

Putting Things in Perspective

Stories from a Hospice Volunteer: Paul

- By Tim Tosta

For me, this is a different story. Most of what I have written about my work at Laguna Honda Hospital - the extraordinary people I have known and the incredible events that I have witnessed - simple flow out of me. I may not know what meaning the story will convey when I start. But, by the time I complete the first draft, it all somehow fits together. Occasionally, I reorder a paragraph or sentence or change a few words here or there, but the story is coherent from the outset.

When I finished the first draft of Paul's story, it wasn't that way. On a summer evening something powerful had occurred for Paul and me. In and of itself, it was extraordinary. I had a feeling that this event fit into a larger story, but I didn't know what that story might be.

I let this story sit on my desk for over a month. I also held onto a telephone number, given to me by our hospice ward's social worker. The number was for Paul's son, who lived in Arizona. I rarely have written about anyone with known relatives. I am concerned that the stories I tell, even with the name changes, might cause upset. I knew that I owed Paul's son a call - first, to tell him the story and second, to ask his permission to tell it.

A few Sundays ago, I reached Paul's son, also Paul. We talked for awhile and, as we talked, I came to realize that this conversation was what I needed to complete the story, to help me understand what my encounters with father and son had all been about.

This story really is about boundaries - the lines we create (or culturally accept) between races, religions, cognitive states, reality and illusion, life and death, individual and unity. Some 30 years ago, in one of his earlier works, philosopher Ken Wilber wrote a book *No Boundary* in which he described the human predicament arising from the process of maintaining boundaries. Wilber observed that to draw boundaries is to manufacture opposites. And, the world of opposites is a world of conflict. Every boundary line has the capability of becoming a battle line. And the firmer one's boundaries, the more entrenched are one's battles. Wilber called for a careful personal examination of our boundaries. Wilber maintained that it is fine to draw lines, provided we don't mistake them for boundaries. Two opposites form one unity. And, as my work at Laguna Honda Hospital has taught me, boundaries dissolve the closer you approach death.



As I entered ward C-2 on that particular summer evening, I noticed that Paul had been relocated to the first bed on the right, upon entering the men's ward. That bed is immediately adjacent to the nurses' station, which features a large viewing window onto the ward. As I passed him, I noticed that he was sleeping, but very fitfully. Paul previously had been located at the ward's far end, on the same side, in what many of us thought of as "Henry's" bed. Henry, an African American, former merchant mariner, had lived with us for three years or more. He was a quiet, pleasant gentleman. In serving him, you always walked away thinking he gave you more than you had given him from your time and effort.

At our shift meeting, I learned that Paul recently had taken a turn for the worse and had become very restless. He wanted to leave his bed but, while capable of sitting up, he was too weak to stand, and so presented a continuous falling risk. Consequently, he had been moved to be kept under closer supervision.

Paul had not been with us all that long. In prior weeks, this gregarious man, age 70, about 5'10", with a wild shock of gray hair and a booming voice, had "held court" at his end of the ward, in stark contrast to his quiet and self-effacing predecessor, Henry. He told jokes and stories, ordered volunteers about in a light-hearted way, and sought more than his share of attention from the nursing staff. But, with his large and affable social countenance, there was a shadow side. Paul was an only child with a high school education from a working class family. His family had been closely affiliated with the Teamsters Union. He had outlived all of his San Francisco based relatives. In his upbringing, boundaries had been drawn which excluded people of color, Jews and homosexuals. Paul was taught to adhere to those boundaries, to practice exclusion and to express the values taught him, long after they were socially taboo. As Paul's son described, "He was an equal opportunity offender" – an "Archie Bunker" type.

Paul was a fifth generation San Franciscan and the third to bear his given name. His son was Paul IV and, although he did not know it until immediately prior to his death, he was the grandfather of Paul V.

Despite the lack of college education, Paul III eventually had come to work for Metropolitan Life Insurance Company as an insurance salesman. His marriage to his wife, the mother of Paul IV ended abruptly when Paul IV was under 5. Father and son had remained largely estranged until only days before his death.

Paul IV believes that at some point his father suffered a stroke. In all events, Paul "went off the deep end," quit work and found himself in public housing, minimally supporting himself through various odd jobs, until even those proved too difficult. As his health further declined, Paul was admitted to San Francisco General Hospital from which he was transferred to the Laguna Honda Hospice, ward C-2.

Paul's stay overlapped with that of Craig, the young Texas "skin head," about whom I have written, who carried several swastikas tattooed to his hands and upper torso. To my knowledge, despite his body décor, no one ever heard Craig express a racist remark. But then, Craig didn't waste words. His ALS (Lou Gehrig's disease) kept conversations to a minimum.

Paul was more forthcoming. He threw his epithets into conversations, with light-hearted humor, suggesting that his malaprops meant no harm. A week prior, in one of our shift meetings, a volunteer discussed how she had been put off by Paul's references to something she had said as being "too jewy"

for his taste. At first, she found it difficult to stay in his company. But she has determined to see through the language, to be in the company of Paul's core being.

We had all just experienced Craig's passing, and I think we all were deeply affected by the courage and presence of this 31 year old man in the face of his ALS. I believe that we had all found it difficult to believe that Craig, tattooed with swastikas and labeled as a "skin head" was, at heart, as bigoted and hateful as his body embellishments suggested. I had come to see his "style" as one of survival in the Texas prison system where he spent many years of his young life. Craig had likely created his boundaries to offer him protection and a way of organizing his world. As his death approached, he may have found that, not only did his boundaries not serve him, they impeded his progress toward death.

Ward C-2 would be hell to a bigot. At any given time, there may be more people of color in the ward than white. The gay community is always well represented. There are always Jewish residents. Our residents suffer all types of cognitive impairments and neuroses. The funny thing is that in the face of death, the distinctions fade. There is no room for petty bigotries.

After our shift meeting, I returned to Paul's bedside. Despite the many conversations about him during our shift meetings, I had not yet attended him. With some 25 occupied beds and only five members to our shift, it is not possible to spend time with every resident in the course of their often short stays.

I'd like to tell you that I have some sort of strategy on how my time is spent, but I don't. My choices are mostly intuitive. On my way into the shift meeting, I may make eye contact with someone or hear something in the shift meeting about a special need or simply try to reconnect with someone who had made an impression on me during my last shift. On this particular evening, as I passed his bed, I knew that I would return to Paul. But it wasn't a calculated decision. There was no deliberation. I just knew.

At the nurse's station there are binders available, for review by the hospice volunteers, that give us a "sketch" about each of the residents. Eric Poche, who administers the Zen Hospice Project volunteer program at Laguna Honda, walks a careful line in preparing these so that he does not reveal information that would violate state or federal privacy laws, while giving us sufficient information to protect ourselves from infection or potential dangerous conduct of a resident. He also alerts us to the resident's particular frailties or sensitivities so that our interventions don't aggravate a condition or situation. Sometimes turnover in the ward is so high that it is impossible to keep the binders current. On that particular summer evening, as I made my way towards Paul's bed, I took a detour to the nurse's station to see what more I could learn about him. There was no sketch on Paul. That was O.K. Sketches can create "boundaries" too. I would attend Paul that evening "not knowing," but with awareness and curiosity.

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In my five years as a hospice volunteer, I have reviewed many resident sketches. One of the things that I have learned about them is that they are not the “truth” about the resident, but only a portrait. In order to truly serve a resident, you must ground your awareness in how you find him at the time you are with him. Something in the sketch may lead you to form an expectation about what you will find, which often can be misleading. Let me give you an example. The note SDAT refers to “Senile Dementia, Alzheimer’s Type.” With respect to some residents, this may mean that you will never have a cogent conversation. The resident’s ability to put thoughts together to form a sentence may be a skill long lost. On the other hand, you can have an intriguing conversation with a resident which leads you to be skeptical of the SDAT label. Only when you return after a short break to the same resident to begin the exact same conversation over again is the SDAT note confirmed.

So I sat with Paul, who continued in apparent fitful sleep. Sleep is another boundary that begins to lose its meaning as people approach death. As the body’s functions begin to break down, system by system, the resident inevitably spends more and more time focusing inward. That is where the attention is needed. That is where the energy is demanded. The remarkable thing is how the resident’s senses nonetheless remain alert to the outside world. The number of times I’ve seen a resident awake to neatly join in a conversation in progress with family members, who had thought him asleep, is legion. Residents can be “in here” and “out there” at the same time.

Dying actually demands a fair amount of work. It is as if we are each embodied with a spirit that must find a way to detach itself from the organism before taking flight. That move inward, frequently witnessed as sleep, could be viewed as the spirit untying thousands upon thousands of tiny little knots that bind it to the body. For those who have reached a certain level of peace and are able to surrender to the inevitable, this disentanglement is less a chore. To those fighting their departure, this separation can be a visible struggle.

As I sat with Paul, he rolled to his left side and grabbed the chrome steel rails which secured the upper section of his hospital bed. The head of the bed had been angled upward maybe thirty degrees. Paul held the rails firmly in his grasp. From his wrist to his shoulders, his arms were firm as he began to shake the rails, as if attempting to force open a barred cell door. He groaned as he shook the cage. I sat toward the foot of the bed on his right, so that his back was toward me. Eventually, he turned his head down and slowly opened his eyes. He acknowledged my presence. Although we had never previously spoken, he looked at me with an extraordinary clarity and said “this is hard.”

“What is hard?” I asked.

“Dying” he replied.

I saw no reason to pull any punches, so I replied, “Yes, it often is.”

Paul closed his eyes and went back to grappling with the bars and shaking them occasionally. After a few moments, his arms relaxed and he appeared to drop back into sleep. I continued to sit. Shortly thereafter, he rolled to his back again and opened his eyes.

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“Who are you?” he asked.

“My name is Tim. I’m a volunteer here on the Monday night shift.”

“I don’t remember you,” he said.

“I don’t think that we have spoken. But I have seen you in the last few weeks. You always seem to have company.”

“Yes, there are a lot of nice people here.”

“Is there anything particular I can do for you now?” I asked.

“Get me across the goal.”

“I don’t understand.”

“The game! It’s football.”

“You’re playing football?”

“Yes”

“You have the ball?”

“Yes” He replied, as if I were too dense to understand what was going on. Paul again rolled to his left and grabbed the bars. I grabbed another chair and rounded the bed so that I was in his line of sight.

“So you’re a football player and you’re carrying the ball?” I asked.

“Yes” he replied.

“How far out are you from the goal” I asked.

“I am on the thirty” he responded.

Paul, despite the football metaphor, was highly engaged in his own death process. He understood the work, but made it into a game. You could say that he was delusional, but for me he was every bit grounded. And as I began to understand what was happening, I joined him as a teammate, to help him reach his goal. I wasn’t sure what I was supposed to do. But like so many things in hospice, your intuition kicks in, your mind quiets down and you blend into the circumstance. Paul rested. I sat quietly. As I looked up, I noticed that I had been joined by Shipra, one of my shift mates. I didn’t know how long she had been there because time had stopped during my engagement with Paul. My focus was entirely on him.

Shipra is the daughter of East Indian parents who came to San Francisco and started the California Institute for Integral Studies, which operated out of the family home when Shipra was just a girl. CIIS is a nationally recognized institution combining the studies of psychology and spirituality. Shipra works with a Peninsula based law firm during the day, managing information technology. She travels to San Francisco for her shift, then returns to her Peninsula home.

Shipra operates from a profound spiritual base. To find her with me as I sat with Paul, helped me keep my focused awareness on his extraordinary transition.

Paul called out “Daddy”? His eyes snapped open and he looked at me with a brightness, almost joy.

“Is your Dad here?” I asked.

“Yes. He is always here when I need him.”

“What a wonderful gift” I replied. “Paul, where do you see him?”

I had gotten up from my chair and moved to the head of his bed. I had slowly released his grip from the bars, taking one of his hands in each of mine, gently holding his hands, but offering some resistance, as if I were gently pulling him forward.

“I see him. He is in the end-zone.” Paul exclaimed.

“I am with you here, Paul. Can you feel me helping you?” I asked.

“Yes. Yes”

“Are we gaining ground?”

“Daddy, I am coming.”

“You know you’re going to make it.”

“I know.”

Then, Paul’s arms went slack and he dropped off to sleep.

All of what I have just described took place in less than an hour. Yet, I was completely exhausted. Whatever had been happening seemed extremely “big” to me. Here was a man with whom I had never spoken, with whom I now had a most profound connection. The boundary between what was real, what was imagined, what was on this earthly plane and what was not, all were erased. I was fully engaged in helping someone die with dignity and grace. I was there to do it in his way, in the world as he saw it.

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I stepped away from the bed after Paul fell asleep. Shipra stayed behind. I returned to his bedside about 15 minutes later, having sat in the hospice garden to recuperate. Paul was still asleep, or so I thought. As I moved my chair next to Shipra, she told me that Paul again had awakened and told her “What a wonderful thing it is to have you with me. You are like angels here to help me. Thank you so much.”

Paul continued to sleep. This time peacefully. After another few minutes, Shipra and I left his bedside for the evening. Paul died a few days later.

At our next shift meeting, I told the story of Paul’s and my effort to get him across the “finish line”. I had trouble telling the story, much as I have had difficulty writing this now, because it was so real and so magic. To ultimately and completely be with and for another, previously unknown to you, with no awareness of yourself, without self, without boundary was the evening’s teaching.

A day or so after my extraordinary visit with his father, Paul IV arrived in San Francisco. Young Paul had told me that he felt guilty about not having supported his father, particularly when he learned that his father was unable to care for himself. But, whatever had happened to him as a child kept him from coming to his father’s aid. When he received a call that his father was near death, he broke those bonds and arrived to be with him. The son described a heart warming visit with his father who, by then, was extremely weak. In the course of their conversation, a relationship was healed and a grandson was discovered.

Paul IV described to me how he had left the hospital to return to his hotel room, for a shower and something to eat, before returning for the evening. About a half hour after leaving the hospital, he received a call that his father had passed. That’s often the way it goes. The wound is healed, the boundary erased, and his father was able to go.

Paul had heard that his father frequented Lefty O’Douls on Geary Street when he worked with Metropolitan Life. Since he had a day until his return flight, he took the opportunity to visit one of his father’s old haunts. At the bar, the son spoke to the Persian bartender who had moved to the U.S. at the age of 40. Paul IV talked to the bartender about his father and of the times he had heard about when his father “held court” on the premises. The bartender asked his father’s name and with a teary smile told the son “your father named me.”

“He what?” the son queried.

“When I came from Iran and got a job here as a bartender, my name was Firuz. Your dad would come in and we would talk. Eventually he told me that I couldn’t make it in this country with a name like Firuz. So he gave me my American name, Frankie. I’ve been known as Frankie ever since.”

So the father, like Archie Bunker, had revealed his big heart. Unbidden, he had helped a stranger.