

STORY OF SUSAN

Chapter 1

Obituary

Fine, Susan (Adelman) M.S.W., L.C.S.W, passed away after a five-year battle with CLL and Lymphoma on March 29, 2009. Married to Jerrold for twenty-seven wonderful years. Mother of Joshua. Stepmother of Howard, Adam and Daniel (Gabrielle). Sister to Joel Adelman (Caren). Susan is remembered by the "sisters" who have loved, feted, laughed, and gave her all of the support anyone could wish for, which she appreciated and returned with love over and over. Susan's energy, determination, hard work and love of life allowed her to live a full, diverse and fascinating lifestyle.

After graduating college she traveled to Europe for over six months with two girl friends and then joined TWA. When promoted to upper management, she became a supervisor and was able to enjoy her passion and travel the world. She became a docent at LACMA, giving her a chance to study and explore her love of art. After returning to graduate school at USC, she obtained her Masters Degree in Social Work, which allowed her to become a L.C.S.W. in private practice in Century City. She was elected to the Board of GLAZA and served as co-chair of the Beastly Ball, its major annual fundraiser. She was a staunch supporter of Israel, women's rights, medical research and Jewish education. She will be missed by all who were touched by her caring, sensitivity, style, humor and most of all for her ability to help others to be more than they thought, so they could try to shoot for the moon, and actually get there as she had.

The disease was just as determined to survive as she was. Only it was unaware of the consequences of its success. We are very grateful for the care and treatment she received at the City Of Hope and especially the close relationship with her oncologist. In lieu of flowers please direct any donations to cancer research.

The family wants to thank those who helped through this difficult time especially Shelley Whizin and Barry Shifrin. Others are too numerous to mention but you know who you are.

Listen to your mother and take a sweater. You are the best. You lit up our lives.

Forward

This is a love story. It is not a story only about the love between two people. It is not a story only about love between men and women, nor is it only about romantic love. It is a story about the love that grows between people who are faced with the knowledge that one among them is fated to die in the not too distant future. It is the story about a large number of people who truly care about another, and who are all brought together finally, on that fateful day of the funeral. It is about the goodness, caring and warmth brought about by feelings of love and joy in caring for and saying good-bye to a woman who was a wife, mother, sister, aunt, niece, and cousin. It is about a person who truly cared about others and how she made them laugh, toe the line and pushed them to live their lives to the fullest they possibly could.

After the service I sat there in the front row with my four sons and wonderful daughter-in-law, while our “family” made up of our friends, filed by the closed coffin and waited outside for us to finally appear. Both my parents and only brother has passed away, Susan’s parents and stepparents had all passed away. Her only brother and wife and daughter were there.

I felt so alone. I know I did everything that could possibly be imagined and more. There was no guilt on anyone’s part. There was only a huge sense of emptiness for me. Everyone had been so perfectly supportive. The days leading up to the funeral were filled with sadness, laughter, storytelling, vigilance and never ending good-byes between Susan and those she loved and who loved her. It wasn’t until I watched the coffin being lowered into the ground that I felt a knife in the pit of my stomach. It was the only time I felt weakened in all of the preceding years. It was only then that I knew she was gone forever.

Over two hundred and fifty people were at the funeral. An equal number had written or called. After the funeral many had asked our friend Shelley or myself to write about it. So much had been said at the service, they all wanted to know everything. Shelley had spoken about Susan’s “death day” equating like a birthday. She described all that she and the others who had participated, had provided for Susan. Her niece had spoken about Susan’s role in her life, in her charity for others, her humor and about her capacity to love others and give them so much of herself. I spoke about us, our son, and how she and I were truly “connected at the hip” and how the synergy of our lives together gave us so much more than we could ever have had by ourselves.

People called me and said they wanted a funeral just like Susan's funeral. They said they came to the funeral burdened and left free of the burden. Although sad at the loss, they left knowing what a good life she had and how well she was cared for through all of her illness and of her end. They were told of her strength and how hard she had fought. And while going through all of that she never lost her humor, never failed to ask about someone about themselves or about their own problems. Even though when she could hardly speak, those who came to the house and saw her during the last few days of her life were touched by her smile and her tears.

Her close friend, and one of the "sisters" Shelley, has written much of what is here. Where appropriate I will let Shelley's own words tell her version.

"Blessings come in all sizes, shapes and experiences. Blessings happen all of the time... *actually in every moment we are aware of being truly "present"...* in every moment we allow *gratitude, appreciation and love into our existence.* Profound moments such as these fill the heart and soul beyond measure. This experience... this particular blessing... still permeates the air... as well as in the hearts of those who were touched... a "living blessing" that continues to BE. It was my privilege to be part of this blessing.

You see... Susan, my sweet, courageous friend of over twenty-two years, passed away from a rare form of lymphoma, called "Richter's Transformation", at the young age of sixty-three, Saturday night, March 28th, 2009, just before midnight. I was fortunate enough to be with her for her last breath and take her on an incredible journey that held the space for her spirit to drift into another realm... in light and in love... with soft, beautiful music playing, *as if the angels themselves were singing just for her*, all the while smelling the sweet scent of "rain" that was gently sprinkled into the air... reminding her senses of the sweetness of life.

This is a true love story. It is not only about Susan and her husband of twenty-seven years, who loved her up in ways that reflected true unconditional love until the very end. It's a story about her women friends, whom she called her "sisters," who shared a special kind of love through a special kind of friendship. It's about a love of a woman wanting a son so much that at forty-seven years old gave birth. It's about a love between a patient and her doctor. It's about a love

between her life and her death. It is far from being a morbid story. It is an uplifting story, filled with grace, dignity and respect.”

On the day of her funeral one of her doctor's said the following;

Eulogy

“Susan Fine was an extraordinary woman, in every respect. She was as tough a fighter as could ever be imagined; always willing to do whatever was necessary in order to save her life, no matter how difficult.

She was as gentle as could be imagined; always willing to do whatever was necessary to help others around her, and to assure that their lives were better for knowing her.

She was as bright and knowledgeable as could be imagined; always reading, always ready for a good discussion, always current and interested in the world around her.

She was a beautiful woman, both on the outside and, importantly, on the inside as well.

She was a driven human being; driven to excel in all that she attempted; driven to have a child—Joshua; driven to go back to school to become a licensed clinical social worker, when this was clearly not “necessary”; driven to start a practice; driven to succeed.

She was a thoughtful and caring woman, whose life was filled with love, and with an abundance of friends. This, in itself, speaks loudly about Susan, herself. She loved many and was loved greatly in return.

Susan's life was full and accomplished and very well lived, and much too short. I feel blessed to have known her, and will always remember Susan as a woman of great substance and grace.”

Initially I hadn't even thought about speaking at the funeral. It wasn't until our Rabbi, David Baron of Temple of the Arts, had asked me if I wanted to say a few words. I told him I would think about it. Later that afternoon I went upstairs reflecting on the past and wrote the following, which I ultimately did read at the service;

Jerrold Fine Eulogy

"It is difficult to know where to begin.

Those of you who know Susan are fully aware of her specialness.

I am sure she would be so flattered to hear and have read all of the wonderful things family, friends, patients and peers have said about her.

About how much she meant to them and the positive impact she had on their lives. She would say "Really?" "Do you really feel that?" And best of all, she would really mean it.

Susan was special even as a little girl. She was entertaining as well, as she was always making people laugh, she was a charmer. As she matured in the business world she became more confident that she could rely on her own innate instincts to validate her views on behavior, manners, integrity, style and doing what was right.

Giving birth to Joshua and getting her Masters degree in Social Work a year later, were the catalysts for helping her to blossom into the woman she ultimately became, for the last fifteen years of her life.

Things never came easily for Susan. And in turn she wasn't an easy person. She had always worked very hard to obtain her goals, no matter how difficult and seemingly impossible to fulfill. But she generally prevailed in the long run.

We fell in love on the first night we met and have been together ever since. It was not easy for either of us in the beginning, but we knew it was good and we stuck it out.

Since the time of her diagnosis over five years ago, we grew ever closer to each other.

In my reflections of our past I realize how important each of us was in our mutual growth and development as adults and as a family.

We were truly partners in life; connected at the hip she would say. We provided each other solace in our disappointments and basked in the joys of our achievements together. We shared a wonderful, fulfilling and exciting life together.

I am so thankful to have been able to spend 27 years of my life with her. I really do not know where I would be today if it were not for her influence on me.

To those who know our son Joshua, and have complimented me on what a fine young man he is, I always respond that the credit really goes to his mother. She was ever present and ever pushing. And that goes for me as well. Ever present, ever pushing.

And when people complimented her on Josh or on her achievements, she never forgot to mention my support as well.

After all, isn't that what partners do for each other? Isn't this what marriage is all about? Pure synergy. Being more together than each of us could be if alone.

How much better a person I am for having Susan being my wife. For being in my life.

I will miss her next to me at night when we would laugh and giggle, or her taking my hand in a movie, taking care of me, taking care of our son, taking care of our family. And for being just so damned special.”

Shelley's Eulogy

"I know that many of you wished you were standing here to speak
About Susan...
Because you loved her as I did...
So I am honored to serve as your heartfelt spokesperson.

I woke up yesterday morning with words that wanted to be spoken...
About Susan and life.
I'd like to share them with you now.

Thoughts came flooding into my mind throughout the night.
"Everyone has a birthday," I heard myself say to myself.
"And everyone has a death-day, too," I also heard.
"What's important is the celebration of one's life, either way."

We prepare for a birth.
We're excited.
We stay calm and create an environment of comfort.
We bring the towels and the warm soapy water.
We bring the midwives to assist.
We make the mother comfortable...waiting for the baby's arrival.
We wait patiently. Only the baby knows when it's time.
We midwife the birth with regard and respect.
So too, can we prepare for one's passing.

This is the kind of experience that I was able to share with Susan and I am so grateful to her for that.
Being with her this past month has truly been a blessing for me
And I know how much she appreciated my being there.

Giving myself the gift of being with Susan...
Without anywhere else to go...
Or anything else to DO...
Without the angst of rushing through the experience...
was the gift.

Only Susan's spirit knew when it was time for her to go.
We just loved her up, played soft, sweet music...
To gently guide her on her way...
And sprayed the scent of sweet "rain" into the air...
So that her senses would remember the sweetness of life.
And then, we waited patiently, as with a birth.

And so it was the gentle passing of Susan's life with ease and comfort.

Sandy was right on when she told me:

"Here was a woman who had a zest for life...
That wouldn't quit.

One week before passing, she still wanted to go to the movies.
Her inner strength was coming through to the very end.
What she heard was, "No, don't go...go back to bed."
What she said was, "No, I'm going. I'm an adult. Don't tell me what to do. I want to go to the movies."
She innately knew it was her last outing...

So, when we finished getting her last platelet transfusion,
I put her in the car and we picked Sandy up...and off we went to Century City to see...
"Confessions of a Shopaholic".

Now, for those of you who knew Susan, this was definitely a new genre of movie for her to see.

She laughed that laugh of hers...

And smiled that wonderful smile and had a great time!

She even ate a half of a chicken salad sandwich on a croissant.

And so she did it, and did it HER way, and even picked her own seat.

We, her caretakers said, "Let's sit here, then you don't have to get out of your wheelchair."

And she said, "No no, let's go up there."

She wanted to go where she wanted to go and that was that.

We practically carried her up the stairs, as she was holding onto the rail and we helped her into her seat...

Certainly making sure she wouldn't fall.

Not on our watch, especially!

Jerry would kill us!

Susan was definitely a spirit to be reckoned with.

We even thought about going out to dinner and then she said,

"No, I think I'm a little tired, I better go home..."

That was a week ago Friday.

On Wednesday we had a gathering for her

With a group of women, she called "her sisters".

We were the fortunate group to celebrate her on that day.

And thank God she was coherent enough to feel us love her up.

That was the last day she was to get out of bed.

And we sit here today, celebrating her life.

She was truly a one of a kind person...

One who was always thoughtful and concerned for everyone's well being.

She was able to help so many people because she was innately attuned to their psyche somehow...

She was so concerned about other people that it didn't matter

What was going on with her, even when receiving treatment.

If you happened to call, she would always ask how YOU were, if everything was ok...and was always eager to hear about YOU.

She always gave the best of herself, no question about it.

We're going to miss her advice...it was so damn good.

We all walk away with a bit of "Susanisms"...how to shop...what to buy...where to eat...and what to do with our lives.

She became our very wise friend.

I love you Susan, and I know you know I do.

Happy journey."

Leslie Tucker is Susan's niece. She was like a kid sister/daughter to Susan and also part of the “sisters” group. This is what she had to say;

Leslie’s Eulogy

"My unselfish, bighearted, kind, altruistic, lover of life, giddy, joyful, emotional, intimate, loving Aunt Susan was such a wonderful person. She loved life so much and didn't want to die and couldn't believe that cancer in her early 60's was her destiny. She loved life so much that she wanted everyone to enjoy it as much as she did and it was evident as she was always guiding people to go to certain restaurants or try certain hotels or travel to certain places or shop at certain stores because she loved those things.

She had a way to make light of life and tell funny stories or sing songs with such humor. I have such a typical Susan video from last December where she is wearing a headscarf to cover her short hair and she said, “Don't I look like I just got off the boat? I need to go make some Borscht”...then she broke into a song of Sunrise/Sunset.

She didn't want people's fears to get in their way of doing things because they would miss out on life. We once went to a spa together and instead of getting the usual massage, we opted for a somewhat scary sounding treatment of a Native American mud bath as only Susan could be the one to say, “Gee that sounds like fun”. ...there we were rubbing mud on each other and sitting on extremely uncomfortable, cold tile benches instead of relaxing on a warm, comfortable massage table.

I believe everyone who came in contact with Susan found her to be one of the most generous people they knew. I first learned how generous she was when I was just a little girl and Susan was in her early 30's because we were driving down Santa Monica Blvd. in Hollywood in her Datsun 280Z when we saw an old lady crossing the street with ragged clothing, worn down sandals and a look of bewilderment on her face. Susan felt compelled to roll down the window and ask if she needed help or a ride home. The lady accepted our ride and when we helped her into her apartment, we noticed how disheveled, hot and dark it was. After we left, Susan immediately called Social Services

to make sure she would be taken care and we later returned with a fan to cool her and some other supplies. How many people do you know that would stop to help a stranger off the street?

I also knew she was generous of her time because she always made time to chat on the phone and get together with friends and family to discuss life or simple everyday things. I have no idea what kind of phone plan she had, but she must have had a zillion free minutes with all the calls she received and made. Not only did she make time on the phone and in person, but always remembered peoples birthdays, anniversaries and other events by sending cards, calls or thoughtful gifts like balloon bouquets or candy bouquets. Anytime we went to Ahh's or the drugstore near her office, she always picked up extra cards...just in case she needed one.

She was sometimes generous with her words and opinions...sometimes not always pleasant, but generous nonetheless. If she didn't like the table at a restaurant she was given or a hotel room she was shown, she would make sure they were told, "I'd like the third table please." Which meant she wouldn't like the second they show her, so might as will give her the best they have?

She was generous in voicing her love and emotions and always told her friends and family how much she loved them. There was no way anyone could doubt her love for them as she expressed it often.

I want to thank you, Susan for showing me all the emotions of life and for teaching me to love life and fight for what I want. We will all miss you terribly. I love you and will meet you in Paris!"

My good friend and confidant, Barry wrote;

A NATURAL DAY

“I shall always remember the day of Susan’s death as a natural day. “Natural” because death is natural, whether it is brought on by “natural causes” or it is the natural end of a rampant, disease that fulminated despite modern care. In either case, nature brings us to the inevitable, inescapable moment when we breathe our last and we become separated from our activities, our thoughts, our feelings, and our very existence.

It has been said that, irrespective of what has transpired with our lives, our activities, our achievements, our failures and distractions, we die alone. It has also been said that the rich are alone only by choice. Susan did not die alone. Irrespective of her resources or the circumstances that Susan would have tried to dictate for the inevitable moment, and she certainly would have thought about it, it is likely that the realities of that day transcended her wishes or plans.

Some people are fortunate enough to die, somewhat sensate, with loved ones around them. The ambience is somber and hushed. Brief expressions of love and affection and some sobbing punctuate the heavy silence. This is understandable; it is human – it is “natural.” Because everyone is aware of the inevitable outcome we begin mourning in anticipation. There is little of this rite of passage that is especially beautiful or inspiring. That is because these scenes do not have Jerry or Shelley or Maritza to embellish the moments, to make these final hours a thing of beauty and an eternal memory.

Many things are written about love and friendship. Commonly, we are offered the notion that love is perfect, all encompassing and all-satisfying. Love is the freedom to be yourself and the freedom not to want to control the activities of those you love. It is the fulfillment of love that something comes back to you from the act of loving and of course, being loved in return. It is being surprised and thrilled that unexpected acts of kindness done for you so anticipate your own needs and values that makes love grow, cascading upwards. Love is not constant.

Perhaps even more common than these notions of love are the notions that while love endures and survives we do not always express it as well as we might or even seem to be in love, irrespective of the underlying feelings. It sometimes seems that our actions do not always uphold the fundamental notion that love is a kindness, it is not a favor you do for someone – somehow expecting something in return.

Jerry and Susan are Husband and Wife. Susan and Maritza are Lady of the house and Keeper of the house. Shelley and Susan are “sisters” in the euphemistic sense that they are close, but not really related by blood. Each of these relationships involving Susan represents a friendship irrespective of the formal or legal relationship.

I do not use the word “friend” casually. I mean it to connote a special relationship, more commitment than involvement, more affection than familiarity. It is possible to love someone without being their friend, but in my construct, you cannot be a friend without loving them. Friendship transcends the notions about implied beneficence involved in the customary relationships between provider and recipient such as doctor / patient, lawyer / client, teacher/student, even parent / child where the provider owes his most enlightened resources to the benefit of the client, patient, student or child. Friendship adds the notions of trust and love.

Thus I shall remember the day and the interaction of Jerry, Shelley and Maritza as the fulfillment of every notion of “natural” friendship that I could imagine. At times, there was Jerry, talking to Susan, curled behind her, cradling gently the body that Susan would soon abandon. There was a tenderness, passion and fondness there that lovers who are friends may sometimes achieve. At times, there was Shelley, also attached to Susan by the length of her body whispering endearments to her. It was not so much that death was hours off, but Shelley and Jerry were trying to fulfill a timeless need, not to say goodbye, but to continue to maintain, even bolster the loving friendship; despite the circumstances. With Maritza, usually in tears, they were trying to make their friend happy, to make a place where their friend was cared for, where her needs were met, where both her body and the inner place where she lived were caressed, where she was loved. Around this hearth, in this cocoon, they took turns entwined in the intimate, passionate

embrace of still living friends - friends that were insulated from embarrassment, from self-awareness and however improbable, even from folly.

I remember my parents' deaths. I remember my father's funeral and was later dismayed that although he and I would talk over the years since his death, I always wished that I had said something at the gravesite. When the time came to bury my mother I was prepared to say something, but when the rabbi asked me whether I wanted to say something, I declined, stating that I did not think that I would be able to make it through my remarks without breaking up, without feeling inadequate to the task, without being pertinent and sufficiently appreciative. "You will speak," the rabbi said. It was not a suggestion, or a recommendation, but a command – probably heaven-sent. "Besides," he said, more gently and understandingly, "everyone will understand that it is your heart that is talking – the words will work themselves out."

That is how it seemed. Though Susan was silent, Shelley and Susan and Jerry and Susan and Maritza and Susan were indeed talking to each other. The words were tender, comforting, respectful and life affirming. It wasn't "girl talk;" "their hearts were talking" and your heart would have to be cold not to be warmed by the unfolding scenes.

We remember some quiet events because they fulfill our notions of how strangely beautiful and unforced they seem. On the day that Susan died, she lived, loved and was loved. Susan, Jerry, Shelley, and Maritza shared something that day that was inspiring and wonderfully natural.

Goodbye, Susan. I am thankful to you and your "friends" for this intimate and touching farewell. It is only natural, that it will reside forever in my memory."

Finally, Shelley wrote in closing: And so it was. Susan Adelman Fine: Loving Wife... Mother... Friend... Sister... Aunt... Licensed Clinical Social Worker... Woman of Valor... So many qualities rolled into one life.

For anyone thinking about taking care of someone you know/love with grace and dignity at the end of his or her life, I say, "DO IT!" Make it special. Give that person something to remember. It doesn't have to be morose, I promise you. It doesn't have to be an awful experience. I know that sounds strange, but the more you love that person up (and yourself by doing so), the more special the experience becomes. *You will never regret it. It is the greatest blessing! It too may become the most profound experience of your life, if you let it!*

Chapter 2

It was November 11, 1982 when I first met Susan Adelman. My oldest son Howard was going to be celebrating his fifteenth birthday with his mother at our home. She was coming over to make him a chocolate cream pie. When he told me what he was going to be doing for his birthday, I excused myself and said that unfortunately I would have to work late and would miss seeing him and his mother, but that he and I would celebrate the next day. His two younger brothers lived with her and although the dynamics made our lives difficult, I worked very hard to maintain a balanced relationship with all three of my sons, no matter how difficult the distance had made it.

That evening I had a meeting that lasted until about 6:30 and knowing it was too early to go home I went to the Rangoon Racquet Club for a drink and a bite to eat, thinking I might bump into someone I knew who was also alone for dinner. Sitting at the far side of the lounge was a woman I knew casually, sitting with a friend and waived me over. I looked for a place on the bench seating and she moved closer to her friend while the woman to her right saw me coming and moved closer to her friend opening a space for me to sit. When I got close enough to see her face I knew I wanted to meet her. She had long brown curly hair with large deep-set brown eyes that smiled with her lips. After a few minutes of small talk with the ladies on my left I turned to her and said, "Hi, my name is Jerry Fine. Would you like to get to know me? I'd like to get to know you."

I don't know why I said that. I had never said it before. It just seemed right. She smiled and said in a throaty, soft perfect voice, that she was having a birthday drink with her girl friend and was then meeting her mother for dinner. I offered dessert and gave her my telephone number if she wanted to call me and we could meet somewhere that was convenient. She said she would call but it might be too late to go out.

Although we were finally married in California on February 18, 1984, I always believed we were married the week we met. We lived our lives as husband and wife since November 1982. We never treated each other any differently after that, except learning to respect each more and love each other even better. I will admit we were much more volatile in the earlier years. It did take a

lot of marriage counseling, individual therapy and the birth of our only child to make it the best it could ever have been.

Chapter 3

Susan was a hard worker. When first living together I asked her to leave the airline as she was still traveling quite a lot on business. It took a while but eventually she agreed on the condition that we could still travel and would fly at least Business Class, if and when we did. Of course this was only after we chose the wedding date and I made the deposit for the dinner. She took a job selling advertising for the Yellow Pages. Her commissions approached \$8,000 per month, but that entailed working twelve hours a day. That was a lot of money in those days. In today's dollars it would be two or three times that amount. As time went on my business was doing better and we didn't need her earnings and so she took a break. When she applied to graduate school at the University Of Southern California, in order to get her Masters Degree in Social Work in 1990, she had to provide a biography. This is how Susan described herself in her own words.

“Autobiographical Statement

of

Susan A. Fine

Armistice Day, November 11, (now known as Veteran's Day) is a day of celebration. Americans celebrate the ending of war, and take the time to recognize the veterans who fought for their country. Armistice Day, in 1945 was a day of particular celebration for Frances and Philip because that was the day their second child and only daughter was born at Rower Fifth Avenue Hospital in New York City. Frances, at 26, was a homemaker and Philip, 29, was a radio technician. I was named Susan Ethel, after my mother's aunt Ethel, who had raised her. I was brought home to a small three-room apartment in the Bensonhurst section of Brooklyn to share a bedroom with my six year old brother Joel.

I loved growing up in Brooklyn, especially because of its ethnicity. Everyone was either Italian or Jewish. We all knew and celebrated each other's holidays and customs, especially

those that gave us a day off from school. We played together and rode our bicycles in the street, even though my mother was always leaning out the window of our fourth floor walk-up apartment to warn me of the dangers of this practice.

I was extremely attached to both my parents, often writing love poems and drawing accompanying pictures for my mother, which she promptly taped to the refrigerator door. I idolized my father and felt very possessive of him. As a child, I would sit on his lap on Sunday so that he could read to me. I look back on my early childhood with fond memories of love and support from my parents. I do remember the terrible fights my brother and I used to have and how I tried to get him in trouble with our parents. He loved to tease me and I always took the bait. Things did improve when Joel and I got older, especially when he no longer had to stay home to baby sit with me. He even occasionally bought me presents, like clothing for my dolls or furniture for my dollhouse. I recall too, that since my father often worked until 10:00 in the evening, Joel was available to help me with my homework. I remember when I was very young, maybe two or three, my father and mother would rent a bungalow in the Mountains, a few hours ride from Brooklyn. They did this to escape the unbearable summer heat of New York, during the pre-air-conditioning era. My father would work in New York City during the week, while we were in the mountains. On Friday nights, my father would drive to our bungalow and join the rest of the family. I remember missing my father after he would leave on Monday mornings but I remember loving our time at the bungalow colony and the day camp I attended. My parents rented a mountain place for us every summer that I can remember, as did many of their friends. All of the fathers arrived on Fridays and departed on Monday mornings. The resort we stayed in was full of families like ours. These were hard working people who saved all year long to provide these summer vacations for their families.

When I wasn't playing in the street or going to day camp I was attending P.S.226. None of the schools in Brooklyn had names. They were designated by a number and the P.S. indicated that it was a public school. During these early years my mother worked in a bank and I often came home to an empty apartment after school. I learned early on to help prepare dinner by

washing the lettuce, peeling potatoes, or boiling water for spaghetti. I liked helping my mother keep house while she was working. During these years however, I noticed that my father and mother always seemed to be fighting. I recall the arguments were frequently about money. When I look back, I wonder how four people lived in a one-bedroom apartment, but I never felt deprived. It seemed natural to share a bedroom with my brother and to see my parents sleep on a convertible sofa in the living room.

In 1955 my parents decided to visit my mother's sister in Los Angeles. We piled into our 1953 Hudson and drove to California, stopping at numerous Howard Johnsons' along the way. I don't remember how many days it took to drive here, but I remember that by the time our visit was over, my father had decided that somehow he was going to one day move us all to this glorious State. For many years my father had his own television and radio repair business in downtown New York. He intended to sell this business and secure a job in Los Angeles, as he wanted to leave New York as soon as possible. It took my father two years to fulfill his dream, when he was able to secure a job with an aircraft company in Los Angeles.

Life changed for me in 1957 when, at the age of twelve, I left my intimate ethnic environment and found myself on an airplane being moved to the West. While I knew I would miss all of my friends, I was very excited about the opportunity of having my own room, since my father had purchased a three bedroom home for us. My older brother and I had never before been on an airplane. I found it to be the most exciting experience of my young life. I made my first career decision that day. I decided I would become a Flight Attendant, just like the Airline Hostess I observed on board the flight that thrilling day in January.

After settling into the Westchester section of Los Angeles, located near the airport, my life began in California. My new school friends noticed that I dressed differently and spoke with a definite "New accent, but these "differences" enabled me to become quite popular with the other kids, who seemed curious about me. I went on to Orville Wright Junior High School, where my clothing and accent mellowed and I blended in as just another "local," and then on to Westchester High School, graduating in 1963.

Growing up, I began to notice and fear my father's temper. While I assumed the role of loving daughter, my brother, six years my senior, took the brunt of my father's anger and frustration. My parent's relationship did not improve with the move from New York and their disagreements continued to escalate. I was eager to leave the house and lived in the dormitory while attending California State University at Northridge.

My brother has always played a major role in my life, often providing the male direction and support I needed. He married at twenty-one after graduating with honors from U.C.L.A. and was long gone from our house when I entered college. He and his wife, along with my mother, always took a keen interest in my activities and welfare and offered a positive balance to my father's negative perspective about life. Although my father always emphasized the importance of a college education and provided the bulk of my financial support, he took very little interest in my course of study. My brother's influence led me to a major in History, as he had done. He felt I could become a teacher or attend law school once I obtained a liberal arts degree. He encouraged me to remain in school at times when I wanted to quit and he helped me to seek out a counselor when life's emotional ups and downs became very difficult. He was a tremendous influence during many of my young adult years and remains someone I greatly admire. During my sophomore year, my parents divorced and because I have always had a very close relationship with my mother, I returned home from living in the dormitory because I feared she was lonely.

From the age of sixteen through, twenty-one I had a "steady" boyfriend who had dropped out of college to work for his father. This "love of my life" caused me much anguish and pain for most of the five years of our relationship. Encouraged by my brother, who recognized the impact of my parent's divorce and coupled by the insecure relationship with my boyfriend, I sought the help of a counselor/therapist at school. I remember her as a wonderful, supportive person who helped me sort out many of my feelings of inadequacy and inferiority. The process of therapy and my family's support and encouragement helped me to stay in school and I graduated in 1967 with a Bachelor of

Arts degree in History. I was not certain of my career goals when I finished college although at one time I had considered becoming a schoolteacher. My childhood "dream" of becoming a flight attendant still loomed large in the back of my mind. The thought of travel and exciting new adventures filled my head. This daydream helped me to cope with the broken heart I suffered as a result of my boyfriend's ongoing indecisiveness about our relationship. At the same time I discovered that my mother was really very self-reliant and eager to go on with her life. It was at this time I realized that she was not at all the lonely, bereft woman I thought who needed me to keep her from being lonely.

Therefore, when two college roommates approached me to tour Europe with them upon graduation, I sold my 1963 VW and cleaned out my bank account of the money I had accumulated all the years I worked through school (I usually worked fifteen to twenty hours per week in a bank, or retail or food stores). I calculated that I had enough money to travel for six months, so long as I did not spend more than \$10 a day. My mother was apprehensive of my taking such a long trip so far away; my brother wished he could have done the same thing when he graduated; and my father thought such a long journey was a waste of money.

This was my first "worldly" adventure and I realized that it would change my life.

Once at home in Los Angeles, after the two week visit in New York where I lined up my first post college job, I announced to my family that I had decided to return to the city of my birth and "escape" my Los Angeles existence. A new life awaited me in New York. I secured a position in the management-training program at Teller, an upscale department store. My brother, who was now involved in the garment industry, was supportive of my decision, although my parents said they would have preferred me to pursue this work in Los Angeles. I had some "fear of failure" about moving to New York and my brother calmed my fear when he reminded me that "if it doesn't work out you can always come back to Los Angeles again." I realized he was right and while I was uncertain that a retail career was my life's work, I nevertheless embarked on this challenge. Although my

training as a fashion buyer was progressing smoothly, I knew that my interests were still to be among people and faraway places.

After seven months at Bonwit Teller I pursued my girlhood dream and secured a position as a flight attendant with Trans World Airlines in 1968. I was qualified in a foreign language and flew the European international routes. Much to my surprise, my family was thrilled with my new career choice. My father still had hopes that I would one day teach school but thought this was a wonderful way to see the world. I was thrilled because I saw this as a way of experiencing "everything" and the opportunity to change my life. This "permanent" move to New York, as this was now my flight domicile, ended the unhappy relationship of my teen years and at twenty-two years old, gave me the opportunity to pursue a whole new lifestyle.

I found myself listening and talking to passengers and learning about so many interesting places and people. I also worked with many different crewmembers that were very open about their private lives and experiences. I found that people were able to open up to me easily and felt comfortable confiding in me about intimate parts of their lives. In addition, each flight felt like a consciousness raising session, as many of the crewmembers and passengers conversed on various subjects, passing the long night hours as we crossed the Atlantic.

I remained in the flight attendant position for two years and during the next fourteen years with TWA I assumed progressively more responsible management positions. Initially, I was promoted to a Flight Attendant Supervisor. The majority of my job responsibilities involved counseling and enforcing flight attendant job performance standards. Prevalent problems among this work force are extreme loneliness, isolation, divorce, child behavior problems, and substance abuse.

At the time, TWA had no Employee Assistance Program and I soon progressed into that role in an informal manner. I assumed this position as one of the flight attendants that reported to me, was having severe alcohol problems. After my successful intervention and her subsequent recovery I became known as the domicile management representative that flight attendants could seek out for help and guidance in these matters. This role involved my attending AA meetings

with them, seeking out appropriate treatment centers and recommending counselors and therapists. Since the company had no formal program in place, I often referred flight attendants to local therapists with whom I had previous contact. My career at TWA continued successfully, with promotions that had added responsibilities in the area of human resources. I concentrated on issues involving training, hiring and termination, testing, career transition and downsizing, as well as counseling for self help programs, therapy interventions and drug and alcohol treatments.

While at TWA I met and a married man who was also from Los Angeles. He had moved to New York to better his career. It was 1969 and the start of the woman's liberation movement, the emergence of sexual freedom, and the war in Viet Nam. In 1971 my career was going well in New York, but my husband had dreams of returning to Los Angeles. Due to his insistence that we move, I had to resign my management position and return to a line flight attendant position, because the majority of management positions were in New York. I had achieved much independence and struggled with my role as the "traditional" wife, just as Gloria Steinem's words about woman's independence and equal opportunity rang in my head. I entered therapy to deal with my conflict of needing to align my needs and wants with those of my "traditional" husband and realized that I was unsure of what I wanted. I was angry with my husband who I felt did not recognize how much my position at TWA meant to me. I was frequently reminded that he, and not I, was the major breadwinner and that I should start giving thought to "settling" down to a more "serious" profession. I was proud and happy with the work I was doing and I looked forward to a long and rewarding career with this company. One year after the move to Los Angeles, I received a promotion to Right Attendant Supervisor in Los Angeles and again assumed the role of counseling and advising flight attendants. Two years later my husband then decided he wanted to move to San Diego to pursue another business opportunity. The move to San Diego created a conflict for me because my supervisory position required me to be in the office at the Los Angeles airport on a five day a week basis. Although I commuted daily from San Diego to Los Angeles, I realized that I was no longer willing to relocate wherever and whenever my husband decided. I was not even sure that I wanted the traditional roles of wife

and mother. I became more attracted to the ideals of the woman's liberation movement and wanted to change my life. I ended my six year marriage in 1975 amidst much turmoil and uncertainty and moved back to Los Angeles. I was only sure of the feeling that there had to be "more out there" for me to discover and I wanted more control of my own destiny. I re-entered therapy and it was valuable and insightful, in helping me realize that I carried much "baggage" around from my childhood; my parent's divorce; the broken five year romance of my teen years and my need to be independent. I related well to my therapist and found that I could open up to her and disclose my most private thoughts. She gave me freedom to express my concerns, self doubts and inadequacies. I saw her role as someone who gave me permission to have my feelings even though I felt showing these emotions were not always allowed in the tradition in which I had been raised. I grew during this time in therapy, trying to understand and hopefully learn from my past mistakes. She gave me a "safe" place to be myself and the confidence to accept who I was and who I wanted to be. Now I know that I lacked maturity and confidence in my first marriage. I have continued in therapy on and off to the present, as my time and finances permit. My husband and I were separated for three years before we made our divorce final. The decision to finally end a marriage that initially had so much promise, was filled with ambivalence. We remained friends and approximately one year later he remarried.

In 1978 I relocated to Kansas City, as I was able to obtain another promotion with TWA in the training and personnel selection department. I remained in that position for three years, gradually becoming aware that I wanted to live my life in Los Angeles again, but this time under different circumstances than before. I realized that now I had the strength to live in Los Angeles on my own terms and not on anyone else's. I returned in 1981 and transferred into a non-management position hoping that eventually a management job would become available. During this time TWA was undergoing the start of many organizational changes. I realized, to achieve career growth, I would need to pursue other professional avenues outside of the airline industry. I struggled with the knowledge that if I was going to grow professionally I would have to eventually resign from the company that had "taken care" of me for sixteen years.

In 1982, I met, and two years later married Jerry Fine, who encouraged me to pursue other options so I took a six-month leave of absence from TWA. During my leave, I was successful in advertising sales and I realized that other career opportunities lie ahead. At the conclusion of my leave of absence, I resigned from TWA with some sadness and trepidation. My sixteen-year career with this company had been the greatest educational experience of my life and I was going to miss the many people I had worked with over the years in addition to missing the industry itself. My new marriage and my success in other fields however, were affirmations to me that I would be successful in almost any field I pursued and I knew instinctively that it was time for a change. I was aware that the only source of satisfaction I have had in my adult working life has been when I was able to help, counsel and advise others. I sought out human resource positions hoping to fulfill that need. At this time of my life, I know that I want to continue in the direction I was pursuing when I was counseling airline employees and to expand my skills in my current role as an outplacement consultant. In the years since 1984 I have found satisfying work in counseling, training and employee support. One of the most challenging projects was one that involved a large gourmet food operation that my husband and I owned. I was responsible for all the training and personnel functions of our eighty-two employees. The most rewarding aspect of the personnel work was the opportunity to work directly with this culturally diverse group of people. I had to deal with substance abuse, personal family problems and finances, as well as issues of motivation and training.

Earlier in life, I never thought I would want to return to school, even though I wanted to counsel employees. I did not really entertain the thought of being a professional counselor, until recently. For many years, people would often tell me that I would be a good therapist. My desire to return to school has been an evolutionary process, fostered with encouragement from my husband, family and therapist. After having gone through counseling, I understand the importance of "working through" issues that block one's growth. I decided to take two classes last semester to see if I could handle the return to academia since leaving college in 1967. I enjoyed the learning process, and I felt energized and gratified. I know that I can help other

people and I realize that in order to do so, an education in the field is essential. I have benefited greatly from the therapeutic process and I know that I can give back much in return.

My life has been filled with many happy and rich experiences, sprinkled with sadness, disappointment and grief. These have all added to my overall personality and have helped make me the person I am. I recognize the value of having someone to talk with, who is unbiased and can help me look at objectively and sometimes critically. I am grateful for my friends and family who have been so supportive and the opportunities I have been able to take advantage of. My therapist, who I have remained in contact with since 1975, is very encouraging of my endeavors. I know my father, who passed away last year, would have been pleased and proud of my new goals. Certainly, my brother is very happy about my educational plans. He is a strong advocate of higher education and he likes that I seem to be following in his footsteps. Eight years ago he abandoned his career in the garment industry, pursued a degree in social welfare, obtained his L.C.S.W., and now has a successful private practice.

The choices I have made in life have brought me to where I am today. I feel confident that this is the right path for me to follow and I am certain that I will succeed. I feel that I have excellent people and the right qualities for helping others. I have the ability to listen well and hear what people are saying and feeling. I see people as inherently trustworthy and dependable and have empathy for their plight and respect for their individual situation. I have a positive belief in myself as a sincere and honest person and I have confidence in my abilities. I have strong beliefs about the responsibility of society to help people in their interpersonal relationships. I place a high value on self help and knowledge learned through experience and maturity and I place a high value on education. I believe that through the experiences I have had in life that I am realistic in my perception of other people's shortcomings, imperfections, frailties and weaknesses. I am capable of focusing on problems outside of myself and feel that it is important at this time in my life, to give back to the community and to society. Though I have met people from all walks of life, I still get pleasure and feelings of wonderment when I meet new people and I continue to enjoy learning from others. I am a highly ethical and moral person

and have the enthusiasm and energy to inspire trust and confidence in others. I am fully aware that dealing with people in therapy can involve hostility or rejection, but I am prepared to take that risk.

Many companies do not yet understand how the personal problems and issues of employees affect the work environment. Business is still learning how to deal with changing employee diversity and the effects on corporate goals. For this reason my emphasis in social welfare will center around helping employees to resolve issues involving, but not limited to age, retirement and lifestyle changes, substance abuse and career transition.

My present work as an outplacement consultant enables me to provide counseling and advice to executives, middle managers and administrative workers, who have been terminated from their positions. This is a program in which I advise individuals on how to use the tools available to become re-employed and how to deal with the emotional issues of job transition, career change, retirement and other issues related to re-employment. Many of those who seek my services suffer from a lack of self-confidence and the knowledge necessary to become more marketable in a changing corporate environment. The current recession requires that more attention be paid to the psychological consequences of reduced employment opportunities due to the downsizing of companies. I would like to continue to help employees deal with the issues that are affecting their jobs, and counsel them with the proper interventions.

As the "graying" of America continues and the baby boom generation approaches their 40s and 50s, I hope to contribute to the community by counseling the aging population in the workplace. My current experience in outplacement has exposed me to the reality that corporations must place more emphasis on the value of the older employee and I, in fact, would like to pursue a sub-concentration in the area of aging. In addition, I presently work with people who are planning their retirement and how they can deal with the emotional realities that accompany this major life change. For many people their self-esteem is tied directly to their jobs and productivity and therefore retirement can create much trauma unless realistically and thoughtfully dealt with.

Companies must also deal more effectively with those employees who need physical and psychological support as a result of exposure to the AIDS virus, and provide guidance to those employees who are expected to continue working in the same environment as those who have tested HIV positive. These are tremendous challenges to the workplace and Human Resource Specialists will rely more heavily in the future on Employee Assistance Personnel to handle these complex matters. This advanced degree will give me the knowledge and credentials to work with people at all levels of need and will help me to perform this function more professionally, with greater insight and skill. All of these issues have great impact in our society. My many years in business have enabled me to see the need for social welfare in industry. I understand that many companies cannot afford full time Employee Assistance Personnel, but it is my goal to provide such a service as an outside consultant.

I feel strongly about my commitment to an advanced degree because I am aware of how much more I can offer others if I am more knowledgeable. I have a number of close friends and business associates who have decided to seek an advanced education, many my age and even older. I have matured, and at forty-six years old, know that I can improve my abilities and add to my counseling expertise. When I was a full time college student in the 1960's my only goal was to graduate----now I have a desire to learn. I believe my greatest strength is my desire to learn and to apply this knowledge in helping others. My undergraduate degree in History was one chosen for preparation to become a schoolteacher. I was eagerly looking for independence after graduation and had no desire to continue in school to obtain a teaching credential. After being out of school for twenty-five years, I registered in two classes in fall of 1991. One class was "Theories of Counseling" and the other was "Child Development." I earned an "A" in both courses and found my desire to learn has grown since I was last a college student. My academic strengths include diligence, commitment, high motivation, maturity, life experience and tenacity. I am very disciplined and would not consider embarking on this emotional and financial commitment unless I was totally prepared.

My academic work in college was above average, while always maintaining a fifteen to

twenty hour a week work schedule. I achieved my best grades during my junior and senior years. Also, my recent academic performance illustrates my high level of motivation and my ability to do excellent work. If I had a weakness in college it was not being motivated to study more diligently while dealing with family and personal relationships. Among my weaker subjects were those related to higher math and science. I now have the maturity to realize that I am able to understand any class material given enough effort and study.

I plan to continue working at my outplacement consulting position while attending school, but only as many hours as my education schedule will allow. I have already been able to save the majority of the tuition necessary to finance my education. My current employer is extremely supportive of higher education, and has the requirement that all employees in career counseling be working towards an advanced degree. Many of my co-workers have already completed Master's Degrees and/or PhD programs, several of them at U.S.C. My hours are flexible and my employer is aware of my commitment to the school schedule.

My husband, a graduate of U.S.C., is very enthusiastic and supportive of my desire to pursue my education. He definitely agrees that a Master's Degree is essential to my continued growth, professionally and personally. He has been my best friend for nine years and has always helped me to become more than I think I can be. We have a solid relationship, built on mutual admiration and trust. He has his own commitments and interests and welcomes the new challenges that school will present for me. We have also discussed at length the possibility of my continuing to work for a PhD to specialize in issues in the aging and retirement communities. I have no restrictive health problems nor do I have any other obligations that may impact on my studies. I anticipate that I will be spending much of my time in the library reading, studying and doing research papers. My experience last semester was very stimulating and challenging and I learned a great deal from the research projects. I am looking forward to exchanging ideas with professors and other students as part of the overall graduate school experience. I am very excited about my return to school and working towards my goal. I feel the program at U.S.C., with the emphasis on industry and the sub-concentration on aging, will be a perfect blend of the program

I am seeking from a nationally known and respected institution. I would be a proud alumnus of the University of Southern California and a supporter of the school in the future. I am fully prepared for the time commitment and the apprenticeship program and am very eager to be accepted. I can assure you that I will be an asset to your program and an advocate of the school. I am fully committed, emotionally, psychologically and financially to achieve my Master's Degree in Social Work.”

I do not recall ever seeing this paper when it was written and only came across it while I was going through her things after she had passed away. It struck me how open Susan was about her life, even though it is somewhat slanted to help her achieve her goal of gaining admittance to graduate school. She was able to live three lifetimes within the one life she had. The first was growing up and immediately upon graduation from college, indulging herself in her love of travel. The second as a junior executive for a major airline, that at the time was the envy of the world, and finally to obtain a graduate degree, become a licensed professional therapist and a mother while at the same time growing into an elegant and gracious woman, retaining her sharp wit and nurturing insight. She surrounded herself with and attracted people of great human worth and she developed relationships with people she could only have imagined associating with.

Chapter 4

Susan was a health advocate. She subscribed to numerous nutritional newsletters and drove everyone crazy with her knowledge of what we could and could not eat. Her mother had survived two bouts with cancer, had scoliosis and suffered from osteoporosis. Susan suffered from the same maladies but the cancer was of a different type and came much later in her life. She worked out regularly with her trainer and she watched her diet. Although blessed with a small frame and a fast metabolism, she ate very well but maintained her petite size. She had a great figure and looked good in almost everything she wore. As the years passed she became a blond and actually grew more beautiful and graceful as she aged. She also had grown as a person and a mother. She had always been a supportive and loving wife.

She became pregnant with Joshua in October 1992 and gave birth in July 1993. She graduated from USC in June 1994, and then did two years of internship and opened her own private practice as an M.S.W. L.C.S.W. in 1996. Joshua brought both of us the kind of joy all parents dream of. Even today he never ceases to amaze everyone with his special manner, maturity, insights and intelligence. The years since Joshua's birth brought us both great satisfactions in our work, and great economic benefits that gave us a life of travel, beauty and substance.

We began to travel the world with Joshua when he was just three years old. We began taking two major trips a year and visited the Galapagos Islands, China, Patagonia, Europe, Machu Picchu and many other places. After all, travel was Susan's greatest pleasure. Joshua had exhibited an unusual interest in animals by age four. This grew into understanding different animal environments and the effect it had on food, coloration, birthing, etc. He became fascinated by their geography, and then he was fascinated by the world of maps and then history. All of these interests were instrumental in determining his desire to travel. Needless to say, Susan and Joshua and I enjoyed our many trips together. Except for one at Christmas time in Hawaii in 2003.

Susan had eaten something or had caught some sort of a bug that gave her a low fever and terrible bloating and stomach discomfort. After meeting with the hotel doctor with no success we decided to drive into Kahalui to visit the emergency room. They did a number of tests on her and

determined that her stomach discomfort was flu related, but they also had determined that she probably had leukemia as her white blood cell count was elevated. We got out of there as quickly as possible. I took the blood report and faxed it to my doctor in Los Angeles. He said not to worry but to make an appointment upon our return. It was then Susan showed me a growth on her upper arm that she intended to show to her dermatologist as soon as we returned. To make a long story short she did develop a melanoma that was removed just weeks after being discovered, and then had a biopsy of her lymph nodes to make sure it hadn't traveled. She also had a bone marrow biopsy, which confirmed she had Chronic Lymphocytic Leukemia (CLL).

So just what is CLL? Chronic Lymphocytic Leukemia (CLL) is one of four main types of [leukemia](#). About 15,490 new cases of CLL will be diagnosed in 2009. It is estimated that 85,710 people in the United States are living with or are in remission from CLL.

Many people with CLL live good-quality lives for years with medical care (about six years of life on average). There are a number of treatments for CLL. In recent years new therapies have been approved and other possible new treatments are being studied in clinical trials.

CLL starts with a change (mutation) to the DNA of a single cell called a [lymphocyte](#). In 95 percent of people with CLL, the change occurs in a B lymphocyte. In the other 5 percent, the cell that transforms from normal to leukemic and has the features of a T lymphocyte or an NK cell. B-cells, T-cells and NK-cells are types of lymphocytes. □ Over time, the CLL cells multiply and replace normal lymphocytes in the [marrow](#) and [lymph nodes](#). Something has told these cells not to die off like they should so that new cells can replace them. The high number of CLL cells in the marrow crowd out normal red and white blood cells, and CLL cells are not able to fight infection like normal lymphocytes do. CLL is more common in people who are over 60 years of age.

This was certainly not something we had consciously considered happening to us at this time of our lives. I had a very close friend who had died of CLL after being diagnosed fifteen years earlier. I visited with him almost every week for seven years, whether at home, the hospital or for lunch. I became very knowledgeable about his illness, various treatments and many the varieties and permutations that can be a part of this blood disease.

In her usual fashion, Susan set out to find the very best providers she could find. One of them was Dr. Thomas Kipps, who was an M.D. researcher at UCSD. His lifetime goal was to eradicate this type of cancer, especially because he had once heard it would be impossible to do so. He not only leads a group of similar researchers funded by the NIH, but is considered a foremost authority on the subject. Unbeknownst to us he had developed a test known as the ZAP 70, which could determine the rate at which the disease would grow and subsequently the approximate amount of time requiring treatment. Although located over one hundred miles away, Susan agreed to become his patient in conjunction with another well known blood researcher located at a local University hospital. Both doctors made us feel welcome and each devoted over two hours to our first visit. Dr. W (who prefers to remain anonymous) had treated my friend who had passed away and as a courtesy to his wife she agreed to take Susan on as a patient as she was mainly a researcher, teacher and consultant to various federal agencies. It turned out that she and Dr. Kipps were actually colleagues who served on a number of panels together. So it was agreed that we would see the local doctor for blood tests and the results would be shared and we would visit Dr. Kipps every six months for follow up. Both had given her the ZAP 70 test and both had concluded that she had an aggressive fast growing type of CLL and would need to be watched regularly.

2004 and 2005 passed quickly. During that time we traveled to France, Peru, Argentina, Chile, Italy and Hawaii. In June of 2006, we had our Bar Mitzvah for Joshua at the Los Angeles Zoo. Susan had joined the Board of GLAZA, the lay leadership group, and had co-chaired their major fundraiser for several years. I would be embarrassed to disclose the cost but I heard from many of our friends and guests that they never had experienced an event like that before. It was described as "the party of the century". Family and friends had come from all over the country to share in our joy. Susan was ecstatic at how everything had worked out. I had already learned to stay out of her way when she decided to do something, whether it was to decorate our home or have a celebration, and the end result was always worth the aggravation, although not always worth the cost.

By October of that year, almost three years had passed since she was first diagnosed. We went to a health spa in Mexico and she knew right away something was wrong. She was weak and could do less than half of the activities she was used to doing. Follow up tests indicated that she would need to begin treatment immediately to stem the growth of the disease. We had hoped that she wouldn't require treatment for at least ten years, as that was not uncommon. Unfortunately for us, the ZAP 70 test was right on target.

The next two and one-half years were spent dealing with the management of her illness. The next three chapters will discuss in detail her treatment for the next twenty-seven months. In the ensuing chapters I will describe the emotions we felt, how our friends, her "sisters", our family, and all of those support persons helped us get through all of this. Each of them has their own special role in Susan's life during the next two and one-half years. Part of the purpose in telling this story is to give others who may need to deal with these type of issues, a little "heads up" or guidance in what to expect. Some of what I talk about may sound a little off-putting or arrogant, as I have been described as being both from time to time. This is really serious "stuff". It is what life is all about. The more we know about how to behave and how to act in helping a loved one through this period of life, is one of the most important things we will ever do. There is very little information or training guidelines available. No one can teach you how to be a loving and caring person. But one can learn how to be with a loved one whose time may be much shorter than ever imagined.

We all know we are going to die one day. We just don't want to know how close that day is too soon. It is a difficult proposition to deal with in your everyday routine when one has to interface with others. As her main caretaker I believe I have a unique vantage point to speak about what is right and what is wrong in conducting oneself during this time. Neither Susan nor I have ever been described as being shy or passive on any issue we care about. We are both pro-active and do not act passively when we see an opening for doing a little bit extra. Being an empowered patient and an empowered caretaker removes any self doubt as to whether or not more could have been done. All of the professionals have their own lives to live as well. If it is important enough to you, then you must make it important to others. Looking backwards with "should

haves”, “could haves” or “I didn’t do enough”, will tear the surviving partner to shreds, even if they followed everything the doctors told them to do.

Chapter 5

The Hospital near our home and the University were going through a difficult period. The University had sold the Hospital to a “for profit” private corporation. Because of the internal battles going on between the staff, the University and the Hospital we determined we did not want to be treated there. So we went to see Dr. Kipps for his advice. A week earlier he had extracted a bone marrow sample and had completed a thorough examination. He then shared the results with Dr. W and they spoke the day before we were to meet with him. We had spoken with her the previous night and she asked that we call her after our meeting with Dr. Kipps. We didn’t expect anything out of the ordinary.

When we were escorted into his examination room, his assistant was reading the results and I heard her whisper under her breath, “right on time, three years.” That is when I discovered the balancing act that doctors faced with this type of illness must deal with. The doctors always know more than they are willing to talk about. The only saving grace for them is that nothing can be predicted with 100% certainty. That is why they play everything so close to the vest. I am generally a pretty good handicapper and try not to buck the odds, except in this situation you don’t get a chance to fight and runaway, because you won’t get a chance to come back and fight another day. Therefore no matter what you hear or feel, you are always trying to beat the odds, even when the odds are ten to one against you. The only issue is how much are you willing to bet in emotion, pain and suffering to beat the odds. Essentially you have to double your bet after each failure and what are you betting? Everything your body needs to function and all of the discomfort one can tolerate, until one is just “spent”. Each patient must be allowed to make his or her own decision. Statistics for learning about these issues can easily be found on the internet, however they are couched in such a circuitous manner you are constantly seeking the information to negate the negative, thinking that the next article will apply to your case. It doesn’t work that way. Each case of cancer, of each type of cancer, is different. This disease doesn’t come from a virus, or from a bacteria, but from a breakdown of the immune system, or the body’s ability to protect itself. It derives from a defect in the DNA string, and although treatments are similar in most cases, different chromosomes need to be treated in different ways with different cocktails, which essentially are designed to rid the body of the aberrations while

attempting to not attack the basic good parts. The goal is to attack the source of the problem, become problem free for a while (short term remission) and then have a bone marrow or a stem cell transplant operation (both are essentially the same). It is similar to having an organ transplant and is discussed in more depth further on.

The news was not very good. Susan's case was much more complex than most and he explained that the chance of getting in to remission to have the necessary bone marrow transplant was even in doubt. After spending as much time with us answering our questions we met with his associate to learn about the transplant procedure.

We tried to be as attentive, but all we wanted to do was to get out of there and drive back home. Since we had driven there four times in the past several weeks we finally had hired a car to take us so we could relax in the back seat together. We never knew what a good decision that was to become.

We started our ride home devastated, depressed and holding each other. I don't think the full impact of what Dr. Kipps had said really hit Susan until we were in the car for about ten minutes. We didn't know what to say to each other. I had complete confidence in Dr. Kipps, as we had grown rather close during the two years. Everything he said had made sense. We were really at a loss. I then remembered to call Dr. W, who was waiting patiently for our call. She told us that she had spoken with Dr. Kipps the prior evening and had disagreed with his prognosis as well as his course of treatment. What the hell was going on? Two respected experts each had different responses. Although the final goal of getting to a bone marrow transplant was what each stated was necessary and would offer the only cure, it was the only thing they did agree on. Dr. W suggested we get a third opinion from another colleague of theirs at M. D. Anderson in Houston, Texas. This was Friday afternoon. Tuesday we were in Houston, Texas.

We brought Joshua with us as it was the beginning of winter break and we needed him close to us. He was very content to come and stay in his own hotel room while we visited the doctor that was recommended. It was a waste of a week. The first day after arriving was spent getting registered. They wanted to give Susan a battery tests she had taken the week before. We had

brought all of the test results with us as well as them being supplied via the internet. They stated that they had their own way of doing things and we would have to submit to this procedure and then return the following week to meet with the doctor. Many of their patients are from out of the area and they have apartments ready for them to move into during the months of treatment. I was aware that Dr. W had already provided all of the test data and scientific observations and conclusions to the doctor. I put my foot down insisted on speaking with the doctor. The doctor agreed it was not necessary for Susan to go through all of the testing and that she did have all she needed to render her second (third) opinion. We agreed to meet at 3:00 PM the next day.

I already had become pretty agitated and believed that the only reason the doctor couldn't meet with us was because she hadn't read the data yet. I was very impressed with the M.D. Anderson Hospital and Research Facilities. It is part of the University of Texas medical program and I would equate it with a U.C.L.A. type of facility. It was not only a teaching and research facility specializing in cancer research and practice, but it was also known as the largest and foremost institution of its kind in the country. I have always preferred to attend non-teaching hospitals (although most hospitals are teaching hospitals and the City Of Hope belongs in that category as well), as I believe the quality of the facilities are better and that close and personal attention, is most needed when undergoing treatment for cancer. Susan and I watched as hundreds of people came and went for their treatments or tests. We were shuttered from building to building. Henry Ford would have been pleased with the efficiency.

We waited for over two hours the following day for our appointment. The place was beginning to close. Finally we were brought into an examination room and a few minutes later the doctor's nurse practitioner came in for the appointment. She began asking a series of questions that were not relevant to our purpose there and I asked if the doctor would be seeing us. She stated that she was very qualified to disseminate what the doctor had told her. Finally, I apologized for cutting her off but requested to see the doctor. About ten minutes later the doctor appeared. Noticeably, she was short of time and somewhat unrevealing except to say she concurred with Dr. W and disagreed with what Dr. Kipps had recommended. She firmly stated that Susan would get into remission using Dr. W's chemotherapy protocol and would eventually have a bone marrow transplant and would be cured for at least five years. Five years? I thought a cure was a cure. No,

I found out. A cure is never guaranteed to last forever, even though many people have survived for more than thirty years. We thanked her for her time and her willingness to stay late and meet with us. We left to take Josh out for dinner and to stew.

This had certainly been a waste of time. I later found out that the cost of the one blood test that Susan had taken there was almost \$12,000. When I called the insurance company to inquire about it I was told that the charges for the same panel from different facilities will range from \$7,500 to \$12,000, but that they all get paid the same amount, which is quite a bit less. Heaven help the person without medical insurance.

We flew home the next day attempting to determine what do next. Susan didn't want to move over one hundred miles away to have treatment. I didn't feel comfortable at the University Hospital. In our next conversation with Dr. W, she then told us she was leaving the University and moving to the City Of Hope. She would be able to continue her research as well occupy a position in the organization, concentrating on improving the facilities and the staffing. We were elated. We had attended the dedication of their new hospital the prior year and were thrilled that she could be treated there. What made it even better was that the City Of Hope had an arrangement with another oncology center just ten minutes from our home which meant we only had to make the fifty minute drive each way to see the doctor, while all of the testing could be done just ten minutes away. We agreed treatment would start the second week of January 2007. I told Dr. Kipp about our plans and he understood and wished us the best. He would be copied with all that was going on as I admired him so much I didn't want to lose the connection.

There was so much to plan for. There was so much to attempt to anticipate. There was so much going on. It began to seem to be over whelming. I never let on to Susan of how concerned I was. In spite of Dr. W's assurances, she never disagreed with Dr. Kipp's evaluation. She only disagreed with his first course of treatment. Things never looked good from that point on but I could never let Susan know my feelings.

There are two separate approaches to telling this story. One is to discuss the nine periods of treatment giving a cursory view of the two years and three months that passed when Susan began

treatment and ultimately died. Then to insert what Shelley Whizin has written which I have edited and corrected for accuracy. The other is to tell of the day-to-day treatments. This routine is not meant to apply to all cases and all cancers. There are just so many subtleties to the disease as well as the treatments that one becomes overwhelmed with all of the possibilities.

The following five chapters were written by Shelley Whizin They discuss what occurred during the approximately six weeks prior to Susan's passing. It is written by a woman and is for women. It is not the way I would tell the story, even though it is wonderfully written. My story begins in Chapter 11, and tells the story from a much earlier time period, when treatment first began in January 2007.

Chapter 6

When someone has had a long illness in a family, and death seems imminent, it stands to reason that the family stays pretty private within their inner, intimate "sacred circle". How many men do you know would open their heart and their home to their wife's friend at this most vulnerable time in their lives? Jerry trusted me enough to let me BE with the love of his life. He let me into their sacred circle. It takes love. It takes trust. Through this trust I was able to hold the space for everyone with a sense of calm, love and care that I knew was possible to create. Something much bigger than myself was occurring in that house... something wonderful... something most assuredly profound... I think that something was a sense of "grace" that came visiting.

Jerry loved Susan that much to give her what she wanted and needed, even if it meant Susan wanted him to leave the room. Being so generous with his heart, Jerry welcomed me into the fold no matter what.

From a Jewish mystical perspective, I related what Jerry did to the concept of "*Tzim Tzum*", when God stepped back to make space for creation. It is my understanding of the Kabala, that God originally took up all of the space in the universe, and there was no room for anything else. When God stepped back to make room for creation God's energy was so compacted... it imploded... and shards of God went flying everywhere into the universe as souls that embrace each human.

Although diagnosed in January 2004, Susan was asymptomatic until October of 2006 and began chemotherapy treatments in January of 2007. After a year of treatment, which included five monthly rounds of chemo treatments, called, FCR, which stands for Fluderabine, Cytosin and Retuximab, and sixteen weeks of Campath, (another type of chemo). Then, as luck would have it, she spent three weeks in the hospital with infections and became transfusion-dependent from May 2007 through to her passing. We were all elated when Susan went into remission in January of 2008. Unfortunately, it would be a short reprieve. Again, as luck would have it, Susan got a lung infection in March of 2008 and was hospitalized for almost two weeks. She had a biopsy,

and as it turned out, it was pneumonia and not another form of cancer. Good news, yes, but the toll it took on Susan's body left her weak with a very vulnerable immune system.

In August of 2008, Susan was diagnosed with an extremely aggressive form of large B cell non-Hodgkin's lymphoma that transforms itself from the attacked CLL cells. It has been named "Richter's Transformation", after Dr. Richter, the one who discovered it. Hearing this news was devastating, as this extremely fast-growing type of lymphoma actually comes from the cells striving for a new form for survival. Susan held out hope for a Bone Marrow Transplant, (BMT), and the only possible cure that would keep her alive. She thought the BMT would be the magic trick... IT would make her body healthy again... IT would be THE answer. But before she could have the BMT, she had to begin chemotherapy once again with a different cocktail that was designed to have an effect on this new type of lymphoma. After that would be accomplished she would have to wait one or two months to be strong enough to tolerate another forty-five days in the hospital.

Susan was determined to be optimistic about her treatments and was determined to have the BMT, and be healthy, wanting to go "back" to the life she loved so very much. She wanted it fulfilled as before by traveling, having adventures, attending her book club nights, movies, having lunches with friends, performing volunteer work, dining out at the newest restaurants, shopping at the finest stores, attending theatre productions, entertaining her friends, maintaining her practice as a social worker in private practice, seeing her patients, which she needed for her own validation, and spending precious time with her family.

Susan definitely lived a full life and had much to potentially look forward to. During this period of time, she was so optimistic she even bought a new needlepoint project, so she could keep herself busy in her upcoming hospital stay during her impending BMT. She was positive in her thinking and felt that whatever step she took, it would be the next step of her recovery.

Suffice it to say, Susan was a trooper. She said, "yes," to the new kind of chemotherapy recommended to treat the Richter's Transformation. It would consist of four rounds beginning in September of 2008 and concluding in December of 2008. If you saw her, so fragile and slight,

you would have thought, there's no way she can tolerate this, but Susan did. Sadly enough, the first cocktail was a bust after two treatments and another was tried two times after that and neither had any impact. In addition to that, after the third round was done, the doctors were assuming it would be a success and needed a biopsy of her lung to resolve some unresolved issues prior to the transplant. This was very painful and kept her in the hospital for another ten days.

In the interim, as the new chemotherapies were shown to be totally ineffective, the lymphoma began to grow quite rapidly. She needed high doses of pain medication. Fortunately her doctor was an expert on pain management. In February of 2009, Susan began palliative radiation therapy for huge lymphoma masses growing in her neck. As a new lymphoma developed in the base of her skull, she developed diplopia and lost some control over her equilibrium and leg muscles. In order to see, she had to wear a black patch over one eye. In addition to treating the neck, a new routine was developed to treat the skull as well. Although the size of the lymphomas went down, she never regained the use of the nerves that had been affected. As the huge group of nodes were treated and died, new ones grew in the adjacent areas of the neck. She held out hope for THE miracle breakthrough that would save her life.

This journey began Monday, March 2nd, 2009. I put everything else in my life on hold so that I would make Susan my priority... my "project". I knew this would be the last leg of Susan's "human journey" and I wanted to be there every day until the "end". I actually had no idea how long the journey would be, but time didn't matter. I felt a strong deep calling and I responded accordingly.

On Thursday, February 26th, Jerry and I spoke on the phone. He told me that Susan wanted him to do more research; to search the globe if he had to in order to find anybody doing anything, however "cutting edge" that might be just the "magic bullet" to save her life. She wanted no stone left unturned. Jerry immediately put an ad on Craig's List to hire people who knew how to search the on internet, and told me that within 30 minutes of posting the ad he had 70 respondents. Selecting four people, Jerry set up a meeting for the following day with the "*No Stone Left Unturned Dream Team*".

Susan was happy that none of us were giving up hope YET, however, Jerry knew from all of the conclusive tests and private conversations with Susan's doctors, that this was probably an exercise in futility, without much hope, but regardless, he would go to the ends of the earth if he had to, just to make Susan happy (*and he has, by the way*). This man, this devoted husband, loved Susan in ways I cannot even express. His love for her would just make your heart sing.

The team met in Jerry's home with David, Eric, Jennifer, Jerry and myself. Paula, the fourth team member, couldn't actually attend the meeting in person, but gave her input on the speakerphone. Objectives were set, a team leader was chosen and everyone knew what their task at hand would be and the wheels were set in motion. I was to be the liaison between the team leader, David, and Jerry. If David could not get a hold of Jerry, then he was to contact me. I proudly took on the role. I wanted to be of help in any way I could. Postings of their findings would be sent directly to Jerry. A log would be maintained of the hours they put in, and whom they contacted, and Jerry would forward any responses to Susan's doctor.

The goal was to reach as many people knowledgeable about this rare illness for which the known treatments had not worked for Susan, hoping that there might be something out there like a magic "bullet". Jerry wanted to give Susan what she wanted and to leave no stone left unturned, searching high and low to find out as much as possible, as quickly as possible. And so the team went to work full throttle.

Responses were received from cancer researchers from all over the world. We heard from Israel, Spain, France, Italy, Germany, England, Norway, Denmark, India, Poland, Cuba, the Philippines, Taiwan, and many from the United States, including the Mayo Clinic, MD Anderson, and Sloan-Kettering. Since Susan's doctor is one of the most knowledgeable, respected and known authority/experts in treating blood diseases in the world, most responses from everywhere proving what I thought. Susan was definitely in the hands of the best, and she knew that as well.

Chapter 7

I told Jerry that I would take Susan for her blood treatments and also for radiation and be with her, so that he could go to the office. This made Susan happy, as she felt very badly that Jerry was giving up his life for her and spending all his time taking her here and there and everywhere. But Jerry, being the primary caretaker, knew that every time she showed up for radiation or for a blood test or a transfusion, new issues would arise, and only he was capable of answering the questions posed to Susan, as her memory was a bit skewed due to the all of the pain medication she needed to take. Although it seemed that I was taking her, I was accompanying them and once satisfied, Jerry could leave and I would bring her home.

In the beginning, I would come over every day, and pick up Susan from whatever treatment she was having, then go back to my house around 11:30 pm, after Susan went to sleep. Jerry trusted me to be his teammate in caring for Susan and Jerry's routine became my routine, with the exception of Jerry taking her into the shower and getting her dressed. He also made her breakfast every day, knowing she didn't want to eat, but getting her to eat and then doling out her medications. He still wanted to do all that. I did help him with giving her a shower once, and it took a lot out of Susan just to do something as simple as take a shower. At some point, we made a spreadsheet of her medicines and posted it on the inside of the cabinet, so that no matter who was doling them out, everyone knew who gave her what, how much was given, and when it was given. The system was necessary and it worked.

Towards the end, just getting Susan in and out of bed was a challenge. I remember I would keep saying to her, "Good job, Sue," when she actually got herself into her wheelchair or back into the bed. At one point, she said to me, "Alright, enough already with the 'good job'...stop saying that. I feel like you're talking to a child." We laughed about it. I thought it was great that her efforts paid off and I wanted to encourage her spirits. I guess that's the supportive part of me.

Radiation left Susan very weak, and also irritated the inside of her mouth. Dryness set in and she was sensitive to food and tastes. Everything tasted metallic to Susan. Her nausea and loss of appetite didn't help either. We would make protein shakes with her favorite flavors and made sure we got the nutrients in the shake to keep her as strong as possible including, Ensure. Since

Susan loved chocolate, we added Josh's organic chocolate milk, but even that didn't taste as good as she would have liked it too. Sometimes Jerry put chocolate syrup in but that made it too sweet. She sipped whatever she could get down and the dozens of medications went in slowly, one pill at a time. Her inability to swallow began to concern the doctors and they told her it might be better to stop the radiation, as they didn't want to cause permanent damage to her throat. Susan said no as she was determined to have radiation to the end of the week and keep on going. She was like the energizer bunny. She was always hopeful. That was just a week before she passed away.

Susan's spirit was still strong. She was truly a force to be reckoned with. Anyone who knew her knew that. Unfortunately, so was the Richter's Transformation. But I have to say that I noticed something fantastic. As her body weakened, her spirit got stronger and her "agitation" about almost everything began to subside. I would tell her so, acknowledging what I noticed, and she would say in that sweet voice of hers, "Really?" And, I would answer, "Really!" and she would smile and rest in a place of resolve. I could see it on her face.

The first few lumps of the lymphoma that grew in her neck just a couple of months prior to this time were surgically removed. Then another fast growing mass began to grow on the right side of her neck. It grew and grew and couldn't be held back by any chemo treatment, nor could it be removed. She was battling her own body. She told me she felt like Frankenstein. She could hardly move her neck and it was very painful. It was then that her doctor prescribed the palliative radiation treatments, to shrink the large mass and easing the discomfort, which gave her hope for another round of a new type of chemotherapy.

Susan was disappointed about the growing masses, and her discomfort was anything but comfortable, but she just covered up the massive lumps and scabs with beautiful designer scarves. Every morning after her shower Jerry would put a white gauze choker around her neck. It was loose enough not to hurt but would cover the horrific scabs that developed. She wore a scarf on her head, covering up her lack of hair and a scarf around her neck, covering up the growths. She did it with such flair and style. I would always say, "Boy, you're stylin' Sue, and, you look so beautiful. You don't even look sick. How do you do that?" She would laugh and

say, "Really? I don't know." And when she smiled, which was very often, her whole face would light up and my heart would light up too.

Prior to her illness, Susan always dressed impeccably with tailored clothes that fit her slim body to a tee. She always wore the most elegant clothing for the most appropriate occasions, with the most interesting jewelry and accessories. So you can imagine, with Susan's sense of style and grace, how she looked like a "pirate" with that black patch over her eye, a scarf around her head and a scarf around her neck. One day I said, "Oh, look Susan, we can play pirate. I'll be Peter Pan, and I began to "fly" in the air. We both laughed. We laughed a lot somehow finding the silliness in the midst of the serious. I loved making her laugh, and I must say, she maintained her innate sense of humor to the very end.

While we were at the treatment center one day, Susan asked me to go to the pharmacy and see if the black eye patch came in beige. I went to the pharmacy, looked all over, and asked the pharmacist if the patch came in beige. He said it only came in black. I saw beige gauzy tape and decided I could wrap the patch in that. I went back to Tower and asked if they had beige gauzy tape. The nurse brought some over and I doctored up her eye patch. She now wore a beige eye patch which didn't stand out so much and she felt much better.

We would even "play" with the eye patch, putting it in the center of her eyebrows, pretending it was for her "third eye"... allowing her to see some inner vision none of us had access to. She was fun to play with and a great sport with the ability to laugh at herself.

Every day Susan went to radiation, and at least three times a week she went for tests or transfusions for red blood cells or platelets, depending on the results of her blood tests. Either way, she would be there for at least three hours, and sometimes five or six hours at a time.

Taking Susan every day to treatment was Jerry's life. He did everything for her. He would wake up in the morning, kiss her on the cheek and say, "Good morning Poopsie, I love you." She would smile, kiss him back with those pretty little thin lips and say, "I love you too, Jer." He would get her dressed and take her to whatever treatment was on the docket for the day. He

hardly went to his office anymore. Jerry's point was that because he knew what was happening at all times with the interactions of the various medications, food restrictions, pains, skin coloring, internal digestive issues, etc., he wanted to be the one to take her to her treatments. Then he could not only correct her answer, or ask a question, she knew he was always protecting her. That was just his way.

Sometimes, Jerry would intercede a little too much for Susan's taste. Sometimes he might say something she didn't like. She would get mad at him, and say, "Why do you do that? Just leave the room; I don't want to see your face here anymore. I will have my girlfriends bring me from now on."

"That was a real lesson for me," Jerry shared. "I realized I couldn't take anything personally during this period. I think it's so important for the caretakers to know that." Jerry became all the more patient with Susan. I'm not saying they didn't have their spats, because they did. Sometimes I would just hear them spar back and forth and it was like watching a tennis game. Jerry later shared with me that this "tension" in their relationship helped to stimulate both of them, that it worked, so they wouldn't be bored. Dynamics in every relationship become habitual, even if the dynamic is not always healthy. Jerry learned that his sarcastic humor could be placed on hold because Susan's condition was not strong enough to banter in the same way they had always done. Jerry learned to become more compassionate, patient and gentle with Susan.

Jerry was the most devoted husband I have ever seen, and the staff at the various treatment centers knew this fact too, and regarded him as Susan's hero. He helped Susan get priority treatment wherever they went and she really appreciated that. "After all, if it is important to you then you have to let others know and make it important to them". I learned that from Jerry.

On Friday, March 20th, I took Susan to have a platelet transfusion after she completed her course of radiation that morning. In the morning, it was becoming more and more difficult for Susan to walk up or down the stairs, due to her hips losing strength caused by the growing lymphoma in her skull and the pressure placed on her sixth cranial nerve. Susan kept insisting that just by

going to her physical therapist, it would get better, but this was not the case. She didn't really want to admit it was the lymphoma causing her inability to walk. By the time we got home, Jerry had an electric lift installed on the stairs for Susan to be able to go up and down without any struggle.

I couldn't believe how quickly he manifested everything Susan needed, no matter what it was. Susan and I imagined and talked about what happens when people have these kinds of illnesses, but don't have the financial resources to make their lives more comfortable. We even thought about others that might even be single and have a few kids with no help at all. Susan never took anything for granted. Susan was fortunate indeed, for she had a husband who adored her and could afford to give her whatever was needed to make her the most comfortable.

On Friday, the 20th of March. We were at the treatment center waiting for Susan to complete her treatment. It was the same day I went across the street to the pharmacy to find the beige eye patch. Upon my return Susan said, "Let's go to the movies." I said, "Great, let's go." Sandy, another close friend of Susan's who was there, also agreed. We then called Jerry who didn't think it was such a good idea to take Susan to the movies. He thought she ought to come home and go back to bed, since he was so familiar with how weak she became after spending so much time at treatment. However, Susan didn't want to go home and go back to bed. She wanted to go to the movies. We spoke to the nurse on staff and the nurse too, thought it was a good idea for us to take Susan to the movies. Jerry wanted us to call Susan's doctor to find out what she thought, and she too thought it was a good idea. Everyone thought it was a good idea, except Jerry.

Jerry called Susan and told her that he didn't think it was a good idea. Susan answered Jerry by saying, "I'm an adult, Jer, don't tell me what to do." He said, "Let me speak to Shelley." Well, he was upset. I could tell by his tone, and he said to me in a disapproving voice, "Shelley, do you really think this is such a good idea?" I said, "Well, as a matter of fact, Jerry, I do. I think it's a great idea!" He harrumphed, and said, "Okay, but you have to keep close to her. She can hardly walk." I said, "Okay." It wasn't that he didn't want Susan to have fun. He was definitely overprotective of her and didn't want her falling and breaking a bone or hurting herself. It was his way of being protective of her.

So, after Susan completed her treatment, we got into the car, picked and off we went to Century City to see "Confessions of a Shopaholic," which is a movie that Susan probably would never have seen under normal circumstances, but I felt it would be a lighthearted film and we would all get a good laugh. The previous week, I took Susan and Sandy to see "Madea Goes to Jail." Now that was definitely a movie Susan would never see and we all laughed and had a great time. I believe sometimes it's important to lighten up a situation with humorous, silly, non-significant experiences, as these two movies were. It was great to see Susan laugh and let the little girl inside of her have a good time just for the sake of having a good time. We got her home safe and sound, and Jerry was relieved and happy that Susan enjoyed herself. After all, what else is there, especially at a time like this?

Chapter 8

MARITZA, THE LADY OF THE HOUSE

I have another story to share, with regards to Maritza who is Susan and Jerry's housekeeper. Let me just say that Maritza LOVED "Miss Susan" very much. She had been working for the family for over five years. Maritza was "personally trained" by Susan, which meant that everything in the house was immaculate, impeccable and in perfect order, just the way Susan liked it and expected it. Maritza was so well trained; she knew exactly how to properly set a table, how to properly handle the delicate treasures and how to properly take care of Miss Susan, Mr. Jerry and Joshua, as well as any guest that came into the house. Maritza is truly the most delightful and devoted woman I know, with an amazing work ethic and loves to keep the house clean. And she's funny too!

This one particular day, Susan had to go to the bathroom. She was at the stage where she was unable to walk hardly at all, and was in a wheel chair. She didn't really want to accept that it was the lymphoma causing her hips to hurt, preventing her from being able to walk. We had to help her get in and out of bed and on and off the toilet. Jerry also rented a porta-potty as well as a walker which was next to her bed, but when she had to do more than urinate, she wanted privacy and wanted to go to her own bathroom.

After we got her into the chair and wheeled her into the bathroom and settled her onto the toilet, we waited outside. Maritza said to me, in her cute Spanish accent, "Miss Shelley, Miss Susan is really lucky. You are a such a good friend. I am so glad you are here for Miss Susan." I said, "Thank you, Maritza. I feel blessed, to be here." Then she said, "You know, Miss Shelley, every woman needs three things: a good husband, a good friend, and a good housekeeper." Well, you can imagine, I cracked up, and we both laughed so hard. I said, "You are so right, Maritza, we all need that. You are funny. I bet you laugh with Susan all the time." There was humor expressed throughout this period of time, because Susan had a fabulous sense of humor, which had always served her in the greatest of ways.

Maritza continues to care for the house and the family. Maritza will miss "Miss Susan" terribly, because she felt that Susan was her teacher, her mother as well as her friend, in many respects.

Chapter 9

We all knew Susan wanted to express herself, but sometimes the words would just come out jumbled, taking one random thought from here and one random thought from there, putting them together into sentences that she thought would make sense, but which would didn't. Sometimes she thought she was making sense, and other times, she knew she wasn't, and it would frustrate her. She saw herself losing the "Susan she knew." And yet, sometimes Susan and I would just look at each other without saying a word, and I knew she knew I could understand her sense of frustration and sense of loss. We would usually just shrug our shoulders at the same time, wince our eyes at each other, and communicate with the looks on our faces. It was in those poignant moments our souls were connected. Jerry tells of the time when he brought her down for breakfast and while cooking the first or second selection Susan said to him, "Honey, aren't you having a good time trying to figure out what I am trying to say?" He would just crack up.

Jerry and Susan spoke daily to Susan's doctor. Frankly, I never saw a doctor so caring and attentive. Susan looked forward to her daily conversations, and somewhere between five and six every evening, Susan would glance at the clock and say, "Oh, my doctor will be calling me any time now."

It came to be that Susan wasn't really able to talk on the telephone very much, for it tired her out. And then I would speak to the doctor if Jerry wasn't there and answer her questions. As the time went on, Susan wouldn't want to talk to anyone but her doctor. Susan loved talking to her friends on the telephone, as it was one of her very favorite pastimes, so for her not to have the energy to talk, was a sign that Susan was really getting weaker.

Sometimes Jerry would have separate conversations with the doctor, where they would discuss the severity of the situation. When the doctor spoke to Susan, she held out hope for Susan and didn't want to damper Susan's spirits with "too much information". I learned that there is such a fine line for a doctor knowing how much information should be revealed to the patient, especially when death seems so near, without a realistic hope for recovery. I had great empathy for Susan's doctor, Jerry and Susan. It was difficult for Jerry, knowing and not speaking of what

he knew, as Susan would hold out for hope, him knowing there was just not any hope to hold onto. At least Jerry had his friend, Barry, also is a doctor, to confide in, share his thoughts, doubts, hopes and fears with. They would meet weekly where Jerry would share his what he learned and discussing losing the love of his life.

Susan's doctor was on top of this case. She loved Susan and did whatever she could to save her life and tried to minimize the pain and the discomfort. She did everything humanly possible to keep Susan alive. She promptly answered the queries Jerry forwarded to her from the internet research, and expressed her appreciation for the time and effort everyone was making on Susan's behalf. It was quite something to watch, this team effort of professionals and amateurs and strangers and helpers and friends and family members, all coalescing around my dear friend Susan.

It was on Monday, March 23rd, that I went back to my house to get a few things, since I knew Jerry was taking Susan to see her doctor at City of Hope. Susan hadn't been able to physically see her doctor in over a month, and I was elated that she was going to have an opportunity to see her face to face, instead of only on the telephone daily, which in and of itself, was quite remarkable.

While at home, Jerry called me to ask me if I wanted to go with them to the doctor's visit at the City of Hope. I was honored and of course I said that I wanted to go. I wanted to be in on everything. I also wanted to meet this doctor who had been so good to my friend. Jerry and Susan picked me up from my apartment and we drove to City of Hope in Duarte, about thirty miles away. Along the way we had to stop, for now Susan couldn't eat nor even keep her medicine down.

Susan's doctor met us in the office where Susan was to get a blood test. She went over the details of the blood test and then we went into a small room. Her doctor was on her lunch hour and made time to see her then so she could spend more time with us. I think it must have been as important for her doctor to see Susan, just as much as it was for Susan to see her doctor. Jerry asked me to come in with them. I stayed in the background, so they could have their privacy.

Susan sat in her wheelchair, weak and lethargic. The doctor sat down facing her, taking her hands she asked, "Susan, tell me what you are feeling." Susan's first words were, "I'm done. I just can't do this anymore I don't want to suffer any longer. It's just too much. You've done so much for me. I know you have tried your best and I love you so much for it. But I think we all know there isn't any hope left." Jerry and I were floored, since neither one of us heard this from Susan before. Susan was always somewhat in denial of the severity of the situation and held out for hope for that miracle cure, that magic bullet. Then, Susan began to console the doctor. That was Susan! She said, "You are the best doctor in the world and I am so grateful to have had you take care of me. I know you did the best you could."

Jerry and I just sat there in amazement. Tears came flowing down over all of our cheeks, including the doctor's. The doctor responded by saying, " I am so sorry, Susan. There was nothing more I could do. This kind of lymphoma is so aggressive, I couldn't control it with any of the treatments we had. You are such a special person and I have been so honored to treat you. I feel I have failed." Susan, in her Susan like way said, "Oh, no, don't feel like that. You did everything you could. You are the best doctor anyone could have ever had."

We all cried at the closure Susan needed to complete with her doctor. The doctor promised that she would do whatever necessary to make Susan as comfortable as possible and promised she would not experience pain. We spent over ninety minutes together, both crying and sometimes laughing and then crying some more. The doctor explained to us that when the time came, Susan would go to sleep and just never wake up again.

Susan spent the rest of the day in a private room, receiving platelets and getting the dressing changed on her PICC line, which took over an hour and a half, since every time the nurse peeled back the existing tape, her skin would come with it. That is how fragile her paper-thin skin became. She was exhausted by the end of the day and we left City of Hope around 5:00 PM. This was the last Monday she would ever have.

Chapter 10

Over the last few years, Susan gathered together a group of women she felt especially close with, she called, her "sisters". When she began treatment, we would get together, as often as time allowed, just to chat, to love Susan up, and to talk about life. It was always stimulating, fun and loving. We all had Susan in common. There was Sandy, Mary Ann, Nora, Leslie, Sue, Cathy and myself. We each came with our own different story, each knowing and loving Susan for many years, but not knowing each other before. Naturally, she had other close friends, but for whatever reason, we were deemed "the sisters" and so it was.

Usually we don't always get to share with a person that is dying, what we would want to say about that person at their funeral. Well, this time was different. On the way home from the meeting with the doctor, Susan said she wanted to have her "sisters" over for lunch on Friday. Jerry somberly said not to wait until Friday and to schedule it for Wednesday, but Susan thought Cathy couldn't come because she had patients. Jerry told her not to worry, that she would be there, and she was, as were all of the others. I was so determined to get Susan's "sisters" together, not just to attend her funeral, but to attend an "awakening", a special gathering to create a sacred space, where these special women in Susan's life could tell Susan what they felt about her in her presence. Something else came to me. I also thought about having each person find a some small trinket that belonged to them, it could even be a button or something small enough to fit into a small voile bag to give to Susan to be placed in her coffin, so she would always have a "piece" of each of us with her.

Susan looked at me with those soulful, beautiful brown eyes of hers and asked, "Shelley, do you think I'm going to die before Friday?" I said, "I don't have any idea when you're going to die Susan, but isn't having the gathering better sooner than having it later? People drop everything for a funeral. Your friends will drop whatever they are doing to say goodbye while you're still alive." I knew she would not be as coherent on Friday, and didn't realize how much she would deteriorate in just two days, and to be gone three days later.

When Jerry dropped me off at my apartment to get my car, I immediately got on the phone and called, the "sisters", telling them about the "awakening" for Susan, and every single woman, said, "I'm on, I'll do whatever it takes to change my schedule to be there." Even her friend, Fran, an extended "sister", flew in from Kansas City that morning and returned that afternoon. "What do you want me to do?" each person asked. I said that I would make an egg soufflé, and Sandy said she would decorate Susan's dining room and make it absolutely fabulous, which she did. Sandy is the decorator of the group. Sue brought Chinese chicken salad and we ordered from the deli. Everyone made it. Everyone sensed the urgency and within twenty minutes all were committed to attend on Wednesday.

The dining room looked eloquent and festive and definitely had the "Sandy touch". The table was covered with Susan's favorite tablecloths and Sandy brought statues of women and jelly-beans and everything that would connote a party. Susan loved entertaining, so this would be the last hurrah she would experience.

What it was like that morning. It took some doing getting Susan down the stairs even with the new lift, but we made it. She sat in her wheelchair at the head of the table, and, thank God, she was coherent enough on that day to hear and feel the love that was being bestowed upon her. I was so glad. I just knew that had we waited just one more day it would never had been so good. She listened and heard everyone's words and we all knew she had "gotten it" by seeing the beautiful smile on her face, and then as the tears rolled down everyone's faces until the next smile came across her face again.

One by one we sat at her side, either reading something we wrote or just expressing our feelings from the heart. Either way, Susan knew this was a special time for all of us and we just loved her up so much. It was the most beautiful ritual I have even seen. Each "sister" gave her a little trinket with an explanation of why she selected that particular item. We were all crying at various times, and it was cathartic, healing and wonderful. Later everyone agreed they had never participated in anything like that, ever. The idea of implementation may have been mine, but the idea for the event was definitely Susan's. It just happened, as did the rest of the weeks occurrences and we actually pulled it off. It was an extraordinary experience for all of us.

We videotaped each person connecting with Susan and you could see on Susan's face the love being absorbed and how she welcomed us with an open heart. We ended around 4:00 pm, when the Rabbi came to visit and to console her. They went into another room, alone where she later told me he said prayers for her told her of his sense of personal loss.

That was the last time Susan was to be out of bed and come downstairs.

Chapter 11

We arrived at the City Of Hope for our first appointment with Dr. W on January 5, 2007. Although having come on time, there was already a problem. Unbeknownst to anyone there was a fire drill given on that Monday morning which had set everything behind schedule. It was also Dr. W's first week at her new position. Although Susan had enough time to take her blood test and have the results ready forty-five minutes later for our appointment, we hadn't counted on the fire drill slowing down the intake department, which meant we would be late having to be enrolled before seeing our doctor. The appointment time then would be too early. Knowing how tight the doctor's schedule would be in her second week, meant that we wouldn't have enough time to meet. I looked around for a solution when I saw a sign that said "Patient Relations". A woman was talking and smiling with an elderly couple as I waited to approach. She saw me and I could tell that she was concluding her conversation with the couple ahead of me. I then explained our situation to her and when she asked if we had been there before. My first inclination was to say no. But then I volunteered that we were there for the opening of the new hospital about two years earlier and once again for the dedication of a family gift.

She never asked my name. She said follow me and I did to one of the intake persons. Jeanne asked me to bring my wife, and we were the next patient seen. I believe that had I not told her of my previous visits we would have gotten the same courtesy. She was pre-registered and the whole thing took less than three minutes. We finished just in time to be called in for our appointment with Dr. W. The purpose of the appointment was to discuss her status, and what to expect during her course of treatment. She was not licensed yet to work in that new facility and so we became the patient of an associate of hers until she got her own hospital privileges.

We spent a lot of time discussing the protocol and the side effects of various herbs and supplements that Susan had been advised to try by everyone. Most were prohibited or actually acted in contravention of what we were trying to achieve. We discussed the possibilities of testing our friends and family for being donors for a BMT. Susan has trouble sleeping if she is uncomfortable. Susan has an irritable bowel. All of Susan's prior medical issues are addressed. She can have Bentyl and/or Carofate for the stomach. She can have Ambien, Valium or Ativan if

nervous or she cannot sleep. She can have Vicodin for pain. We think all is covered. It is only with time and varying situations that we learn that it is impossible to have everything covered.

The protocol is for her to have six rounds of chemotherapy. Each round is three full days in week one and three weeks off and then round two, etc. After that she will have sixteen weeks of Campath (Cambridge Pathologies), which is a “consolidator”. That treatment consists of a shot every other day for sixteen weeks and she can have the shot at the clinic near our home.

Assuming she gets into remission (the definition keeps changing but essentially it means she is free of any CLL cells in her blood or bone marrow), the goal would be to have a bone marrow transplant. The Fludauridine, Cytosine and Rituximab is a standard treatment for CLL and they are well versed in all of the side effects. Dexamethasone is also added.

We begin week one by returning to the City Of Hope (COH) on January 9 through January 11. The days are pretty much the same although the infusion time is less for days two and three because she only gets one of the drugs on the first day of each cycle. Normal white blood cell count is 4,000 to 11,000 per μL ($\text{cells}/\mu\text{L} = \text{cells per micro liter}$). Susan begins with a count of 178,000. Within one week the count is down to 69,000 and by week three it is 13,000. Wow, this is great. But then her red cell (hemoglobin) count drops below 8 g/dL (grams per deciliter). She already had gone to 10 g/dL in October which is when she became weak and was anemic, as normal is 12 to 14 g/dL , and platelets go from 158 μL (150,000 to 400,000 platelets per micro liter (μL) is considered normal), to 60 μL (too low but manageable).

She finished the chemo on Friday, feeling pretty well. On Saturday she had absolutely no energy. She has terrible aches and is worried something happened. We spoke with Dr. W and she explained that Susan was given large doses of steroids that are used to shrink any enlarged nodes impacted by the CLL, which has a side effect of helping her feel energetic. Once it left her system she crashed. After that first time she was given diminishing amounts of prednisone over three or four days, which helped her experience a softer landing.

She was feeling well enough that she said I could take a three-day business trip to Florida. While there, she confessed to me later, that she had been constipated and in an attempt to have an

enema, she noticed a slight amount of blood. Within a few days she had a fever of 102 degrees and on January 11, she had to be hospitalized. Standard protocol is to be hospitalized if the fever exceeds 101 degrees. Two weeks after coming home she spent five days in isolation at the City Of Hope hospital. This hospital is specifically designed to treat people with cancer and who also undergo bone marrow transplants. It would be impossible to describe the high quality of the staff, the care they provide, the standard operating procedures devoted to this area of medicine. When entering her room everyone dons gloves, mask and gown, which are discarded upon leaving and fresh one's used when re-entering. There is entertainment and movies on the television, a DVD player, high-speed internet connections and a sense of family provided by everyone.

The infectious disease staff attempts to try and define what caused the infection. The likelihood is it came through the open wound but no one really knows. In fact, most of the infections the patients acquire are generated from within their own body. We all carry viruses and bacteria that help us ward off new invasions of the invisible world that invades our bodies all of the time, and our own viruses that guard us are held in check by our own immune system. It's all pretty interesting stuff when one figures out what is really happening. The more I learned the more curious I got and started doing my own research to verify what was being done. I made graphs and charted every blood test Susan had. It is mind-boggling trying to understand the interactions and effects of every change in the body's chemistry. I have a new respect for medical practitioners and researchers. I marveled at the knowledge they had of so many complex interfacings. And thanks also to the PDA, which can hold every bit of medical and pharmaceutical reference books and allow the user to have immediate information at their finger tips.

The infectious disease department was unable to identify what caused the fever, and they confess that they are only certain about 40% of the time. Susan also had her first transfusion of red blood cells. It doesn't matter though because in five days she came home and went back to work seeing her patients. Work was always very important to her and she had bonded with many of them. She continued to see many of them during the next two years, while being treated herself for her own illness.

Susan's attitude was that she was a healthy person being treated for a problem, not a sick person being treated. Her positive attitude gave her the strength to endure more than anyone could imagine she would have to endure.

Chapter 12

The second round began February 21-23, six weeks after the first treatment. We were old hands at this now. There were no surprises and Susan was actually able to go to work, albeit on a limited schedule, six days after the infusion. Her blood counts showed that the chemotherapy cocktail was working. Her white count was so low that after the third infusion on March 21-23 that she had to take Neupogen to build it back up and Aranesp to build up the red cell count. These are relatively new drugs and some negative publicity had come out how some people were abusing the ability to build up their red cell count for their own purposes, even though their counts are within normal limits.

As I was reviewing the course of treatment so far, absentmindedly I had said something that was not very positive. I believe I was just thinking out loud when Susan said “What are you trying to do, get my anxieties up before tomorrow?” I was at a loss and apologized. This was not like her and the strength that she had always shown was waning. She lashed out at me and we didn’t speak until we got into the car that morning. She didn’t want the radio on and she made me turn off my cell phone. When we got closer to our destination she said that she didn’t want me to take her there again, ever. That her girlfriends (the sisters), would take her and wouldn’t try to aggravate her. I sat there quietly and was really trying to figure out what I could do or say to make it better but I was at a loss. When we pulled into the drop off area, she said she was going in and I should meet her at the infusion room.

I did as she had asked. When she was finally all settled in bed with her newspapers, etc., I said I was going to get a cup of coffee, and asked if she wanted me to bring her anything? She said, “Go get your coffee and don’t come back. I don’t want to see you here again. I will call someone to me pick me up. Just leave”. So I went for the coffee and had no thought of leaving, and while walking by Jeanne at the Patient Relations station she said, “Hi Jerry how is Susan today?” When I told her what Susan had just said she responded, “That’s great. That means she still has plenty of fight left in her and shows how much she trusts your love. She’s angry and she has good reason to be angry, and who can she unload on if not you? Now you back in there, right now and tell her that you love her and that you are not leaving. That you know if the roles were

reversed and you were in that bed instead of her, that she would be doing exactly the same for you.”

Well once again I did what I was told to do and when I finished Susan looked up at me and she said “Honey, I love you so much” and with a big smile she held her arms up and I leaned down for big kiss. That was the only time that Susan had ever spoken like that in all of the time we spent together during this period. I admit there were times that tempers were short but they became less and less, or I just became more immune. Honestly, I don’t remember.

After the fourth treatment on April 18-20, the doctor was so thrilled to see how well Susan was doing that it is decided to extend the cycle from six sessions to eight sessions. This was being considered for insurance purposes, as they were having trouble finding a match for a donor for the bone marrow transplant, which was supposed to be the next course of treatment after achieving remission. This was like a subtle bomb that was dropped so casually that as I watched for a reaction for Susan I realized that she only heard the good part and not the negative. I knew her chemistry was very complicated from our discussions with Dr. Kipps but after all, he thought she wouldn’t be strong enough to withstand the full course of Fluderabine and now she had done so well two more sessions were being added. We didn’t discuss the ramifications of this new information but I did contact the donor/match center and they assured me they were still looking and were optimistic about locating a candidate.

Bone marrow donors are always kept anonymous, unless they are compatible members of the family, which can occur in about one out of four chances. There can be no influencing them, compensating them or negotiating with them. They are volunteering not only their time for free, but their comfort for as long as two days. Their blood is harvested for the stem cells via a filter-like system that removes the desired amount of stem cells and then puts the blood back. It takes a number of hours to complete donation. I do not believe there are any after affects other than knowing you provided a very unique product to hopefully save a life and affect a cure for a stranger with an illness that can be horrific. I am happy to report that we were eventually able to locate two good matches. That means that only two people out of a database of over seven million registered donors were determined to be possible donors.

Prior to beginning even the first round of chemotherapy, it was suggested that Susan order two wigs in case her hair fell out. We knew things were going our way because she was getting to look even more beautiful and she hadn't lost any her hair on her head, but it did thin out in other areas.

Chapter 13

The fifth session began May 16-18. Everything went as planned. The routine was always the same. We would arrive at the City Of Hope by about 9:00 a.m. and leave by 3:30 p.m. or by 5:00 p.m. depending on what was going on. They had about sixteen infusion chairs where people would come for one or two hours at a time, and about eight small hospital rooms with beds. In order to avoid some of the negative reactions to the different drugs Susan was given Benadryl, which is an antihistamine, but which would also put her to sleep. She would always take a lot of reading material with her but rarely got past two or three pages.

She had already planned to see patients the following week and we were very optimistic in trying to decide where we would go on vacation after the chemotherapy was completed. We knew it had to be in the U S, including Hawaii, because she had to remain in a clean and sanitary environment and near a major hospital in case any problems might arise. On May 16 we began session number five and successfully concluded it three days later. By May 25 she had developed a fever of 104 degrees. Rushing her into the hospital, I remember she was shivering so badly they had to put about four heated blankets covering her and she was still shivering. I took off my shoes and got into bed next to her, holding her as tight as I could so the warmth of the blankets and my body would help warm her up. I think the shivering subsided because I was so close. She fell asleep and as I got out of the bed I looked at her dripping wet hair, and her face, all red and splotchy. I felt so badly for her and what she had to endure.

She was there seven days and required blood transfusions every other day. The chemotherapy was really doing a number on her. So much so, that it was determined she could have no more. They were afraid she wouldn't survive it another time. Dr. Kipp's prediction had almost come to fruition. It took two months for her to go for as long as eighteen days without a transfusion. We left for Honolulu in early August for seven days. Wheelchairs became the norm at airports. A car was waiting for us when we landed. The greatest distance she had to walk was from our room to the elevator to the café next to the sand where we hung out during the day. Her most exhausting

task each day was drying her hair. She could hardly hold the hair dryer up long enough for the humidity drenched hair to dry.

Susan insisted on eating dinner out every evening, as that was one of her most favorite things to do. She had done her research and had the concierge make the reservations for us. We got out of the car at the front door and we were picked up at the front door and driven back to the hotel. For the first few days she seemed fine. We even had one evening of romance as Joshua, who was always with us, also always had his own room. By the last day she could hardly walk to the restroom on the ground floor of the hotel. At dinner that evening I saw the effort she made not to show her weariness. When we got home we went to the clinic immediately. She had a hemoglobin count of 5.5. This was not only very dangerous, but no one could believe she was in Hawaii the previous evening and had gone out for dinner as well. She got the necessary transfusions and was well enough to start the sixteen-week program of Campath.

Chapter 14

Although still transfusion dependent she could go almost two weeks without having to worry about dropping everything to have another transfusion. It took the City Of Hope about two or three hours to find the blood for Susan, as she had developed anti-bodies that narrowed the choices. It took the clinic near our home, two days to find blood for her as they got it from Cedars-Sinai hospital. And as good a place as it was, it still didn't come close to matching the facilities at the City Of Hope.

She had twelve weeks of Campath until November 16 when she developed a fever and went back into the City Of Hope. The infectious disease staff could never identify the cause of the fevers, but with the right antibiotics they were quickly brought under control. But that ended the Campath treatments. Still transfusion dependent, she worked her reduced regular schedule. She tried to maintain normality at home, mostly to show Joshua that she was getting better. We always ate dinner together and laughed and talked about politics and school. I continued working as well and we had great help at home. Even if Susan came home early and napped, no one really knew it. The "casita," a separate apartment for guests, became her escape. She said it was like going to a hotel, which was also one of her favorite activities. On December 10 she had a bone marrow draw where it was examined for CLL and other potential abnormalities.

Chapter 15

We needed to celebrate. Where shall we go? How about the big island of Hawaii? It was December 2007, at Christmas time. It is very difficult to get air transport and rooms so late. We got what we needed (not what we wanted, but so what) and stayed for ten days. All the time Susan was getting stronger and stronger and feeling better and better. As soon as a donor could be found and she would be strong enough she will be able to have the bone marrow transplant and be cured. It looks like her hard work and endurance is paying off.

In January we went to San Diego to visit Dr. Kipps and his wife. We couldn't wait to share the good news about her remission. They both were so happy for us. He was also confident that a proper donor would be found. We stayed at our favorite hotel in La Jolla and the evening was magic for us.

In February Susan decided she wanted to go to Fort Lauderdale to visit her aunt, her father's only living relative. She had macular degeneration and was unable to see. Additionally, she had just been cured of colon cancer. Susan believed it would be the last time she would be able to see her. At spring break, she and Joshua went for four days. Although it was tiring for her, Joshua was a big help and it was a good trip for her. When she returned she had a low-grade fever for over a week. It was not high enough for her to go to the hospital and she was feeling well enough to work. She began to notice that her breathing was becoming more labored. Suddenly she had a high fever and on April 10, ten days after returning from Florida, we were back on our way to the City Of Hope. It was about 8:30 in the evening and we called Joshua into our room to tell him. He offered to help us pack up her bags for a long stay. This included taking all of her own medicines (even though they weren't allowed), computer, iPod, cell phone charger, foods she like to snack on, pillow, hair and facial products, etc. As we were carrying all of the bags to the car Joshua asked Susan, "Mom, is there anything I can do for you?" She looked at him and with a smile on her face she asked, "Did you practice the piano today?" Needless to say, we all laughed and he promised to do so as soon as we left.

The next day we were told that she had contracted pneumonia. Was it because of her trip to Florida? The odds are probably against that because every other infection had come from within her own body. I don't think we will ever know.

This was a longer stay than normal. She remained in the hospital for ten days. She became more transfusion dependent and we had to wait several months for her to get her strength back anyway. When we got home in late April we were told two good bone marrow donor matches had been found. One was a male and one was a female. The doctor preferred the male and we started thinking that she would have the transplant in September or October. Two years had now passed since we knew treatment was required.

We had our setbacks but always seemed to overcome the negatives. In late August Susan felt a lump on the side of her neck. We went to see Dr. W and she wanted to have it removed right away and a biopsy done as soon as possible. We received the results on August 29.

We had never heard of Richter's Transformation. It occurs in about 18% of people with CLL who achieve remission. It essentially occurs when the CLL cells morph into large B cell non-Hodgkin's lymphoma. This little bastard that had caused all of trouble didn't want to go easily. He was determined to live on no matter what form he had to be in order to survive, even though he would kill Susan and himself and all of his minions in the process.

I also learned that not only did she develop Richter's Transformation, but there were minute signs that the CLL had shown signs of returning. So getting into remission means that there is an inability of finding CLL cells in the bone marrow or the blood. But eventually they begin to return to the bone marrow, hence the need for the transplantation of new bone marrow.

We had to start a new regimen of chemotherapy right away to attack the lymphoma. If we could just get a result of knocking it back, not even getting into remission, Susan could still have the bone marrow transplant. They would kill it when they would kill all of bone marrow. But if they were unable to do that, the bone marrow transplant could not happen. If the transplant killed everything but the lymphoma, she wouldn't survive and it would be a very difficult death.

We were told that there was maybe a 10% chance of success. Knowing Susan's need for positive attitudes I said I would take those odds anytime. There were many times in my life when I was able to pull a success from nowhere at the last minute. I wanted her to know that I was with her, because I knew she would never throw in the towel. But I also had read about Richter's Transformation on my own by then. Even though there had been some success with treatment, the length of the success could be measured in months, not years. I never told her that. My heart was broken. Soon after that I began the grieving process.

Chapter 16

One Saturday evening in October we were home and there was a movie on television that we had missed when it was in the theaters. It took place in Paris and consisted of about eight vignettes done by different directors. Some were very entertaining and some were not. One segment began by showing a couple that were not getting along and the husband stormed out of the house and went directly into the arms of his blond buxom lover. While they were making plans to run away to a far off land together, the man's cell phone rang and his wife cried, "I've got CLL". The man immediately ran home to be with his wife. He later called his lover and told her he could never see her again because he needed to care for his wife. At that point I didn't know if I should change the station, as I knew Susan did not want to watch any movies that contained issues of cancer or death. I was at a loss. I looked over towards her and was unable to discern if she was in shock or was really watching. The vignette was soon over, but the important theme of that vignette was how much deeper the man's love for his wife grew as time goes on while he is caring for her. I can attest that the same thing happened to me. I don't believe that I have ever been able to love so deeply and to be as emotionally committed, as I felt with Susan during this time. I had no desire to do anything but be with her. I stopped going to my office and spent my time thinking of ways I could make things better for her. I especially had to be careful about what I said and how I behaved in order not to let her see any difference in me.

I tell of this now because I have heard of men running away from their wives and families when faced with dealing with a terminal illness. It brings out the worst in some men. In others, it demonstrates the best of who we can be. I miss my wife very much and I know that she is not ever coming back to me. I can never replace exactly what we had. But I also know that I did everything I could do to love her and to take care of her. For carrying those feelings of love, dedication and respect, I can live with myself without having any regrets of my behavior or feelings. It is important to remember that for those of us that survive, living alone with ourselves can be a very painful existence. We may be able to block it from our consciousness but not from our psyche.

Chapter 17

She had five straight days of the new regimen beginning September 9. A second round was to be given in October. She was beginning to feel better and wanted to go away for her birthday in early November. This time we went to Maui. We went to our favorite island and our favorite hotel. It was not crowded at all. She could no longer walk up the hill to come home from the beach, but the bellman came to the beach when we called and picked us. During the last round of chemotherapy Susan had lost her hair and kept her head covered with scarves. Anyone who sees a woman as thin as she was and dressed like that as well, knows what is going on. People were very considerate and understanding. It was a nice rest but before we departed for home Susan said to me, "Honey I know you know something. Have you been talking with the doctor?" I lied and told her no, but I had spoken with the doctor about my research. She had admitted to me that the situation looked pretty bleak. "Whatever you know, I don't want to know, but I can tell your attitude has changed. I need to be optimistic, strong and confident. Please don't take that away from me." I promised not to do that but also said that we both knew it was a difficult situation. I could not help but think how empty my life would be without her. She began to count our blessings and thanked me for the wonderful life we had together. I had fulfilled every one of her dreams much more than she ever could have imagined. And besides, if it was me who was sick and not her, she did not think she could ever survive without my presence, and if it had to be one of us, it was better this way for everyone. We didn't discuss it again until two nights before she died.

On our way to the airport she wanted to stop at a favorite Antique Jeweler in the Grand Waialua Hotel because she wanted to see if they had something she was looking for. Sure enough they had it and although she said it was lovely, she thought it was too costly. I was able to negotiate a very good deal and insisted on buying it. She was thrilled. How else could I show her that I believed she was going to be able to live and enjoy it for many years.

In November she began treatment with a different chemotherapy cocktail. The lymphoma that she had surgically removed before the first round of chemotherapy had returned. The doctors decided to leave it so as to see the effectiveness of the new protocol. The transplant team had felt

that Susan had a difficult case. She had contracted Hepatitis B before we even met and wanted to make sure that it would have no negative effect on the transplant. Additionally she had some blotches on the x-ray of her lungs and during a CAT scan it showed that they were not growing and were shrinking in some places, there were new ones popping up. They needed to know if it was pneumonia, a virus, lymphoma, etc., so they determined that as long as she was in the hospital she should have a sample removed from her lung and have a biopsy done. I think this was the most difficult procedure she had to deal with. A tube had been inserted in her lung for drainage after the surgery that had to remain for at least three days. Coughing was extremely painful as well as even changing positions. Her blood counts dropped to dangerous low levels and the healing process was dragged out because of the damage to her immune system. I had never seen her so weak and needy.

She became upset every time I wanted to leave the hospital, even though she had slept all day while I was there. Sitting in her room wearing a facemask, gloves and a paper gown was very uncomfortable. I tried to get home to have dinner with Joshua and when that failed I insisted on leaving so as time to see him before he went to sleep. I got up every day to see him at breakfast and off to school and then drove to be with Susan.

It was at this time that we made arrangements for my son Daniel and his wife Gaby to come stay at our house for the month that Susan would be having the transplant. This way I wouldn't have to come home every night and I could even sleep in her room or get a nearby hotel if I wanted. The only problem was we still didn't know when the transplant would be. It is very imposing to ask people to readjust their lives to your adjust to your moving target. It seemed most likely it would take place in late December so we made plans for them and Joshua to go to Hawaii over the Christmas break. They had a wonderful time. We stayed home watching the lymph node daily. Susan was so certain it was shrinking. I never said anything but I knew the newest protocol had failed. In the prior three months she had been given various chemotherapy drugs. In all she was given rituxan, etoposide, cytoxan, adriamycin, vincristine, steroids, ifosfamide and carboplatin, Susan was also still very weak from the lung surgery and had become transfusion dependant all over again.

Christmas and New Years were pretty bleak around our house. But the doctor had prescribed a good regimen for pain management. As the time went on she kept increasing the dosage. Susan was never in pain for more than fifteen minutes at any one time and that was only because she would forget to take something in advance. She now was relieved of the responsibility of having to take her eleven pills in the morning, two in early afternoon and three at night. The task was left to the rest of us. She never realized that we were monitoring her, we just asked her first so as to remind her what she needed. If she didn't remember, the last person to fulfill her order would check the appropriate boxes on a list that I printed up as a weekly schedule. One of the negatives of taking the pain medications was not only an increase in her loss of memory, but when speaking she would get her words mixed up. Once she had asked Joshua if he had heard from that school in Brazil yet. No one knew what she was talking about and then she would laugh.

One morning we were downstairs and while I was making her breakfast (as I needed to do every day to make sure that she was eating). She said to me, "Honey, aren't you having fun trying to figure out what I am trying to say?" I nearly fell on the floor laughing. This was my Susan. She would never lose her humor or stop from commenting on the human predicament. While we both were laughing we hugged and kissed. Then we got sad. And then she made a funny face and asked me for the salt.

By January it became obvious to me that there was not going to be a bone marrow transplant. Not only had the lymphoma not shrunk but grew so fast that it was determined that she needed to have radiation to shrink and dispose of the node. Before she even started radiation, a new one began to grow alongside the one that was about to get the radiation. The doctor focused on the major one. It was a six-week long regimen.

The lump grew to be about one-half the size of a small pear and had developed a scab that covered about 20% of her neck and was pretty awful to look at. I covered her neck every morning after her shower, with a layer of gauze that looked like a collar that was then removed for the radiation treatment and then replaced by the therapist, after the fifteen minute session was over. In addition to that she wore a scarf around her neck and a different one over her head. She also needed to wear her eye patch. We went for radiation therapy every other day for six weeks

as Susan was determined to complete the program in order to have her transplant. Then afterwards, or on the next day, we would go to the clinic for a blood test or a transfusion. In the afternoon she usually would take a two-hour nap in the casita where she would also try to receive visitors after awakening.

One morning Susan woke with a headache and couldn't focus her eyes. She had developed diplopia and had double vision. In addition, she was beginning to lose some control of her legs. An MRI revealed that she had a lymphoma growing in the skull at the base of the brain. It was putting pressure on the brain and had affected the sixth cranial nerve and so the radiology needed to be directed at her neck and the skull at the same time.

The pressure was soon relieved but the damage had been done. She was unable to focus her eyes and she could only see with one eye. It became necessary for her to wear an eye patch. By the end of January I believed she had only about two months to live. This began to consume my thinking, as I knew if it were true I had to begin making plans for a number of things that would become more and more important as time went on.

Without letting Susan know, I felt that I had to communicate the severity of the situation to our fifteen-year-old son, Joshua. If I told him the awful truth, he would not be able to disclose what he knew to Susan, as she was not ready to accept what was to come. If he had to keep it a secret the burden might be too much for him to bear. Two years earlier, Susan, with her great sensitivity, had suggested that we introduce Joshua to a therapist she had trained with. This had proven to be a wise decision. Not only did it give Joshua time to bond with another male, but he was also able to provide us with information that indicated that Joshua knew little, and didn't want to know more. This mechanism kept him safe during the long course of treatment. When I had turned sixty-six years old, the prior August, Joshua had said to me, "Congratulations dad, you are only twelve years away from the average life span of the American male." I thanked him for the information and was very happy to know how much longer I had to live. In response he told me not to worry and that I would be able to live much longer than that because I had access to such good health care. He also reminded me that mom also was doing well because of the care

she was getting. I think back to this because I envied his ability not to have to deal with all of this. I also silently thanked Susan for her ability to make everything seem so normal.

Joshua's therapist also arbitrated between Susan and myself when we had disagreements about how to deal with some of the many issues that arise with all teenage boys. He was a great resource and became a wonderful friend. I discussed my dilemma with him and he agreed that Joshua needed to be told the truth. But he didn't believe he needed to be told that day. We could wait. He suggested we both could tell him together or just Susan and I could do it. Susan and I agreed to tell him together, that although she was not giving up hope, things were becoming more difficult. I became very frustrated because I could tell he was not getting the message with all of the sugar coating. Finally, one day speaking in mid-February I could no longer let the issue just be ignored. One day, when Joshua and I were driving home, I pulled over to the curb and stopped the car. I asked him, "Josh, have you thought about what your life might be like without mom?" He responded that he had thought about it and that he thought he could handle it, and then asked me how much time she had. "At least six months, right?" I looked at him and tears were welling up in my eyes, and I responded, "much less". Then I explained to him why mom couldn't bring herself to tell him herself. I repeated how hard she was fighting to live and how important it was for her to believe that she was going to get better. We agreed we would not tell Susan about our discussion. I told him though, that he could discuss it with his therapist.

Susan also had a therapist that she had seen off and on for over thirty years. He was in his late eighties now and though she saw him less and less he was a part-time father figure and part-time mentor. I knew they both cared for each other and Susan would tell me how much he would laugh with her whenever they met. I wondered why she was paying him. After all, I think he enjoyed seeing her as much she enjoyed seeing him. Although I had answered the telephone when he would call we had never met or spoken. When Susan would tell me that Dr. G agreed with her position over one of our many disagreements, I told her that until I get to tell my side of the story to him it would have no bearing on my position. I was certain he didn't even like me, or even think I was good enough for Susan.

I called Dr. G to ask if he would see me without Susan knowing and he agreed. When I sat down in his office he told me that over the years he had come to know Joshua and I very well. He felt as if he was a member of our family. He told me that many times he had disagreed with Susan and had agreed with my position. He told me how much he respected me. He told me he knew from the very beginning, how much Susan and I loved each other and how good we were for each other. He then told me that down deep inside she really knew what was happening to her. She just didn't want me to know that she knew, in order to protect herself and I from dealing with the inevitable. He explained why it was important to continue the way we were handling the situation and yes, Joshua needed to be told the truth, but not yet.

He also related to me that he wanted to make plans to make house calls to see Susan as it was very important for her to be guided through this by someone other than myself. I never knew how Susan had managed to be so ill and still be so successful in protecting those of us around her, even though we had our own perceptions of what was going on. It gets really confusing, but after all, these were confusing times.

The doctor had explained to me that it was very important for Susan to always have hope. The doctors could not predict with all certainty the outcome of a case. But as time began to run out for Susan I wondered when would be the best time to have a discussion about it. Unbeknownst to me, Susan was having that very discussion with Shelley, and made her not tell me because she wanted to protect me from the pain of losing her.

Another issue that required special attention was based on a discussion we had a long time ago and never discussed again. Susan wanted to pass away at home in her own bed, free of pain or discomfort. This meant that as the end approached I would not take her to the hospital, where the agony could be drawn out. Dying at home with dignity, is not very easy to accomplish. Laws govern much of what we can do and cannot do. Hospitals and the medical community are determined to provide every patient the chance to live no matter what the quality of their life, whether short term in the hospital or short term at home. If one passes at home, the paramedics come in and try to revive the patient, whether they want it or not. Susan had witnessed their aggressive tactics when her mother, who was sent home from the hospital to die, passed away the

following morning of a stroke. The paramedics came in, laid her on the floor and did everything they could to revive her. Once they saw it was a lost cause, they left her there, on the floor, packed up their stuff and left. We could never figure out what the fire truck was for.

Susan never would allow anyone to tell her what she could or could not do. She did not want hospice care, paramedic revival attempts or hospital protocols to interfere with her final days. It was my job to see that the paramedics were held at bay, that she got the proper pain medication and to see that she was only with her family, while lying in her bed waiting for the inevitable. I was able to accomplish everything the way she wanted it. The doctor provided me with a special three page signed "Do Not Resuscitate" order. I had checked with my local fire department for their rules, as they are mandated to do their work unless a Medical Practitioner tells them differently. I verified the policies of my local Police Department. I learned how to give her the drugs she needed to fend off the great pain that would be coming near the end.

There were business matters that needed to be addressed. There was Estate planning issues that needed to be settled. There was a need to have our family close by. My children came in from out of town. Their main objective was to soften the pain for their younger brother and they were wonderful. My daughter-in-law demonstrated great strength, kindness and love as she helped Shelley and I with certain personal matters pertaining to Susan's well-being and privacy. I will always be grateful for the kindness and love of everyone during this time.

By the first week of March when Susan was nearing the completion of the radiology, she began complaining about her hip. She wanted to go to see her physical therapist. She was arguing with the radiologist when he told her that there was nothing a physical therapist could do for her because the pain was related to the lymphoma. She refused to acknowledge this prognosis and continued to complain to anyone that would listen to her. Finally, she understood, but said nothing.

Shelley had decided she wanted to move in with us and did so in that week as well. She was an angel of mercy. She even filled Susan's prescription for medical marijuana and got Susan to smoke enough to be relaxed, giggle and eat dinner. We had some fun dinners over the next two weeks, but the time was short-lived and went by too fast. Susan and I still slept together every

night and although I couldn't hold her close, we would fall asleep holding hands. She knew what was going on but didn't talk about it.

On the Monday before she passed away, I invited Shelley to go with us to the City Of Hope to meet with the doctor, as they had often spoken on the telephone together. As I wheeled Susan around to her appointment room Dr. W was inside waiting for us. She pulled up a stool and taking Susan's hands in her hands and looking into her eyes she said, "Tell me what you are feeling." I was standing behind Susan leaning against a counter when I heard her say, "I'm done doctor. I know you have done everything you could have done for me. I love you for all that you have done for me. But I know there is nothing there for me to hope for. Am I right?" Dr. W responded by saying how sorry she was, but there really wasn't anything left to be done. We all began to cry softly and for a few minutes all that I could hear was sobbing. Next door there was a restroom and there must have been a horse in there because the stream was so powerful and long we all started to look at each other and silently question how soon before this would stop. It didn't and then we started to smile and then laugh and it still continued, until finally we all stopped crying and laughing while we waited for the silence to return so that we continue our talk.

Susan had decided to stop taking her antibiotics, which meant that she would not have many days left, although it was never articulated in that manner. Her body was ravaged with several infections that left untreated would cause her organs to shut down one by one. The doctor did a wonderful job of easing any anxieties, telling Susan that she would not feel anything. She would just fall asleep and then just not wake up.

What went on afterwards was covered in an earlier chapter written by Shelley Whizin. She left her telling of the story off on that Wednesday after the "gathering" with the "sisters".

Chapter 18

THAT FATEFUL DAY

The night before Susan passed away, Jerry and I agreed on the schedule for the following day. We had no idea “it” was to be “the” day. Susan did not want Josh to find her already gone. We assured her that would not happen. Jerry was leaving at 7:30AM to take care of something he couldn't do during the week. I was to replace him in staying in the room with Susan, so she would not be left alone, just in case. I certainly learned a great deal about Jerry and the true meaning of generosity of spirit during this time. I gained a newfound respect for Jerry and loved the fact that he allowed himself to hear insights about himself and how he affects other people with his words, and how his male energy was sometimes a little too harsh for Susan's tolerance. He learned to be sensitive to her needs in a very different way.

In the morning, after Jerry had awakened, Susan was still sleeping. It was dark, so Susan wouldn't be disturbed. Only a slight beam of light came through the crack in the curtains. I entered the room and began my "watch", as we agreed.

Since my intention in being with Susan was to bring a sense of peace to her soul and help her transition with grace, dignity and respect, *with a little fun thrown in for good measure*, I thought, "Why does 'dying' have to be so morose? Why can't it be sweet and loving and kind and gentle with soft beautiful music...with a scent of sweet smells to remind the senses of such a beautiful life? After all, death is absolutely a part of life. *All of us are not getting out of here alive. We better make it damn good!*" And so it was on that beautiful Saturday... that fateful day that Susan's spirit was to leave her body.

For a while, I stretched out on the bed, gently stroking Susan's head *and the little hair she had growing out like a baby*. I turned on her iPod, as I had downloaded some of my favorite peaceful pieces of music, *(which she had used at various times to meditate)*. I picked "Heavenly", a CD produced by Victoria's Secrets. I know that sounds corny, but this music sounded like angels singing and was so soothing and healing, *(It was the same music I used for her video, which was shown at her funeral before the service. If you were there, you know what I mean)*. I also played

the musical version of “Graceful Passages”, which is a CD of songs from different traditions that address the passing of one’s life in a beautiful way.

I wanted to set the tone of a calming, healing feeling (*and knew that since hearing is the last sense to “go”, deep down she could hear whatever I played, even though she was not conscious*). And so, as the beautiful music played in the background, I sprayed the scent of "rain", an essential oil, into the air, filling the room with a gentle mist that smelled fresh and clean and sweet. *I even sprayed it on me throughout the day, so when I went near her, she could smell me too. I didn't really know if this sense was intact but I figured it smelled so good, how could it not be a good thing?*

We did not know that Susan's passing would actually be THAT day... however, there were signs we were told to look for, so I stayed in the room, thinking I would do some work behind the curtain, without disturbing her and watch her at the same time. I set up my computer and stayed in the bay window between the curtain and the window (*I felt like the wizard of Oz behind the curtain*), sitting in the sunshine, while Susan lay in the dark, cozy in her own bed. Susan's wish was to die at home and not in a hospital or strange place where she didn't know anyone. *Wouldn't you?* I would move the curtain aside every two minutes, just to check on her, but frankly I couldn't concentrate on anything that I "thought" I was "supposed" to be doing. *What was I thinking in thinking I would actually get any work accomplished? How silly of me!* I WANTED to just BE PRESENT without anything else to "do". *It's amazing how sometimes we think we have to "fill up the time" with something other than just BEING in the stillness of life.* So, the "wizard" (me) came out from behind the curtain, packed up my stuff and put it aside. There was to be no work for me that day!

As I stood beside the bed, looking at Susan's fragile little body breathing heavily, I noticed she was a bit uncomfortable moving her legs back and forth, grimacing. I sensed that she was in pain and was told that Susan's doctor needed to be called right away if she looked like she was in pain. I phoned Jerry immediately, and he called Susan's doctor and his best friend, Barry. Barry rushed over, as Jerry had to go to get the medication. Barry and the doctor agreed that until Jerry returned with the new medication that could be given through her PICC line that we should mash

up her pain pills that she couldn't swallow any longer, and feed them to her by putting the paste on my finger and putting it under Susan's tongue. This did seem to calm her. *Barry was another angel to be at Susan's bedside. We spent eight hours together, making Susan as comfortable as possible, as her doctor promised.*

Before Barry arrived, I noticed that Susan kept kicking the covers off of her, even in her unconscious stupor. "What was going on?" I wondered. When her legs kicked the covers way off of her legs, I noticed a huge pool of stool, urine and blood underneath her body that had leaked through the Depends she was wearing (*sorry for the graphic description, but I don't know how else to describe it. I hope you're not grossed out. I'm convinced that GRACE embraced this experience, as I was anything but grossed out. I just knew this was a huge sign that Susan's life was near its end*).

My friend, Susan, was lying in this pool of wet, (*not stinky though, as she had not eaten for days*). It was right after that moment I called Jerry. I had never experienced anything like this with anyone, so my imagination/television/movie experience/common sense said, "Once the organs begin to shut down and the body releases, the time is near."

I looked at her and said, "Okay Susan, today is a beautiful day, and if today is the day you are going to die, you're going to go in the light. (*I was alone with her*). You are not going to go in the dark." So, I opened up the drapes about half way and the glorious sunshine filled the room with light... just enough.

Barry arrived and took Susan's pulse right away. He also exuded a sense of calm. He reported she had a struggling heart rate and he could see she was in pain. Medication was on its way, but it would take some time. (*Her spirit's journey was close by, but I had no idea how much time, twenty minutes??? An hour??? Four hours? Eight?*). It was not easy to see her in the uncomfortable state she was in. Barry was busy on the phone communicating with Susan's doctor and Jerry. All the wheels were set in motion and there was nothing to do but wait.

THE MIDWIVES

I just couldn't leave Susan like that in a pool of wet. I had to change her. I had to do it before Jerry would arrive home to see her like that. Susan would be humiliated. I had to give her the dignity she deserved. It was then I asked Maritza and Carmen (*another part-time housekeeper*) to get a bucket with warm soapy water and lots of towels and clean sheets. I asked Barry to stand by, as I may need him to help me maneuver Susan's body.

Maritza and Carmen came into that room with one thing in mind: to help Susan regain her dignity. I had gone into her closet and picked a nice white buttoned-down shirt with a zebra print scarf to tie around her neck. We were ready. It was then I felt like a midwife...preparing for a birth with the bucket, soapy water and towels, (*but in this case, we were preparing for a death and the birth of her soul into a new experience*).

With great care and love, the three of us cleaned Susan, managing to do everything ourselves. As Maritza and Carmen stripped the bed, I washed Susan's body, (*yes, even her tushy*) with total regard and respect. *It was as if I was washing one of my grandchildren, with no other thought than to leave her sparkling clean.*

We had to roll her on one side (*and be VERY careful, as she had a PICC line in her right arm and the growths in her throat and body, and she was so very fragile*), then the other side in order to roll the sheets and mattress pad away from her, as we replaced the soiled sheets with the soft (*probably 800 thread count*) clean sheets. *Susan always had the best of the best!* We then dressed her and covered her... and she was ready... dignity, grace and all!

When Jerry returned with the proper pain medication we all became so relaxed and after he administered the first dose within a few moments I could tell Susan was not having any pain or discomfort.

THE SPIRIT'S ADVENTURE

After everyone left the room, I lay in bed beside Susan, and while the music was playing, guided her on a gentle and brief journey. “Just let your body sink into the bed,” I whispered softly in her ear. “Allow a soft, soothing, healing light to enter the top of your head as you breathe in, slowly, gently. Imagine this light entering each and every part of your body, as you breathe it in. That’s right. Gently, soothing light. This light enters your head, circulating in your brain, circulating around your face. All the muscles in your face just relax, letting go of any tension in the body. Now just let this soothing, healing light travel down through your neck, your throat, your shoulders, down into your arms and into your fingers...breathing in this soft, soothing, healing light, as it travels down into your shoulder blades, down your back into each vertebrae. Feel this soft, soothing, healing light circulating into your heart, your lungs, your stomach, your intestines...circulating in your hips, as your body feels heavier and heavier...your spirit is floating higher and higher, feeling this gentle soothing light down into your legs and now you are bathed in this light, inside and out.

“With every breath you take, this light expands all around you, gently holding you, as a baby is held in the womb... you feel safe and loved and comforted. You find yourself inside a big bubble of this gentle, soothing, healing light. This bubble begins to lift and takes your spirit higher and higher, gently floating up and up. You see beneath you a field of beautifully colored flowers. You can smell them... see them... appreciate them. You are whole, healthy and feeling wonderful.

“And now, you are floating over a beautiful crystal clear lake, where you see your reflection as this whole, beautiful and perfect being. You feel a sense of calm... and love... and joy. Just let yourself drift higher and higher until this bubble lifts as high as high can be. You are among the stars now, as you look down upon the earth and feel a sense of well being...drifting, floating, as you feel your spirit become part of the universe. And just let yourself be there, just for a little while, enjoying the freedom to fly.”

And the music played and there was a loud stillness in the air. After awhile, I brought her back into her body lying in her bed and repeated this journey another three to four times during the day. So you can imagine what it felt like for me in that room. It was magic!

I asked Josh, Daniel and Gaby, Jerry and Susan's son and daughter-in-law, if they wanted to come in the room to say goodbye... to have closure..."for today just might be the day," I said. They each came in and said their "goodbye's" even if Susan didn't answer back. She "knew" they were there. I know she knew.

Sandy, also came over that day, and said she could feel a sense of calm, and knew that something wonderful was taking place. *How often does anyone say that about someone when they are dying? I'm telling you, GRACE was holding the space with/for each and every one of us.*

SUSAN'S FINAL BREATH

Barry left around 7:00 PM. There was really nothing for him to do and besides he had to go to his mother-in-law's birthday party. Everyone was pooped, as it was a long day. We all went downstairs to say goodbye and stayed downstairs for about fifteen minutes or so. Jerry or I would go up to stay with Susan. It was after 11:00 P.M. while I laying next to Susan, stroking her hair I noticed her eyes were open (*not focusing on anything, her eyes were just flickering, so I knew she wasn't conscious*) and breathing very short, quick gasps. I knew this was it. I knew she would be "going" any minute now. I am sooooo glad I followed my instincts to stay in her room. I immediately sprayed "rain" into the air once again... guiding her into the light one last time... and within two minutes, she had let out her final breath. How lucky for me that I was there. I knew there wasn't time to go and get Jerry, so I savored the moment. As soon as her last breath was expressed, I called for Jerry to come up and told him that she was gone.

Josh was in his room. Daniel and Gaby were outside in the casita, sleeping, and Jerry and I just stood there looking at Susan, sending her on her way with love. I closed Susan's eyes and then Jerry lay down and held her. He kissed her on her cheeks and her lips and said, "Goodbye Popsie. Sleep well."

Jerry then wiped his eyes and went into Josh's room and told him that mom was gone. They held each other and Jerry came out and called the police and the paramedics. They came over within minutes. Routine questions were asked. Jerry had a "DNR" (Directive Not to Resuscitate) and gave it to the police. After all the appropriate paperwork, they deemed her time of death, 12:33 AM. Shortly thereafter, the mortuary arrived, wrapped Susan in a vinyl bag, zipped her up, carried her downstairs, put her on a gurney, strapped her in, and away she went, never to step foot in her home again. She died in her home, as she wished. Her next stop would be the mortuary.

The following day, Jerry and I went to there to meet with the funeral director, bringing Susan's favorite outfit that she wore for Josh's Bar Mitzvah...*even Lucy, her wig of choice.*

THE FUNERAL

Susan wanted to create a video of her talking to Josh about her life, so he would always have something to remember her by. I did shoot some footage of her, early on in the month and towards the end, however, when she saw herself, she didn't want anyone seeing her in that physical state, so we stopped filming.

Then, one night, I had a vision of producing a video of her life, using photographs and music to be played at the funeral. At first, it seemed a little "weird" and then we all got into it. Sunday was the day that Gaby worked on the photo collage of Susan, while I created the video montage of Susan's life. It was my second time using iMovie, and I was not extremely proficient at it, but knew "enough" to create something simple. I used the music I played for Susan during her exquisite transition, as I wanted everyone to feel what she had experienced. *I was going to bring the scent of "rain" and spray it in the chapel, but Jerry thought it was a bit too much. At first, he wasn't even sure he wanted a video, but when he saw the final product, he was so touched that he called the cemetery and made sure there would be a monitor able to show the video outside the chapel, so people would be able to view it before the service.*

Gaby and I worked well as a great team. Both of us worked into the wee hours of the morning. The following day, Howard, Jerry's number one son, came over and fixed whatever needed to be fixed on the video, and I have to admit, the video turned out beautifully! It made us all cry and touched us deeply. It was a beautiful way to honor Susan and bring her memory into the hearts of those that attended the funeral.

So, on that day of the service, Jerry, Maritza, Josh and I drove to the cemetery together. The casket was opened and there was Susan, laying there, not looking like herself at all. In fact, her skin was grayish and very very cold. There was definitely no life left in her body, but I knew that her spirit was free. I gently touched her hand and told her how much I loved her and thanked her for giving me the greatest experience of my life. I then inserted the "sister's" trinkets into the casket, and placed some photographs and letters in there, as well. Once Jerry saw Susan, he decided it would be better to tell Josh and other family members that it might be better for them not to see Susan that way. Some chose to look anyway, to say good-bye and others chose not to look, and then the casket was closed.

Before you even entered the chapel, the video was playing on a screen outside and you could hear the mesmerizing music and see the photo collage and enlarged portrait of Susan setting on easels. It definitely set the tone that something special was happening. This was not your ordinary funeral. This was Susan's funeral and everyone felt the "something" different.

Chapter 19

As you can tell by now I am not a writer and had never planned to write about this. There was something different about the circumstances and the issues surrounding Susan's death. There are many personal details I could write about that make this a more important read for some people but that is not its purpose. Our Rabbi, David Baron had asked Shelley to write about Susan's "Death Day". People had asked Shelley to describe what she did for Susan. The women wanted to know what could or should they be expected to do when they had to face a similar situation.

There are hundreds of special things that Susan and I had said to each other that meant a lot to each of us. I have shared some of them here, and many others I have not, as I believe it would be indulgent to do so. I have no regrets other than the pain of knowing Susan is not here with me and that she will never be here with me again.

I had asked my nephew Sean Tucker to videotape the service with a Flip video, but to do so without anyone noticing. Afterwards, I sent it to close family members who couldn't make it to the funeral. All were greatly appreciative for the chance to hear the laudatory remarks about their Aunt Susan, "Sutchki", and to see the beautiful service. Others who have asked to see the video were genuinely taken with the tenor the service.

Friends that had said they wanted a funeral just like Susan's would now know what went into making it seem so special. I do not believe that it could be duplicated, as it was never planned for from the beginning. It just kind of fell together. It is up to each of us to deal with the loss of a loved one in which we are the most comfortable. This was my way. It doesn't mean it has to be your way.