophy within the patients' own homes. In our hospice and in many like it in other communities, the patient's primary physician and the primary hospice nurse coordinated the patient's care. The resources of a team that includes social workers, nurses, volunteers, clergy, and a physician consultant can be drawn upon, depending on a given patient's condition and needs. Unlike a residential hospice, home hospice does not provide twenty-four-hour supervision, and considerable responsibility is placed upon family members and friends to provide a large proportion of the patient's physical and emotional care. Applying a comfort-oriented approach to a patient's medical care does not require a formal hospice program, though the resources that become available in such programs can mean that the plan becomes more sophisticated and comprehensive.

The comfort-care philosophy can be used to guide treatment in any setting, including an acute hospital. However, it is most commonly offered by physicians only after all possibly effective medical treatments have been completely exhausted and the patient is near death. It is less frequently explored with patients whose quality of life is deteriorating, and whose burdens from acute medical treatments are increasing. The latter considerations are more subjective and personal, and are dependent on the patient's own experience, views, and values. By exploring truly distinct approaches to treatment such as comfort care earlier in a patient's illness, and by being more honest about traditional medicine's potential limitations, patients can be given more control and choice about their treatment. The decision to continue trying every possible life-prolonging medical treatment no matter what the odds or side effects should be the result of a process of informed consent. There is nothing inherently preferable about an aggressive medical approach or a comfort-oriented strategy. The choice should belong to the patient.

³⁹ pp. 76-79.

Comfort care involves distinct trade-offs and priorities compared to traditional medical care. In traditional medical care, increased suffering is reluctantly accepted as a side effect of treatment that is directed primarily at extending the patient's life. In comfort care, unintended shortening of a patient's life can be accepted as a potential side effect of treatment, provided the primary purpose of the treatment is to relieve suffering. The underlying religious and ethical principle is called the "double effect," which absolves physicians from responsibility for indirectly contributing to the patient's death, provided they intended purely to alleviate the patient's symptoms. It places considerable weight on the physician's unambiguous intent to relieve suffering and not to intentionally shorten life.

Accepting the double effect in the care of the terminally ill has humanized and substantially improved the quality of life before death for many patients. It has freed doctors to use narcotic pain relievers so that they can effectively treat severe physical pain without fear of being morally or legally accountable if that treatment inadvertently contributes to an earlier death. Comfort care promises to humanize the process of dying, and to focus medical attention more on improving the quality than the quantity of the time remaining. In practice, comfort care allows physicians to use their considerable personal and professional resources to attend to the patient's suffering with the same intensity that they apply to prolonging the patient's life in traditional medical care.

Another fundamental difference between comfort care and traditional medical care is the relative emphasis given to the *patient as a person* compared to the patient's underlying disease. In the intensive-care unit, which represents the extreme of traditional medical care, invasive, often painful measures are used to monitor and treat a patient's underlying disease. Although every attempt is usually made to treat the person respectfully, the disease is the primary focus, not the patient. Comfort care, in contrast, involves the intensive care of the person. Treatment of the underlying disease is only relevant in how it contributes to the patient's overall quality of life. All treatments, procedures, and routines directed at the disease that do not directly contribute to the patient's comfort and personal integrity are discontinued. Treatment of uncomfortable sensations and symptoms takes clear precedence over treatment of the underlying disease.

Drugs to Relieve Pain

Walter Jacob

Questions and Reform Jewish Answers—New American Reform Responsa
New York, 1992, #151

Question: Does Jewish tradition set a limit to the use of drugs in order to alleviate pain? Frequently, physicians seem hesitant to prescribe drugs due to the fear of addiction or other reasons. What is our attitude toward pain and its alleviation? (Rena T. Hirsh, Santa Barbara CA)

Answer: Jewish tradition is not ascetic and does not endorse self affliction through pain. The only exception is *Yom Kippur*, along with some of the lesser fast days. On that day, we are commanded to "afflict our souls," but that does not entail real suffering, only fasting and abstinence from sexual intercourse. Even fasting is not necessary for those who are physically impaired. We feel no necessity to renounce this world and its blessings and so need not afflict ourselves in order to attain salvation in the next world. This is in vivid contrast to some forms of Christianity.

It is true that rabbinic tradition has interpreted the suffering of the people of Israel and of individuals, as either Divine punishment or as a test (*Job; B. B. 5a; Shabbat 55a*, etc.). However, in none of these sources and many others, has anyone been asked to seek suffering, rather than try to avoid it. During illness we may use every medical means available to avoid pain (Shulhan Arukh Yoreh Deah 241.13 and commentaries).

There are enormous variations in the pain threshold of individuals. Many physicians refuse to consider this or do not appropriately deal with the entire issue of pain. Sometimes, this is because specialists, who do not communicate with each other, are treating the patient; each is concerned with a specific organ or system and none is aware of the total effect on the patient. At other times, it is simply due to indifference and a lack of interest in the patient, possibly because the attending physician has never suffered any serious pain. There is certainly nothing within Jewish tradition which would restrain the treatment of pain. We would have a greater fear of continuous pain than addiction.

We must be equally concerned with the pain of the terminally ill. There is a fine line of distinction between alleviating pain and prescribing a drug which may hasten death. When the pain is great the physician should alleviate the pain and not be overly concerned about the latter consequence, as death is certain in any case. (W. Jacob ed., *American Reform Responsa* #79, etc.).

There is nothing within Jewish tradition that would keep pain relieving drugs from being given when medically indicated. We would hope that the patient be made as comfortable as possible and that this will help recovery or make the last days of life easier.

August 1991

Relieving Pain of a Dying Patient

Solomon B. Freehof

American Reform Responsa, Vol. LXXXV, 1975, No. 76.

Question: A dying patient is suffering great pain. There are medicines available which will relieve his agony. However, the physician says that the pain-relieving medication might react on the weakened respiratory system of the patient and bring death sooner. May, then, such medicine be used for the alleviation of the patient's agony? Would it make a difference to our conclusion if the patient himself gave permission for the use of this pain-killing medicine? (Rabbi Sidney H. Brooks, Omaha, Nebraska)

Answer: Let us discuss the second question first, namely, what difference would it make if the patient himself gives permission for the use of this medicine, though he knows it may hasten his death? There have been some discussions in the law in recent years of the difference it would make if a dying patient gave certain permissions with regard to the handling of his body after death. For example, he might ask for certain parts of the usual funeral ritual to be omitted; and some authorities say that he may permit autopsy. If I remember rightly, this permission was given by the late Rabbi Hillel Posek of Tel Aviv. But all these statements, giving the dying man the right to make such requests, deal with what should be done with his body after death, but not with any permission that he may give for hastening his death. After all, for a man to ask that his life be ended sooner is the equivalent of his committing suicide (or asking someone else to shorten his life for him). Suicide is definitely forbidden by Jewish law.

However, we are dealing with a person who is in great physical agony. That fact makes an important difference. A person under great stress is no longer considered in Jewish law to be a free agent. He is, as the phrase has it, *Anus*, "under stress or compulsion." Such a person is forgiven the act of suicide, and the usual funeral rites—which generally are forbidden in the case of suicide—are permitted to the man whose suicide is under great stress. The classic example for this permissibility is King Saul on Mount Gilboa. His death (falling on his sword) and the forgiveness granted him gave rise to the classic phrase, in this case, "*Anus keSha-ul*." Thus, in many cases in the legal literature the person committing suicide was forgiven and given full religious rites after death, if in his last days he was under great stress. (See the various references given in *Recent Reform Responsa*, pages 114ff, especially the example of the boys and girls being taken captive to Rome who committed suicide [B. Gittin 57b]; the responsum of Joseph Weil, 114; and that of Mordecai Benet, *Parashat Mordechai*, Yoreh De-a 25; and the other responsa given in *Recent Reform Responsa*.)

However, a caution must be observed here. The law does not mean that a person may ask for death if he is in agony, but it means that if in his agony he does so, it is pardonable. In other words, here we must apply the well-known principle in Jewish law, the distinction between *Lechatechila*, "doing an action to begin with," and *Bedi-avad*, "after the action is done." Thus, we do not say that *Lechatechila* it is permissible for a man to ask for death, but *Bedi-avad*, if under great stress he has done so, it is forgivable.

So far we have discussed the situation from the point of view of the action of the patient. Now we must consider the question from the point of view of the physician. Is a physician justified in administering a pain reliever to a dying patient in agony when the physician knows beforehand that the medicine will tend to weaken his heart and perhaps hasten his death?

Jewish traditional law absolutely forbids hastening the death of a dying patient. It requires meticulous care in the environs of the dying patient, not to do anything that might hasten his death. All these laws are codified in the *Shulchan Aruch*, Yoreh De-a 339. See the full discussion in *Modern Reform Responsa*, pp. 197ff. If, therefore, this were definitely a lethal medicine, the direct effect of which would be to put an end to the patient's life, the use of such medicine would be absolutely forbidden. But this medicine is neither immediately, nor intentionally, directly lethal; its prime purpose and main effect is the alleviation of pain. The harmful effect on the heart of the patient is only incidental to its purpose and is only a possible

secondary reaction. The question, therefore, amounts to this: May we take that amount of risk to the patient's life in order to relieve the great agony which he is now suffering?

Interestingly enough, there is little discussion in the classic legal literature, beginning with the Talmud, about the relief of pain. Most of the discussion deals with the theological question of why pain is sent to us and how we are to endure it and with our attitude to God because of it. As for the paucity of reference on the relief of pain—that can be understood because, after all, in those days they had very little knowledge of opiates or narcotics. However, the Talmud does mention one pain-killing medicine which could be used in the ceremony of piercing the ear of a slave (Kiddushin 21b). This is the basis of all modern legal discussion as to whether anesthetic may be used in circumcision (see *Current Reform Responsa*, pp. 102ff). It should be noted in that responsum that most of the scholars agree on the permissibility of the relief of pain, at least in that ceremony.

But in the case which we are discussing, it is more than a question of relieving pain of a wound or an operation. It is a question of relieving pain at the risk of shortening life. Now, granted that it is forbidden to take any steps that will definitely shorten the life of the patient (as mentioned heretofore)—may it not be permitted in the case of a dying patient to take some risk with his remaining hours or days, if the risk is taken for his benefit?

This question may be answered in the affirmative. The law in this regard is based upon the Talmud (Avoda Zara 27a-b). There the question is whether we may make use of a Gentile physician (in that case, an idolater). What is involved is the enmity on the part of an idolater toward the Israelite, and the fact that the physician may—out of enmity—do harm to the patient. It makes a difference in the law whether the man is an amateur or a professional. The latter may generally always be employed. Also it makes a difference as to the present state of the patient's health, as follows: If the patient is dying anyhow, more risks may be taken for the chance of his possible benefit. The phrase used for these last dying hours is *chayei sha-a*, and the general statement of the law is that we may risk these fragile closing hours and take a chance on a medicine that may benefit the patient (cf. *Shulchan Aruch*, Yoreh De-a 154). See *Modern Reform Responsa*, p. 199, and especially the classic responsum on this subject by Jacob Reischer of Metz, *Shevat Ya-akov* III, 75. In other words, this is the case of a dying patient, and that law permits us in such a case to risk the *chayei sha-a* for his potential benefit.

In other words, we may take definite action to relieve pain, even if it is of some risk to the *chayei sha-a*, the last hours. In fact, it is possible to reason as follows: It is true that the medicine to relieve his pain may weaken his heart, but does not the great pain itself weaken his heart? And: May it not be that relieving the pain may strengthen him more than the medicine might weaken him? At all events, it is a matter of judgment, and in general we may say that in order to relieve his pain, we may incur some risk as to his final hours.

Resources to Help Dispel Myths About Pain Management

New York State Task Force on Life and the Law

A common thread running through the ethical debate over physician-assisted suicide is whether doctors adequately treat patient pain. Now a national pain resource center can answer questions about common issues such as tolerance to pain medication, addiction, and respiratory depression.

Funded by a grant from the New York City-based Mayday Fund, the national center is located at the City of Hope Medical Center in Duarte, CA. The Mayday Pain Resource Center (MPRC) is a clearing-house of information and resources to enable individuals and institutions to improve the quality of pain management, says Betty Ferrell, PhD, FAAN, associate research scientist at City of Hope and co-director of the MPRC.

To contribute to the MPRC any materials related to pain management that will benefit others, call (818) 359-8111, ext. 3829.

Following are additional pain management resources for ethics committees to use in staff education:

Agency for Health Care Policy and Research

Executive Office Center, Suite 501, 2101 E. Jefferson St., Rockville MD 20852

(800) 358-9295 to order these free publications:

Acute pain management: *Pain Control After Surgery: A Patient's Guide, Clinical Practice Guideline on Acute Pain Management, Quick Reference Guide on Acute Pain Management in Adults, and Quick Reference Guide to Acute Pain Management in Infants, Children, and Adolescents.*

Cancer pain management: *Managing Cancer Pain (Patient Guide), Clinical Practice Guideline on Management of Cancer Pain, and Quick Reference Guide on Management of Cancer Pain: Adults.*

American Pain Society

5700 Old Orchard Road, first floor, Skokie IL 60077-1057

(708) 966-5595

Publishes *Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain* and a membership directory of health care professionals and institutions, and conducts educational programs.

American Society of Clinical Oncology

435 N. Michigan Ave., Suite 1717, Chicago IL 60611-4067

(312) 644-0828

Conducts educational programs for physicians. The society's "Cancer pain assessment and treatment curriculum guidelines" appear in the *Journal of Clinical Oncology* (1992; 10:1976-1982).

International Association for the Study of Pain

909 NE 43rd St., Ste. 306, Seattle WA 98105

(206) 547-6409

Publishes *Core Curriculum for Professional Education in Pain.*

Memorial Sloan-Kettering Cancer Center

1275 York Ave., New York NY 10021

National pain hotline for health care professionals and patients: (212) 639-7918.
Operates project to train educators and clinicians nationwide in palliative care.

Washington State Medical Association

2033 Sixth Ave., Ste. 1100, Seattle WA 98121

(206) 441-9762

Publishes *Pain Management and Care of the Terminal Patient*, a handbook for health care professionals.

Wisconsin Cancer Pain Initiative

3675 Medical Sciences Center, University of Wisconsin Medical School, 1300 University Ave., Madison WI 53706

(608) 262-0978

Publishes *Handbook of Cancer Pain Management*, a handbook for health care professionals.

Compassionate and Comfort Care at the End of Life

UAHC Resolution⁴⁰

Background: Because the synagogue is the focus of our communal life and the setting of our collective deliberations about life's most important events, we affirm the obligation of the synagogue community to educate its members regarding Judaism's belief in the dignity and sanctity of human life.

As the end of life approaches, the choices before us become difficult and troubling. Possibilities of survival engendered by medical technology may also unnaturally prolong the dying process.

Our movement has already affirmed the right to refuse medical treatment that only prolongs the act of dying, but it is clear that not all needs are met by withholding or withdrawal of medical treatment at the end of life. There are those who, nearing the end of life's journey, would choose to live. We have yet to assert the obligations that our community has to those who cannot be cured or their disease but whose future promises nothing but pain and suffering. While acknowledging that many would choose not to endure such a life, most such choices do not need to be made when adequate palliative care and support can be provided.

Guided by the *mitzvah* of *pikuach nefesh*, we must strive toward an achievable goal, to provide a quality of life that is at least tolerable for each one whose journey ends in pain and suffering. Our effort must ensure that only rarely will that choice be beyond human strength. We assert that most of the tragic choices to end life can be avoided through the combined efforts of caring doctors, clergy, providers, family, and community. By providing caring support for families and assisting in the development of hospices and similar environments where spiritual and physical needs are met, our congregations can help to preserve the meaning and purpose of our lives as we approach the end of the journey.

THEREFORE, the Union of American Hebrew Congregations resolves to:

1. Address our society's need to provide adequate comfort care at the end of life;
2. Develop and distribute more educational and programmatic material regarding a liberal Jewish approach to end-of-life decisions;
3. Develop and distribute material that would raise awareness of the issues of pain and suffering and quality of life in order to enable sound decision making by all concerned;
4. Encourage the expansion of opportunities for rabbinic and cantorial students and rabbis and cantors in the field to participate in training programs designed to develop skills in end-of-life issues;
5. Call upon our congregations to develop connections with Jewish hospice programs in their communities and to explore their creation where they do not exist; and
6. Call on the Committee on Bio-Ethics to work with the Central Conference of American Rabbis' Committee on Responsa to provide us with guidance with respect to physician-assisted death and active voluntary euthanasia.

⁴⁰ Adopted by the 63rd General Assembly of the Union of American Hebrew Congregations at the National Biennial in Atlanta GA, November 30-December 3, 1995.

UAHC Committee on Bio-Ethics

UAHC Committee on Older Adults

Dr. Harvey Gordon, Chair, Bio-Ethics

Morton Finkelstein, Chair, Older Adults

Joan Wachstein Co-Chair, Older Adults

Dr. Les Zendle, Co-Chair, Bio-Ethics

Sandra Brotzman, Chair, Caring Community

Beverly Singer, Co-Chair, Caring Community

Rabbi Richard E. Address, Director, Committee on Older Adults and Bio-Ethics

Eileen R. Kobrin, Program Coordinator, Committee on Older Adults and Bio-Ethics