

Putting Things in Perspective

Stories from a Hospice Volunteer: Alejandro

- By Tim Tosta

In Autumn 1991, my pathologist, Dr. Sagebill reported to me that the tissue excised from my right shoulder, which contained a Level IV melanoma tumor, had provided “clear margins,” meaning that no further surgery would be required. Moreover, because the margins existed, it was very likely that the tumor had not metastasized. However, because the cancer was “mature” due to past misdiagnoses, it was deeply embedded and close to the blood supply. Consequently, I was directed to the UCSF Melanoma Center four times annually. I also was subject to a regimen of regular blood testing and chest x-rays to identify any metastatic tumors as early as possible. Dr. Sagebill cautioned that I would probably not have an “all clear” about metastases for about seven years.

At the outset, I grossly underestimated the power of those periodic exams. Fifteen years, fifteen subsequent surgeries and almost sixty examinations later, I see my visits to the Melanoma Center as more of a pilgrimage than a medical protocol. The visits ground me in the reality of my mortality. They highlight the paradox with which I have wrestled for the past 15 years, between wanting to return to life “as normal” and knowing that my cancer experience had forever precluded that “normal” life.

My experience with cancer was a “whole being” experience. It affected my body, my mind, my emotions and my spirit. It helped me see that I had been oblivious to much of my life. But, having acknowledged these omissions, what was my path away from my current circumstance? Where was I to find the map to guide me along this path? And where would this path lead?

The Melanoma Center referred me to an in-house psychologist treating cancer patients. I availed myself of the opportunity to meet, but after one visit, I knew that my difficulty was not one of “denial” that I had had cancer. It also was not that I had become psychologically maimed by the experience. Rather, I saw, intuitively, that the cancer may well have been one of the best things ever to happen to me.

So began my journey. I was 43 years old. I had survived, for the moment anyway, a cancer, which for six weeks I believed might prove fatal. Although I was raised Roman Catholic, I had walked away from the Church in my early 20’s and considered myself “spiritually adrift.” I still found it difficult, if not impossible, to talk to my immediate family about the extraordinary fear that had embraced me for the past months and the daunting course that might lay before me.



Hummingbird at Mt. Crested Butte

I had read Joseph Campbell’s *The Power of Myth* and saw that I faced what Campbell calls the “Hero’s Journey.” I had to move away from all that was familiar and comfortable. I knew that, in doing so, I put myself and everyone close to me at risk, since I did not know where the journey would lead. I knew that I might meet resistance from those close to me as I changed behaviors, examined fundamental values and engaged in new and diverse experiences, outside of my comfort zone.

In a way, the Melanoma Center became the beacon from which I took my bearings. The Melanoma Center offered the promise of safe passage. At the same time, its very existence evidenced potential rocky shores.

Upon each of my early visits to Mt. Zion Hospital, where the Melanoma Center is housed, I brought with me two distinct feelings. On the one hand was the fear that I had experienced from my original diagnosis. On the other hand, I began to see the changes that the entire cancer process had wrought and how many of my behaviors and attitudes had inalterably changed. Interestingly, I found that even when I didn’t have an appointment, if I were to drive in the vicinity of Mt. Zion Hospital, similar feelings would emerge. On occasion, that led to an intentional course correction away from Mt. Zion. On other occasions, I would chart a course nearer the hospital to explore my feelings.

I see life as composed of four quadrants - body, mind, emotion and spirit. I began my quest with an exploration of the first two. My approach was academic. I identified books written by or for cancer survivors. I located volumes on cancer recovery generally, and melanoma specifically. I investigated various diets and other practices intended to make my body more cancer resistant and I read psychology books on the health effects of a positive outlook. I reviewed books on time management. I contemplated what most brought joy to my life and how I might fit more of whatever that was into my current circumstance.

Perhaps not surprisingly, the reading that most resonated with me in the first year or so of exploration espoused the interconnectedness of mind, body, emotion and spirit. To attempt to treat one without the others seemed to me, in the end, to be futile. So, while diet and exercise were important, it was equally important to deconstruct habitual behaviors giving rise to negative emotions. Moreover, the medical research more than amply confirmed that those with a spiritual practice experienced less disease and greater longevity.

So my areas of inquiry expanded. I undertook the study of philosophy and the study of comparative religions. I morphed my exercise regimen into a yoga practice, not knowing the depths of understanding that yoga would invite me to explore.

And, with this holistic inquiry came the most fundamental questions. What is the purpose of my life? Who is the "I" to which I refer? Is it an independent being, or part of a greater whole? Is it directed by a greater power, or the product of a series of behaviors cobbled together to make a unique individual? Needless to say, this was rather heavy stuff to be contemplating "on the side" of work and family obligations. But, the deeper my inquiry, the more answers emerged.

Let me just give you one example. From studies as seemingly disparate as the art of listening, health and healing, and the stages of dying, I continued to find the same metaphor. The "I" or "self" is a composite of life experiences, a personal documentary film. That is, each of our personal histories gives rise to a story line about ourselves, which shapes our perceptions, handicaps our creativity, encumbers us with prejudices, and creates much of life's turmoil. To listen to one another effectively, is to step outside our movie so we are not handicapped by our perceptions, permitting us unfettered access to the speaker. To heal is to step outside our docudrama of ourselves as "sick" to recognize that much of life functions fully. It is only in seeing the beauty of what surrounds us, even if ill, that we establish an outlook which will permit us to recover from ailments. To die a "good death," is to find meaning in our docudrama, even if it means a last-minute rewrite of the script, taking the focus off ourselves to embrace the entire universe in which we have operated. It is only in rewriting our scripts that we have a chance to find the meaning which our life already has, but which we failed to see, let alone understand.

So that brings us to Alejandro.

Alejandro's Story

Alejandro arrived at Laguna Honda a few months prior to my starting work there. He is in his mid-eighties. Alejandro is a small, wiry but strong man. He carries enormous presence. He was born in northern Spain, but later moved to southern France. He began a life of world travel as a young man, which kept him from ever calling any one place "home."

Alejandro suffers from lung cancer. At the time I began volunteering, Alejandro had limited mobility. He became

non-ambulatory shortly after my arrival. To my great fascination, once his strength had gone, he generally chose to remain in bed. He appeared not to wish to suffer the indignity of being moved in and out of wheelchairs, although on occasion he would do so.

When I first met Alejandro, interaction with him was on his terms. It was his ball and his court. His rules governed the 30 square feet of his domain. Alejandro was situated in the second bed on the right, upon entering the men's ward. Because the nurses' station, with its large plate glass window, was situated on the right side entrance to the men's ward, the first bed often remained unoccupied or was removed altogether. This probably was for one of two reasons. First, it was difficult to block off the large window to the nursing station, so the first bed had no privacy. Second, if you provided privacy, the nurses would be denied the wide-angle view of the ward. Mind you, the first bed wasn't always empty. At times, particularly restless residents were placed there because they required close supervision. For the most part, these residents had little awareness of the lack of privacy afforded them.

But, even on the main ward, privacy is limited. Each bed has above it a circular track from which hangs a very light polyester curtain. The curtain is some God awful color in the spectrum between pink and orange.

Alejandro's curtain was often closed. Woe be to the volunteer with the temerity to poke his head behind the curtain. Alejandro cherished his limited privacy. He did not receive well those who invaded it. Alejandro was a voracious reader. Every flat surface in his limited space was generally covered with newspapers and magazines. He seemed able to read for hours on end, only to be interrupted by hospital staff for meals, medication and the physician's rounds. Laguna Honda staff, of course, could not comply with Alejandro's rules. That did not mean that staff was less likely to incur his anger. To them, Alejandro's wrath was just part of the job.

In our family, we subscribe to way too many magazines. We get, among others, the New York Times, the New Yorker, Atlantic, Newsweek, National Geographic and assorted magazines pertaining to arts, music, history, politics and philosophy. More often than not, there were more magazines than time to read them. Often issues made their way to the recycling pile unread.

I began to do my magazine recycling through Alejandro. He was very appreciative of the additional reading material. I learned that it was safe to make a delivery when his curtain was drawn back. With each visit, Alejandro and I would chit-chat for a bit.

I enjoyed the conversations with Alejandro about his world travels, his work life, and his women. But I was most taken with his philosophy concerning his illness and pending demise. Alejandro would have done Jean-Paul Sartre proud.

He would wax on eloquently, "Life is what it is. You can do nothing to control it. You have to make the best of things." About his impending demise, he would add, "I wish it would come sooner, rather than later. I am very bored. I enjoy my reading. I learn new things every day. But, I wish I could just go." When asked "What do you think is next?" he would reply "There is nothing. When you die, it's over. There is nothing more."

One morning, as I left my driveway on the way to the city, I saw that my neighbor had stacked some 30 years of National Geographic beside the curb for recycling. I decided that recycling through Hospice and Alejandro was preferable to Waste Management, so I hijacked the volumes and meted them out to Alejandro and the ward for several months. On his "open curtain" days, we would discuss what he had read, what excited him, what he found interesting. It didn't matter that this information would never be applied to any purpose. It was precious to him simply to have the knowledge.

When I returned from my August vacation in Colorado, I found a very changed Alejandro. His bright eyes and toothless smile were gone. I found a very old man in the fetal position, immobile, with sheets covering almost every inch of him. Residents often change rapidly. You really have to appreciate the present time you have with them, as they may change so dramatically from visit to visit.

Our first conversation after this decline was brief. Alejandro was explaining that, despite the weakness and fatigue that had recently claimed him, "My mind is very clear. There is no problem with my thinking." After a few variations on the same theme, I came to realize that Alejandro knew that he was losing his cognitive ability, despite his protests. One clue was that his curtain began to remain open. That was not Alejandro. What little remaining control he once had over his life included controlling access by means of the curtain. But now, that was gone too.

The following week when I arrived at his bedside, he looked at me without recognition. He spoke to me in Spanish, a language in which I was once fluent, but had not practiced for 25 years. He could see my frustration over my diminished Spanish skills. I asked "Alejandro, Ingles, por favor." He replied in Spanish that he did not speak English. He went on in Spanish, "Are you some kind of moron? We all speak Spanish. I know that you can speak Spanish. Don't be an idiot." In Spanish, I asked him if he remembered how to speak French. He looked at me again and again, labeled me an idiot and told me that he didn't speak French. However, he delivered that message to me in French. There was a point in the conversation when I thought "Alejandro is having me on." At one point his eyes lit up a bit, and he gave me that broad, toothless smile. Was he really having fun with me on the language thing?

After a few minutes more, I came to see that he truly did not know which language he was speaking and, clearly, English was not available that evening.

The following week, when we had our "shift meeting," I learned from other volunteers that Alejandro had continued to speak in either Spanish or French, but not English. But, whether it was a language problem with the volunteers or just growing fatigue, Alejandro was cutting back on communication altogether. He began to sleep more and more. For a couple of weeks, Alejandro slept through my entire shift. The staff moved him from the second bed to the first, immediately adjacent to the nurses' station. In the daytime, they began to put him into the functional equivalent of a child's high chair called a "Gerichair." Once in the chair, and secured by the tray, Alejandro was confined. There was simply no way that he could extricate himself from the restraint. In my view, the Gerichair must have been developed during the Spanish Inquisition. While seated in it, Alejandro directed his attention and remaining energy to shaking, rattling, twisting and fumbling with the edges of the tray to get freedom. It perhaps was not torture to him. But it felt like torture to me to observe him.

Then Alejandro was moved to a quiet room. Either his behavior was sufficiently disruptive to the other residents as to require his isolation and/or his demise was imminent. I did not know. But a few short days ago as Ellen, my shiftmate, and I were walking toward the common room, we found a bewildered Alejandro in his room in Gerichair captivity. He asked "When are they going to let me go to my bed? I want to go back to my bed." At that time, he was seated immediately adjacent to his bed, so he had me a bit confused. "Alejandro," I said, "this is where you sleep. You have slept here for a couple of weeks now."

"No. No. This is not where I sleep. It is somewhere else."

Clearly, it was pointless to engage him on this point. So, I just sat quietly. Then, he said to me "I am lost." I asked "Do you mean you don't know where you are?" His response floored me. "No, I do not know who I am."

"My God," I thought. Alejandro is no longer living his movie. He has entirely forgotten it.

So, there sat my friend Alejandro who was, at that moment, egoless. He had no movie in which he had the leading role. If he had limited perceptions, he wasn't aware of them. If he had prejudices, they were gone for now. And, unlike Campbell's hero, he had not arrived in his present state by any heroic journey. Rather, his biology had crashed and burned around him.

Despite all of our past conversations in which Alejandro held forth his philosophy, which he might not have known as existentialism, I remained a doubter. I did not believe he wished death to come sooner. I did not trust that he was not afraid to die. Right or wrong, I believed that Alejandro had important work left to do. Had his work been done, he would have passed.

So, I decided to try to help Alejandro restore himself. Our conversation went something like this:

“Do you remember how many languages you speak? I have heard you speak in English, Spanish and French. Do you know how you learned all those languages?”

“I also speak Italian, Portuguese and Catalan.”

“How did you come to speak so many languages?”

“I know that I traveled all over the world. I love to travel. I have been in every country in Europe, I have traveled throughout The Americas, North and South. The only places I haven’t been are in Asia. I never had an interest in going there.”

“How were you able to travel to so many places?”

“I would just go. I would work for a trucking company as a driver and take goods all over Europe. I would get a job as an engineer on a merchant vessel and travel to South America. I worked in mines in Canada digging coal. I would do whatever I had to do to get to the place I wanted to go, find a job there, stay as long as I wished, then go somewhere else.”

“What countries did you enjoy?”

“Oh, I spent wonderful times in Brazil and Argentina. I loved Honduras. Canada was hard. I didn’t like that job.”

“Were you ever married? Did you have any children?”

“I had many women, but never married. I have two children by one of those women.”

“Do you know where your children are?”

“They’re probably still in Brazil where they were born.”

“Do you remember your name?”

This stopped Alejandro cold. He looked at me in disbelief and he said “Of course, I am Alejandro del Greco.”

“Of course, I was just checking.”

And so our conversation went on for maybe an hour. He regaled me with stories of gambling (he loved the horses, he said), and his days as a rugby player. The agitation which characterized the early evening had departed. He no longer wished to retire. I again saw that “aliveness” which I was so accustomed to seeing in his eyes. So I asked, “Alejandro, are you still lost?”

“What a stupid thing to say! Of course I am not lost!”

“Do you know who you are?”

“Why do you ask such a ridiculous question? I am Alejandro del Greco.”

With that, our conversation was over.

In almost every wisdom tradition, there is a “Hero’s Journey.” It is not the outward journey of Homer’s *Odyssey*. Rather, it is an introspective passage. It requires going beyond the limitations of our current beliefs, perspectives, judgments and prejudices to find our “essence,” being or soul which is wise, good and compassionate. It is no small journey. People seek these insights for years, if not decades, with only an occasional glimpse of the truth and little more than a “sense” of what may lie at the journey’s end.

The various wisdom traditions generally reach accord on one basic truth. The purpose of life comes only with an understanding of our relationship to all other life on the planet. None of us stands alone, acts alone, loves alone or dies alone. We are each interconnected with all other living things. With this knowledge, you begin to direct your life along an entirely different path, even if your time remaining is a matter of days or hours. Alejandro was back on track to continue his journey.

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>.