



## The National Institute for Jewish Hospice

In the Face of Insanity:

How Do Caregivers Maintain Their Own Sanity

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I have a confession to make.

No, it's not my Yom Kippur, the Jewish Day of Atonement. Nor am I prepared for Viddui, when at the point of death, I would repeat for the last time the affirmation of my spiritual faith.

Rather, in all honesty, I must disclose that I was not all that enthusiastic when the National Institute for Jewish Hospice was created a quarter of a century ago.

Prior to its establishment, I had been involved in the field of thanatology for two decades. (My book, *Explaining Death to Children* was published in 1962.) I had the privilege of speaking on the subject of death and dying before many Catholic archdioceses and Protestant enclaves. I explained my presence before them as a rabbi with the quotation from Shakespeare's *Merchant of Venice*: "Hath not a Jew hands? Hath not a Jew organs? If you prick us, do we not bleed!" In other words, whatever one's denomination, "pain is pain," "grief is grief". Why make artificial religious distinctions when the bereaved suffer a grievous loss? We all share similar points of references.

My epiphany occurred when I was invited to speak at a small town in Minnesota. At the airport, a social worker asked if I would speak to a Jewish patient who had not been responsive to the medical staff. I was skeptical, knowing that I did not have any secret passwords that would unlock some mystical connection.

I came close to the patient and told him that I was a rabbi and then uttered a few words in English, Hebrew, and Yiddish. To my amazement, he sat up and spoke. He told me that he had been a Holocaust survivor and was fearful of this strange environment. After I left, there was a Menorah placed near his bed, matzah was served on Passover, and over time, this reluctant convalescent became a more active, accepting, receptive participant.

Too often, when a patient is terminally ill, the question is only whether they want hospice or not, whether they desire chemotherapy or not, or whether they desire to be resuscitated or not. Our single focus should not only assist them during this difficult physical

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extremity, but to also help them negotiate their apprehensions about death, about their limited mortality, about suffering, about their needs while they are still living.

A religious crisis is not infrequent during their trauma. “Are there special prayers or ceremonies that they value?” “How would they want their religious holidays to be commemorated?” “Are there favorite hymns, Bible readings, daily devotions, that offer them a source of serenity?” “Is there a clergyperson who they would like to see?” “Are there special ritual objects that they would like close to them?” (A Star of David made my mother feel very comfortable in a wonderful Catholic hospital.) Do they ask, “Why me?” “How could God do this to me?” “Is it God’s will?” “Am I being punished?”

Many may feel uncomfortable when patients discuss matters of faith. Fortunately, there is renewed interest in the writing of such scholars as Carl Jung, Viktor Frankl, Benson’s mind-body connections, and the 12-step program of Alcoholics Anonymous that have fostered a greater awareness and openness to the patients’ spiritual needs. Remember the admonition of America’s Medical Association in urging their members to not focus only upon bodies in need of repair. “They must further their holistic investigations to the beliefs and patients’ awareness of their unique transcendental values.” When Dr. Cecily Saunders launched St. Christopher’s Hospice in London, she stated as one of the aims that there be a relief of pain, encompassing the physical, emotional, social, and spiritual.

After this long preamble, the topic for today: In the Face of Insanity, How Do Caretakers Maintain Their Own Sanity. And no one can deny that we live in a crazy, mixed-up, dysfunctional, unhinged, berserk world. Can we recall a time ever of such despondency, dolefulness, despairing, and pessimism? A simple question – who you trust? The government? The police? The clergy? Recall the recent elections when every opposing candidate was either labeled as morally corrupt or mentally challenged. In a recent poll the only reliable believable truth telling personalities were Walter Cronkite, Mr. Fred Rogers, and Oprah Winfrey. Those of us who labor in health care professions have our own unique problems. Just think of our blizzard of paperwork, irresponsible regulations, hysterical family members, and.

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vulnerable patients with end-of-life decisions. This is compounded with the present economic crunch when critical personnel are dismissed and the remaining staff have to perform the job of those no longer employed.

What to do?

The great Hillel, the Elder is speaking to me and I hope to you. He lived in the first pre-Christian century and said, "What is hateful to you, do not do unto your neighbor." Of course, Jesus later used this thought to say, "Do unto others what you would like them to do unto you." Hillel uttered these words in Hebrew, "Em Ayn Ani." Translation: "If I am not for myself who will be for me? But if I am only for myself, who am I? And if not now, when?"

*"If I am not for myself who am I?"*

Enlightened self-interest is not only necessary but mandatory. We cannot be good-nurturers until we first nurture ourselves. Recall the words of the flight attendant, "If necessary, where there are children first unbuckle your own seatbelt, then the child's."

What to do when the reservoir of adaptive energy is squandered, when each task becomes a hassle rather than a challenge? The following are sure-fire recipes for forcing the body into overdrive, making life joyless, and dispatching professionals into early graves.

*"Quis custodiet ispos custode?"*

*(Who guards the guardians? Alternate translation: Who cares for the caregivers?) Juvenal, Satires VI, 347*

How do stay stressed (as if you needed instruction): set unattainable goals. In your mind you have an image of yourself as the heroic problem-solver, a kind of superman/woman, maybe a little "messianic." Thus you are more invulnerable to personal needs than the rest of the population.

*Don't Show Your Vulnerabilities*

You were raised to be strong in the face of adversity, to put on a "brave front" no matter what. Act one way even when you're feeling the opposite. You don't want others to discover your imperfections.

*Friends are for Quakers*

You may be a solo performer in a private practice, or the sole

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or the sole clergy person in a church/synagogue/mosque. Or you are responsible for many employed in a large organization or institution. You are always giving to the lonely and emotionally undernourished your unstinting time and endless compassion. You are the expert in human support. You really don't need a supportive network.

*Who Has the Time?*

The work that you are doing is so crucial that without your support the universe would be doomed. It is essential that you over-commit your time and over promise your counselees. As far as family is concerned, one day when your schedule is less hectic, you will make it up to them.

*Never Say No*

"Please me." Your whole life may have been devoted to pleasing Mother and Father. If you acted, thought, or felt in a way that was not acceptable to them, you were scolded or made to feel guilty. Now, you need to please everyone else. Make them happy by living up to their expectation, however unrealistic.

*Relaxation—What's That?*

Adequate rest, listening to soothing music, visiting a museum, walking in the park, going on a vacation—sounds great, but you're just too occupied, at least right now. You can't slow down and sit quietly.

*Exercise the Brain, Not the Body*

The mind must be vibrantly alive. Intellectuals don't go in for breaking a sweat, cycling, jogging, swimming, or even walking. Time should be better used for noble causes. A few hours sleep is all you really require.

*Food Isn't a Priority*

Read a professional journal while eating. If you're in a hurry, there's a fast food restaurant nearby. You'll take care of those extra pounds tomorrow. A jolt from caffeine is just what you need when you are tired and rushing to meet another deadline.

*Your Profession is Your Life*

In your high-tension career, it is impossible to separate your life from your work. Rescuing others from stressful lives makes you feel so good about yourself. When placed upon a pedestal by clients, sacrifices are demanded. Address their needs from sunrise

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to sunset. Work through lunch. Occasionally break bread with colleagues while discussing common concerns. Bring unfinished business home at the conclusion of the workday and use weekends to achieve the myriad details that you just didn't have the chance to complete.

Does any of the above ring a familiar bell? You who freely and wisely give sage advice to others about self-care have neglected an important person—you! But don't stop here. Hillel has more to say. "But if I am only for myself, who am I?"

As you search within yourself, it is also essential that you reach out to others. The philosopher Martin Buber highlighted the importance of others. "One person is no person. The solitary heart has to throb with the hearts of other." In building a synagogue, a window is required to see beyond your own needs.

A dying person said to Cicely Saunders, "I am a traveler on the journey from one life to the next, and I need a place where I can be welcomed and looked after and cared for and be myself on that journey." No, you do not have the power to control their illness or make it go away, but as hospice people you can reach out with an outstretched hand, a listening ear, an understanding mind. Your kindred spirit helps to share their feelings, thoughts, and fears. You are an essential part of the road map of their daunting journey.

What a privilege and blessing to be part of the hospice team! Patient and family openly and honestly express their inner emotions so that plans of care will meet their unique needs. On one hand, when the unfortunate, dismissive words are uttered, "There is nothing more to be done," hospice is both death accepting and life enhancing. Hospice is not disease centered but patient focused. (Illness is but part of their physical, social, and spiritual human composite.) When cure is no longer possible, compassionate care becomes the ultimate concern.

Often when asked, "How can you work with people that are dying?" you probably answer, "You get more out of it than you give working with a great interdisciplinary team." You understand the words of Ecclesiastes 7, "It is better to be in a house of mourning, than a house of fasting." Confronted with the finitude of life you rethink your priorities, refine your goals, and redefine your future.

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How I so appreciate this 25<sup>th</sup> anniversary of the National Institute for Jewish Hospice. Rabbi Maurice Lamm is not only my colleague, but also my dear friend, my role model, my mentor. His book Consolation: The Spiritual Journey Beyond Grief is the best volume I have ever read on the subject. Shirley Lamm, his beloved wife, is a Jewish scholar in her own right; she is so largely responsible for the unbelievable development of Jewish Hospice. Together, with their staff, they have trained medical personnel in the bio-ethical and spiritual issues of end-of-life matters. In addition, they have brought a clearer understanding of theology, practices, mourning rites customized to assist chaplains, social workers therapists, and volunteers to both understand their Jewish patients and help them in their spiritual pilgrimage.

As Rabbi Lamm writes: "Hoping for a miracle does not mean you do not accept God's decree. The first imperative Jewish life is: Hold on. The final imperative is: "Let go."

In the face of insanity, what do we do? We end as we started.

Take Care of Yourself: "If I am not for myself, who will be for me?"

Take compassionate care of others: "If I am only for myself, what am I?"

When to start: NOW!

What's on your bucket list?

L'chayim – to life.

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