



Hospice with a Zen Twist: A Talk with Zen Hospice Project Founder Frank Ostaseski

Steve Heilig, MPH

Although housed in an anonymous Victorian house on Page Street, San Francisco's Zen Hospice Project (ZHP) is world-renowned for its pioneering model of training hospice volunteers, providing direct services to patients, and offering educational programs to the broader public. Now celebrating its 15th year, the ZHP has been featured on national television and in major publications, draws other hospice and clinical professionals from around the world to learn from ZHP programs, and continues to serve patients at the Page Street Guest House and at Laguna Honda Hospital.

ZHP founding director Frank Ostaseski has recently stepped down as Executive Director, but he remains on the board of directors and as a "Guiding Teacher." His current pet project is the development of the educational arm of ZHP. A central focus is the intensive End-of-Life Counselor Program, which boasts "star" faculty including the likes of Rachel Naomi Remen, MD, Charlie Garfield, PhD, and Ram Dass. The one-year professional development course trains more experienced people, including physicians, to be educators, advocates, and guides to the dying.

Volunteers at the ZHP range from those with no healthcare background at all to experienced physicians and other clinicians. One current volunteer is actually a Dean Emeritus of the UCSF School of Nursing; Jane Norbeck, RN, DNSc, reflects on why she became a volunteer:

"As a member of a service-oriented profession, I wanted an opportunity for service that was simple and direct, compared to the complexity and remoteness of our health care system. The Zen Hospice Project answered this need and offered an even richer opportunity than I had anticipated. During the months I've served, I have learned how powerful the kindness of strangers can be, perhaps because it's unconditional. The masks we usually wear in society seem unnecessary and tend to fall away, opening a door for deep connection."

Longtime San Francisco internist James Forster, MD also has good things to say about the Zen Hospice as a place to refer patients: "It's a very pleasant place for patients in a difficult time. The care is very good, and there's a real sense of peace and tranquility there."

I recently spoke with Frank Ostaseski about the Zen Hospice Program...

Steve Heilig: How did you come to start the Zen Hospice Program?

Frank Ostaseski: The San Francisco Zen Center found caring for its own community members to be rewarding. They wondered if they could extend that service in a somewhat more formal manner. That's when I came into the picture. I had helped to start other hospice and AIDS organizations, and it felt right to me to ground hospice work in spiritual practice.

We started working with other existing hospice providers in the community, first at San Francisco General Hospital, where we helped patients who couldn't qualify for other hospices. We provided volunteers at existing facilities and co-created the hospice at Laguna Honda Hospital. Around 1989, we opened our own residential facility.

This was during the peak of the HIV epidemic here?

Yes, at that point 90 percent of our clients were HIV patients; now we might see 4 to 5 percent of our clients with HIV, and the rest with cancer and everything else.

About how many patients has ZHP served, and how many volunteers have been trained?

We figure we serve between 150 and 200 patients over the year, so over the past 15 years I guess that makes about 3,000 total. And we've trained about 800 volunteers- including you.

And that training was one of the most worthwhile educational experiences I've had. Your volunteers come from all walks of life, right?

Yes, physicians, nurses, students and ordinary people with no healthcare experience. Our belief is that all of us know how to do this deep down in our bones. The training reminds us of our innate capacity to care for one another. We teach people more than skills-we teach them how to be a true companion at the bedside. That's where some kind of meditation or other spiritual practice comes into play.

But I tell people that one doesn't have to be a Buddhist to either work at ZHP or to die there.

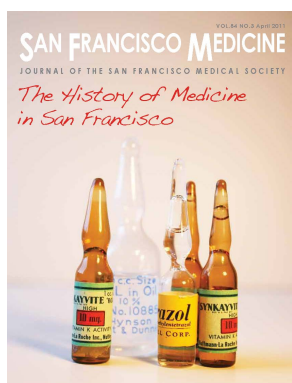
Most of our patients don't care beans about Buddhism, they come to us because they need a bed. We ask that our volunteers have some kind of spiritual practice so that they can bring that kind of inquiry and maturity to the bedside. If we haven't examined our own inner life, we can't be of much use to people who may be going through some kind of emotional or spiritual crisis as they are dying.

You work with many physicians as referral sources, ongoing clinicians, and trainees. Do you think there is a change occurring in how the medical profession deals with the dying?

Certainly things are improving by an increasing emphasis on palliative care. But there are still problems, and many people tend to blame physicians. Some of this is justified; too many physicians are still wedded to old treatment models of cure no matter the cost to quality of life. But we have to remember that doctors reflect the public's wishes; when patients stop demanding to know "How much longer do I have to live?" and relinquishing all the responsibility to their doctors, doctors may stop inflating those estimates and denying mortality. We may be asking too much of physicians these days and have to offer them support in helping these patients. Some of our workshops do just that.

Once you have a patient, how do you work with physicians? Some doctors get upset that their patient is "taken over" by hospices, and others want that.

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We encourage the existing physician to stay involved, to manage the case in consultation with the hospice nurse and medical director of Hospice by the Bay. We encourage visits, as it helps that patient to know that their doctor has not abandoned them. In general, my sense is that when physicians get more involved with their dying patients, they learn lessons that fundamentally shift their care of everyone.

Most importantly, medical people need to start having conversations about mortality long before it's a real issue—discussing advance directives and so on. And asking not only about medical issues but about their spiritual beliefs. It's not the task of the physician to be their counselor, but it is important to know how these factors are important to the patient. Do they think of themselves as religious or spiritual? Are they part of a supportive community? How does their faith help them deal with their illness? How do they want the physician to address these issues in their healthcare?

A big issue now is pain relief—is that an issue for ZHP?

Pain management is a top concern, and often we have to work with physicians who are not as familiar with it, to educate them because they simply have not had the training. So the medical director and nurse case manager will have conversations with them. We've also had UC medical residents rotate through for education in this aspect of care.

How about the "assisted dying" issue? Do you get such requests from patients, and if so, how do you respond?

I'd say that many patients at some juncture ask us to end their lives. Frequently this request arises out of frustration, unrelieved pain, or fear of the unknown. It may be the only strategy they have to take care of an unmet need or unexplored issue. So we have to address the underlying concerns; if we do that well, the request often dissolves and the patient is more able to embrace their life.

But my impression is that some form of assisted dying occurs frequently in hospitals and hospices, in the guise of "terminal sedation," which has been endorsed as permissible now by both the AMA and the Supreme Court. The distinction rests upon what ethicists call the "double effect." So it's all about intention, which seems to resonate with some Buddhist teachings.

It's fair to say that some hospices including us have used terminal sedation to manage severe pain or symptoms. In our case, it's been very rare and could only occur after all other reasonable methods are tried and in close consultation with the patient, the family, and physician. The intention, then, is not to hasten death but to relieve suffering. And so yes, clarity of intention and an explicit discussion are prerequisites for the skillful use of this intervention.

In the USA, we still have only 20 to 30 percent of people dying with hospice services. Is that a problem?

Yes, because hospice is wonderful, but it's not the only answer. People can die well—in nursing homes and even in intensive care units, or at home with other kinds of care. The real question is do these other services apply the lessons learned at hospices? Comfort care, honest dialogue, a recognition and support for the fact that dying is much more than a medical event.

Basically there are two major hindrances to hospice care. First, many health professionals still see a hospice referral as "giving up" instead of viewing hospice as the most appropriate care for the stage of their patient's illness. Secondly, for a person being discharged from a hospital, the choice between hospice care and, say, a nursing home is not financially neutral. Nationally, the Medicare benefit pays about \$110 per day—for everything: medications, nursing care, social work, health aides, etc.—which is ludicrous. There is no reimbursement for residential services. In a nursing facility, it may be \$350 per diem, and in hospitals it can be thousands of dollars. And physicians largely aren't paid for any time they spend on the phone managing hospice patients.

Do you think being candid about death with patients risks depressing them?

I don't think denying reality serves anyone. But I also don't have to force the truth on anybody—people know. I remember once standing in a hospital hallway with a family that asked, "Please don't tell our father he is dying," and when I went into his room, he asked me to shut the door and then said "Please don't tell my family I'm dying." Everyone was concerned that this information would cause the other to lose hope. But hope for what? Just more time? So when we ask the question what would you do with the time? More often than not the answers are simple yet profound: "I would tell the people I love that I love them." And so a little exploration, coupled with a willingness to not turn away from suffering, opens to a deeper understanding. What we hoped we might do "someday" begins to be lived today.

We do have trained counselors, but our volunteers are not therapists. They do what any good friend might do. They sit down, talk less and listen more, touch where appropriate, and through companionship help a person to inquire more deeply into their difficult experience. If there's one person in the room who isn't so frightened about dying, it gives the patient confidence to explore their fear.

So how does one become someone who is not afraid of dying?

I don't mean to suggest I have no fear about dying. But I'm much less afraid than when I started Zen Hospice. Living with death on a daily basis allows it to enter into your psyche. Dying is in the life of everything, and resisting this truth leads to incredible pain. As we become more familiar with this truth, our fear dissipates. But we have to do our homework. When I am working with someone who is dying, I am exploring my own grief, my own fear. It takes courage and flexibility. It's a mystery we need to live into, opening, risking, forgiving constantly. This is the ground of true service.

The Zen Hospice Project's offerings may be found at www.zenhospice.org or at 415/863-2910. This includes details on the End-of-Life Counselor Program, six one-day programs in the coming year, and more.

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