

Putting Things in Perspective

Stories from a Hospice Volunteer: Tim

- By Tim Tosta

How did I decide to do Hospice volunteer work? The Zen Hospice program was first described to me by my friend, David Cohn, owner of the Atrium Restaurant on California Street. David is a former resident of the San Francisco Zen Center. David also was one of the founders of Greens, a vegetarian restaurant operated by the Zen Center at San Francisco's Fort Mason. An experienced volunteer, David described the work as "one of the best things I have ever done." I knew from his description that this was something to explore.

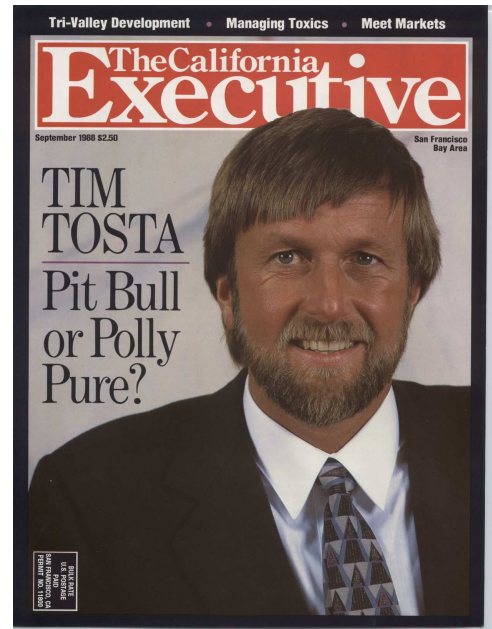
From my first conversation with David, I believe a year may have passed before I applied for training. During that period, I read numerous books and articles about death and the dying process, about the hospice movement and volunteer care giving. I attended four full-day Saturday seminars on death and dying conducted by Frank Ostaseski, founder of the Zen Hospice Project. I then attended a five day retreat in Marin for medical professionals, hospice volunteers and other caregivers involved with the dying process. In Spring 2004, I applied to the Zen Hospice Project for training.

But, truth be told, the circuitous path to my Hospice work actually goes back some fifteen years.

Tim's Story, Part I

I was born and raised in Santa Cruz, California. In fact, my mother delivered me in the same hospital (Sister's) in which she was born, twenty-five years earlier. I lived continuously in Santa Cruz through graduation from Santa Cruz High School, in 1967.

Santa Cruz, throughout my upbringing, was much smaller than it is today. I remember signs entering Santa Cruz heralding a population of 16,000—now it is well over 60,000. Another statistic I recall from my youth was that, at the time, Santa Cruz had the highest percentage of population over the age of 65 of any California town or city. That was consistent with my view of the world. I was raised in the close company of elderly grandparents, a great grandmother, many great uncles and aunts, all living within a short distance from my home.



That family concentration, the relatively small town size and the perceived low risk of physical danger permitted me remarkably free reign as a kid to bicycle not only throughout Santa Cruz, but to outlying burbs such as Soquel, Capitola, Felton, Boulder Creek, and Davenport.

I grew up in a "beach town" culture. Beach time wasn't limited to weekends. If I planned my day right, which I often did, I could get in some surfing before my first period high school class. The father of my good friend, Bruce, was a doctor at Sister's Hospital, which before its demolition, was situated immediately across the street from Cowell's Beach, around the bend from Steamer Lane, one of the Northern California's most recognized surf venues.

Bruce's father located a storage closet where we could store our boards. If I got to the hospital by 6:30 a.m., I could get in a good hour of waves, dump my board in storage and get to class, fully encrusted with salt, but highly receptive for learning.

And then, there were idle nights on the beach, year round. In fact, winter was a great season for gathering drift wood, washed up by storms. It generally only took a day or two for our foraged wood to dry enough to create raging bon fires of several feet in diameter. The local surf gang shared some fine winter evenings.

We would “hang” late into the night, telling tales of our surf “conquests,” anticipating when the next big “swell” from the season’s Pacific storms could be expected in Santa Cruz and discussing who was riding which maker’s board. So one dimensional were our lives that one of the most important parts of the newspaper was the tides chart. Those minus four foot tides, which caused big waves, were a cause for celebration.

As a kid, I really didn’t travel much. But, I knew very well the Pacific Coast from Marin County, in the north, to Big Sur, in the south. The greatest trial of my youth was to brave the fifty plus degree waters of the North Coast, without a wet suit.

In a way, most of my young life was “shirtless.” A great tan elevated you on the surfing social ladder. It was a common practice to see kids at the beach comparing forearms as to whose tan was deeper, browner, more likely to endure. Despite my father’s Portuguese heritage, which should have lent me a tanning advantage, I was cursed with my mother’s fair complexion, blue eyes, blondish hair, freckles and lots of moles.

One of our cultural rituals was to hit the beach to soak up the sun as early in the season as you could weather the temperature. We first gathered on the beach as early as the end of February. By April, we were well on our way in the year’s tanning season. Due to my complexion, my ritual included a first serious burn, followed by blisters and a good peel, setting me up for a deep summer tan.

At the time, we had no real consciousness of the potential skin damage from the sun’s rays. We did not use sunscreen. Rather, we slathered ourselves in baby oil and a number of other bizarre concoctions with the intention of deepening and enriching our tans.

The amazing thing about this tanning tradition was that I did not cease it upon leaving home. At Princeton, I could be found lying on the campus lawns with the Jersey shore boys as soon as the snow melted and the trees began to bud. There was a certain Zen-ness about sunbathing. Or, at least that was how I perceived it at the time.

I continued my tanning behavior through Berkeley law school and, when the realities of a career intervened to impede my summer ritual, I found that the Downtown Olympic Club had three tanning beds, generally available during the noon hour. So, when I wasn’t otherwise meeting with clients, hustling new business or deepening my relations with local politicians and public officials, I would do an hour of “meditation” between the plastic sheets of a tanning bed.

In the late 80’s, I was featured on the cover of the *California Executive* magazine. I was so deeply tanned from my Olympic Club sessions, that but for the blue eyes and blond hair, I actually appeared Portuguese. Then, I thought that I looked pretty good. I look back at that “head shot” with a decidedly different perspective now.

Obviously, in the thirty odd years from my sun drenched youth to early adulthood, much has been discovered about the dangers of sun exposure. Somewhere in the early 80’s, I began to regularly seek the services of a dermatologist to assess my skin’s condition. That is when I first became aware of melanoma, a deadly form of skin cancer.

In 1986, I had a mole on my right shoulder removed by a procedure known as a “shaved biopsy.” This procedure amounted to little more than shaving off the mole itself with almost no underlying tissue. The mole then was sent to a pathologist to assess whether or not it (or any surrounding tissue) exhibited any abnormalities. The results of the 1986 test were normal.

However, in 1989, I complained to my dermatologist that something was strange about the area from which the mole had been removed. I could feel something a little hard beneath my skin and the area constantly itched. Another limited biopsy was performed. Again, the dermatologist gave me the “all clear.”

Finally, in 1991, I just knew there was something wrong. I went to my dermatologist and asked him to deliver all of my slides from the 1986 and 1989 biopsies to the Melanoma Center at the University of California at San Francisco. He complied with my request and the slides were sent to Dr. Richard Sagebiel, then the head pathologist at the Melanoma Center.

A few weeks later, on a late Friday afternoon, I received a voicemail message from my dermatologist that I should return his call immediately as he had something important to discuss with me. Of course, by the time I received the message, his office was closed. So, I spent the entire weekend dreaming up bleak scenarios as to the reason for his call.

When we finally spoke on the following Monday, the chagrined doctor advised me that the original biopsy in 1986 actually showed a melanoma. It was missed twice. No explanation was offered. But, five years had passed from when the melanoma should have been discovered. The threat created by allowing the cancer to grow for that period, was that the tumor had metastasized. Then, like thousands of grenades, these discharged cancer cells could have lodged themselves in various organs and tissues of my body. From these scattered cancer cells, new lethal tumors could grow. Cancer treatments, such as x-ray and chemotherapy, simply do not work with melanoma. If there are metastases, the treatment process is to identify each tumor and surgically remove it – a type of “search and destroy” strategy.

I never will know exactly what motivated my doctor to then give me his evaluation of the situation – perhaps guilt, perhaps fear (he knew I was a lawyer), or perhaps some errant notion of full disclosure. But in that telephone conversation, he proceeded to tell me that, given the long term presence of the melanoma, it was probably metastatic and, if the metastases had begun, my life expectancy would be about two years.

The following six weeks were, and are, a bit of a blur. At that time, there were very few support systems or “trail maps” for people given a melanoma diagnosis. Of course, friends gave me the names of their recommended oncologists. Certainly, there could be no “answers” as to my prognosis until a surgeon had been identified and retained, a medical procedure performed, a pathological examination completed, and a consult had between the surgeon and the pathologist.

In 1991, I had been married to Nancy for 11 years.

Meredith, our eldest, was approaching 10, James was seven and Jill was three. And, for all of the wonderful moments, from having witnessed the birth of each child, to attending their birthday parties, snuggling with them at night, watching countless Disney movies and spending endless weekends at Baker Beach, it came to me painfully that I largely had been an absentee father. While in hot pursuit of my career, I would actually say to myself that “I will live my life later.” I don’t know how I could have been so stupid.

I know now that life is only what we have here and now. It is not something to be postponed. Every breath serves as a reminder of its passing. However, I just couldn’t see it at the time.

“ We all live under death sentences. The sentence begins the day we are born and our job is to make the best of what we are given. ”

So, I spent that six weeks interviewing doctors, researching treatments and trying to come to my own conclusions about my prognosis. When you are told that you might die within two years, having a physician tell you that he cannot even meet with you for 10 days seems like an

eternity. And, even then, should you like the physician and place your trust in him, it likely would be another two weeks before the procedure could be performed and another week for the pathology report to become available.

I also learned that there was a division in treatment approaches to my situation between an older and younger generation of surgeons. As with breast cancer, the older generation was inclined toward radical, invasive surgeries. The first surgeon that I interviewed advised that he would be removing tissue from my shoulder with a circumference the approximate size of a grapefruit. He would graft skin to make the scar less prominent. He hoped that the removal of underlying muscle wouldn’t interfere significantly with the use of my right arm.

The younger surgeons approached the procedure differently. Their practice was to remove only that amount of tissue necessary to provide a “margin” between the cancer and remaining healthy tissue. If the margin was not adequate, further surgery would be performed until a satisfactory margin had been obtained. I also learned that in using this less invasive approach, the surgery could be performed by a plastic surgeon rather than an oncologist. Music to my ears!

Behind all of the urgency in attending to the immediate medical issue, I experienced incredible emotional stress. Shortly after announcement of the “bad news,” I found it impossible to sleep. I began taking “over the counter” sleeping pills. But I would awake, like clockwork, at 2 a.m. and find myself unable to sleep the rest of the night. During those sleepless nights, my mind, surprisingly, was not awash with thoughts. There was almost no mental activity. Rather, I recall a pervasive feeling of darkness, which at the time I could only describe as “dread.” How I was able to get up each day and continue to perform as a lawyer, I’ll never know. I began to see the irony in having moved from surfing the Pacific’s waves to surfing the early morning television channels, incapable of sleep.

I also found that I simply could not talk to my immediate family about my experience and my fears. Obviously, my children were too young. And, talking about my possible demise just seemed too great a burden to place on Nancy, my sister or my parents. They were aware of my diagnosis, but I found that I could not talk about my prognosis. This left me very isolated.

Then there was a bombardment of practical concerns. Where do I stand on life insurance? I certainly couldn’t buy any now. Did I exercise that last available option on my disability coverage? What financial means will my family have when I’m gone? Maybe the financial future for my family rested in a malpractice claim against my dermatologist and his pathologist? Did I want to spend the rest of my time engaged in a medical malpractice suit?

There emerged a peculiar dichotomy between my mind and body. I thought about how my “body,” through the cancer, was betraying “me.” But, wait! Isn’t my body “me”? Or is “me” only my mind?

Finally, the procedure was performed by Dr. Greenberg, a plastic surgeon. Soon, Dr. Sagebiel called to advise that there appeared to be clear margins around the excised tissue. Dr. Sagebiel advised that the tumor appeared not to have metastasized. Nonetheless, he advised that for the next seven years, I would be closely monitored by the Melanoma Center to confirm the prognosis.

Was the death sentence removed or simply delayed? Some 15 years later, I again see the irony of this thinking. We all live under death sentences. The sentence begins the day we are born and our job is to make the best of what we are given. I didn’t see it then, but at least my “reprieve” offered me the opportunity to make amends for a life “lived,” but not adequately appreciated.

I knew that I needed to find a balance that, on the one hand, would allow me to adequately provide for my family, but, on the other would grant me time to be with my family and friends and to contribute to the world in some more meaningful way.

But where to begin?

(To be continued)

Note: My volunteer work is through an organization called Zen Hospice Project. For more information about the organization and how to become a volunteer, please visit <http://www.zenhospice.org>.