Nancy’s Journey

It had all started so simple. Nancy slipped and fell in the bathroom…

We live in a little town called June Lake at 7700 feet, a vacation home we turned into our semi-retired home. June Lake is five hours north of Los Angeles and three hours south of Reno, Nevada.

In October 2008, Nancy had gone down to Los Angles to attend a conference for her job and taken the opportunity to visit her mom, Maggie. She also decided to fly over to Phoenix for the day to visit our new grandson on his first birthday—she had been there at his birth. Finally returning home on a Sunday, just before I left for work. I work part time at a local restaurant and was covering a Sunday night shift which turned into a late night.

When I got home, Nancy said she had slipped and was in some discomfort, obviously in some pain. We both decided to go to the ER to make sure nothing was broken or fractured. The fall was a sort of split and she had hit hard on the inside. Had I fell that way, or any other man we would have “cracked a nut” and screamed bloody murder, but she simply hit hard on bone.

Nothing unusual showed up on the x-ray and after a few hours of observation, she was released with some pain meds and sent home. She took a few days off work hoping the pain would get better, but when it didn’t she went back to work.

Nancy had been instructed to follow up with her doctor in a week, but her regular doctor was on leave, so she had to see an alternate. Even though she could barley walk and was in obvious pain the doctor prescribed aspirin and sent her on her way. Unfortunately she had to see this same doctor once again, who then prescribed physical therapy without ever finding out what was actually wrong.

Fortunately her regular doctor returned and she was able to see her during the Thanksgiving weekend, who immediately suggested they run some tests to get to the bottom of this, one of which was to see a sports medicine doctor to review the injury. Since we live in a resort town, sports related injuries are very common. This doctor ordered an MRI as soon as he saw her walk in.

Within a couple of hours, we had a Disc in our hands with instructions to go to a large regional hospital who could do a further review and confirm the preliminary diagnosis. We went home, packed a few things and hit the highway headed for Los Angeles. I would come to learn was 331 miles door to door.

We checked into the UCLA ER and explained the situation, as well as handing over the Disc we brought with her MRI. A long night in the ER confirmed the suspicions, but further tests were ordered, including a biopsy.

After a few days, Nancy was released and spent a couple of days at her best friend's house, staying in the LA area, while I went back home to work. On a follow up trip back down to LA, I took her to her Mom's house to rest, again so she could stay local. After a few days I went back home to June Lake.

Nancy called me to tell me some lady from a lab called and said: "yeah, you have Sarcoma" and hung up. What a way to find out you have cancer! Although we had been told the possibilities and were expecting as much, it still was a pretty cold way to be confirmed. I looked it up on line and found out it is a very rare form of cancer. At this time we didn't know the particular type yet.

We made an appointment with the oncologists to discuss her options. His plan was to administer two treatments of chemo, 24 hours a day for eight days with a three-week break. Nancy was scheduled to enter the hospital on December 24th to start the first treatment, but we all agreed to wait until Friday the 26th, deciding there was no point in spending Christmas day in the hospital. We arrived early Friday morning to get her prepared—they need to do a bunch of prep work prior to starting the chemo drip.

It had also been discovered the fall had popped a nerve onto a legion, causing the severe pain. Nancy was further scheduled to receive radiation treatments concurrently.

Per the doctor's instructions, I had gone back home for a few days to catch up, while she was in the hospital.

Nancy had been set up with a chemo drip (IV) and other fluids, which seemed simple enough. However the radiation treatments were across town, so she had to be packed up, including her IVs, loaded onto a gurney, put into a transport, ferried to the location, unloaded, zapped, loaded back on the transport and ferried back to the hospital.

I returned at the end of the first week and spent the weekend with her. She still had a couple of radiation treatments left into the following week. Once again I went home and came back on the weekend, a 331 mile one way trip.

They then discovered her immune system had been depleted due to the combination of chemo and radiation treatments, so she was kept another week in the hospital. Once again I went home.

While I was back home, Nancy was moved to a rehab facility for recovery. An ordeal and story for another time. I made plans to be back for her birthday weekend, which also included a follow up with the oncologist. For convenience, Nancy had been issued a wheelchair, because she still had trouble walking. Upon meeting with the oncologist, he suggested we get another x-ray of the popped nerve and the surrounding area.

Nancy's birthday weekend was also a three day weekend. We saw the doctor on Friday and had the x-rays done that Friday afternoon. Since she was scheduled to be in the facility for another week—for rest and recovery, including physical therapy, we agreed I should head home, which I did.

On Tuesday morning (Monday was the holiday) I got a call that I needed to bring my wife in for an emergency hip replacement surgery in the next thirty minutes. After explaining over and over I was 331 miles away and couldn't do anything in the next thirty minutes, I got a "huh?" And a "I'll call you back." Meanwhile, I was able to reach Nancy, who had just gotten the same call.

The decision was made to have a transport pick her up at the facility and take her to the hospital, but since she was going to emergency they couldn't bring any of her possessions. I had just brought her clothes, pjs, toiletries and the like. Items she would need on a daily basis in rehab, not to mention she still had birthday flowers, cards, stuffed animals and the like. While we were trying to figure all of it out, the transport guys said not to worry, they would pack everything up and take it with. All through this ordeal, it was near impossible to make people understand we lived so far away and couldn't just jump!

Her surgery was scheduled for the Friday afternoon and I was back the day before to be with her. The cancer had weakened the ball in her hip and had fractured. They had an orthopedic cancer surgeon perform the operation. Apparently, when you have cancer all operations require a different set of rules. When the surgeon came in to tell me the operation went well, he also explained the cancer was wide spread.

Nancy had lippo sarcoma, which is a cancer of the fatty cells, or the soft tissue. In addition to having spread through out her body, the cancer also leached onto her bones, which is what happened to her hip—my understanding of what the doctors said. Once again, Nancy went back to rehab and was eventually released to her Mom's, required to stay local, for further rehabilitation. Unfortunately, this delayed her second chemo treatment while she recovered. The requirement was at least five weeks.

While she was recovering from the hip replacement, we still visited the oncologist and had follow up scans done. A legion was discovered at the base of her skull that required radiation. The original plan was for ten treatments, but the radiologist decided 15 lower dose treatments would be better. However, this only further delayed the second chemo, which meant the cancer was continuing to grow unabated.

Once the radiation treatments were completed and she was given a couple of weeks to recover, Nancy was admitted back into the hospital for chemo round two. Although there was no radiation this time, she still was pretty beat down by this one, so much so they stopped the treatment after seven days, one day short. She stayed a few more days to recover then it was back to her mom's house, the stay local order, to rest and recuperate.

On a follow up with the oncologist, we campaigned for and got permission to bring her home to June Lake, for a week, actually 10 days.

After a brief respite, we came back to LA and met with the clinical oncologist to apply for and enter a clinical trial chemo program specific to sarcoma. This treatment would be in an outpatient capacity. We would arrive on Monday, a pump would be installed into her port for 24 hours, then we would return on Tuesday and have it removed with a repeat in three weeks. After the treatment, Nancy would be able to go home. Yes, our home in June Lake. However, she was sick three to five days after each treatment, but she was home. We did this for four of the five treatments. They decided she didn't need the last one as she was making improvements.

Next we applied and she was accepted into another clinical trial, involving a pill regiment. No one knew if the pill was real or a placebo. She had to take four pills every morning for five days, with two days off and a follow up visit to the doctor every three weeks back in LA. But, again she was home.

On our December trip to LA for a doctor follow up, we had dinner with family and friends and Nancy seemed to be doing quite well. We had a lovely Christmas (2009) at home and looked forward to the New Year.

On New Year's Day, Nancy started experiencing some discomfort and shortness of breath. By Monday, she called the local doctor to get an appointment even though we were going down for a treatment the following weekend. We saw the doctor on Wednesday and by this time Nancy was already in distress. She was taken to emergency and admitted for more tests. Those tests revealed a large mass had formed in her lung cavity compressing her lungs. The next day, the doctors considered their options and after much discussion, it was decided she would take a med-flight back down to LA to let her medical team there try a few more steps.

Nancy arrived in the early morning hours of Friday. I made it down by mid-afternoon. By Saturday, the third different doctor said she probably wouldn't leave the hospital. Saturday night we had our conversation. The conversation you ultimately have.

Once she was stabilized they decided to undergo an aggressive radiation treatment to stop the rapid growth of the mass in her lung cavity. Nancy underwent another 15 treatments of intense radiation over a four-week period. In effect. bought her a little more time, but beat her down pretty badly. Halfway into the treatments, her main doctor said she could leave the hospital. Much to our surprise and relief she was breathing on her own and had recovered enough she could leave, but again stay local. We moved into her best friends place. Our home away from home.

Once again the cancer had grown unabated, while she was undergoing the radiation treatment. After the radiation treatments, we spent a grueling week visiting the doctor twice, another MRI … this all finally proved to be too much as Nancy continued to deteriorate. After another week to recover at her mom's house, I came back down arriving early on a Sunday afternoon, February 28. Nancy was not doing well and we decided to go to the emergency room. She was suffering from severe nausea and violent vomiting and had been most of the weekend. The original center mass was preying on her intestines and stomach, preventing her from eating or drinking anything.

On the morning after the emergency room visit, Monday March 1, I met with the doctor and he informed me the center mass was just too much and he didn't believe there was anymore they could do for her. The diagnosis was then discussed with her main oncologist, who concurred. The doctor further explained, due to her rapidly deteriorating condition, she had maybe a few days left to a week to 14 days on the outside, and the best course of action now would be for her to begin end of life care.

Nancy had told me the night before she couldn't do this anymore. We had made a pact as long as she wanted to fight, we would. But, when she had enough or didn't have anything left I would respect her decision. The cancer had continued to grow unabated since the New Year's Day episode and the tumors had again grown in the center mass, crushing her stomach and intestines, leaving her unable to eat or drink anything. The intense radiation treatments had arrested the growth in her lung cavity, but had so depleted her she had little to no strength left. The pain was continuing to increase every day and the latest meds, although continually increased, were of little help.

The doctor talked to Nancy about the diagnosis and she said she was done fighting. He asked her if she wanted to be somewhat alert and have some pain, or pain free, but probably not alert at all. She said pain free. Please, no more pain.

Day one and two were spent in the hospital while they worked out the hospice details. Her brother came by on Tuesday morning and they had their talk. Nancy had asked to stay in the hospital through Wednesday, which actually worked out. Day three, Wednesday, the paperwork, medicines and such were all worked out and she was transported to a facility for her end of life care. She was processed in, a DNR and a do not transport were added to her chart. I spent the first night with her.

On that night the hospice check in nurse came by to check on her and when Nancy said her pain was still a five, he said: “oh no, we can’t have that” and prescribed further meds basically putting her to sleep.

Day four and five, her mom and best friend came by while we held vigil. Day six, Saturday, her brother and sister-in-law came by as well. Her best friend went home, but came back to spend the week with her mom and I. At this point, Nancy basically slept, not much activity due to the combination of meds.

On day 11, while I was sitting next to her, she gave a large gasp and I saw her one eye—the cancer had taken the other eye, roll back and I thought this was it. However, a moment later she opened the eye, looked at me and asked: “Hi Honey, what’s up?” She did the same thing on Friday, day 12. On Saturday, day 13, the family came by to visit with her.

On Monday, day 15, she asked me: “What’s happening? Why am I still here?” To which, I did not have an answer, nor did anyone else. From that day on she asked me every morning, which of course I still did not have an answer.

During that period, she seemed to get stronger and better, holding conversations, very alert and not missing much. Each night, I went home fully expecting to get the call, but it never came. Each morning, I walked in and there she was, with her morning question.

I would arrive just before 7am each morning and because it was early in the year, the sun was just coming up. I would walk in, set my coffee on the tray, put her purse on the nightstand next to her and open the blind on my side at the foot of the bed. It was a ritual, I would take her purse home, to Maggie’s house every night and bring it back in the morning. Sometimes she would ask for it and I would set the purse in her lap, but she would eventually fall back asleep and I would put the purse back on the nightstand.

There were two chairs by her bed, one right next to her on the side of the bed and the other at the foot of the bed where I usually held court. If she would wake up, she could see me sitting there. However, during these mornings when she was alert—she had decided to take the second med at night so she could be awake during the day even if she was in a bit of pain, I would open the blind by her and I would sit in the chair at her side, while we had a little chit-chat. We talked about many things and nothing.

I had tried desperately to get her back to her beloved June Lake, but the situation wouldn't allow it. I spoke with the doctors, the nurses and the hospice people and they did consider it for a moment, but decided it just wouldn't work and the best course would be for her to remain where she was.

Even with all the meds, Nancy remained alert and responsive. On most mornings our chit-chats were fairly comprehensive, with her giving me instructions of course! I held nothing back and we discussed everything going on, usually in detail. She understood. On one of those mornings, she was very lively and animated. She turned her head fully toward me focusing on me with the one eye—she usually stared straight ahead as we talked, but this time she focused in on me. Gathering herself and pointing she said, and I quote exactly here: "So, I'm going to die in Orange County? How the fuck did that happen?" I smiled back at her surprised. Nancy was not one to use the language, it was usually left to me. She turned back facing forward still shaking her head.

On Friday, day 19, she turned to me with that one eye and said: "Okay, don't lie to me now. I want the truth. Why am I still here?" Of course, I still did not have an answer. On days 21, 22, 23 and 24, she mostly slept, but on day 25, the morning was memorable.

When I arrived a little before 7am as I usually did, all the lights were on and she was wide-awake and obviously very agitated. She spoke in such clarity it was amazing. Her voice and speech had been deteriorating both from the disease and the heavy medication. When I asked her how she was doing, she responded: "How dose it look like I'm doing?" She followed that up with: "I need to die today." And for me to call her mom to get her here because: "I need to die today." I got her mom on the phone and Nancy told her:" You need to be here, because I need to die today."

Four days prior to being hospitalized, she had been unable to eat or drink anything and because she couldn't keep anything down, she stopped trying. We had developed a routine of her taking liquid, swishing it around in her mouth and spitting it back out, but recently her throat had healed enough from the radiation treatments she was able to swallow. Unfortunately, she immediately vomited everything back up. She and I reached a deal that if she didn't mind throwing everything back up I didn’t mind cleaning it up. She had her spit cup she kept close by and we used for this venture. However, this morning she drank water as fast as I could pour it and somehow kept it all down. Obviously something else was happening here.

I finally was able to get from her what was going on. Apparently she had a bad night and needed to die so she wouldn’t have another bad night. The bad people wouldn’t get her, she said. Apparently when this particular overnight crew came in to change her they had been a little too rough and had so scared her, not to mention caused her great pain she couldn’t bear to go through it another night. She said again she couldn’t bear to have the bad people attack her again. The problem was the center mass didn’t move as fast as she did. She had to be rolled slowly to let the mass catch up, otherwise it would drop down hard or over depending on which way she was turned, causing her excruciating pain. All of the regular staff knew and understood this situation and except for this one night had never been a problem. I reported the incident to the day nurse who called her supervisor, who tried to apologize to Nancy, but Nancy wasn’t haven’t any.

Nancy was livid. Finally, her mom arrived and we were able to get her to take the other medicine that relaxes her she only wanted to take at night so she could be awake during the day. After, she was able to calm down. Once the medicine kicked in she slept in exactly the same position for the next seven hours. She was only awakened by the hospice nurse making her daily visit after which she went right back to sleep. I explained to the hospice nurse what had happened. The hospice nurse also looked into the incident. We had a Chaplin come by that night to do the spiritual thing as well, hoping to sooth her.

On Friday morning, day 26, she was much more relaxed, but still talkative and responsive. She said: “I guess I kind of freaked out yesterday huh?” Later that morning, a hospice doctor came by to look Nancy over—truly surprised she was still alive. Of course, Nancy asked this doctor why she was still here. The doctor looked at me, but I pointed back to Nancy, saying I certainly did not have the answer. The doctor said since Nancy was in such good health otherwise, heart and lungs strong, her body was fighting back hard, keeping her going. In essence, her good health was keeping her alive, while it was also helping the cancer grow rapidly. Nancy seemed to except the explanation. All in all, she had a fairly good day. Chatty with the doctor and the nurses who came by. In good spirits, napping, drifting as we came to call it.

Saturday, day 27, she remained talkative and upbeat. Her brother and sister-in law came by as did her best friend and mom. On this day, Nancy held court, giving directions on what she wanted to drink, and how she wanted to drink it. She always wanted the ice on the bottom, the cold ice, not the ice on top in her drinks. She would shake the cup rattling the ice around as she drank, a feat both mesmerizing and cute watching her. She kept us all hoping, focusing in with the one eye. We all visited until early afternoon. Nancy started to drift after and basically rested. A pretty great day.

Sunday, day 28, I arrived a little earlier than usual and when she saw me enter, she watched me for a moment with her one eye, then said: “So, I guess I’m still here huh?” To which I responded: “Yup.” And she responded: “Oh Christ.”

I thought, oh boy, its going to be one of those days, but she basically slept the rest of the day, waking for moments at a time wanting a sip of water, but falling asleep before she could drink it or finish it. That night as I was preparing to go home. We had a routine, the swing shift nurse would help change her, freshen her up and give her the adavan, an anti-anxiety drug, the other med, to help her sleep through the night, but because she couldn’t keep anything down the drug was administered through an eye dropper under her tongue. I would wait a few minutes for the drug to kick in. Tuck her in. Put the call button in her left hand. The pain med drug button in her right hand. And kiss her good night on the forehead. However, this night I said I wanted a real kiss. I saw her pucker her lips and I bent down to plant a wet one on her. As I pulled away I heard this faint chuckle. In her drug induced speech she whispered slowly: “Ha, ha, ha, you kissed me on my adavan, now you’ll be asleep like me. Ha, ha, ha.” I actually started feeling my lower lip, until I noticed the wide grin on her face. She had gotten me again. I waited another moment before leaving. Those were the last words she spoke.

Monday, day 29, she was asleep when I arrived and they told me she slept through the night. Tuesday, day 30 was about the same. On Wednesday, day 31, I had to go home, to June Lake, 350 miles away for the day to take care of a few things. I arrived back early on Thursday, day 32. Nancy was quite a bit agitated, but seemed to calm down once she saw me in my usual post at the foot of her bed. The staff said she had kept them hoping the day before and was glad I was back to take care of her. They said with the greatest affection.

On Friday, day 33, I arrived early as usual. Nancy was in some distress. The nurse came in and gave me the look. We tried to calm her down, which she finally did knowing I was there. I sat next to her and held her hand.

Nancy died at 9:55a on April 2, 2010, Good Friday.

Her strength, stamina and courage continued to beat the odds. Although given 3 to 14 days, she hung in there for 33 days, all of them in good spirits, witty charming and graceful to the very end. I shall miss her every day.