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## Realities of the Dying

*Rabbi Dr. Maurice Lamm*







**The National Institute for Jewish Hospice**

1-800-446-4448

[www.nijh.org](http://www.nijh.org)

## **Realities of the Dying**

Rabbi Dr. Maurice Lamm

### **NIJH In Your Will**

After providing for your family and loved ones, you may want to put the National Institute for Jewish Hospice in your will, thus helping to assure the long-term future of this sacred work. Bequests are free of estate tax, and can substantially reduce the amount of your assets claimed by the government. You can give needed support to NIJH by simply including the following words in your will;

I give, devise, and bequeath to the National Institute for Jewish Hospice (insert amount being given here) to be used to support the help for Jewish terminally ill patients.

A bequest can be a specific dollar amount, a percentage of an estate, or all or part of the residue of an estate. You can also name NIJH as a contingency beneficiary, in the event someone named in your will is no longer living.

*We recommend that a lawyer help you in drafting or amending a will.*

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## Realities of the Dying

### For Caregivers

Family, Friends, Volunteers, Professionals

This booklet is addressed to you –  
whether Jewish or non-Jewish –  
who seek to provide care for  
the terminally ill Jewish patient.

We hope this booklet will better equip those  
whose goal it is to get into the mind of the  
terminally ill patient. It is meant to help you  
understand what the realities are for those  
who are lying in bed day after day, waiting  
for the inevitable, and to help them  
live through this time.

*The masculine gender in this booklet  
is used in its generic sense.*

NIJH was established in 1985 to help alleviate suffering in serious and terminal illness. It's 55,000 members comprise business and professional leaders, and a consortium of endowing foundations. It communicates with hospices, hospitals, family services, medical organizations, and all health-care agencies, alerting them to the plight of the Jewish terminally ill.

The NIJH accreditation program provides training to hospices, geriatric centers or hospitals in the United States. NIJH has accredited hundreds of hospices

NIJH provides booklets, books, CDs and monographs confronting issues such as truth telling and euthanasia; providing insights into the art of hoping, the techniques of caring, and the understanding of pain. The NIJH Jewish Living Will and Durable Power of Attorney is also available.

#### **24 hour toll-free number**

A toll-free 800 number is functioning at all times. Information and guidance are provided about the availability and locations of hospices, hospitals, health professionals, home-care services, clergymen, psychologists, physicians, nurses and social workers especially pertinent to helping the terminally ill. Professionals will listen with understanding and provide relevant advice and direction.

#### **Information**

Over three and a half million letters have been sent out to virtually all Jewish families in the United States to elevate their consciousness concerning the plight of the seriously ill.

These letters, authored by the late Norman Cousins, Jack Klugman, Beatrice Arthur, Alan Alda, Judge Wapner, the late Jessica Tandy and Rabbi Maurice Lamm, have elicited numerous queries and much support and encouragement. NIJH responds to an average of over 500 letters a month.

NIJH's Board of Governors, headed by Rabbi Dr. Maurice Lamm, NIJH President, and Shirley Lamm, NIJH Executive Director, includes nationally known leaders in business, academia, government, and religion, who have given their names to support the cause of the Jewish terminally ill.

- ◇ fear of becoming dependent on others, of losing control over physical function, of being a nuisance;
- ◇ fear of what will become of the surviving spouse and children or others who had formerly been dependent of the patient;
- ◇ fear of failing to complete some life task or fulfill some obligation;
- ◇ fear of illness or death as a divine punishment;
- ◇ fear reflecting what the patient sees in the eyes of those around him;
- ◇ fear of the non-existence, of the unknown or of what happens after death.

Obviously, some of these fears may be misplaced and easily dispelled. If the patient's fear is of abandonment, assurances that his friends have no intention of leaving him may provide some comfort. If the patient fears becoming a nuisance, loved ones can make it clear that they welcome the opportunity and honor of caring for him. Other fears may not be so easily dispelled, but cry out for an opportunity for expression by the patient. It is interesting to note that for many dying patients the unknown and death itself may be the least of their fears and concerns.

Another personal emotional issue which you may uncover by listening to the patient is the need to be forgiven or to forgive another – and the need for permission to die from loved ones. Some patients may also regress to infantile behavior as a reaction to their loss of independence. But care-givers need to be very careful in providing adults with adult care and to avoid infantilizing patients, even though they may exhibit the mental behavior of infants.

Remaining open to what the patient is really saying – in words and gestures – will go a long way toward better understanding of what he is experiencing and how we can respond.

The realities of dying vary with each person. The common thread in all dying patients is that this condition is unique in every individual's life. To know in advance what this experience may be like is to prepare oneself to better manage this crucial moment. This foreknowledge facilitates love, and at this stage of life there is no more effective medicine than love.

## Realities of the Dying

Rabbi Dr. Maurice Lamm

*“Basic to understanding the problems of caring for the dying is an awareness that with all its mysteries and ultimate questions, death is a concrete event, mostly smelly and mean, preceded and followed by pain”*  
Eric J. Casseell (“Being and Becoming Dead”)

At the National Institute for Jewish Hospice we are concerned with the actual experience of people with serious and/or terminal illness such as cancer. The reason for exploring these realities is to enable us to gain a better understanding of what a serious ill loved one is likely to be going through on a daily basis. This understanding should also better equip those we guide to face such a person, and to encourage, support and just be with him through whatever he needs to be doing at this point of his life – whether that is recovering or dying.

We explore issues of hope, healing and truth-telling, the concept of the whole person, and the nature of pain and suffering for the ill person, as well as how hospice programs attempt to address some of these concerns for the terminally ill patients. We discuss how the dying individual must be seen as a whole person with interrelated physical, spiritual, psychological, emotional, and social facets, all of which are effected by the illness.

We have described in a series of booklets already published how hospice care arose in response to a tendency in the modern health care system to dehumanize dying patients by failing to treat them as people. For modern medicine, the seriously ill patient had become a biomedical “thing” which had to be kept alive as long as possible by heroic high-tech interventions, with little consideration for the experience and meaning of the illness to the real person inhabiting the body.

Here we try to focus more specifically on what dying patients commonly experience. However, in considering this actual experience, it is worth keeping in mind what Elisabeth Kubler-Ross said about her original pioneering work with dying patients. She called these patients her “teachers,” because they taught her something of what it means to be dying.

It is presumptuous for a healthy person to say to someone who is dying: "I know just exactly how you feel," because we don't. However, if we listen to them, they may tell us everything we need to know for the time we shall spend with them. What follows must be a gross generalization, because each person's dying is truly unique. But the alternative is to be silent and that is not acceptable. However, the experiences of hospice programs at least provide us with a starting place for considering the experience of the dying.

It is also important to remember, as Dr. Avery Weisman puts it, that "everyone has misgivings and qualms about death, including the professionals who preside at different stages of dying." Our personal dreads and fears about dying and our own mortality may well stand in our way of listening to the dying person who is now in front of us. So, for security, we fall back on our generalizations, truisms and misconceptions about dying. You may not fully resolve your own feelings about death and mortality until your own final days – if then. However, being of personal service and support to someone who is confronting death at least requires that you be aware of your own fears, and try to not let them get in the way of your interaction with the dying person you are visiting.

1. For someone who is terminally ill with a disease such as cancer, for example, two parallel sets of phenomena are happening. First of all, there is the physical deterioration and wasting from illness, leading to a host of symptoms and manifestations that most often fill the sick person's entire consciousness. There is literally no escaping from the pain, discomfort, restlessness and exhaustion, and also from the frustration with a body that has betrayed his cherished expectations of health and longevity. Sleep is an escape, but even sleep often becomes problematic.
2. At the same time, dying raises a host of emotional and psychological questions about meaning – the meaning of the illness, of the future, and of life itself.

Dying challenges us to face the ultimate reality of our

It is essential to take our cues from the patient, rather than try to move him beyond the denial or anger or depression that he needs to be feeling at this time. All dying patients – even those who have reached a state of acceptance – will feel some kind of hope for continued existence. It may be better to see these five stages as "states" in which dying patients may find themselves, and to use these states as imperfect models for understanding the patient's behavior and feelings.

### Other Losses

The main reason for considering Kubler-Ross's stages of dying is to provide us with some understanding of the dying patient's circumstances and thereby to better offer empathy, compassion, and support. It may also be helpful to consider the specific losses and limitations which the patient is experiencing as he progresses through his illness, or the specific fears raised by the illness, and to gently draw out these losses or fears in conversations with the patient.

There are other losses, of course that need to be factored into the equation – the loss of job, of the ability to be the breadwinner, of social status, of personal mobility, of role in family, of relationships with friends, of the ability to take care of personal grooming, of control over bodily functions, etc. How these losses are experienced will depend on the patient's personality interests and desires, and his family and social role.

If you understand which losses are most bitter to the patient, you may be able to suggest ways to compensate and return to him a measure of control and independence. For instance, letting the patient decide when to receive his bed bath and what to eat, or offering to take him on an outing of his choosing, can go a long way to restoring a sense of participating in his own destiny.

Some of the most common fears that a dying person may experience include:

- ◇ fear of abandonment;
- ◇ fear of pain or mutilation;
- ◇ fear of separation from loved ones, from home, from job, etc.

1 This pamphlet makes no suggestions for physical treatment. This falls totally in the domain of medical practitioners. Please do not construe a popular description of physical conditions as authoritative medicine.

This way, rather than taking these outbursts personally.

3. The third case, *bargaining*, is an almost childlike gesture in which the patient tries to negotiate with God or fate to obtain an extension on his “death sentence.” This bargaining is an attempt to postpone the bad news that can no longer be denied or willed away through anger.
4. Bargaining is followed by *depression*, “when the patient can no longer deny his illness. His numbness or stoicism, his anger and rage will soon be replaced with a sense of great loss.” There is a distinction, also, between the depression that is a reaction to all of the immediate difficulties and losses imposed by the illness, and the depression that comes from “preparatory grief that the terminally ill patient has to undergo in order to prepare himself for his final separation from this world.” For this latter type of depression, our customary offerings of encouragement and reassurance will not be very meaningful and may distract the patient from the emotional work that he has to do.
5. A final stage is *acceptance*, accompanied by an emotional separation or decathexis from life. “if a patient has had enough time.... and has been given some help in working through the previously described stages, he will reach a stage during which he is neither depressed nor angry about his “fate”,” she writes.

It would be easy to misconstrue these five stages of dying as a roadmap to the path all dying patients follow. However, Kubler-Ross’s book implies – and later studies have clarified – that these stages are not so clear-cut. Dying patients will frequently move from one stage to another, depending on their mood on any given day. And some may never experience one or more of these identified stages. We may feel that acceptance is the desired end stage, but some patients may not choose to become accepting, and they should not be forced to.

mortality and the possibility of non-being – a reality which some psychologists tell us the unconscious psyche can never fully integrate. Is this the end for me? Is my life on this earth really drawing to a close? What will happen after I die? Emotional reactions to this circumstance – shock, depression, despair, denial, hope resignation, acceptance – are experienced I constantly shifting mixtures.

And these two realms of experience – the physical and the emotional – interact and interrelate on many levels, for instance, how the experience of physical pain leads to strange and surprising emotional reactions. In turn, this physical experience is itself shaped by many emotional variables long cherished but hidden under our surface. Attitudes about life and healing also greatly influence the experience of terminal illness. And mental states such as confusion, anxiety and depression – while reflecting the emotional life of the individual – may have direct physical causes and manifestations related to the illness and its symptoms.

Terminal illness is also a time of many losses: the loss of independence and control over one’s life; of the ability to care for oneself; of personal dignity; of control over medical routines and over physical functions such as bowel and bladder; of trust in the relationship with one’s body; of job, friends, activities and interests; and finally, of closest loved one and life itself. With loss comes grief and we should never forget that the dying patient may feel many of the same grief reactions as the loved ones he will leave behind. Because dying raises so many questions that cannot be answered, it is also a time of intense fears.

However, dying can also be a reflective twilight time, a time of transition between life and death in the same way that the real twilight is a beautiful transition between day and night. Although it is a time of suffering, it can also be – and often is – an occasion of great peace, serenity, personal growth, renewed faith, intimacy with loved ones, as well as an opportunity for reflection, review and new insights into one’s life. And for some people it can be some or all of these things simultaneously – a tragic, sad, chaotic, rich and full time unlike any other in life.

## Terminal Illness

Obviously, the physical experience of serious or terminal illness depends largely on the disease. In past generations people were more likely to die of accidents or catastrophic diseases or epidemics that struck suddenly and quickly led to death. However, advances in medical research and technology have resulted in a gradually aging population, which is more prone to chronic degenerative illnesses such as cancer and heart diseases.

The vast majority of patients in hospice programs are diagnosed with cancer – a disease that lends itself to relatively predictable progressions. Therefore, hospice experience in symptom management applies most directly to advanced cancer. However, other illnesses also result in definable and stratifiable terminal stages. These include advanced or end-stage pulmonary diseases (emphysema and chronic obstructive pulmonary disease); heart disease (e.g., ischemic heart disease secondary to coronary atherosclerosis, cardiomyopathy, congestive heart failure and CVAs – heart attacks); renal diseases, such as end-stage diabetes and liver diseases such as cirrhosis. Another life-threatening disease included in many hospices is amyotrophic lateral sclerosis – ALS or Lou Gehrig’s disease – a progressive wasting of the muscles. In the late 1980s hospices were increasingly dominated by AIDS (the acquired immune deficiency syndrome), which resembles the wasting of end-stage cancer, but with even more troubling physical complaints.

## Pain as a Symptom of Terminal Illness

Any discussion of the physical realities of the life-threatening or terminal illnesses such as cancer begins with the issue of pain. Many professionals consider the relief of pain to be their first and most important responsibility – because emotional and spiritual needs or family conflicts are difficult to address when the patient’s immediate experience is dominated by pain.

There is, of course, a qualitative emotional difference between acute pain – which can give us important information about threats to the body – and chronic pain, which seems to the patient to have no time limit or hope of resolution, and which leads to feelings of hopelessness and despair. Such chronic pain can truly dominate the

hospital by Dr. Elisabeth Kubler-Ross in the mid 1960s, culminating in the publication of her book *On Death and Dying* in 1969. She and her students took the then unprecedented step of interviewing dying patients about their true feelings and perceptions of their illness.

“We decided that the best possible way we could study death and dying was by asking terminally ill patients to be our teachers,” she writes. Although medical and nursing staff displayed considerable reluctance and even hostility for the idea, almost all patients who were asked to participate did so eagerly, glad to have someone who would listen to their feelings. Kubler-Ross also emphasizes that the patients were not informed of their terminal condition during her interviews. However, they knew it anyway, whether or not they were told directly from physicians.

Based on interviews with two hundred terminally ill patients, Kubler-Ross identified five stages of dying which patients with a slowly advancing degenerative disease might go through. These stages are not fixed and universally true, according to empirical data in 1991. But they serve to identify and outline commonly experienced reactions.

1. The first reaction is *denial and isolation*, in which the patient says ‘no, not me, it cannot be true.’ There is a distinction between the initial denial which is one of shock, and the ongoing partial denial which almost all patients use throughout their illness. The ongoing denial allows them to gradually assimilate the full meaning of their predicament, and “is a healthy way of dealing with the uncomfortable and painful situation,” she explains. It “allows the patient to collect himself and, with time, mobilize other, less radical defenses.”
2. The initial shock and denial may be followed by *anger*, as it dawns on the patient that “oh yes, it is me, it was not a mistake.” Denial is replaced by feelings of anger, rage, envy and resentment, displaced in all directions – even to medical staff and loved ones. Although this anger may seem highly irrational, it is important for loved ones to try to understand the patient’s position and why he is acting



When a patient nears death from a degenerative disease such as cancer, there is both a physical and psychological withdrawal on many levels. Willing intake of food and water may cease and the patient's sensation of pain may be lessened. The patient may be sleeping most of the day or in a comatose state, and even if awake, may seem emotionally withdrawn. Many treatments, such as for infections or inadequate hydration or nutrition, are usually no longer needed at this point.

It is almost as if the patient and his body have come to a tacit understanding – regardless of previous attitudes held by the patient – that the physical deterioration, discomfort, pain and weariness have made it no longer viable to continue living. The body has worn out and the patient is tired of running the treadmill of painful and uncomfortable symptoms. Nature slowly administers a general anesthesia before she permits time's scythe to complete the most major of operations. The desire for life gives way to indifference and waiting; the sensations diminish; vitality fades; the fear of death mingles with the longing for rest. At this point many patients will say that they are "ready to die," and, as the inhabitant of the ravaged body, they are in the best position to recognize this changed status.

Any seriously ill person who is at home should be receiving visits from a hospice team or from a physician or a visiting nurse, whose job includes providing clear and simple instructions and explanations to family members. If an ill friend of yours is suffering from distressing symptoms that the family seems unable to handle or understand, you may encourage them to call the physician or visiting nurse for better directions – or offer to make the call for them.

If a patient's death at home is expected, the physician or visiting nurse can give the family reassurance and coaching about what to expect when the patient does die and how to handle the final arrangements with minimal distress and trauma. Ideally, such planning and support at the time of death may help mute the suddenness of the sting and prevent the spectacle of ambulances, paramedics and resuscitation efforts.

### **Stages of Dying**

One of the landmarks in the modern movement of attention to the needs of the dying was the study of dying patients in a Chicago

patient's entire consciousness and his psychological, emotional, social and spiritual experience of illness. Chronic pain can also contribute to physical deterioration because of sleeplessness, loss of appetite and the anxiety it provokes.

Various studies indicate that patients with advanced cancer report moderate to severe pain forty to ninety percent of the time. The pain can be caused by:

1. the malignancy and its growth and attack on body tissues
2. medical treatment for the cancer, or
3. a host of coincidental factors or byproducts of the disease.

Derek Doyle has identified eight principal types of pain with advanced cancer: Bone pain, visceral pain (especially the liver, kidneys and bladder), headache, colic, nerve entrapment, joint pain, muscular pain, and skin pain.

By concentrating on the relief of pain, that hospice movement has given us many insights on how to relieve even the most severe pain of advanced cancer. The hospice approach, first of all, is to recognize that pain has many components – psychological, emotional, social and spiritual as well as physical. This is not meant in the slightest way to suggest that pain is, "all in a person's mind" In fact, it is all too cruel and real for the person. But we do know that attitude, diversion, resolution of personal issues, even just a sympathetic listener can help moderate the patient's experience of pain.

Hospice's second contribution to pain management is to insist that pain in dying patients never be treated "P.R.N." (i.e., as needed). Although aspirin and similar medications may be adequate for some pain, morphine or other opiates are usually indicated if the pain is severe. Hospice-oriented physicians will give the patient enough morphine to bring the pain under control – no matter how much it takes – and will carefully monitor results until they discover the correct dosage. They realize that fears of addiction are not appropriate to the dying patient and that severely ill cancer patients can often tolerate quantities of morphine that would be fatal for the healthy person.

Caring physicians also understand that it is much easier to keep the patient pain-free with medication than it is to try to bring severe pain under control. Therefore the pain medication is given around

the clock, often at four or six hour intervals, rather than waiting for the patient to re-experience pain and then request medication.

In practice this means that the large doses required to bring the pain under control can be greatly reduced to a maintenance level once the pain is controlled, keeping the patient alert and relatively pain-free. By removing the formerly chronic pain from the patient's experience, the vicious cycle of despair and hopelessness caused by the pain and contributing to its severity is curtailed. The memory of that past pain and anticipation of future pain also ceases to be the dominant feature of the patient's constant experience.

Although this simple approach has demonstrated its effectiveness in countless terminal cases – making possible Dr. Cicely Saunders' promise to newly admitted patients at St. Christopher's Hospice that she would cure their pain – physicians, family members and patients themselves do not always permit this approach to be implemented, because of lack of understanding or misplaced fears about addiction. At the same time the physician must be sensitive to some of the side effects of morphine – particularly frowziness and constipation. The drowsiness may be a temporary reaction, requiring reassurance for family members that the patient will return to his former alertness within a few days.

### **Other Physical Symptoms**

Among the other physical complaints (which may never effect you or the patient) with advanced cancer are;

- ◇ **Loss of appetite and unwillingness to eat**, sometimes accompanied by altered sense of taste, difficulty in swallowing, mouth infections or a very dry mouth. For the moderately ill cancer patient, special planning with the consultation of a dietician may encourage the patient to eat more. Small, frequent, attractive meals, a glass of wine before eating and liquid food supplements may also help the patient to take in adequate nutrition. However, as the disease enters the final stage, it is common for patients to stop eating altogether, and families may need gentle encouragement that they should no longer try to force food

onto the patient;

- ◇ **Nausea and vomiting** caused by morphine and other medications or by the tumor;

- ◇ **Dehydration**, sometimes accompanied by thirst and dry mouth. Often seriously ill patients may be hydrated intravenously, although at the very end this may make the patients passing less comfortable;

- ◇ **Constipation and diarrhea**, both often related to medications or to inadequate diet. Sometimes an immobile patient will develop a total intestinal blockage which can be terribly painful and distressing, requiring active intervention by the physician;

- ◇ **Decubitus ulcers** – painful pressure sores on the skin caused by lack of circulation – which can develop if bedbound patients are not turned frequently;

- ◇ **Edema**, which is fluid build-up and swelling in the extremities, particularly around the ankles;

- ◇ **Pruritus** or skin itching; and

- ◇ **Seizures and Convulsions**

In addition, many changes in mental status may have an origin in the physical effects of the tumor or medications, exacerbated by an unfamiliar environment of the different daily routines of a hospital. Depressions, insomnia, drowsiness, confusion – even dementia and hallucinations – are not uncommon reactions, and both the patient and family need reassurance that these are normal side effects of the diseases or treatment.

Dr. Lamerton explains that, “physical death from disease proceeds by degrees. Organs fail at different rates. When a body begins to die, it does so from below upwards.” If attentive symptom control has been practiced by the physician or hospice team, the pain and discomfort can be ameliorated.