

Why I am a Hospice Volunteer

It was a warm Fall morning in 1956. Elvis Presley, Jerry Lee Lewis and Fats Domino were on the radio and my brother Joe and my sister Amy and I were given our brown lunch bags and sent off to school by our mother. It started as a regular day, but it turned out to be one I would never forget. The John Marshall School was not very far away, an easy 10 or 15 minute walk. We left our house on Washington Street in the Dorchester section of Boston, and walked past Toffee's corner store, past the Jenney Gas station and the Magnet Theater to Dorchester 5 corners, where we waited for the traffic light to change to red and yellow so we could cross to Bowdoin Street. We continued along Bowdoin Street, past the Flying "A" gas station where my Uncle Joe worked, to the school and played with the other kids in the schoolyard until the bell rang and called us to order.

For the past few days I had been proudly recording the marks that each of my classmates received on the before school work papers we each completed in the first 10 minutes of the school day. Every morning the teacher would hand out mimeographed work papers with reading or math problems, which we would have to solve. My job was to record the marks that each person received in a neat black notebook. I was to do this everyday. Bobby Sweeney had started this job, but he had been out of school for some time and Miss Nelson asked if I

would take over this responsibility. I eagerly accepted and was proud of my new duties. Later that morning, after we had filed back into the classroom after recess, Miss Nelson asked for all of us to listen carefully to her. She told us that our classmate, Bobby Sweeney, had just died of pneumonia. He would never be coming back to school.

I was crushed. I was devastated. How could that be? Bobby was a nice kid; we all liked him I cried and cried and cried, my head laying on my arms, folded atop the wooden desk with the hinged top and the ink well in the upper corner. I was 9 years old. I was confused. I didn't understand. 9 year olds don't die. What did Bobby do to make God take him? I was scared. Why did Miss Nelson give his job to me? I was convinced that because I had taken over his job, I was responsible for Bobby's death. I didn't know what to do. I didn't know what not to do. I tried talking with my Mom about it, but she really didn't say much. She went to wakes all the time and death didn't seem to bother her at all. But I was a mess. After returning home from school that day I told her that Bobby had died. She said she was sorry. I asked her what happens at a wake. She told me people come in and say a prayer at the casket and tell the mother and father they were sorry. That was all. She didn't offer to come with me. She offered no real support.

The word had come down that Bobby Sweeney would be waked at the Funeral Home next to Mothers' Rest, on Washington Street, just four or five trolley stops from my

house. Some of the other kids said they'd go to the Funeral Home after school, and I said I'd go too. I said I would meet them there, hopefully gathering strength from them, so I could apologize to Bobby. After school I went home and after washing my face and combing my hair, I walked back along Washington Street, past Toffee's corner store, past the the Jenney gas station, the Magnet Theater, past the 5 corners, past the A & P to the Funeral Home. There it was, on the other side of the street, a large Victorian house with a wrap around porch. The building was painted white with some yellow trim, and black shutters on every window. A few days had come and gone since the teacher told us about Bobby and I was still scared, unable to process this, make sense out of it. I remember waiting across the street from the Funeral Home near the trolley stop. Waiting for a classmate to come along, that I could walk in with them. As I had done for almost every minute of the past few days, I wondered what dead people looked like. Would he be shriveled up like a prune? I wondered if Bobby could hear me. Would he hear the fragile voice inside of me? Would he accept my pain? What if he came back to life and was mad at me for taking his job? What do dead people do all day? Do dead people go to school? Are their teachers dead people? Do they have a baseball team? The Boston Dead sox? Can they watch television? My biggest fear was that bobby would be so mad that he would come back to life and beat me up.

I waited across the street, near the trolley stop. I waited a long time. The trolley went by about every 10 or 15 minutes and three or four trolleys went by, but none of my classmates appeared. I was alone. I was scared. I was frozen. I was petrified. My mind said Go ahead, Pete, take the first step, look both ways first, make sure no cars were coming, and then cross the street. You can do it. But when no cars were coming, my legs wouldn't move. I just couldn't do it. I couldn't face Bobby Sweeney. I was just too scared. After a few more minutes, perhaps standing there for over 45 minutes, I turned and with a lump in my throat the size of a baseball, I walked back along Washington Street, past the A and P, the five corners, the Magnet Theatre and the Jenney Gas Station, and Toffee's corner store toward home.

I quietly went to my room and laid on my bed. I was ashamed of myself. My fear was so much stronger than my will. I didn't know what happens to dead people and my fear of the unknown was inescapable. No one I knew had ever died before. We had never had a pet. I had never experienced death and the thought that I was somehow influential in Bobby Sweeney's death was terrifying. The fear of dead people, necrophobia, haunted me for days, which turned into weeks, and months and years, and decades. I wasn't just afraid of dead people, I was afraid of coffins, funeral homes, cemeteries, scary, zombie movies, ghouls, werewolves, ghosts, funerals, even black limousines.

I had hoped that these feelings would go away, that I would grow out of them, but they didn't go away. They got even stronger. If I was walking along Washington St, when I approached the funeral home, I would cross the street and walk on the other side. I never, ever cut through a cemetery. I could not watch movies with ghosts, zombies or possessed people in them. I would become that 9 year old boy standing across the street from the white Victorian funeral home with the wrap around porch, yellow trim and black shutters. And I would begin to sweat and I could feel my heart beating faster and faster, louder and louder. As I got older, into my teens, I tried to talk to myself about this, but the fear was too strong. I had become mentally paralyzed.

10 years went by. It was now the mid 60's. I had graduated from high school and enlisted in the US Navy. I was 19; Marilyn and I had not yet married and I was stationed at a Naval air station in Pennsylvania, living on the base in Barracks #18. One night a shipmate of mine, Ken Marcus, and I were sitting in the lounge watching TV when an Air Force officer entered and volunteered us for a "little job" near the hangar. Assuring us that it would not take long, he drove us toward the big Hangar where a very large cargo plane was parked, the big ramp at the back of the plane was down and the cargo bay was open: It was ready to be emptied. Adjacent to the plane was a large tractor trailer, painted gov't olive drab green. As we walked up the

loading ramp at the back of the plane, my heart sunk. I could feel myself sweat, my mouth became dry, I could not swallow and speak. I was horrified. Inside the plane were flag draped caskets – 156 of them. Each contained the remains of American soldiers who had been killed in action in Viet Nam. Normally delivered to Washington, DC, bad weather necessitated the landing in Pennsylvania. My job was to place the caskets one by one onto a rolling wagon and walk them down the ramp to the ground where others would roll them into the truck.

I remember reading the name of the first soldier. He was born in January 1947, he was one month older than I. I thought about what he might have looked like: was he tall? Did he have any brothers or sisters? Had he graduated from high school? Was he a farmer? Was his Dad, like mine a WW2 vet? I pictured his family receiving his body, his mother crying uncontrollably. I realized then that I had been biting the inside of my lip to prevent me from crying myself. To keep my sanity I stopped reading the information sheets and just did what I had to do, shaking, and in silence. Several hours went by and as the last casket was removed, the Air Force officer said he'd drive us back to the barracks. I shook my head and tried to say no thanks, but no sounds came out of my mouth. As the first lights of dawn appeared low in the sky, Marcus and I walked back to the barracks. Neither of us said a word and afterward, we never talked about it. I just locked it away in the back corner of my mind.

This experience did many things to me. Amongst other things, it galvanized my fear of dead things, started me thinking about the horrors of war and it turned me into a pacifist. That night I promised myself that if I ever married and had a son, I would bring him up to be a gentle, peace loving man and prohibit him from ever joining the military and going to war. I didn't want to take the chance that my son would come home in a flag draped coffin. I pledged that our family would go to Canada if he were ever drafted. (Pause) Funny how life turns out.

Time marched on as it always does and when I had to go to a funeral or a wake, I would go, but I didn't like it, and I suffered through it. Finally, as I was in my late 40's or early 50's, I decided to confront this fear and kick it in the butt. I started to talk to myself as I worked during the day, assuring myself that my fears were unfounded, and that I should forgive that 9 year old boy who didn't have the courage to walk across the street and pay his respects to Bobby Sweeney's family. I should give myself a break. Start a new. Turn the page. Re-set the clock. Have a do over. It took a long time, and progress was slow at first, but I began to feel more comfortable thinking about it and eventually, I started to act on it. I pictured the white Victorian funeral home with the wrap around porch, yellow trim and black shutters, but with the big front door wide open, and kids playing in the park next door. It seemed...welcoming. I asked Bobby Sweeney to forgive me. I assured him that I didn't mean to take his job away from him, that I didn't want him to die. Little by little, my fears began to disappear. Slowly at first, and

it took years, but I was getting better. More confident. Before I arrived at a wake, I would rehearse my lines – what I would say to the grieving family- and I could remember those lines and deliver them with poise. I didn't sweat as much and after several deaths of aunts, uncles and friends, I felt much more comfortable. I still don't watch scary movies. I don't like ghost stories. When I am at a cemetery, I still look behind me – in case an evil spirit is sneaking up.

Now that I could participate in the final services, I was ready for the next big step. What job or position could I fill that would completely banish my fear of death? I thought about this on and off for many years, and then finally it struck me: I should become a hospice volunteer. By this time, Marilyn and I, now in our early 60's, had begun the process of applying for Canadian residency. My Aunt Anna was in a nursing home in Massachusetts and was dying. After her death we would be free to leave MA and start our new life in Canada. During the last several months of my aunt's life Marilyn and I visited often, and I began to recognize how important my visits were to her. And I actually became less anxious being around dying people. After Auntie Anna's death, we moved to Port Perry, and one of my first challenges was to investigate becoming a hospice volunteer. I read several books about hospice work and contacted Durham Hospice in Whitby and arranged an interview there. I was accepted into their program and signed

up for the compulsory evening course: Introduction to Hospice Care. Most of the people in the class were nurses or other medical professionals. I have limited medical experience, but understood the requirements and studied hard and did well. My reading continued and I became more comfortable talking about death. Immediately after graduation, I received my first assignment: A man who lived in Bowmanville, and was a wood carver. He was several years younger than me. With a bit of anxiety, but a lot more confidence and poise, I rang the doorbell and introduced myself. For the next few months, I visited a few times each week, arranging visits around his doctor's appointments and medical tests. We enjoyed a positive relationship: we talked a lot and he taught me about wood carving, and I showed him my woodturnings. A win/win! As happens, his condition (cancer, metastasized to several organs) spread rapidly and soon, he died. After seeing Bruce for a few months at his worst, it was comforting to see pictures of him at the funeral home, when he was at his best – in his younger years, looking strong and confident. His widow thanked me for all the time I had given Bruce and told me that he really enjoyed my visits.

One of the things that happens to a dying person is a severe change in daily routine and isolation. Sometimes, friends drop out. Many people are afraid to be near a dying person, for fear that the Grim Reaper will come while they are there and they will be powerless to help. Oftentimes, especially men, experience isolation and lack of control of their lives. For many

men, especially those who had been active and “in control” of their lives, this presents a very tough challenge. Having a dying friend reminds us of our own mortality. A man talking to a woman talks and feels different than when he talks to another man. But there are far more dying men than there are male hospice volunteers. In the basic course I took: Introduction to Hospice Care, out of a class of about 50, I was one of two men. In the advanced class, I was the only man. Much of what I do as a volunteer is social. Just chatting with the patient: about his pain, about his condition, his doctor’s visits, the weather, his hobbies, his travels, his family, The Blue Jays, when the Leafs might next win a Cup, his professional life. Because I am part of a caring team, I report back to my supervisor at Durham Hospice updating her on the patient’s condition, any changes, his outlook, his needs, what pain he might be experiencing, how his spouse or primary caretaker might be feeling. Any additional supplies or services he might need. I report what I see “in the trenches”.

After Bruce died, I was not without a patient for very long. I received a call from my supervisor at Durham Hospice inviting me to help a new patient. I willingly accepted. Mark was also younger than I. He was only 51. Spinal cord cancer.

Wheelchair bound. During one of my first visits, Mark had said that he used to curl and play hockey in a men’s league, and canoed, and played softball in the summer and that now he couldn’t do anything. “I’m just waiting to die”, he said. Those words cut right through me and I heard myself ask him if he

could glue little pieces of wood together, holding a small bowl that I had made. He said he could, and at our next visit, we started assembling wedges to make a few small bowls. I showed him how to orient and glue the pieces together. He learned quickly and within a few days he had assembled three small bowls. He wasn't waiting to die anymore. He had something to do, which did not require him to walk and that was unique and challenging, and physical. He was excited. I was scheduled to visit Mark again on Monday but on Sunday night I received a phone call from a friend of Mark's telling me he had died very suddenly that day. Mark's wife had asked him to return the wooden pieces to me. When I received them I could see that the bowls were nearly complete and that the assembly work was excellent: tight joints, great alignment, no glue smears. There was only one thing to do. I mounted the blanks onto my lathe and turned them, and applied a hand rubbed oil finish, completing the work Mark had started. I brought the three bowls to the funeral and gave them to Mark's widow. When she opened the box and saw what was inside, she cried and hugged me for a long time. I had never before felt both euphoric and horrible at the same time. I'll never forget that feeling.

My next patient, John, was also suffering from cancer. In addition, his kidneys had stopped working and he was on dialysis three days a week. Visiting was not easy, we tried to squeeze in visits between dialysis and doctor's visits. We also made several bowls together, which he gave to his children. He

was also younger than I, and said he wanted to live long enough to cash his first retirement cheque. He did. Three different times, his son had called me telling me that his dad was in hospital and was not doing well, and not expected to make it through the night. Three different times I went to the hospital to be with John at his passing. Three different times he told me that I should go home because he was not dying tonight; he had too much to live for. He was right. He still has not died, and has cashed that first retirement cheque, and many more. His dire condition has improved, and I was asked to accept another patient, as John was doing really well and despite still having a terminal prognosis, no longer needed hospice care, and my time would be better spent with someone closer to death and more in need. And I am lucky enough to be able to move on.

As a hospice volunteer, one almost becomes part of the family. I have had the great pleasure of meeting the spouses, sons and daughters, even grandchildren of some of my patients. The family members appreciate what I do and appreciate my willingness to cut them loose for a short time, to go shopping, to have a coffee at Tim Horton's, to visit a friend, to just get out of the house and forget, if only for a few moments. A hospice volunteer helps the whole family, not just the dying person.

To those who have never suffered a severe trauma, the pain lingers for a very, very long time. I am 72 years old. Bobby Sweeney died 63 years ago. The pain is mostly gone now, but there are days when with my mind's eye, I can see that 9 year old boy across the street from the white Victorian house with the wrap around porch, yellow trim and black shutters on every window. And it seems like it all happened yesterday. To those women or young children who have been victimized by a horrible act and are traumatized: I know your pain. To those men who suggest: "Come on, lady, that was 20 years ago, get over it". They just don't understand. That pain, though not physical, is real...and it hurts. If you have felt this pain, seek help. Either from a counselor or from your separate self. Know that you are not alone.

It wasn't until much later in my life that I wondered why my mother didn't take the time to explain more about death and grieving and the funeral system to me when that traumatic death occurred. That would have saved me a ton of anxiety and I would have gained a lot of understanding. Years ago, when a neighbor and classmate of our high school aged daughter died, we were very different parents than mine were. I guess that's progress.

While I have highlighted the cases of several of my patients here, there were others, and some who did not live long enough for me to see them. Several times, I received some

patient information, phoned to set up an appointment, and the next day received a call from Hospice that the patient had died. Sometimes when I tell people that I am a hospice volunteer, they say that they could never do that. They don't see that it really is a two way street. I get just as much back from the patient as I give to them, oftentimes much more. Being a volunteer with dying people has helped me to grow in ways I never thought possible. Not only has it helped me over my fear of dead things, it has helped me to slow down and savor the moment. It has made me very grateful for the health and well being I have enjoyed, for the love I share with Marilyn, my kids and grandkids and with all of you, my spiritual family. (pause)

And once in a while, after a hospice visit, I feel Bobby Sweeney's hand on my shoulder, and he says: "Good job, Peter. Good job."