

Putting Things in Perspective

Stories from a Hospice Volunteer: Marion

- By Tim Tosta

I arrived late for my shift after the July 4th holiday. As I passed through the women's ward, I noticed the curtain drawn around Marion's bed. I had worried about her over the holiday. The previous Monday, Marion had never been sufficiently awake to have one of the weekly chats I'd come to love.

Because of my late arrival, and the drawn curtain, I didn't have time to "check in" on her before our shift meeting. I already had missed the meditation, a 15 minute prelude to our meeting that I had come to relish perhaps more than any other meditation in the week. It is the session in which the power of meditation stands out for me, providing the quiet and the firm ground I seek to meet the needs of my friends in the ward. Meditation allows me to witness that involuntary stream of thoughts that constantly races through my mind. Through observing them, my thoughts are subdued. Like the fog receding over Twin Peaks, I am left with a "blue sky" mind. That mind allows me to truly be present in the ward.

Somewhere around 4 p.m. every Monday, I begin to "shut down" my business mind and prepare to depart my office for Laguna Honda. I assemble the material that I anticipate reading after the evening shift, but never do. I make one last pass through the unviewed email prior to shutting down the computer. I check voicemail on the office line, then on my cell line, to insure that I haven't missed anything critical in the last hour or so. Then I "check in," before "checking out," with colleagues. I continue to believe, despite prior experience to the contrary, that all of this can be completed within a half hour, so that I might have a reasonably calm transition as I drive up Market Street, over Twin Peaks, turning right at Juvenile Hall and right again at the next driveway to enter the Laguna Honda parking lot. Rarely does the planned half hour "shut down" work. More often than not, I scramble out of the office at 4:45 p.m., leaving only 15 minutes to make the two-mile trek to the Hospital, in peak hour Market Street traffic. Rather than the blissful transition which I continually seek, I find myself cranking up, recognizing, ironically, that I will miss the clarifying and calming affect of the evening's meditation session. This particular evening, as I sat again embarrassed in front of my colleagues for yet another late arrival, somebody was describing the new resident, Jesse, who arrived that day and already had charmed the afternoon shift with her presence.

Our meetings allow each volunteer to share her experiences and feelings at the beginning and end of each shift, without interruption or questioning. The comments about Jesse,



reported by more than one volunteer, were intriguing. In my quick pass through the women's ward, I had not noticed anyone new. Normally, I would recognize a strange face, particularly given, for the first time in quite awhile, the hospice population was unusually low. Dr. Kerr, who manages resident intake, had been on vacation.

Because of our meeting practice, I knew that I would wait until everyone had spoken to learn more about Jesse. I imagined I would seek her out that evening. My anticipation, however, was shattered when, at the end of the meeting in response to my question, "Where is Jesse?" a colleague replied, "She's in Marion's bed."

My eyes darted to the white board, which hangs to the left of the sunroom door as you enter the room, and contains a running list of names of residents who have passed in the calendar quarter. Sometimes the list is less than current. But that evening it confirmed, that Marion had indeed left us.

All the more, I regretted that we had not spoken the week before. Two weeks prior, I had noticed that Marion was expressing greater confusion than previously. I had unwound the wires of her headset, through which she listened to her radio, from the clear plastic tubing that brought oxygen to her nostrils to ease her breathing. If nothing else, Marion had always been organized. Since she had arrived, almost a year earlier, organization proved to be one of the few things over which she maintained some control. A breast cancer patient, tethered to an oxygen tank, Marion had not left her bed since arriving. When she first came to us, her best friend, Suzie, had brought a variety of useful containers, which either sat on Marion's bed or hung from it. These allowed Marion to organize her few remaining possessions, giving her access to her notebooks, her reading, her radio and her clock. There she also kept her reading glasses, headset, Kleenex and her beautiful royal-blue baseball cap, with a Superman insignia. The cap rarely was stored, usually resting instead as a crown on Marion's brilliant head of long, white hair, which spread over the pillow and down to her shoulders framing her long, slender, gentle face.

Marion was an anomalous resident at hospice. She had the wherewithal to pay for private care, but she had chosen a public hospital, electing to reside in an open ward with the City's indigent. Marion had come to Hospice at age 85. She had self diagnosed her cancer in the early 1980s. But, rather than seek invasive medical treatment, Marion chose to self medicate through a strict vegetarian diet, vitamins and nutritional supplements. This regimen served her well for some 20 years. But in the last five years, in Marion's words, "My lumps got worse."

Cancer has many manifestations. My experiences with breast cancer, before Marion, involved residents with metastasis to the bone (lower spinal column and pelvis) and/or brain. Most appeared to be in considerable pain. Marion's cancer was different. Maybe it was the disease or, perhaps, it was her response to it, but Marion rarely complained.

She was admitted first to a prominent local hospital. But as is often the case, when it was clear that Marion was terminal, she was encouraged to find care elsewhere. The predominate western view is that doctors heal and hospital care is for those in healing. When healing is no longer an option, traditional Western medicine breaks down. There are exceptions, as evidenced by the growing fields of palliative and hospice care. But, by and large, terminal patients are viewed as medical failures. Whether conscious or not, the medical response is "out of sight, out of mind." In addition, Marion was described as having a "malodorous necrotic malignant ulcer" on her left breast, which meant that the cancerous tumor had erupted through the skin of Marion's breast, where tissue had begun to die, giving rise to an accompanying pungent odor.

In my time at the hospice, I have inured myself to many odors. I no longer run from the smell of stale urine, vomit or dirty

diapers. Odor is one of the strongest triggering mechanisms of memory. And, odor, more than any other sense, draws out our most profound emotional reactions. Scientists don't exactly know why odor has the effects that it does. One simple reason may be that the distance between the sensory detectors of the nose and the interpretative smell center of the brain is the shortest of any of the body's senses.

Despite my acclimation to odor at hospice, there is one exception. The smell of dead tissue disturbs me. There is something about it, perhaps its finality, that distinguishes it from other odors. You may believe that you don't know the smell I speak of, but you do. You know from something in the forest, or lying by the edge of the road, or trapped behind a wall in your home. You know it, you avoid it. But, perhaps, you have never named it.

When a resident passes at hospice, we prepare the body for presentation to the family. The family usually arrives and departs within three to four hours. In that short time, there is a remarkable transition. From the moment of death, you see the body as the former container of the spirit. With the spirit gone, only a husk remains. Within hours of death, the husk's transformation is well under way. All of the tissue, bile and complex chemical compounds that sustained life begin the husk's deconstruction. Gases are formed, breakdown occurs, odors emanate. These are the facts of death.

But with Marion, part of her was dying as she lived. Her tumor had begun to cut off the blood supply to itself and to the surrounding tissue. That tissue died at the body's surface, giving off death's unique odor. I was told by one of the staff that, given her prognosis, the hospital had been quite anxious to get Marion to a new location. Odor from her dying tissue was carrying beyond her private room, permeating other patient rooms and common areas with its signature message – "death is occurring here."

One of the reasons that Marion chose Laguna Honda was that several nursing homes declined her admission because of a combination of the odor issue and the degree of care required to keep it in check. And, I must admit, when Marion first arrived to occupy the bed in which she died, the odor made it difficult for me to approach her. To my embarrassment, the "road kill" odor kept me away. But Dr. Kerr, with the empathy and insight that makes him an extraordinary hospice physician, handled the situation. I don't know what he did, but soon, attending Marion's "malodorous ulcer" required little more than changing a dirty diaper. By that simple act, I could approach Marion and learn of her beauty, sharing in her kindness for the ensuing year.

Being situated, as Marion was, in one of the ward's corners, is a mixed blessing. Depending on the ward's practice, you may be either first or last to receive service. From cleaning the patient or her bed and delivering her meals to administering medication and submitting to medical exams, service occurs systematically by location. Like having a last name that begins with "a" or "z," a patient's experience of time is shaped by the random decision of

which bed she was given to occupy. For ambulatory residents, a corner bed can place them the furthest distance from the restroom. To us, that may seem unimportant. However, when your every step requires significant energy and thought, and your pace is exceedingly slow, a few extra feet can change your day. Since Marion was non-ambulatory, this was not an issue. But, the ward's corners are depositories of ambient noise. Even with curtains drawn, sounds bounce off the walls and pour down from the ceiling. I have sat by those corner beds and heard conversations in hushed tones from 30 feet away. Similarly, if a corner resident is noisy, the corners serve as "broadcast facilities," sending every painful utterance for those at a distance to hear.

Marion's friend, Suzie, had made some "lemonade" from Marion's location. She had found a bulletin board measuring about 4 ft. high and 6 ft. across and hung it against the right side of Marion's bed. From Marion's apartment, Suzie gathered photographs, pictures from magazines, and other curios, which, when pinned to the board, became a collage of all things important in Marion's life.

There was a photograph of Marion's parents standing on either side of a small table upon which sat Marion's Siamese cat. Her father, who bore a striking resemblance to Harry Truman, was to the right and his lovely wife, representing all things refined, gentle and caring in a 1940s housewife, framed the cat on the left. Marion told me, "This picture contains the three things in life I loved most." Hanging lower to the left on the board was a close up of the same beloved Siamese. It was such a vivid photograph with its subtle colors of black, blue, beige and gray that it was hard to imagine that the cat could not just spring from the page. Marion had gone through a period of wanting to be a photographer and she beautifully photographed the things she loved. But Marion's parents advised her, "There is no money in photography. You would do better to marry well or find a good trade."

Above and to the right of the photograph of her parents hung a picture of Marion. She appeared to be in her mid 30s, with the same brilliant mane of hair, only then it was brown with blonde highlights. The photographer had caught Marion one evening performing as a belly dancer. The moment frozen in time caught Marion with her back arched, her eyes focused somewhere in space. Her sheer, lime-green, with orange sash and veil costume, while revealing, was not risqué, and it glistened in the spotlight. Marion couldn't remember when the photograph was taken. But, she recalled, "It was in San Francisco." Given her birth in 1921, and her apparent age in the photograph, I guessed that it must have been in late 1940s or early 1950s.

The fact that Marion kept the picture, and indeed prized it, coupled with the fact that Suzie had chosen it for her board, told me that Marion appreciated her own uniqueness, independence and lively spirit. Complementing the dance photo, at the board's

upper left, hung a painting of a Mediterranean seaside village with Moorish architecture. Perhaps Spain under Muslim rule? The picture, like her dancing, affirmed Marion's love of fantasy, magic, and romance.

Colorful photographs of hydrangeas, foxgloves and lilies bordered the bottom of the bulletin board. Marion loved flowers – their color, texture and smell. Maybe this love came from her farm days. Maybe it came from a time when she thought she should be a photographer. Or maybe it came from her love of color, expression and the zest for life that led this farmer's daughter to take up belly dancing long before its social acceptability.

Marion told me, "I was raised in Eastern Oregon. My parents were from the Mid-west. As a child, I wasn't much tuned into the world, although I knew as a teenager that we were in the midst of the Great Depression." Despite her obvious intelligence, Marion added, "I was discouraged by my parents from pursuing college. My mother wanted me to train as a secretary so I would always be able to make a living." Marion married, left home, divorced, had no children and never remarried. From our conversations, I suspect that Marion sought a husband for the same reason that she attended trade school – economic security. Her husband was so inconsequential to her life, that when we spoke, she couldn't even remember his name or how long she was married.

When she arrived in San Francisco, she joined the secretarial pool of a local bank. Marion's skills allowed her to climb until she became the (no doubt) underpaid but highly powerful assistant to one of the bank's senior executives. Though successful at work, she led a narrow life at home. "I lived alone for almost 50 years in an apartment at the Nob Hill edge of the Tenderloin. I watched both neighborhoods go through changes. My work was my life. I didn't socialize. I knew that I was capable of more, but I had reconciled myself to doing my work and living alone. I didn't mind."

Marion told me that she had been shy throughout her life. But, when she arrived at hospice, she confided "I began to blossom." The hospice volunteers and hospital staff, like honey bees, were drawn to this blossom's nectar. She was open. She was happy. She was inquisitive. She was caring. One evening, she told me "You know, I really love you and the other volunteers".

"From all that I have heard, the volunteers all love you too," I replied.

Marion continued. "Before coming here, Suzie was not only my best friend, she was my only friend. I really don't know how I got there. But with my career and my work acquaintances, I guess I decided I really didn't need or want any more people in my life. That worked for all those years. I didn't know any better until I came here."

"Here, people have taken the time to sit, to listen, to hear about things important to me, things that made up my life."

"I don't think that I'm special at all. But here you make me feel like I am. I wish that I had taken the time in my life to get to know more people. I know that they wouldn't have been as caring as you all are here. But I think that I missed a lot."

"But Marion," I observed, "the more time I spend here, the more I come to believe that we all have a purpose, we all have a job to do. The funny thing is, most of us don't know what that job is for the better part of our lives. I think that I may just be starting to get a glimpse of mine. It has something to do with this work, here, at Laguna Honda."

I continued, "Maybe your work had to do with finding us and showing us something we often fail to fully appreciate – the value of others. I know I too often take those I love for granted. Every week you help me see what I sometimes forget."

"I don't know what this is all about," Marion responded, "but it certainly is wonderful and I am so glad I found it."

At hospice, Marion looked squarely into the face of her death. In fact, she studied it. She was able to read until her last month, and because she talked openly about her pending death, volunteers brought her reading materials on death and dying. It was remarkable to sit with someone who was curious about what most of us avoid in fear. She wanted to know my thoughts on the existence of an after life, whether reincarnation held any sway with me or whether the end was simply the end. I told her that her questions were those I was asking myself. I had no good answers now. But, I know that I would someday. In hospice, we learn that one of the greatest gifts we can give residents is our attention. Marion always reciprocated by giving her full attention to me in these important conversations.

When she didn't feel like chatting, Marion often would ask me to read to her, or to play music. Once, at my favorite bookstore in Crested Butte, Colorado, I bought a small volume by Suzanne Trott entitled The Holy Man. The Holy Man is a collection of stories about a long, long line of people who gathered each summer to visit the Holy Man at his humble mountain hermitage. The line moved slowly up the mountain for the entire summer. When the weather changed at the season's end, the line would disburse only to form again the next spring. Seekers would spend a month or more, advancing only a few feet a day, to knock on the Holy Man's door. There, the door would be opened by a small humble man in robes, named Joe, who greeted the pilgrim, walked him or her the short distance to the back of his abode, only to show the pilgrim the rear door. The stories told of the people as they waited in line; as they walked that short distance inside the hut to the exit door; as they were returned down the mountain in disappointment or anger or bliss. Each pilgrim's journey was an extraordinary teaching.

I carried the book each week in my backpack to read to Marion. We occasionally would forget where we left off and begin again. Marion particularly enjoyed chapter 6, "The Fearful Woman." It was the story of Eleanor, described as a "high strung woman in her early thirties," who upon meeting Joe, the Holy Man, at his front door proclaimed "I'm afraid of death." In their brief stroll, Joe commented "because life and death are interdependent, your fear of death has become a fear of life so that you are unable to live." Joe continued, "While it is quite unacceptable that one day we will simply come to an end of our existence, there you are. We will. It is inescapable. It is our sorry lot."

Joe then suggested to Eleanor that, when she thought about nonbeing, instead of letting her mind scramble away in terror, she should remain still, and calm, take deep breathes, look at her inevitable death, reflect upon it, get used to it. "Do this every day," Joe added.

Joe advised Eleanor to make it a practice to dwell upon her eventual nonbeing. Joe confirmed to Eleanor that she had courage. She needed to gradually let her fear of death be absorbed by her courage.

Joe counseled that no one knows what happens after death. We only know that we cease to exist on earth. Joe told Eleanor that while it might not be easy for her to build up her courage, she would find a most wonderful reward right away. Joe proclaimed, "You will begin to enjoy your life, to use your life. A recognition and acceptance of death...will enable you to live fully."

Often, I would look up to find that Marion had fallen asleep while I was reading. Her head drooped forward, I could only see the blue baseball cap with a Superman insignia set off against a mane of glistening white hair.

Marion had discovered the Holy Man's wisdom in her year with us, and she had put it into practice. Without ever leaving her bed in the far corner of the women's ward, Marion had drawn upon the courage of the belly dancer within her to embrace life and all of us in it. She lived her final year in the love and friendship that she previously had denied herself. She overcame her shyness, her resignation, her fears. Marion found death not to be her enemy, but her friend. It enabled her to find her life's purpose, which she uncompromisingly fulfilled.

Marion was a great teacher and a wonderful friend. Thank you Marion.