

# Putting Things in Perspective

## *Stories from a Hospice Volunteer: Craig*

- By Tim Tosta

**W**e are each the “star” of our own biopic. Our story provides a framework against which we assess what is going on in our lives, from the big stuff – family, career, physical and emotional well being, to the little things – wardrobe, hair style, choice of automobile and place to go for vacation. Before my cancer diagnosis, I liked my script. A middleclass, publicly educated kid from a small California coastal town gets lured to the Ivy League by a famous television producer (all true, but another story); returns to California to attend a prestigious law school; opens his own law office upon graduation and proceeds to a life of modest recognition, power and prosperity; all while marrying the love of his life and raising beautiful, intelligent, talented and creative children. Perhaps, not a very provocative script, but one, nonetheless, that served this protagonist well. Or so I thought.

The problem with living your biopic is that it may not always serve you. In living a “scripted life”, you often miss important questions, fail to perceive critical new information, and shut down certain systems designed to make your life more fulfilling.

It was only after I was given a terminal cancer prognosis at the age of 41, that I first began a serious inquiry into how I found myself in my current career. It was a lengthy examination into what and who had influenced me in making that career decision (family, culture, teachers), my own youthful assessment of which career would provide me with a desirable “lifestyle”, what work would complement my perceived cognitive skills and personality. Some years later, at about 50, I gave myself renewed permission to continue in my career and, in many ways, that renewal invigorated my work and my life. But, my cancer also prompted a broader investigation into my life’s purpose. Career was a part of that analysis, but it now seemed, a much smaller part than I previously had imagined.

As I have come to see it, the quest for purpose, or some might call it meaning, is the fundamental inquiry of human existence. To a greater or lesser extent, each of us knows this. But from our early 20’s to our mid-40’s, we ignore the query, captive as we are to our raging hormones, our careers, our need to find a mate, to procreate and to raise our families. But, at some point, as we begin to look at the remainder of our lives, the purpose question reemerges.

In my case, I had not given this matter the time or the attention that it deserved. My cancer diagnosis was my invitation from the universe that it was time to take “purpose” seriously. A terminal cancer prognosis trumps a mid-life crisis. For me, there was no



running away from home, no hot convertible, nor any of the other standard distractions to carry me across the gulf from the prestige, power, and wealth, to which I previously aspired, to that which I believed was necessary to live a purposeful life.

In the more than 18 years since I began this journey, I have begun to see how pandemic is our quest for purpose. We may not see it for what it is and we often don’t get it right. As an “advanced” Western culture, we have defaulted to material wealth over meaning. We have succumbed to addictions of mind and body to distract our minds and numb our bodies out of the recognition that much of what we do to support our own lives, let alone the lives of those for whom we most care, isn’t really working. More importantly, not only is our material quest unfulfilling, it threatens the future of the human race and the survival of the planet.

Should it come as a surprise to us that our lives are out of balance, when we really don’t have a life’s purpose against which to set our goals, define our intentions, and establish our priorities? How can one have balance when, lacking purpose, we don’t even understand the scale?

So when people ask me “How can you every week at hospice look into the faces of the dying?” - I know one thing: the purpose of my work, my life, in those moments is to help these residents make that powerful transition with as much compassion, grace and, I would say, elegance as possible.

When I walk through the doors of Ward C-2, at Laguna Honda Hospital, all those years of legal training and experience, all of the power, recognition and prosperity that I allegedly have accumulated is beyond irrelevant. Moreover, during the time that I spend with

residents who I am is completely irrelevant. I spend more time telling them who I am not (a doctor, a nurse, a social worker, etc.) than who I am. And, when pressed, I tell them that I am just a “volunteer.” The support that I am giving and the connections that we are making are not defined by my role. On occasion, a resident may ask what I do for a living or where I live, or if I am married and have children. But that is the exception, and not the rule.

After my 5 years at hospice, the nursing staff knows me. Of the regulars, one knows my first name, another simply calls me “lawyer”. To the others, I am a familiar face, the guy who brings his ukulele and sings, or the biggest guy on the Monday evening shift upon whom staff can call to move heavy objects, including a resident’s body to the morgue. Coming every Monday from the financial district where recognition, power and wealth are the currencies by which value is measured to a domain of anonymity and compassionate service is remarkably freeing for me. In a way, it takes my ego out of the picture. I exist in present moment awareness of others. And in that awareness of others, I see things, I feel things, I intuit things that are simply not a part of my day to day life. I take that awareness home with me at shift’s end. Can I hold that insight and compassion to apply it to the other parts of my life and work? And, if I do, how will that enhance my life and the lives of my family, friends and colleagues?

Let me introduce you to Craig. I first heard about him at our shift change meeting at which the afternoon volunteers, for the benefit of the evening shift, offer their insights as to the state of our residents. Craig had just arrived days previously – then late March. He suffered from Amyotrophic Lateral Sclerosis (ALS), also known as “Lou Gehrig’s Disease”. ALS is a progressive neurodegenerative disease that progressively kills the motor neurons in the brain and the spinal cord. The motor neurons are the nerves that reach from the brain and the spinal cord to the muscles throughout the body. When the neurons die, the brain can no longer control muscle movement. As the disease progresses, the patient becomes progressively paralyzed and, ultimately, as the muscle movement necessary for breathing cannot be sustained, the patient dies. ALS is one of those diseases that is not very well understood, and there is no cure or treatment that halts its progression. Like many diseases of its type, it is variable. No two people share the same experience with ALS. In some, the deterioration is extremely rapid. In others, the ALS seems to “burn out” or progress at an extraordinarily slow rate. Consequently, neither the doctors nor the patient can really anticipate what will come next.

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Craig was young, too young. He was only 31 years old. We don’t see that many young people in C-2. When we do, they are usually in the final stages of an AIDS-related illness, hepatitis C or liver failure so the physical deterioration from the disease masks the resident’s actual age.

As I first approached Craig in the common room, there was no question that he was young. He was seated in a wheelchair, positioned parallel to the dining table, so that I had a clear view of him as I approached. He was tall, perhaps 6’4” or more, and too big for his wheelchair. His feet had been removed from the foot rests, and were extended in front of him on the floor. He sat with his arms folded on his lap, his right hand resting on the left. He was leaning forward so that I couldn’t immediately see his face, but I noted his close cropped hair.

As I approached Craig, he looked up. I immediately was struck by his handsome features, his steely blue eyes and what looked to me to be a pained expression. Also striking was a peculiar tattoo which rested across his chin and proceeded up his right cheek. Craig was Caucasian, but the tattoo pattern could have been one rooted in the indigenous cultures of Africa or the South Pacific. It was brown hued and expressed as a series of four sided shapes spread across the surface of a triangle that proceeded narrowly from the left chin and opened to the right cheek. If Craig was not a third world traveler, or zealous anthropologist, it was my guess that this was a mark sported by someone who had served time in a correctional facility.

Before I could make my introduction, Craig raised his head, met my eyes and asked “Can you take me out for a smoke?” “Sure” I replied.

Ward C-2 has a beautiful garden. The garden is where the residents prefer to go to smoke. It was built in the mid 1980’s and, until recently, had been maintained by Marvin, a gentle soul and resident of San Francisco’s Zen Center. The garden contains fountains, wind chimes, ferns, bamboo groves, rhododendrons, native grasses, tables and chairs, as well as a small gazebo for inclement weather. How a garden survives in this small slice of land, situated between the two 6-story wings of an early 20th century structure is a testament to Marvin’s horticultural genius, insight and intention that the C-2 residents be served by this unique environment. The garden, in fact, is so special that it had been the subject of professional papers on the importance of gardens as therapy, particularly in the hospice setting. Marvin died last year shortly after having been ordained a Zen priest. The garden’s care has passed to others who share Marvin’s purpose to maintain this extraordinary place.

Unfortunately, that March evening, it was raining. But for Craig, as for so many other residents, going out for a smoke was a pleasure irrespective of weather conditions. Having confirmed that Craig had his cigarettes and a lighter, I proceeded to prepare him for his outing. From our shift meeting, I had learned that Craig had lost movement below his waist and in his left arm. Paralysis was proceeding through his right arm, but he could still lift his forearm and hand to a height slightly below the breastbone.

One of the extraordinary lessons that I've learned in hospice is how important it is to slow down and be present with a resident. When I took a second look at Craig's posture in the chair, I realized why I had seen the pained look in his face. Because of his size, his weight and the chair's architecture, Craig's buttocks had slid forward leaving tremendous weight bearing down on a curved spine. So my first job was to realign him into a comfortable seated position.

Not knowing exactly where Craig was in the progress of his disease, I had a lot to think about. First was communication. Even though he had made his request, I did not know how much effort speech required of him. I didn't want to tax his strength with a number of questions, but I needed to understand where he was relative to movement and pain. So I asked, "You look uncomfortable in the chair. Would it help if I repositioned you?"

His reply, "That would be great."

"I need to understand whether this will cause you pain, so you can tell me in words or gestures." Then I described how I would reseat him. In the course of the adjustment, Craig efficiently communicated how the adjustment was going and what more I needed to do to give him comfort. I was amazed. He wasn't exactly barking orders. But, he knew what he needed with incredible precision and directed me with equal clarity on how to effect the outcome.

Next, I knelt before him to place his feet back into the wheelchair footrests. Craig dictated the procedure that he wished me to follow, including the sequence of movements, and how to hold him to give him support and avoid pain. In the course of my movements, I found myself extraordinarily sensitive to giving Craig what he needed. I would look up between steps to get confirmation that he was still comfortable and remained in charge. This was how we began our relationship. Me, kneeling on the floor, gently moving the paralyzed limbs of a 31 year old man.

After Craig was comfortably situated in his chair, we dealt with the issue of blankets. It was not just rainy, but also blustery and cold outside. Our goal was the gazebo, some 30 feet distant from the common room door. The gazebo offered shelter from the wind and rain, but it probably would be like an icebox inside. I placed blankets around his torso and legs, then a second set around his neck, shoulders and upper body. Finally I covered his head and shoulders with a third blanket which would serve as the "rain coat" for our short dash to the gazebo.

Of course, you never move fast with someone in a wheelchair. Fast is stupid. In fact, I am generally learning that as a life lesson. Being aware and moving with purpose is how most of life should go, most particularly, when you are engaged in the care of another.

Truth be told, I hate smoking. I hate being around smoking. For the first 2 years of my life, I was asthmatic and for the next 25 or so suffered horrific allergies which manifested in various breathing difficulties. Being around smoking recalls to me those times when breathing wasn't easy, but I've had to change my attitude about smoking at C-2. Many of our residents are often most happy and most engaging while on their smoking forays. The garden certainly is an inducement, but smoking is the activity. I guess if I were in this hospice ward and wasn't suffering from extreme respiratory difficulties, there wouldn't be a lot more that smoking could do to me in my remaining time. So I eventually let my smoking judgments go. I just do what I can to be with the residents as they indulge their pleasure.

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The gazebo is a little octagonal redwood structure with an approximate 8 foot diameter. There is room inside for maybe 2 wheelchairs, 1 ordinary chair and little more. The structure is about 12 feet high, with the roof pitching in toward the center. Plexi-glass enclosures extend up from about 3 feet off the ground to the start of the pitch of the roof. There are no operable openings, but for the door. The design of the roof allows smoke to escape through the structure's top.

That evening, as I moved Craig to the gazebo, I found it occupied by Larry. Larry was a street person, in his last days in his battle with cancer. Long unruly black and grey hair, a mottled complexion and an unruly appearance from years of living on the streets gave him an initially frightful countenance. But, he rarely was angry and seemed, with his remaining strength, to want to help the other residents in the ward. He almost never spoke, but he conveyed a sense of caring simply with a look. I situated Craig in the gazebo, and retrieved the cigarettes and lighter from his pocket. He instructed me as follows:

"I need you to put the cigarette between my lips to light it. When it is lit, take the cigarette from my mouth and put it between my middle and ring fingers. I can smoke it down from there. I no longer have any feeling in my hands, so you have to watch the cigarette. I don't want to it to burn me. When it gets short, you can hold the butt up to my lips and I will smoke it down from there."

With the same clarity, presence and efficient direction, Craig smoked his first cigarette.

As he smoked, we talked. Craig told me that he had been a basketball player in Texas. Apparently, he was a good one, but his career ended before it began, in high school. He never went to college. He just “went to work.” He told me that, after his ALS diagnosis, he married a woman with advancing multiple sclerosis. Neither worked. They lived their lives on public support, taking care of themselves and each other. At a public library they had researched where, lacking money, they might be able to receive better health care. Their research led to their move to California. Craig told me that upon arriving here, the doctors “gave me 6 to 10 months. But I’m hoping to live longer than that. I don’t want to die. I have a beautiful wife. I’m young. I have a lot of life ahead of me.”

As he talked, Craig would lean forward in his wheelchair bringing his head down to meet his right arm at breast height to take a drag. The conversation was slow. It really didn’t need to be any other way. I really liked this young man. He was smart. He was clear. And, despite what his body was doing, he was very much alive.

After a second cigarette, we headed back to the common room. There we found Fabrice, one of my shift mates, seated with Tremaine, a resident, at the common room dining table. Tremaine, an African American, had come from Louisiana to California for work 50 years earlier. He worked at the shipyards and, at some point, got into heroine use. Consequently, he lost his job, lived on the streets, and developed Hepatitis C. But Hep C wasn’t what was killing Tremaine. He also had developed prostate cancer and was beginning to fail rapidly. Fabrice, in his mid-30s, is of Italian and French heritage, raised in France. He is a research scientist with Genentech. Fabrice has one of the biggest hearts and most caring demeanors I ever have seen in a man of his age. Tremaine and Fabrice were setting up the board for what had become their weekly chess competition. And it was a competition. You might think that a street person on methadone might not present much of a match for a European trained scientist, but Fabrice usually was given a run for his money. The games often would last an hour or more. This particular evening would be the penultimate match for these gentle combatants. Tremaine shortly thereafter would lose his ability to concentrate and would die less than a month later.

Craig saw the board being arranged. I asked if he would be interested in watching the match. To some, this would seem like inviting someone to watch paint dry, but Craig was remarkably

interested. I relieved him of the blankets, repositioned him in the wheelchair and allowed his very long legs to again extend to the floor. Craig sat with Tremaine. I sat opposite him with Fabrice.

The game began. For almost an hour, the four of us sat in silence as the game developed, reached its crescendo and drew to its conclusion. Fabrice won, but not easily. It was a very close match. As I sat there, I considered how blessed I was to be able to sit in silence and watch chess with these people whose lives were so different from mine, but with whom we shared so much humanity.

At the end of the game, Craig asked me to return him to his bed. He told me that he was very tired. I wheeled him back to his bed and recognized that I could not move him from his chair to the bed. He had no strength in his legs. He could not stand. He was much too big to lift without risk to him or me. Consequently, I understood that the move would be made by a lift, the hospital’s version of a small crane which moves nonambulatory residents by placing straps around them and effectively lifting them out of their chairs and moving them over their beds where they then are lowered onto the bed. I never have seen this process occur in any manner that seemed dignified. When Craig thanked me for the evening and told me he was fine, I left his bedside. I surmised that he did not want me to witness the indignity of his transfer.

It struck me as I drove home that evening how little it takes to make a relationship. It is the way we are with one another, not what we do with one another, that makes a relationship. I was grateful for the evening and for Craig. I considered the issue which we, as volunteers, always face - would I see Craig again?

When I arrived for my next shift, I was advised upon entering the common room that Craig had died that morning. His passing had occurred sooner than many of us had anticipated. It certainly was not what I had expected, although I was trained not to have such expectations.

Craig had made a profound impact on the ward in his short stay. There was something very present about him. In a way, he was charismatic. He evoked a positive response in most volunteers, staff and residents alike. Sure, it was a tragedy that someone so young should die, but there was something else with Craig. I think it was his clarity of purpose in living his last days, his directness in knowing what he needed, and his courage in asking for help in the face of his devastating disease.

It is very common for volunteers to sit with the body of one of our residents who has passed. As I sat with him that early Monday evening, Craig was visited by volunteers as well as other residents. I heard comments like “Too young.” “Great kid.” “What a shame.” And as is frequently my honor on Monday evenings, I was allowed to provide Craig one final service. After his body was cleaned by the nurse assistants and placed in a body bag, I moved him to the gurney and delivered him to the morgue.

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I don't know the number of times I have made this passage with a resident. I have transferred many people whom I have regarded as friends out the C-2 doorway to the second floor elevator, up one floor and down that long populated third floor hallway to an unmarked door on the left, leading to the white tiled room into which bodies are conveyed until released to family, or if none, the state, for burial. It is always an honor to make this short trip. Everyone I pass with the gurney knows my cargo and, in one way or another, acknowledges the passing. This day, people in wheelchairs who were gathered in circles, involved in conversation, parted like the sea for my passing. Residents hang their heads in honor and remembrance. Conversation stops as residents pay homage to the fact that every passing is important, every life is significant, every human deserves respect and honor.

The following week at our shift meeting, I talked with my colleagues about the profound effect Craig had on me despite our short time together. One of my colleagues confessed that she had not approached Craig. I asked "Why was that?" She replied "I was put off by the 'swastikas'?" "The swastikas?, I asked – "What swastikas?"

"On his hands and on the back of his neck" she replied.

I don't know why. The facial tattoo was obvious, but I had not seen the swastikas. I then learned that while in prison, Craig had been a skin-head, a member of the bigoted gang of white supremacists. In fact, a day or two before he died, Craig had asked if he could have his head shaved. This request was never fulfilled because he died before it could be carried out.

I spent some time thinking about the new information I had received. Craig had spent six years in a Texas prison. He was a neo-Nazi, a skin head. He had been a heroin addict. I grieved that his way of addressing life caused those consequences. But for the time that I was with him I witnessed an intelligent, brave soul dealing with a frightening disease. Death has a way of stripping everything from you as it approaches, leaving only your essence.

There is a belief in most spiritual traditions that all humans are good, but some are lead astray by circumstance. I subscribe to that belief and had it confirmed to me by Craig in his last week of life. As he sat with Tremaine, Fabrice and me, I witnessed nothing more than another good soul in communion with others - nothing more, nothing less.