

Excerpts From Conversations with Frank Ostaseski

By Joe Flower

"In all the world, what is most wondrous? In all the world, what is most wondrous is that man, woman, and child, though they see people dying all around them, do not believe it will happen to them."

— Bhagavid Gita

Introduction:

He is, as you might expect, quiet. Not merely soft-spoken, he allows his sentences to fall with a cadence that is at once thoughtful, calm, and precise. There are spaces in his conversation. He will say to himself, "What can I say that is useful here?" A big man with short-cropped white hair, he carries in his speech and person the gravitas of someone who has sat thousands of hours in meditation and, perhaps of equal weight, thousands of hours with people on the cusp of death.

Frank Ostaseski is the founder of the Zen Hospice Project in San Francisco [www.ZenHospice.org], and director of its educational arm, the Institute on Dying. His work has been featured in the Bill Moyers series On Our Own Terms, the PBS series With Eyes Open, the Oprah Winfrey Show and numerous national publications. He cochairs the Robert Wood Johnson Foundation's Last Acts Spirituality Committee.

It's a Buddhist teaching: Suffering is seen as a fact of life. Face it squarely. Notice what is actually there. Behind its façade of exoticism — austere robes, inscrutable koans, incense, and incomprehensible chants — Zen turns out to be, at bedrock, hard-headed common sense about life and its problems.

Death is one of life's biggest problems. Whatever your faith, whatever your sense of an afterlife, most people would agree that we don't handle death very well in this culture. We mostly turn away from it.

In facing death squarely for fifteen years, and building an organization of people to do the same, Ostaseski has learned a lot that is valuable, not only about how we might deal better with death, but about dealing with the living in our institutions. In discussions at several of his workshops, then in my study at the end of a long cold day in February, Ostaseski talked about dealing with nurse burnout, exhausted physicians, spirituality, body language, mindfulness, compassion, and death. "People in this country mostly die in fear — and we can do something about that," he says. "You want healthcare reform? This would be healthcare reform."

Ostaseski:

We started Zen Hospice in 1987 because people who had done this before, informally, with community members and friends, had found it to be immensely valuable — both to

the person in the bed and the person serving. We began with indigent cancer patients, seeing them in their Tenderloin hotels, or on the park benches behind City Hall.

That established two central programs: a five-bed residential program, The Guest House, and a palliative care unit which we collaborated in founding at Laguna Honda Hospital, a long-term care facility.

We went there because it's what many would consider their worst nightmare, the belly of the beast, an old-style open-ward hospital, thirty or forty people to a ward, 1100 beds in all, the largest public long-term facility in the country. If you are elderly, if you have little or no insurance, if you have no one to care for you in San Francisco, this is where you wind up.

When we first helped to establish the hospice unit there was a lot of denial that death even occurred there. This was a geriatric hospital, yet I remember being told by one of the head administrators, "Nobody dies in my hospital."

Over the years with the support of the administration and staff we were able to transform such a seemingly impersonal unit into a place of compassion and community? It had very humble beginnings. In that unit there are 28 beds in three large rooms. We turned the first room into a common room. We planted a garden on a ramshackle hillside just outside. It was the very first thing we did, the first team meeting — the staff, their spouses and significant others, their children. When everyone has their hands in the dirt, hierarchy tends to break down. People began to see each other as human beings, as opposed to their roles. We were able to transfer that experience from the very simple activity of making a garden together into how to create an interdisciplinary team and make this work within this unit.

We've been there since 1988, and the hospice unit has become the jewel of the hospital. It's the reference point when JCAHO people and others come to visit. They point to the hospice as an example of what could be done throughout the entire facility. They look at the therapeutic value of the sense of community that has been created here between the core staff, the volunteers, and the residents themselves, the patients. They ask: How could that transfer to other units and other institutions?

It's a private/public collaboration. On a weekly basis, we insert into that unit some 80 to 90 volunteers, who come on a regular basis from nine in the morning until midnight, and sometimes stay all night. These volunteers form a critical mass of compassion that transforms this unit. These volunteers act not only as an aide to the patients and their families, but as a model for the staff.

Full Attention

In their hearts, the staff always wants to do good work. But sometimes their responsibilities discourage them from the practices of simple human kindness. They're so busy doing procedures that they don't always have the opportunity to sit with a patient,

for example, to support a family member.

We have to recognize that health care professionals are under tremendous pressure. They have very little time. But to give someone our full attention requires more discipline and focus, not necessarily more time.

One simple change is to sit down at the bedside instead of standing at the foot of the bed. This expresses my concern and care. It says that I don't necessarily need to be in a rush here with you. This is an important message to send to a patient, that I have some time for your problem, that together we can work this out.

When a nurse takes a pulse, it doesn't require more time for her to look the patient in the eye instead of her watch. What would it be like if we took the pulse for 30 seconds, and took the next 30 seconds and gave it completely to the relationship with the patient. How would that change the way in which the care was provided?

These are very simple gestures which convey our respect, our care and concern. Come into the room, sit down, speak less, listen more.

Engaging the patient in all dimensions

We've watched the movement in the last dozen years from clinician-centered care to patient-centered care. But too often we cling to the patriarchal notion that we know what this patient needs, so we don't engage them in their own care. We are missing an enormous resource. It can start with a simple question: "What do you think is going on?"

Then we can also bring other dimensions of the patient's experience to bear. For example, to include the spiritual life is to bring forth other resources. "Do you have some connection to a faith community? How does your faith affect the way in which you meet your illness? How would you like us to deal with your faith? How would you like to reach out to that community for support?" These are simple questions. You don't have to be a chaplain to ask them. They tells us about the person's support system.

The basis of spiritual support is quite simple. It's a willingness to be there, not to turn away from the mysterious and the unanswerable.

In my neck of the woods — end of life care — this is absolutely essential. We cannot care for people at the end of life in the same way that we care for them at other points in their illness. They have a wholly different set of needs that have to be addressed. The first is to recognize that dying is not primarily a medical event. It's much more an issue of relationships. It's our relationship to ourselves, to those we love and who care for us, and to whatever image of God or ultimate kindness we hold in our life. Much of accompanying the dying is a matter of facilitating these relationships.

We have to bring the best of what medicine has to offer, particularly in the areas of pain management and symptom control. But the medical model is simply not large enough to contain the experience of dying.

Palliative care

Hospitals are set up on a model of curing. But there is a juncture after which curing is no longer the right treatment plan. A palliative care plan that aims at managing symptoms with the goal of a dignified death may be much more suitable. Hospitals are embracing more palliative medicine. A good example would be Beth Israel Medical Center in New York where Dr. Russell K. Portenoy has built the award-winning Department of Pain Medicine and Palliative Care [www.StopPain.org]. The University of California at San Francisco Medical Center has also developed such a program. It includes what is called the "comfort care suite" where people can actually die in the hospital away from the tubes and machines and noise of a typical intensive care unit.

Yet, in many hospitals, palliative care has simply not gotten the respect and attention that it deserves. So all too commonly, the curative model simply fails people at the ends of their lives. Their pain is uncontrolled, their symptoms are not well-managed, the psychosocial issues and the needs of the family are not well addressed.

The referral process is also important. Frequently, the referrals from hospital to hospice come very late. As a result, hospice programs have an average length of stay under 20 days. That is simply not enough time to work with the complexities of an individual's end of life care.

Exhausted clinicians

A physician came to one of my workshops. Her training had exhausted her. Her training was designed to exhaust her, actually. Now she was working in a major city hospital. One of her jobs, on the night shift, was to declare people dead. She said it was very mechanical for her. She just felt as though she were losing her humanity. She hoped that I might be able to give her some Buddhist practice which could help. I usually go toward the individual's past experience, trusting that we can discover something that would be useful. I said to her that it might be possible to learn something about Buddhism in a short time, but instead maybe she should look to her own lineage, that of physicians, of healers. What could she find in her own lineage that might support her? I told her how we care for people after they die, how we bathe their bodies, how we treat them with as much respect after death as before.

Months later, a mutual friend who runs a support group for physicians asked me, "What did you say to this woman?" This physician was doing something very interesting. When she made her rounds, in addition to carrying her stethoscope, she carried a small bag with a special cloth, a candle, and a vial of sweeet oil. She would make a small altar on the table next to the person who had died. She placed the candle on it, along with something that was special to the person who had died. If there were family members there, she would talk to them. She would anoint the person with the oil, and sometimes say a prayer. Every spiritual tradition has some way of anointing the dead. It was a radical step for her.

I know of an orderly who works in an ER where, after someone has died, and a code has been performed on them, and the chest has been split open, and everybody leaves the room, the orderly is the one who comes in and bathes the body. He leans over to the person who has died and he says, "You know, what's happened here is that you have died." He just speaks to them. He said he doesn't know if the person can hear them or not, but he figures it can't hurt. And then he says, "Now I'm going to wash your body with as much dignity and respect as you deserve." And then he sets about bathing their body. No one else wants to come into this room. The nurses and physicians have left. He takes his time and does it with great attention.

There are people who are making a difference in hospital systems everywhere. I hear about them just as often as I hear about the burned out nurse or the exhausted physician. Hospitals need to identify these heroes and bring them forth as examples.

If you look at all the literature on burn-out and talk to lots of healthcare providers, as I have, it's rare that people say that the work itself burns them out. It's usually the organizational structures within which they work — an unnecessary amount of regulation, inhuman schedules, a failure to recognize the very personal human needs of someone who is working on the edge of death day in and day out, almost no support system, the expectation that the healthcare provider should be a work unit rather than a human being.

I have seen a few things that help in progressive units that I have visited or consulted on. Some have made a physical place where staff can step away and have a quiet moment. It is useful when staff on units come together for a few moments of silence or prayers as the case may be, to re-clarify their intention as they go forward to do service in the day.

We have found that when healthcare workers engage family members in the care of their loved ones, it not only empowers the family member, it buoys the emotional life of the healthcare worker. For example, in post-cardiac units, family members come in and learn how to do the cleaning, how to work with the new technology. This helps the nurse or other clinicians feel that they have something really important to offer other than just their procedures.

Most people got into medicine because they care. These are good-hearted people, and they are leaving their professions in droves, because they can't really express their heart. They can't find a place for their own compassion to come forward.

Turning toward suffering

Look at our training. Look at the ways in which we are continuing to train people to turn away from suffering, instead of to turn toward it. The word "compassion," which I so love, and which gets over-used in this culture, means literally "suffer with others." It's the little word "with" in the middle which is so important, because it implies a certain kind of intimacy, a willingness to "be with." This doesn't mean that we have to get lost in the

suffering of others. We have to be able to build an empathetic bridge from our own experience to theirs. So if we never turn toward our own suffering ñ and healthcare workers are generally encouraged not to — we are increasingly unable to make that bridge. This notion that we should build a shell around us, armor ourselves with our objectivity, in an effort to protect ourselves from pain, is a ludicrous, bankrupt strategy.

All this armoring seems to do is prohibit tenderness from coming in. What it tends to do is lock away the pain and suffering of the healthcare professional until it rots them from the inside out. Maybe we can't open our hearts to every patient we encounter, but if we don't open our hearts to any of them, we become brittle and hard. Most importantly, we stop being able to listen.

When I am exhausted, I don't listen well. If I am not taking good care of myself, as a clinician, I will miss a lot, and I won't provide the best care that I can. Many hospitals are doing progressive programs that help their employees, patients and family members reduce their stress. These stress reduction programs are primarily programs in mindfulness and meditation — which is really just learning to listen intimately to ourselves — so that people have some way of moving toward their suffering instead of away.

This is a radical idea. It's like setting a new telephone pole. It's a little unstable at first. Fear arises and we may want to run. But, if it starts to fall, you don't want to run. The only safe place is right up close. You want to put your hands on it.

We're always running away from suffering. Or we become overwhelmed by it, or we repress it. And it comes back and hits us in the back of the head. What happens if we go right up and put our hands on it, get to know it really well, become intimate with it? What do we know about our fear, about grief, about our response to helplessness? Suppose, in a time when we weren't in a crisis, we got to know it a little bit, and began to see the kinds of thoughts that come through the mind, the way in which the body takes shape when we start to get afraid, so that we could recognize it in its arising, before we get swept away by it. Then we might be able to interact with it more skillfully.

We often have a lot of anger at denial. Denial is not ignorance. They know. It's a protective mechanism, a response to fear. When I see they are afraid, I discover my own courage. I get more tender toward them, and toward myself. The study of fear breeds courage.

The unconscious is always trying to tell us what's next — and most of the time we're not listening.

Dealing with Death

We have rituals when people die in a hospital unit, but they are rather procedural. They don't serve to refresh anybody. In most cases when someone dies the curtain is pulled around the body, they are given a cursory bath, a tag is put on the toe, and they are sent to

the morgue. Nothing more is done. On our hospice unit in the hospital in Laguna Honda, when someone dies, we say it's not an emergency. We sit down with the person that has died. We take away all the things having to do with medicine. We bathe their bodies with respect, sometimes involving family members, at least involving the staff who have cared for this person over time. That process of bathing serves much more than its functional need. It also serves as an opportunity for people to say goodbye. They may have grown very fond of the person. Or perhaps they didn't have the time to care for the person before they died.

When the first patient died on the hospice unit, we had a staff of nurses who had just been assigned to the unit, they hadn't chosen to be there. So when the first patient died, they came into the room and imagined that they would just go about their standard procedure. One of my colleagues was sitting there at the bed. When the nurses saw my friend sitting there, they didn't know what to do. You can't do this in front of this other person. So my friend just said something like, "Wasn't he the most wonderful guy?" and the nurse said, "Oh, he was, he had such a great heart." And the next thing you know they had pulled up chairs to the bedside. They began to talk about this fellow, tell stories about him, about how he had impacted their lives. After that they went to bathe his body in a way that that refreshed everybody in the process. Now we have a written (delete) policy on the unit that when someone dies — in this county hospital — we will take care of them in this way. It took us 10 years to establish such a policy. But if we can do it there, we can do it anywhere.

In hospice care, we continue to give fairly intensive care. It takes the form of intensive compassion, intensive attention to the needs of this individual, to see that their symptoms and pain are well managed, that their spiritual needs are addressed, that their family needs are considered, that they have an opportunity to finish whatever business is left unfinished for them — all facilitated by the interdisciplinary team. Often times in hospice care you'll find nurses saying, "I am finally now doing the kind of nursing that I had always hoped I'd be able to do as a nurse."

One calm person in the room can make all the difference to someone who is dying. Just as we might lend the strength of the body in helping someone to the commode, we can lent the stability of the mind. Once I was in a room with a family surrounding the bed of a dying patient. While they were well-meaning and they were trying to cheer him up and remind him of his old life, it was a bit overwhelming. I had never met him before. So I sat quietly in the corner of the room, watching the family interacting, and the professionals coming and going. At one point the man got upset. He screamed, "Everybody out of the room!" We all got up to leave, but he pointed at me and said, "Not you." I sat back down. He said, "You were the only one in the room who was calm in the face of my fear. Everybody else got more frightened, so I got more frightened."

Not knowing

Mindfulness is paying attention on purpose. Mindfulness is learning to listen very

precisely and intimately to our own experience and the world around us. Mindfulness is a willingness to listen beyond our skills and expertise, to be informed by what we don't know in the situation

In Zen practice, there is a great teaching that says, "Not knowing is most intimate." When we don't know, we have to stay very close to the situation in order to be informed by it. It's a bit like walking into a cave without a flashlight ñ you have to feel your way along the wall. To "not know" means to be willing to allow the situation itself to show us where we are going, to include dimensions of the encounter that at first we did not think were so valuable.

Mindfulness means to pay attention to ourselves as a healthcare provider as we come in the room. It means to pay attention to what is happening to the patient, and to the context that we might find ourselves in. When we do that we often discover resources in ourselves that we never would have imagined that we had, and opportunities for interactions that we might have otherwise missed. When I come into a room driven only by my agenda to get this thing done, all I will see is the narrow field of that agenda. Individuals cannot be healed by such a narrow view. We have to take into consideration the needs of the whole patient. That includes their spiritual life, their emotional life, their physical needs as well. You might be able to cure their illness for a while, but we may have damaged them just as much in that process. When we take away their dignity, we may reduce their sense of self-esteem, we may reduce their sense of trust in themselves, and in the system.

Compassion

Compassion is entirely a mutually beneficial exchange. It's not like I have this bucket of compassion over here that I can dole out to you. The only way in which I come to a place of compassion is by turning toward my own suffering. That's the only place that our appreciation of another person's suffering arises. That's the ground of compassion.

It can't be extended only as some kind of intellectual construct or spiritual practice. It can only arise out of a reciprocal relationship. My suffering informs my life and helps me feel some empathy and tenderness for your suffering, so I extend myself to you. And in doing that I am also caring for myself. It's a cycle of mutual benefit.

When I am working with someone who is dying, I am also looking at my own fear of dying and meeting my own grief. In caring for others I am always caring for myself.

When I work in this way the issues of burnout and exhaustion tend not to be so large and looming.

Compassion breaks down the walls of separateness. The notion that we are these individual units, completely separate, by itself adds an enormous amount of unnecessary pain and suffering. When we cut ourselves off from others, we also cut ourselves off from the resource of their compassion. We get duller and flatter and more cold and our bodies

get hard, and our hearts get hard.

The care of someone who is dying is nothing special. We've been doing this for each other for thousands of generations. Of late we have just forgotten and have become frightened of it. We have so professionalized and dehumanized the care of the dying that we have forgotten what a great gift it is to be with someone at such a vulnerable moment. We have started to forget the gifts that dying patients have to give us, what they can teach us about living fully. This isn't just Buddhist rhetoric. When we come to the end of our lives, we discover the meaning and value of that life. We see what is really important.

The primary lesson here is: This is a precarious life. It's precisely because it is so precarious that we must see its preciousness. Then we want to jump into life and not waste a moment. When there are people we love we tell them that we love them. We don't put off our life until some other time.

Hospital systems have within them one of the greatest teachers of all time — the teacher of death. Usually we turn away from it. We fight it. We see it as the enemy, as failure. Rilke has the great line: "Love and death are the two greatest gifts that are passed on to us, and usually they are passed on unopened."

What would it be like if we included death more, invited it into the facility more, sat down with it, had a cup of tea and really got to know it? One day we will celebrate death the way that we celebrate life. We will begin to see that it is our wise uncle.

There are three different ways that I could imagine working with a sick or dying person. The first is the capacity to listen completely. As Carl Rogers the great psychologist would say, "Listening with fresh and unfrightened ears." The thing we want most from one another is our attention.

The second is through the gift of touch. You don't need to be a massage therapist or a body worker. Just holding a hand can convey love, concern, care, respect. We can do this in a hospital environment.

The final way is recognizing people as also having a spiritual dimension. It's not a matter of esoteric practices, or even religious practices. It's more about eliciting people's stories — because stories are a way in which people find the meaning, the value, the purpose of their life. To elicit story is to elicit the spiritual life of that person.

It's about dealing with the body, the emotions, the spirit.

We have five basic precepts that guide our work inside the hospice that perhaps apply in other settings.

The first is: Welcome everything. Push away nothing. This means to create an environment of receptivity, an environment in which whatever needs to happen, can

happen. A care-giving system that is characterized by fearless receptivity.

The second is: Bring your whole self to the experience. In order to be people who heal we have to be part of the equation. This is intimate work, and you can't do it from a distance. Professional warmth doesn't heal. In order to be of service, we have to examine our own relationship to sickness, old age, and death.

The third is: Don't wait. Waiting is full of expectations. When we are waiting for the next moment we're missing what this one has to offer. Don't wait until the end of your life to see the lessons it has to offer.

The fourth is: Find a place of rest in the middle of things. Often in the busy-ness of healthcare, we can't just stop our experience. But is there a way we can find a place of rest right in the middle of what we're actually doing, by bringing our attention fully and completely to whatever it is that we are doing: Washing our hands. Just wash. We might find that in that moment of full attention, we are refreshed.

The final precept is: Cultivate "don't know" mind. This means to stay really close to the situation and allow it to inform our actions. When we think about what we know, as compared to all that we don't know, what we don't know is so much vaster. Yet we rarely leave opportunity for that to enter. We become narrowly focused on our expertise, and miss all the other resources that might be there — imagination, intuition, the urgings that arise in our bodies, what might arise from dialogue.

Those five precepts are truly useful in our work, and may well be useful to others.