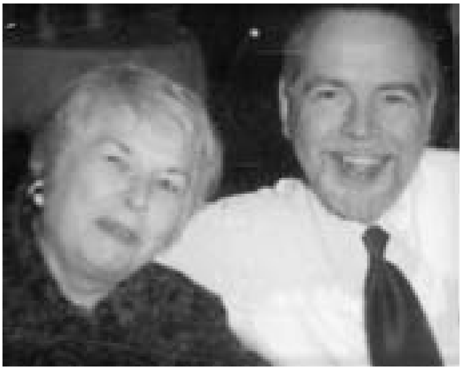
Mom's Story



The Last Thanksgiving

Celebrating Mom's beating CHF

. . . . little did we know she had
stomach cancer and would
die within just six months.

Mom's Story

The story of a courageous woman and her fight against Congestive Heart Failure & Cancer

by

Lee T. Sowers

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PREFACE

This is a story about the life and death of my Mother. While Mom was just shy of her 79th Birthday when she died, I still rate her death as tragic because of the circumstances and long path of medical malfeasance, misfeasance, and plain incompetence that contributed to her ordeal and death. Mom's Story was written to help others cope with terminal illnesses, especially cancer and congestive heart failure, and to help their loved ones be more effective caregivers and to urge their friends and family be more supportive. As we Baby Boomers age, our families will all face these same challenges.

Which is why Mom wanted me to share her story and why I wrote this book. She would have wanted others to benefit from her successes and sufferings, her trials and her triumphs. Mom always helped others and made sure they got something useful from her experiences. At the end of the book are Mom's Ten Commandments, followed by a more in depth exploration of some key areas touched on in this book. While I know that everyone reading this is not suffering from Mom's conditions of CHF and Cancer, this information will still prove useful to them and their loved ones. If other people have a richer and longer life, and if they can help their loved ones survive a serious illness in hospitals and nursing homes, then something good will have come from Mom's Story.

You will be able to tell from some of the events in Mom's Story, like the attacks on 9-11, that this book has been a number of years in the making. In truth, while I started writing this soon after Mom's Death, it was some years before I could bring myself to bear the pain of reliving many of the events depicted here. And while some medical procedures may have changed, and the public is becoming more aware of health issues, such as the dangers of eating too much salt, I believe that the most important messages in Mom's Story are timeless, so that even now she would want me to tell it.

Written for all of the Parents, Children, Senior Citizens and Baby Boomers in America.

Dedicated to My Mom.

IMPORTANT CONTENT DISCLAIMER!

Any similarities to real persons, living or dead, or businesses, corporations or other entities are unintended and merely coincidental. I have left out my mother's family name, and in fact have left out the names of myriad doctors, nurses, hospitals and nursing homes, because we live in a litigious society.

While people may attempt to guess some of the locations and places where the events in Mom's story occurred, I discourage any attempt to do so and have simply called them by initials or words like ReHab bearing no relation to their true names. Place names have been changed to protect the innocent and the guilty and the un-involved alike. There are many such facilities and readers should not try to infer that Mom's story or my comments apply to any one in particular. indeed some anecdotes, while completely true, encompass events that happened at several different times and places.

I am not a doctor and Mom's Story is just that, a Story. It is presented as a story and it's intent is not to give any medical information, advice or identify treatment for any condition. Comments from doctors were specific to my Mom's condition and must not be taken as medical advice. My comments on the care in medical facilities is based on personal experience and should not to be construed as applying to the medical industry in general. IF YOU HAVE MEDICAL ISSUES CONSULT YOUR OWN FAMILY DOCTOR.

Readers should always contact and question their own physicians before taking any medications, making any dietary changes or undergoing any course of treatment for any disease or condition. Indeed the whole purpose of Mom's Story is to get people to question and understand their conditions and treatment options. So do not read Mom's Story as anything other than A STORY that urges you to ASK your own questions!

THE AUTHOR DOES NOT INTEND ANY OF THE CONTENT OF THIS BOOK TO BE TAKEN AS MEDICAL ADVICE OR MEDICAL INFORMATION. CONSULT YOUR OWN PHYSICIANS!

CHAPTER 1

Mom's Early Years

MY MOTHER, MARGARET Mary, was born in the mid-summer heat during the heydays of the Roaring Twenties. Mom, as I always called her, or Peggy as all of her close friends called her, grew up during the Great Depression in a very strict and conservative Roman Catholic family. Mom was the middle sibling of five children, with a sister, Helen, and three brothers, Paul, Bobby and Billy. She had a stern mother, Anne Francis, and a hard working and equally stern Welsh father, George Bertram. George had served on General Blackjack Pershing's staff during the Punitive Expedition in Mexico against Pancho Villa in 1916 and again in Europe during The Great War where he was strafed and wounded by German planes during the battle of the Argonne Forrest. After the war he opened an artificial limb business with a family member who had lost a leg during The Great War. Their business prospered well during the early 20's, but as with many small family businesses back then, it fell on hard times during The Great Depression.

Mom's family lived in urban northern New Jersey during The Great Depression. Many people lost their jobs and many businesses closed, my Grandfather George's included. Jobs were scarce and people took any work they could find to feed their families. In Mom's family there was usually food, but never really enough, and Grandpa George and Grandma Anne spent many hungry nights so their kids could eat. Dinner was whatever you could find, and consisted of starchy foods like potatoes which could be stretched a long way. Meat was a treat and fish was scarce. George took whatever work he could find and Anne cooked, cleaned and did odd jobs to make ends meet. Mom would tell me stories about stuffing newspapers in her shoes to patch the holes in the soles and of patching and re-patching handmade clothes handed down from brother to sister to brother again. There was no such thing as a store bought suit or dress in those days.

Mom told me many stories about her youth and growing up poor during The Depression. School was hard, the school days were long and the teachers very strict. Everyone walked to school in the city. Today's luxury of a bus to ride while listening to your iTunes was unheard of. After school the kids all helped with chores at home and worked at any odd jobs that could be found. Toys were crude and scarce by today's standards, and your imagination was your biggest entertainment. There was no TV and few people could afford to go to the movies or theaters even at 5 cents a show.

Radio was just coming into general availability and if you had one it was the family's most treasured possession and everyone would gather around to listen to the news. Families were a much more closely knit group then than they are today and parents demanded and got great respect from their children. In those days only a lucky few went to college, and in most middle class families like Mom's, the men looked forward to a life working in the factories. If they were lucky and could find work. The women looked forward to marrying young and working hard at home to raise a large family.

When Roosevelt took office in the early 1930's the whole family would sit around and listen to his "Fireside Chats". If they were lucky enough to have a radio. I remember how much Mom loved FDR. Most middle class American's and even many Europeans I have known that were of Mom's generation all loved FDR. Today, revisionist historians and pundits can say what they want, but FDR was one of the most beloved American Presidents of modern times. Whole families broke down and cried when he died.

Mom also really liked Presidents Nixon and Reagan. She favored their strong no nonsense kind of leadership as opposed to the "make everyone feel good" politicians. It also surprised me how Mom and her generation liked Nixon even after Watergate and his resignation. Mom was part of what we today call The Greatest Generation, people who grew up during The Great Depression and World War II. They had a strong set of values and ethics forged in the furnace of hard times and a worldwide war. Values and ethics which are not often found today among the succeeding "me" generations.

Mom graduated High School when she was only 16, she was really smart and had been advanced several grades ahead of her classmates. They don't do that today for fear of "insulting" the average students. Having graduated very young, she was forced to turn down a college scholarship in order to take a job to help provide for her brothers and sisters. World War II had just started, making jobs more plentiful, and Mom landed a job censoring war films, the famous newsreel films we see today which show brief bits of action. Mom took the raw, uncensored film and helped to make those "edited" clips. She would eliminate all of the photos where a person who had been badly wounded or killed could be identified, no sense in having parents see their son killed on screen.

The newsreel war films were gruesome and gory in the extreme, and Mom had a nervous breakdown after a year of seeing men maimed and killed on film. Even in Black & White, it was a lot to take in when you were just 16. The laws regarding "child labor" were not nearly as strict during the war years in the 1940's as they are today. Adding to that pain, Mom's high school sweetheart was drafted and killed. A conscientious objector, he became an Army Medic. But that didn't stop a German sniper from killing him. Ever after, my Mom had a strong dislike of anything to do with the military or war.

When Mom reached 18, she got a new job working in a defense plant where she met my father, who shortly thereafter enlisted in the Army Air Corps to become a pilot. Even though she disliked the military, Mom deeply loved my future father and she followed him from base to base throughout his pilot training. He washed out as a pilot late in the war when the need for foot soldiers outweighed the need for pilots. Mom and dad were married in beautiful San Antonio, Texas as the war finally, at last, drew to a close.

As with most kids who grew up during The Depression and WWII, harsh experiences as children and young adults left lingering memories that colored their actions for the rest of their lives. Mom also developed character traits during the hardships of her youth which shaped her personality. She was extremely frugal. Even later in life when times were better, she always sought bargains and true value and never indulged herself in expensive clothes, jewelry or possessions. She only ever had one or two purses or pairs of shoes and a couple of good dresses and work suits. Her most prized possessions were family keepsakes and jewelry given to her by her mother. Priceless possessions.

Even while working very hard and being successful in life, Mom never accumulated much money or great wealth. She gave it away as she earned it, always preferring a simple lifestyle. First and foremost she gave it to me. Only now do I realize how much of Mom's money, time and love were lavished on me. In a whole lifetime I could never repay it all. Second, she gave it to our close friends and close relatives, especially my grandfather, and also to many others in need. We almost always had someone living with us who would trade housework and repairs for room and board, a direct leftover from the Great Depression days. Mom helped people of all backgrounds, and at one time or another we had an American Indian, Black Minister, and disabled Marine staying with us. We also had relatives who lived with us, most notably my Grandfather, George.

During the Great Depression everyone learned how to cook. You cooked to survive, unlike today where many women can't cook, even from a box with instructions, and their kids live of off burgers and fast food. Mom was a wonderful cook, and could make a hearty and healthy meal from almost anything the store had on sale that day. We always ate healthy, often fish, long before it was fashionable. She used salt sparingly, preferring garlic, herbs and spices for flavor instead of salt. Mom also limited fatty foods, she called them greasy foods, and had one glass of wine or a mixed drink each day. When she developed a heart condition later in her life due to a childhood illness, surgeons were amazed at her otherwise good condition and said that while she was in her late seventies, she had arteries and circulation as good as a healthy 40 year old.

Mom's entire family had incredible, albeit offbeat, senses of humor. On Halloween, Mom would go out on mischief night with me and put thawed (i.e. gooey and disgusting) chicken necks in people's mail boxes. She got that from my Grandpa who in the good days had owned racing horses with his one legged brother. They would stage "accidents" for the new jockeys where his brother would detach his wooden leg, throw it over his shoulder and lay screaming on the track. Nice initiation. Paul, my uncle, would pull up his shirt and have conversations with his belly button, "Mr. Cyclops".

Grandpa had worked in the theater during The Depression as a sound effects man. In those days there were no electronic sound effects, they came out of the mouth of the sound effects man. Grandpa could carry on a complete conversation talking like Donald Duck. I think there is a correlation between talent, intelligence and a sense of humor. During WWII Grandpa became a Master Tool & Die Maker, and he was also a ranked Chess Champion. My uncles all became engineers. My Mom was really smart too.

Sadly for me, especially in recent years, Mom hated having her photo taken. When she had been very young she had a bad infection in her nose and sinuses and they had to do surgery to cure it. During The Depression some surgeries were often done right in the doctor's office with a minimum of anesthetic and little attention to cosmetic outcomes. As a result of this painful procedure during her childhood, later in life Mom was always reluctant to visit the doctor or have an operation. She also had permanent scarring from this operation. The scars above her lip and by her nose were not large, or very noticeable from any distance, but they looked just like Mom had smeared her lipstick.

Mom's scars could be covered to some extent with makeup, and unless you were very close, they were very hard to notice. But Mom had been the brunt of so many "smeared lipstick" taunts and comments by both kids and adults while growing up, that she became very self conscious of those scars. Which is why she always hated having her picture taken. Those very few pictures that I do have are among my most treasured possessions. When I look at the few priceless pictures of Mom that I have, I can see the changes over the years. But to me, Mom was always Mom, and my mental vision of her is timeless and is a synthesis of my fondest memories over the last 50 years.

In addition to being really smart, Mom was very pretty. Movie star pretty. And very strong willed. There is a difference between strong willed and stubborn. Mom was strong willed, but not stubborn. She could be persuaded by solid logic and could change her mind and opinion when the facts dictated it. But BS just didn't work on Mom. Today we would say that Mom "did not suffer fools gladly". She respected intelligence and strength and hated what she called "namby pamby" men without a backbone. Later on in life Mom could hold her own with any group of men in any business situation. And in the days before Women's Lib, she was simply awesome and even awe inspiring.

Mom truly believed the man should wear the pants in the house, both literally and figuratively. In fact I rarely saw Mom in pants, slacks or shorts, or even jeans in the summer or on an infrequent vacation. Most often she wore a professional business suit, skirt, blouse and jacket, whether teaching, building houses, or working in real estate. Mom was one of the most professionally dressed women I have ever seen. Not that she spent much money on her clothes, we didn't have that much to spend. But she would spend time picking out inexpensive jewelry, scarves and other accessories to perfectly match her several good suits. As people would often say, my Mom looked like a million dollars. She looked like she could have been the First Lady, extremely professional.

Mom and I often watched movies together, not in theaters where it cost money, but on TV. B&W in the early years of TV, and later in color, especially after Cable TV exploded and opened vast movie archives for everyday viewing. I have always related people I knew to movie actors and actresses. To me, the actress that most typifies Mom was Katherine Hepburn. In *The African Queen* with Humphrey Bogart and *Desk Set* with Spencer Tracy, Hepburn's strong personality, wit, brains, and most of all, her inner strength of character to do what was right, remind me of Mom come to life on screen.

Interestingly, those were two of Mom's favorite movies and Katie (as Mom called her) was one of her favorite actresses. Even more interesting are the parallels in their lives. Mom never remarried after my dad died, neither did Katie Hepburn after her first marriage. Katie did have some lifelong friends, like Spencer Tracy, as my Mom did with her close friend Pat, of which more later. And if you had to pick two actors who wore pants and were not namby pamby, "Bogey" and Spencer are on the top of that list. Mom's favorite modern day actor was Harrison Ford. A very special trio of favorites.

Mom had great Faith, which is not to say that we religiously went to Church every Sunday. She was often working and I was often sick. Mom believed that God was with you and that you did not need to be in Church to pray. Mom would often quote the Biblical line; "where ever two or more are gathered in my name . . . . ". Mom prayed several times each day. She also prayed the St. Jude Novenas and he was her patron Saint. Mom had issues with people who went to Mass for an hour on Sunday and then, having done their Christian duty, broke every rule in The Good Book during the week.

Mom lived a Christian Life, always helping others even when we had little. Treating others with kindness and dignity. Looking to God and Saint Jude for guidance and support, and then following their will and guidance. In fact, Grandpa was even more religious, going to Mass daily and praying the Liturgy of the Hours, the same prayers that Priests say throughout the day. I also have several relatives that are ordained clergy. Religion, or perhaps more accurately Faith, was an important part of our life. Today I am an active Catholic Extraordinary Minister taking Communion to the sick.

Mom called her favorite story of faith "Footprints in The Sand" and she used to tell it to me when I was young and when we faced difficulties throughout our lives. It was not Mom's creation and has been variously attributed to several authors, including; Mary Stevenson, 1936; Carolyn Carty, 1963, and Margaret Fishback Powers, 1964. Perhaps the original author will never be known. Below is the story as Mom used to tell it to me.

One night as I was reflecting back on my life I saw my journey as a pathway along the sand at the edge of the ocean reflecting the moonlight. In the sand, stretching as far back as I could see were footprints. Footprints in the sand. For most of the way there were two sets of footprints walking side by side, however at some points there was only one set. I knew that The Lord had walked by my side for most of my life, but was troubled to see that at the worst times in my life when I had almost given up in despair, there was only one set of footprints. So I asked The Lord, "Why when I needed you the most did you desert me?" And The Lord replied, "My dear child, at the darkest points in your life when you see only one set of Footprints, that was when I carried you." Amen.

CHAPTER 2

Family Life with Mom & Dad

DAD LANDED A good job in defense electronics after the war, a field which was just taking off in the 50's. He actually designed electronic components that went into the first guided missiles. It was a job that paid well, so Mom could be a "stay at home" Mom and take care of the house and cook and clean, just like a good 1950's wife. On the other hand dad was always in his electronics lab in the basement when he was home, working on the newest electronic toys or his huge collection of "HAM" radio gear. From what I have heard, Mom and dad had a typical 50's family before I arrived on the scene.

I was born several years after WWII at the tail end of the 1st Cohort of Baby Boomers. I was rough on poor Mom from the start. Born two months premature, a boy when I was supposed to be a girl, I caused enough internal damage on the way out that Mom could never have more children. And I was a sick kid. How Mom found the deep reserves of love and patience to put up with me and raise me as well as she did I will never know. I had scarlet fever, multiple cases of strep throat, the kind of measles you can only get once five times, and so many cases of tonsillitis that the doctors couldn't find a time when I wasn't sick to take them out. So sick I could hardly ever eat, I was very skinny.

Mom worked hard at home and any time not spent on cleaning and cooking (Mom was a fantastic cook) was spent teaching me to read and write. I had a good two years of reading and writing before ever starting 1st grade. All through school I did much better in "reading and writing" than in math, and I think the head start Mom gave me was the main reason. But what really fascinated me was my father's lab in the basement, and with his help I spent months building a radio, which was my pride and joy, only to find out I had just been attaching meaningless parts to an old circuit board. I was crushed. I wanted it to work! Mom and dad had a furious argument over that, but he insisted I was too young to learn anything. As a result, even to this day I am turned off by electronics.

Because my dad blew me off, I turned to two other key "father figures" in my life, my Grandfather George, Mom's dad, and my Godfather Foo. Actually his name was Foose, but when I was young it always came out of my mouth as "Foo". Foo was a close friend of the family, which is why he was chosen as my Godfather. Grandpa was a ranked Chess Champion, and Foo was a graduate of the Naval Academy. I spent some time in the Navy, and to this day play chess and strategy games, and love reading and writing. Obvious traits from my influences as a kid. I have often wondered what path my life might have taken if my dad paid any attention to me and my interest in electronics.

Mom said dad had been nice before he got sick. It turns out his 3 pack a day cigarette habit caused lung cancer which spread to his head and made him crazy. More of that sad and scary story in a minute, but my memories of dad even before he got sick were not fond ones. He constantly ignored me to work in his electronics lab in the basement, but he wouldn't teach me anything about electronics because I was just a "dumb kid". Meanwhile by the time I was four years old Mom had taught me to read and write. I guess the smart kids can read and write at two. Dad also didn't like Mom's cooking, and constantly complained about it. He preferred meals that were simple and always the same, dull and boring. Pork roll sandwiches for breakfast, meat and potatoes for dinner, cereal before bedtime. Poor dad missed out on some really good food. So did I.

CHAPTER 3

Mom's Wonderful Cooking

BECAUSE I WAS often sick, and my medications irritated my stomach, my childhood food choices were usually limited to rice, mashed and baked potatoes. A burger or hot dog would make me gag. I could eat Fried Rice and that is probably where my fixation on Chinese food started, to this day I eat Chinese food four or five times a week. My stomach meant I missed out on much of Mom's great cooking when I was young. But when I was healthy enough to eat, and as I grew older and got healthier, I always loved Mom's cooking. Rarely today can I find food that good even in the best restaurants!

We also had frequent house and dinner guests of every kind, my grandfather, Foo and the Presbyterian Minister who lived next door were all "frequent diners". Not only did Mom make many close friends, but since she was such an outstanding cook many of them would arrive with food in hand hoping Mom would whip up one of her wonderful dinners. Mom would cook, Foo would make mixed drinks and sing. Foo couldn't sing worth a darn but mixed great Martinis and Manhattans. Grandpa would sit at one end of our massive dining room table and argue Theology with the Presbyterian Minister, who would remind my friends that it was "caning time". And only I knew he was joking!

My grandfather, my godfather, and our relatives who visited always loved Mom's meals. Pork chops and sauerkraut, Chicken a la King fit for a king, beef stroganoff over noodles, kielbasa and new potatoes, London broil and garlic mashed potatoes before they were a fad. Plus all of the side dishes and trimmings. Homemade baked beans, asparagus in cream sauce, cauliflower au gratin, potato salad, cucumber salad with vinaigrette dressing (one of Mom's favorites), spinach with bacon, and the list goes on.

We also always ate plenty of seafood, from tuna, to frozen fish sticks and often fresh fish like flounder, shrimp, and salmon. Salmon was always one of Mom's favorites. Mom was also great at breakfast, waffles, pancakes, and especially eggs in all styles, and omelets. My favorite was "Popeye" eggs, named after the cartoon character popular during The Depression. Mom's version was to take a piece of white bread, pinch a hole in the middle, like a donut hole, lightly toast it in a frying pan, and then break an egg onto the toast so that the yolk filled the hole and then cook it over easy. The best of fried eggs and an egg sandwich all rolled into one. Mom's one weakness was hot dogs.

While Mom loved good juicy burgers, California Burgers with lettuce, tomato and onions, she adored hot dogs with mustard, relish and sauerkraut on a toasted bun.

Hot dogs and burgers aside, Mom also knew how to cook healthy even before it was "In" like it is today. Mom would go easy on the portions, use the freshest ingredients possible, limit fatty meats and hold the salt. We ate much more chicken and pork than fatty beef. Mom also never believed in heavily salting food while cooking, preferring to use other herbs and spices to add flavor, fresh garlic being one of her favorites. When she could, Mom spent hours lovingly cooking gourmet quality meals, but when pushed for time she would still fill the table with good wholesome and healthy comfort foods.

In later years Mom loved the cooking shows, Jacques and Julia, Iron Chef, the original Japanese version, and the Two Fat Ladies were her favorites. Mom and I both had a taste for Asian food, especially Indian, Chinese and Japanese. Mom could make great curried chicken, better than I can find in some of the best Indian Restaurants. One of Mom's last business ventures was introducing Sushi into local bars and restaurants as that craze took hold in the Northeast during the late 90's. But that was decades away.

CHAPTER 4

Family Life without Dad

HAVING DIGRESSED A bit on Mom's wonderful cooking, let me return now to the situation that caused Mom to leave dad and live on her own as a single parent in the days before it was stylish. Unbeknownst to Mom and I, dad had developed cancer as a result of his three pack a day Lucky Strike cigarette habit. Years before the doctors found it in his lungs while doing an emergency appendectomy, the cancer had already metastasized and spread into other organs and his brain. That's why one day he took a shotgun and ran around outside the House for an hour threatening to kill Mom and I. To this day I am not sure if the cancer explains the other things, like his sullen moods, that I didn't like.

Fortunately, nobody died on the "day of the gun", but the situation between my Mom and dad deteriorated from there until they were barely on speaking terms. In those days, society took a much different view of domestic violence. It was always the wife's fault, in this case my mother, who didn't know how to get along with her husband. That was the same attitude adopted by the Church and most of our relatives. Kiss and make up, if he was trying to kill you then it must have be your fault, so go be a better wife!

I still think the root problem was me. Dad desperately wanted a large family, preferably of boys, as was in vogue at the time. As a son I was a disappointment to dad. Weak, sickly, more prone to want to learn how to read and write than play sports and pick fights with other kids, in short a nerd. And because of the damage I caused Mom on the way out during a difficult birth, she couldn't have any more "replacements". I had single handedly spoiled my dad's dreams of having a large and robust family. So sorry dad.

Wisely, Mom decided to leave dad while we were still alive. She found the courage to leave our home and take me to another state. We moved from Pennsylvania to New Jersey, far enough away where we hoped dad could not hurt us. With the help of her parents, she managed to scrape together the money to buy a small house in one of those "instant" suburban developments so popular in the late 50's. In those days a house could be had for the price of a high end car. Mom's father, Grandpa, was retiring and her parents bought also bought a new house and moved in just down the street from us. We spent New Year's Day 1960 in our new house. Tragically, Mom's mother died from breast cancer shortly afterward, and Grandpa moved in with us. Tragedy always seemed to follow close on the heels of any good fortune for Mom and me.

It was really tough going. Surviving on your own as a single parent was much harder in those days when getting credit to buy a house, a car, or anything else was nearly impossible. Life as a single mom is difficult enough today, but in 1960 it was nearly unheard of. Thank God for the Catholic Church. The Pastor, a wonderful man, Monsignor Donovan, gave Mom a job as a Kindergarten teacher. As Pastor of a parish school he could bend the rules on college degrees and certifications, and Mom became a star with the nuns, students and parents. She had over 70 students in her class (in the days before Teacher's Unions, classes were much larger) and it would take us hours to open up all of Mom's Christmas presents. Teaching allowed us to survive. Barely. We were not starving but we were never rich and always had to skimp on everything. Mom's childhood during The Great Depression had prepared her well for these tough times.

Through heroic efforts, Mom managed to make ends meet, which meant she did without things for herself many times. The full extent of her sacrifices to keep me clothed and fed would only become known to me in later years. I remember everything was always scarce, food, clothes, entertainment. I got new clothes for school and for Christmas or Easter. I marvel at how today's kids get not just one new outfit, but a full new wardrobe every season when the fashions change. I didn't help matters in the clothes department because I grew so fast and tall that I was always growing out of my good new clothes. A real treat was once a week when we would have cold cuts to make deli sandwiches for dinner, and perhaps some soda and some chips. To this day it is an incredible treat for me to go to the deli and splurge on lunch meats to make sandwiches.

As for food, my stomach still limited the choices. According to doctors I had an “upset” stomach from the constant worry about what my dad would show up and do next. Like the day he came and beat up a family friend with a shovel in our backyard. In a way that incident was fortunate, because it involved an “outsider”, which was illegal and got you arrested even then. Had he just beaten up my Mom with the shovel it would have been no biggie in those days. I remember Mom’s discussions with the police, who consistently and patiently explained that they couldn’t do anything until dad actually did something to hurt Mom or I, like kill her, or kidnap me. The law protects you only after you are dead. Police turned a blind eye to domestic violence in the 1960’s.

CHAPTER 5

Mom's Success

ALWAYS A HARD worker, Mom strove for more than simple survival working as a teacher. She studied and passed the real estate exam, becoming one of the first licensed female Realtors® in New Jersey. Mom sold real estate part time on weekends and full time during summer vacations. After a few years she became a Broker, one of the first female Brokers, and gave up teaching to do real estate full time. By the time I had reached junior high, Mom had a thriving real estate business and even became a home builder. She was a general contractor, farming work out to carpenters, plumbers, and masons, while she managed the project with her company Mar-Homes (from Margaret).

By the time I was in high school Mom was doing very well and had even purchased investment properties that gave us rental income. While not rich, at least we were no longer living on the edge. Perhaps remembering the lean years, we still lived frugally and all of the extra money beyond what we needed was used by Mom to help other less fortunate people, especially immigrants who fled eastern Europe after WWII. We had many Estonian, Latvian, Lithuanian and Polish friends while I was in junior high and high school and I became immersed in their culture, lifestyle and value system. They were a hearty, hard working, sports loving group of people who had great fondness for family, especially their elders and parents who they deeply respected and cared for.

Many were in the building and construction trades and Mom helped them get settled into new lives, find good work, and speak, read and write English. In return we were adopted into their close knit families and spent many fun filled weekends at their events, outings and parties. With my foreign friends, I played soccer, not football, in high school. By high school I had finally outgrown my propensity for childhood illness and could, and did, eat almost anything. I loved the wonderful German, Polish and Eastern European foods. I can remember my Mom helping make the famous Blut Wurst (blood sausage) for the Holidays. At times we felt like we were a European family.

While I was in high school Mom developed a close relationship with a very nice gentleman, Tom, a mortgage banker she met in the construction business. His wife had died of cancer just like my dad. While they grew close, Mom never remarried, I believe because of the scars from the episodes with my her high school sweetheart and dad. Interestingly, both my dad and her new friend, were named Tom, but whereas my dad had been German, this Tom was pure Irish, a star college athlete and a civilian pilot.

Among Tom's Irish football teammates was a gentleman named Cahill, who became New Jersey Governor, and who appointed Tom State Director of Aviation. Mom and Tom and I spent many wonderful weekends flying around visiting airports, air shows and events. I had my Student Pilot's License before I could drive. Tom and Mom got invited to all of the events at the Governor's Mansion. With her success in real estate, and me heading off to college, Mom finally had time for a personal life. Throughout the early seventies Mom and Tom spent much time together and traveled far and wide, both by plane and on cruises. She would call me from the Caribbean, Florida, Las Vegas and California. As she turned 50, I was happy to see Mom finally be able to enjoy life and have a relationship. I look back now and think these must have been Mom's best years.

But as I approached graduation from college in the mid-seventies things took a turn for the worse for Mom. Tom broke up with Mom and although it was never clear why, she always suspected it was for a much younger woman. First my dad and then the new Tom. Mom never again gave her heart to another man. I was sad, I liked the new Tom and had hoped we could all be a family one day. But that was never meant to happen.

The country was in a mess too. After the Vietnam War ended we had the usual post war recession and this one was long and deep. We were also mired in the Oil Crisis with gas lines and skyrocketing prices, crushing interest rates (home mortgage rates in the teens were common) and runaway inflation. All of this killed the real estate business and dried up the job market. I was lucky to get a scholarship to grad school. Mom decided to move to Texas while I was going to grad school there because Texas was the King of Oil in the US, and thus was the one place where the economy was booming. Especially in real estate as people migrated there in droves from the Rust Belt in the Northeast and Midwest. Real estate values in the Northeast tanked and Mom was lucky to sell off her properties for the mortgage balances. She would have to start over again.

After completing grad school and working for a few years, the economy began to slowly improve and Mom and I began to miss our friends and relatives in New Jersey. We also missed the more seasonal weather and our favorite foods. Houston in those days was all about Tex Mex and Chinese food with a ton of both Mexican and Asian immigrants, both legal and illegal. We longed for a good old fashioned (Jersey Style) sub sandwich, pizza, Italian food, or even a good seafood dinner. In Texas they cook their subs and call them Poor Boys. And if you wanted pizza it was Pizza Hut or nothing. So in the early 80's we moved back to New Jersey where I was lucky enough with my graduate degree to land a job teaching college as an Instructor at Rider University (then Rider College).

The move was not uneventful, Mom was injured. Most of our belongings were stolen in Texas while we were on an extended vacation house hunting in New Jersey. Mom's back injury was serious, a heavy sliding glass door came off of its tracks and fell on her in a house we were renting and it re-injured the same area that had been injured in a serious car accident when I was a kid. In that accident, Dad had been driving when we were rammed by a car driven by a drunken sailor. The car landed on top of our car and bounced off, killing two sailors returning from leave. We were luckier, we were alive.

My dad had an injured wrist, and I had several teeth knocked out when my jaw hit a door handle, but Mom got the worst of it. She had seen the car coming, flying toward us after hitting a guardrail, and bent over to protect me. As she bent over to protect me, her legs got wedged under the back seat from the impact, severely twisting her lower back and knees, spraining and straining most of the ligaments and muscles in the process. Her injuries were serious. It had taken Mom weeks of bed rest to recover.

When the heavy sliding glass patio door fell on Mom, it re-injured the same area the accident had, except Mom was now in her 50's. This time she was again bed ridden for weeks and had limited mobility for months. She saw both doctors and chiropractors on a regular basis. The chiropractors were better. All the doctors could offer short of surgery were pills and platitudes. The chiropractors relieved her pain and restored some mobility. After the second injury to her back from the sliding glass door, Mom was never the same physically, and her knees in particular always gave her lots of trouble.

CHAPTER 6

Mom's Golden Years

MOM'S LIMITED MOBILITY meant that she could not get back into real estate right away, so she looked for other work. Mom had always been keen on helping people, whether the immigrants looking to settle in to a new life in America, our friends, or even just people she ran into in everyday life. While Mom realized the value of a dollar, she also realized that your riches can't be counted just in dollars. Anything extra she had she used to help others, without pretense, or fanfare, and often even without thanks. Mom lived the life of a good and helpful Christian. She was truly caring and unselfish. If everyone lived that way, even if only all of the people packing churches on Sundays lived such a Christian life during the week, then our world would be a better place.

Since Mom was injured and could not work, but I had just gotten my teaching job, Mom and I decided to share a place when we first moved back to New Jersey. Mom was the real estate pro and instead of continuing to rent she found us a bargain "fixer upper" where the owner was willing to hold a mortgage for us which was fortunate. Having recently moved and changed jobs neither of us qualified for a mortgage under the strict rules in those days, having someone "hold" a mortgage was the only route open to us. I didn't mind living with Mom, or having Mom live with me. I guess who was living with whom depended on your perspective. Among my close European friends during my teens, it was very common to have several generations sharing the same household.

I do not use the term "fixer upper" lightly. It was a quaint old Victorian House in need of much repair. The Garage Apartment out back had no stairs. When I climbed a ladder up to see what was up there, I found a 19th Century lace up "Granny Boot", a dented World War I army helmet, and a book of 1917 army songs in the middle of the floor. It was now 1981 and the stairs had obviously been gone for quite some time!

The house was not much better, it had only one bathroom with no fixtures and no working plumbing. The dire condition of the house fit our dire financial condition. Mom had not worked for month's since she was injured, and while I had my Instructors pay from Rider, college pay was notoriously poor so most of the faculty had consulting and research gigs on the side. I did not. We were just scraping by. Again.

When I was young and sick, Mom had been teaching and taking care of me. Now Mom was injured and I was teaching and taking care of her. They say what goes around comes around. Another major factor was that almost all of our belongings had been stolen while we were in New Jersey house hunting, and it took the insurance company more than three years to settle up. We were left trying to live and replace everything from clothes to furniture on my small "instructor's" salary, which at the time was less than beginning public school elementary teachers were making!

We moved into our new house right before Christmas and I remember we were down to just a few dollars. I bought Mom a pretty card, and she bought me (ever the Chinese Food lover) a fancy pair of Chopsticks. No tree. No presents. Not even a toilet or sink, the bathroom was totally non functional and needed to be rebuilt, and a malfunctioning ancient oil heater that had to be restarted several times every night, in the middle of the night. But it was our place, a place that we could call home again. There was a big urn from the early 1900's in the living room and Mom and I joked on Christmas Eve that as bad as things were, we at least still had the proverbial "pot to piss in"!

As it turned out, Mom and I would continue living together for years. Over the years as our fortunes waxed and waned, we both took turns supporting each other when one of us fell on hard times. When times were good we helped out others by providing free room and board. When times were bad we would get help in return from our boarders. Our European friends thought this was normal, since in many families, parents, children and even grandparents shared households, while our American friends could never quite seem to grasp the idea. But it worked and we overcame our many misfortunes.

As Mom's back got better she went back to work. Not up to the rigors of real estate yet, Mom looked for other work. She had always liked helping people and found a job managing a local assisted living facility for senior citizens and disabled people. Mom always went the extra mile and was very popular with the people, if not the owners. Going the extra mile to help the residents cut into their profits. Such facilities are all about providing just the bare minimum of care as cheaply as possible. Mom met Pat at this job, he was in charge of the physical plant, heating and A/C etc. Pat had been a long time boiler operator and machinist and from long exposure to the asbestos in boiler rooms had developed COPD. Mom and Pat and Pat's family and I all became fast friends and remained that way for life. We essentially all became one big family.

During the years, I had a series of close personal relationships or "significant others" as I believe they are called. We shared good times and travels with Mom and Pat and Pat's family. Many people have asked why I never got married, and some have even implied some sort of sinister relationship between Mom and I. While I have often asked myself why I never got married, the simple truth is not nearly as spicy as some would like. The plain truth is that marriage, more precisely commitment, never held any allure for me. I saw how crushed Mom had been after my Dad died. Even though he was a monster in my mind, Mom had been deeply in love with him when they first met and married. I also remember the tears in her eyes when she spoke of her high school sweetheart killed by the sniper in WWII, and I shared much of her pain when the new Tom had dumped her. My life and Mom's had been too pain filled, and I simply wasn't into deep relationships.

Marriage is a deep commitment, but a girl friend you can leave home when you have something better to do. A wife you are stuck with. And I was too much into, dare I say passionate about, the other things I did in life and the other interests I had. I had a professional career, was a writer, historian, defense analyst and simulations designer, as well as a craftsman and caster of fine pewter collectibles. There were never enough hours in my day to do everything I wanted to, and so I continued a series of close dating relationships without ever settling down. Heaven knows I had opportunities.

Even today I prefer living alone with my myriad of other interests to settling down by the fireplace with a wife. I attribute this to my childhood, when I was often sick and indoors instead of out playing with other kids. I had to find ways to entertain myself, which I did by reading and studying history. I still prefer a good book to a hot date.

After a few years, Mom and Pat left their jobs at the assisted living facility and tried several business ventures, but Mom kept coming back to real estate as a sure source of income. Mom had a great system, she had two little black books, one with investors seeking to buy commercial property and the other with commercial real estate for sale. By matching up those investors with her good income producing property listings, she was able to make a decent living and ended up running several real estate offices across the state. And Mom stayed active in real estate well into her seventies.

Real Estate allowed Mom time to tend to Pat and his worsening COPD and his developing CHF. She was able to help him get a reasonable settlement and full disability. Even though disabled, Pat would accompany Mom on her real estate travels which she liked. Pat was a tough, non nonsense, good looking Italian who no one dared mess with. Being in commercial real estate, Mom had to travel to some locations that were, shall we say, not as safe as your basic residential real estate locations. Pat and Mom made a great team and as I said, both of our families became fast friends.

Being so busy with my career, I was happy to see Mom have someone like Pat to be around and help her. Even disabled, Pat could do things my Mom could not. As the 90's ended and the new millennium approached, Mom, now in her mid seventies, finally realized that she could not keep the pace forever. And Pat was getting weaker and could not accompany her on her real estate forays. I had actually begun to help Mom with the real estate in lieu of Pat, and actually got a Mortgage Loan Officers license so I could help her finance her deals. We made a good pair in the Real Estate business.

Mom had always loved eating and preparing good food, so she acquired a Deli. Her plan was to transition out of real estate which required travel and extensive hours to settle down working a few hours a day in her new Deli. So that she could wrap up the real estate, and not have to spend all day in the Deli, Mom also acquired an Asian Partner, Jack, to help her run the Deli and prepare the food and sandwiches. They added a new twist, Sushi Catering. Sushi was just becoming all the rage at the Jersey Shore and they helped some restaurants capitalize on it by adding Sushi to their Happy Hours.

After Jack and Mom had been running the Deli for a few months, Jack's wife decided to move to New England. Jack was sad to leave the Deli, but Asian women rule Asian families and their men and so he left. And he left Mom with quite a dilemma. At the time Mom was still the broker for several real estate offices and had counted on Jack to manage the Deli and the staff when she could not be there. True, Mom was trying to phase out her real estate business, but it still demanded her time wrapping things up.

At 77 not only was Mom managing several real estate offices, but she was running and working in her Deli in her "spare" time! I would help at the Deli on weekends. But since I had a job and was only around on the weekends to help, I became concerned about Mom's hectic pace and her health. She was overworked and tired, but would not give up either venture. I should have pressed Mom to simply quit. But you had to know Mom, if she had sold her Deli and real estate offices the next day she would have been back starting a new business. Mom was never one to sit around and watch the grass grow.

CHAPTER 7

Heartbreak

ONE FALL DAY on the way home Mom had an accident. An SUV rammed her car in the rear at a traffic light. The blow was more than physical for Mom. She had always been fearful of accidents since the one during my childhood. That was one reason she liked someone like Pat to go with her on her travels. Mom became really reluctant to drive after the accident and her health seemed to take a turn for the worse. She developed a bad chest infection followed by a bad cough which just didn't seem to want to go away.

As winter changed to spring, it had been months since Mom's accident, but she still hadn't recovered from the bumps and bruises. She had been going for treatments for the chest, arm, neck and back bruises caused by the accident. And if anything her arthritis seemed worse than ever. Mom would have great difficulty walking even short distances and was constantly short of breath and tired more easily than ever. She would fall asleep in the afternoon and had trouble staying awake to drive home.

Mom had been seeing the doctor for her accident injuries, and the chest infection, so I figured that if anything major was wrong they would have caught it. For Mom, trying to manage the Deli and the Real Estate business was extremely taxing. But no one could hold Mom down. She would never give up the Real Estate and really didn't want to part with her Deli. Always interested in food, the Deli was her dream. Since Mom had been seeing doctors for months, I had attributed her poor health to overwork and exhaustion.

Mom and I had always treated Birthday's as something special. Mine, being late in May, almost always fell on the Memorial Day Holiday weekend. I used to take the Friday off, which made a nice four day weekend when added to the Monday Holiday. I also used to take a day off for Mom's Birthday in late July and we would try to do something special. For her 77th Birthday in 2001, I wanted to do something extra nice, but Mom just wasn't up to it. At least I had persuaded Mom to take her Birthday off, the new help at the Deli could handle it for a day, and I felt that Mom really needed to get away and relax a bit.

Mom and I spent the day touring the Jersey Shore. We had always loved to visit the Shore and see the Ocean, often just to sit and watch the boats and have ice cream. It was relaxing and the fresh air was wonderful. Since we did that often at our favorite local seashore places, this time we decided to travel all along the coast. We worked our way past all the towns, Spring Lake, Avalon, Belmar, up to Asbury Park. In its day Asbury used to be a thriving resort town, now it was but a shadow of former self.

Mom used to tell stories about how she and her family traveled down from North Jersey, Newark and Irvington, when she was just a kid to go to Asbury Park. It was an adventure getting there and the place to go during the 30's. For me it was hard to imagine those times seeing the wreck it had become by 2001. I could see that Mom's health was failing, and wondered how many more Birthdays we would get to spend together? I was determined to take Mom back to the doctors and get some answers.

Mom had stopped seeing the doctors upon completing treatment for her injuries and her chest infection finally seemed to be gone. But her cough and lack of energy lingered through the summer. Now Mom was never one to run to the doctor, in fact she would only go when really, really sick, but when her energy level didn't return to normal, like that of a 40 year old, and her cough persisted, I knew it was time to get her to go back to the doctors and make them look until they found out what was wrong. I was very worried that Mom might have developed pneumonia as a result of her chest infection.

Mom had X-rays and tests taken and when the results came back we were stunned. It turned out that her condition had nothing to do with the accident, instead Mom had developed moderate to severe Congestive Heart Failure (CHF). That was the same thing Pat had (along with his COPD) and suddenly they shared more than friendship. Mom was also suffering from cardiomyopathy, an enlarged and weakened heart. Mom's persistent cough had been caused by the fluid build-up in her lungs from the CHF, and her lack of energy came from reduced cardio output and poor circulation, a result of her weak heart. As yet we did not know the reasons for her heart condition, but having helped Pat for years, Mom and I were well aware of the seriousness CHF. Today, I still wonder why the doctors never discovered this during the months of treatment for her accident.

While her hard work over the last few years had not caused Mom's condition, small consolation to me, it had aggravated the severe symptoms of CHF. We later learned that the cause of Mom's condition had been strep throat and an undiagnosed case of Rheumatic Fever during childhood. This caused mitral valve heart damage, leading to "mitral valve regurgitation" resulting in her enlarged heart and CHF. Mom had carried this ticking time bomb with her for her whole life and not realized it. Mom's sister had the same condition. It's amazing the things your "family" physician can miss in the course of treating routine illnesses and injuries. Cardiologists could pick up not only the peculiar beat (called a gallop) stemming from the CHF, but also the valve problem with a simple stethoscope. Mom should have been seeing a cardiologist for years.

Our family physician's attitude was not quite "take two aspirin and go lie down", however the diagnosis of CHF did not seem to cause him near the concern that it did Mom and I. He assured us that her condition was "not immediately life threatening" and referred Mom to a local cardiologist. We met with him, but he also did not seem overly concerned. He scheduled a test to measure heart function (Ejection Fraction) by means of ultrasound, called an Echo Cardio Gram, and also prescribed a diuretic (pills that reduce fluid build-up) and told Mom to reduce her salt usage and limit her fluid intake.

Talking to those doctors. one would think CHF was no big deal. I thought it was part of the "physician persona"; never tell a patient they are going to die. Doctors are human and as such they dislike giving out bad news, especially to long time patients they know. Our family doctor actually said "ah big heart, big heart is good" while looking at Mom's X-Rays. OK, so your family physician is not a cardiac expert, in fact what they don't know can kill you, but the Cardiologist we saw should have known all of the very serious implications of Mom's condition and fully briefed us during our first visit.

Mom had a more sinister view, which I came to share after my experiences with Mom and her heart condition. This country places all of its value on "the Children", but places no value on its Senior Citizens. They have lived their life, done their thing, had their chances. Now please die gracefully, buy quickly, and get out of the way of the Young People. It wasn't that Mom's condition wasn't serious, it was that no one in the medical establishment was going to take the condition of a woman, who was neither rich nor famous, in her late seventies, seriously. When you're old no one wants you.

While Mom was taking the ultrasound test, the technician called me in and, violating every rule in the book, warned me to watch Mom closely over the weekend (it was Saturday of Labor Day weekend) until Mom could see the Cardiologist again. This sounded grim and kept me on edge over the weekend. But when we met with the Cardiologist again on Tuesday, he was no more concerned than he had been during the first visit, and simply prescribed an additional medication, digitalis, to strengthen Mom's heart. Back then, I trusted doctors. After what the technician had said to me, I felt relieved. I had no idea that by early next morning Mom would be near death. You hear stories of people walking out of doctors offices and dropping dead. Believe them.

I learned later that what the echo-cardiogram technician had seen was that Mom's heart was barely beating, it was sort of just wobbling around in her chest, resulting in a very low "Ejection Fraction" or blood flow to the rest of Mom's body. Mom should have immediately been admitted to the Hospital ER when she first saw the Cardiologist, if not earlier by her family physician who told me the condition was not "life threatening". News Flash, ALL CHF is immediately life threatening from something called Sudden Cardiac Death. The stress put on the heart by uncontrolled CHF can cause the heart to start beating very fast and irregularly, or to just simply stop beating, at any time. Both are called Cardiac Arrest, and it's always, *always*, fatal unless treated within minutes.

Cardiac Arrest should not to be confused with "Heart Attack", or Myocardial Infarction, which is a blockage or blood clot in the heart. That's the one where you do take an aspirin, get treatment within an hour, and usually have a good prognosis of survival and recovery. Cardiac Arrest, a.k.a. Sudden Cardiac Death, which is often incorrectly called a "massive heart attack”, is where the person collapses and dies on the spot. Unless there happens to be a cardiac defibrillation unit within immediate reach, the prognosis is grim. Thousands of people with CHF keel over dead each year from this syndrome. So much for “not immediately life threatening”. Uncontrolled CHF is a ticking time bomb.

Early Wednesday Morning, after her Tuesday cardiologist visit, Mom started acting funny. She was very weak, and not coherent. Mom also had very bad indigestion all night and slept poorly. It was indigestion and not a heart attack, but it was also a symptom. In its weakened condition and over stressed by the CHF fluid build-up, Mom’s heart had started beating irregularly, and was barely pumping any blood. The lack of oxygen getting to her stomach and brain is what caused Mom’s indigestion and dopiness. I actually thought the indigestion and “dopiness” were adverse reactions to the new medications she was taking, so against her objections I called an ambulance to take Mom to the ER just as a precaution. This was a fateful decision because as it turned out going to the ER right away was what ended up savings Mom’s life.

By the time Mom made it to the ER, thankfully a mere 5 minutes from our house, her heart was beating so fast and irregularly (just fluttering and not really beating) that it was hardly pumping any blood. Mom was barely conscious. Mom’s arrhythmia attack brought on by her CHF had progressed to full Sudden Cardiac Death in a matter of minutes. Had she not been in the ER, and had the EMS Team not alerted the “Crash Cart Team” on the short drive to the hospital, Mom would have died right there on the spot.

Mom actually suffered Cardiac Arrest (in her case an extremely fast rhythm where the heart is just fluttering and not pumping blood) on the table in the ER. If you are going to have Cardiac Arrest, the ER is probably the only place you can and live. The Emergency Room Staff at the Hospital and CCC later told me that getting her quickly to the hospital saved her life. So if anyone you know has heart problems and begins acting out of the ordinary, mentally dopy, complaining of pain, weakness, etc, get them to the ER, do not wait for developments, because the next development might well be death.

When we got to the ER, they immediately summoned the “on call” cardiologist. I actually believe the EMT’s had done this on the way to the

ER because they had a crash crew and cart waiting for Mom. On later visits to the ER when we drove ourselves it took quite a while to get attention. Another good rule, unless you are driving past the hospital when you have an emergency, call an ambulance! They have equipment on board and can start treatment that you can't when driving, plus they can radio ahead and have the appropriate staff waiting. And a little known secret I learned is that patients arriving by ambulance always take priority over "walk-ins". Hospitals do not want to admit it, but it's a fact of life or death. So take an ambulance ride to the ER.

The EMS crew that drove the ambulance and the ER Crew on duty that day were smart, sharp, and at the top of their game. It's often the luck of the draw and Mom was lucky. They summoned the "on call" cardiologist, and he happened to be one of the best in the business and was actually in the ER at the time. He took one look at Mom and her vitals, she was hooked up to the Monitors at this point, and said: Sudden Death! I have to shock (Defib) her now without anesthesia or she will die, so sorry! He proceeded to use the Defib "Paddles" and BANG Mom's heart rhythm immediately settled down to normal and she became fully lucid within minutes, sat up on the Gurney and said "can I leave now, I have a lot of work to do?" A line which has become famous in that ER!

But that wasn't about to happen because Mom's heart was so weak, her Ejection Fraction was down to 5%, so low that it was hard to measure it. Mom's poor heart could not maintain her blood pressure which fell to 70 over 40, not a living BP. It was touch and go for an hour. Finally the cardiologist decided to perform a new experimental emergency procedure (for this hospital) of inserting a balloon pump into Mom's Heart Cavity. They went in through the large vein in her leg with a catheter and placed a balloon into her heart. The balloon expanded and contracted with her heartbeat to provide additional pumping action, thereby raising her EF and hopefully her BP.

This was an extremely serious procedure, and we later learned that Mom was the first patient (of this doctor's) that had ever lived after it was performed. The doctor told me years later that since he performed it on Mom, his first patient that survived, he has saved many lives with this procedure. The man was a genius. Something good did come from this experience after all. Faith told me there had to be a reason for all of this.

The emergency procedure with the Balloon Pump had temporarily saved Mom's life, but her heart was still not capable of keeping her alive by itself. At this point Mom was also on oxygen and a respirator to keep her breathing. Essentially Mom was on full Life Support. Even with the pump and oxygen Mom was unconscious and barely clinging to life. After an hour she was stable enough to transport to CCC via Life Flight or Ambulance. They chose the ambulance, a Life Flight is reserved for the living.

Later I found out that both the CCC and Hospital staffs were actually running a betting pool that Mom didn't make it there alive! Now CCC was a good 30 miles from the Hospital and we did it at 70+ mph during mid day down the center line of a two lane highway crowded with traffic. I wondered if any of us would make it there alive! Next time you see an ambulance in a hurry, make way beause it could be someone's mom dying. Mom beat the odds and made it to the CCC alive. Barely alive.

CHAPTER 8

The Heart Hospital

HAVING BEAT THE odds, and the betting pool, Mom was still a mess. And her survival was still very much in doubt. Her Heart was over twice its normal size; her lungs were full of water from the CHF with something like 22 liters of fluid in them, her mitral valve was virtually non-functional and her ejection fraction was hovering between 5 and 10%. Essentially, Mom's heart was just gurgling blood, not pumping it. Her resting heartbeat was 140-150 and her blood pressure was 70/30. She was being kept alive with full life support, oxygen and the balloon pump, plus a wide variety of medications. Already complications were setting in, her very low blood pressure was taking its toll. Mom's liver and kidneys began to shut down. The emergency ICU (Intensive Care Unit) Staff worked on her for hours. Mom was still just barely alive when they finished that night.

Mom might not make it through the night. So they let me sleep on a chair right in her room in the ICU; asking me to leave only whenever a procedure had to be performed. It was heart breaking to see Mom in such a condition. She was surrounded by IV "poles", IV's hang off of these poles with little blue control boxes that dispense medications in precise doses, either constantly, or at pre-determined intervals, click, click, click. Each "pole" can hold up to four IV Units and Mom had 3 full poles (11 IV's) plus the Balloon Pump and the Respirator. She also had a "central line", and open IV in the main artery in her neck, where they could directly inject more medications and take blood samples without making her more of a pin cushion. There wasn't much room left to stick anything into Mom, nor much else they could give her, and she looked so small and helpless laying there surrounded with all of the equipment, IV's and monitors.

The IV's were giving Mom all kinds of medications with odd sounding names such as dopamine and dobutamine; plus an amnesiac so she didn't remember any of the pain and had no anxiety in her deep sleep. They did another Electrocardiogram and a Catheterization where they can actually look into your heart and determined that Mom's root problem was her faulty mitral valve, which we had not known until now.

Heart valves are like gates and your blood is like the cows (or horses if you prefer) going through them. The cows run through the gate when the heart pumps and then you quick close the gate behind them so they can't get back in. In Mom's case, the two halves of the gate (mitral valve) were not meeting and so the blood was not staying in her arteries, it was just "regurgitating" back into her heart and pooling up in there.

The Doctor's believed this condition was caused by a childhood illness probably Rheumatic Fever, which Mom's sister had, which Mom may have also have had that went undiagnosed. Mom had had strep throat which was often mis-diagnosed as strep when in fact it was RF. Over the years her heart had grown in size to compensate for the weakened pumping action caused by her "leaky mitral valve", and in turn as her heart enlarged, the valve (gate) let more and more of the blood back, leading to her CHF. It had reached a point where her overtaxed heart had simply packed it in, and she had suffered the Cardiac Arrest. Perhaps hospitalization when her doctors first found her CHF would have prevented the Sudden Death episode, but again they all treated CHF as non-life threatening. In my experience, if you are over 60 doctors in general are not nearly as concerned with "life threatening" conditions as when you are under 40.

Mom survived the first night. A miracle in itself. Several of the ICU doctors, one in particular, a new resident, spent much of the night reviewing the Echo-grams. And from him I learned a valuable lesson. A vast majority of doctors and nurses are good people, that's why they became doctors and nurses in the first place. As patients, or relatives, we may at times find them aloof, brusque, or seemingly uncaring and definitely lacking in "bedside" manner. But this is not true, and comes from two factors; first, most of the better doctors are brilliant and aloof, some would even say arrogant, which is a trait often associated with brilliance; second, seeing so much pain suffering and death they need a coping mechanism, which is to focus on "the facts", not "the person" involved.

Therefore Rule Number One for getting the best care is to be the “squeaky wheel”. Demand attention, information, explanations and above all, options. They will think you’re a pain in the ass (and they’ll probably be right) but once they catch on that the person in that bed is not just another patient, but a very important person and that someone is willing to fight for them, they will join in and make it their battle too. Then you will get the great care you or your loved one deserves. I also learned that some of the best “plain English” information about a patient’s condition can be gotten from the nursing staff. Many nurses will also share their opinions on the various doctors.

The surgeons had performed the Catheterization on Mom to determine exactly what her problem was and to check for other cardio vascular problems. The Catheterization and Echo Cardiogram had revealed that while the cardiomyopathy and mitral valve were the two major problems, very little else was wrong. They said that Mom had the arteries of a forty year old, and was in very good health. I wondered if this was due to Mom’s wonderful cooking which had always been high in veggies, wine, garlic, fish and low in meats and salt. She cooked and ate very similarly to the so called Mediterranean Diet. That her circulatory system was in great shape at least gave her a fighting chance.

The next morning brought an interesting scene that is still talked about in that ICU. The Chief of Surgery wanted to operate immediately to repair Mom’s mitral valve. He said that Mom’s condition would not improve until the faulty valve was fixed, and that even if by some miracle she lived, she would have no quality of life because her heart was so weak. The head of the Intensive Care Unit wanted to wait for Mom’s condition to stabilize, insisting that open heart surgery in her present condition would kill her right on the operating table. They had a screaming match over Mom’s bed with the full ICU nursing staff looking on: “I’m not going to let you kill my patient” versus “she’s going to die anyway!” And then they both turned to me and waited for me to make a decision.

Mom did not have a Living Will, so as her son and nearest relative I got to make the medical decisions. Everyone should have a Living Will. Especially so that when you are lying unconscious and near death in some ER or ICU, people, specifically your family, doctors and care givers, know what your wishes are. Fortunately, Mom and I had often talked about her wishes and feelings. She did not want to be kept alive as a vegetable on life support for a long time, nor have major surgery or procedures, but preferred to be treated with medications if possible. Now it was my decision. Some decision, let Mom be operated on, with a high probability she would die right on the OR Table, or let Mom linger on full life support where she would likely die anyway within a few days!

Well, I just wasn't willing to accept those options. They say seek a second opinion. And I'd already heard two opinions, from the two most senior medical staff at the hospital. But I wanted a third option, and there were certainly enough doctors floating around. The resident that had spent the night reviewing Mom's tests told me that there might be another option. He believed that her condition had worsened so abruptly because she might have gotten a "cold" or viral infection in her weakened heart. If we could keep her alive on Life Support long enough, the swelling of her heart might subside enough to allow the mitral valve "gate" to work well enough again that she would have a fighting chance to recover with medication instead of the heart valve surgery.

What to do? I made a trip to the Chapel and prayed. Mom would have chosen surgery as a last resort. Looking at her lying there, hanging on by a thread, it didn't seem that she could possibly survive open heart surgery. In the hardest decision of my life, I told the surgical team NOT to operate and I actually refused to sign the consent forms. I opted to try and treat the condition with medication as the Resident had suggested. This was not a decision without pressure from the hospital and surgical staff. Several times members of the surgical team came by with consent forms and persisted in trying to get me to sign. Just sign the form and we'll fix Mom right up. Not on my watch.

I wasn't giving in. Mom survived her next night in ICU too and her condition slowly improved over the next several days. The ICU staff stopped letting me stay all night, and made me go home for a few hours between midnight and 8am. At first I thought that was because I had fought the big guys, but then I realized that Mom was slowly moving out of danger and they felt that I could be away for a few hours at a time. After four days, when it was obvious Mom was improving, a member of the surgical team came by and said that further tests showed that the shock of the operation would have killed Mom. Then he shook my hand and said; "you made the right decision". I started getting winks and smiles from the nursing staff and respect from other doctors too.

Mom slowly started improving with the special medications. When I say Mom had been improving, she had been in the Hospital for a week now, but was still in Intensive Care, unconscious and on a Respirator, with 6 or 7 IV's. They had managed to remove the Balloon Pump after 5 days, the maximum amount of time they dared leave it in. To everyone's great relief Mom's heart kept beating on its own, albeit very fast at almost 100 beats per minute at rest, but it now maintained her blood pressure, very low, at about 80 over 40. But with the strong medications Mom was on now, she could live with that Heart Rate and BP. At last Mom was alive on her own heartbeat again. The rest of her organs had taken a beating, her liver, kidneys, and blood sugar were all horrible, but the IV's were controlling what they could and everything else was still working, even if just a little bit. However, Mom was clearly getting better day by day. Truly A Miracle.

Having been unconscious since right after she was defibrillated, Mom chose a particularly interesting day to wake up. My routine had been to stop in the morning around 9am after morning doctor's rounds. On this bright sunny late summer day, I was listening to the New York City news. I tuned in just after the first plane had crashed into the World Trade Center. Some of the most graphic reporting was coming from the traffic helicopters, and their tone was one of incredulity. How could anyone be so stupid as to fly an airplane into a skyscraper on a perfectly clear, sunny day?

Within several minutes they announced that a second plane had flown into the other Trade Center Tower. While I, and the rest of the world, was absorbing the implications, the traffic reporter announced that he had to leave the air, he had been given an order by TRACON (Air Traffic Control) that he had never heard before: he was told to "land immediately because they were going to 'sterilize' the air space". Even if you are not familiar with military jargon, that sounds real serious. But since had I studied military history, it became immediately apparent what it meant, the US was under air attack!

And as if to punctuate this realization, two F-16's came thundering over my car heading north toward New York City on full afterburner several hundred feet off the deck. I was passing a major Air Base where several fighters are kept on Standby Alert, a leftover from the Cold War Days. CCC was located near to one of the largest Army/Navy/Air Force Military complexes on the East Coast. Much of the military was alerted and "scrambled" immediately on 9-11. We went to War Alert Status much faster than has ever even been revealed on the TV Conspiracy Theory documentaries about that day. I know, I watched it happen; by 9:15 am, these bases were on full war alert status!

In fact the main road to CCC, the one I was driving on, was a public highway that ran next to, and then through, the bases. As I approached the Base Complex, the largest caravan of NJ State Police I have ever seen, over a dozen SUVs and EMS, vehicles came screaming down the highway. Several peeled off at each base entrance blocking anyone from entering or exiting. And as I rounded the corner to drive through the base, I saw Tanks and Armored Personnel Carriers pulling up to block the highway. Armed soldiers in battle gear were putting concrete roadblocks into place. Others were standing around donning equipment and painting green and black camouflage on their faces. I could see Live Ammunition in the .50 cal Machine Guns on top of the vehicles. A soldier with a blackened face and M-16 in full battle gear waved me past him and down the road to CCC. I looked in my rear view mirror a front end loader dumped a concrete barricade down right behind my car. I was the last civilian to use that road.

I was thinking, My God we must be at war! At CCC there was pure pandemonium. There were patients, relatives, staff and doctors in the rooms with eyes glued to the TV. In the hallways, other people were crying, or kneeling and praying, or just watching in stunned silence. With a sense of déjà vu it reminded me of that other unforgettable day in my youth almost 40 years before when Kennedy had been assassinated. For a brief moment in time, the world seemed frozen in place. Like my Mom, on that fateful sunny September Day, the World skipped a heartbeat. It would take my Mom and my country a long time and a lot of tender loving care to recover, and they would never be the same.

Many of the staff at CCC were Military Reservists and had already been called up; instantly. Many others had loved ones who worked at the local bases, and they were cut off from news or contact with them. I can tell you I have never seen such instant “going to war” activity as I did that day. And I had lived near these bases for most of my life; during Viet Nam (the Gulf of Tonkin Incident); the Arab-Israeli Wars when we flew supplies and reinforcements to Israel, and later the actions in Grenada and Panama.

Perhaps the only time I saw a similar, but not equal level of action, was during the Cuban Missile Crisis. If you followed 9/11’s events from the very beginning, you’ll remember that at first we had no clear idea of what was happening or the full extent of the attacks. After the Pentagon was hit, there were erroneous reports of other attacks. No one was sure when it was really over until hours later. Since these bases were the closest major military installations to New York, the military was taking no chances.

I finally made it to Mom’s room in Intensive Care, and she was just beginning to regain consciousness. She could blink and nod, but not speak because she still had the respirator tube in her mouth. We were all elated that Mom could respond to us. Prior tests had revealed that her ordeal had probably not caused any brain damage, and it was very reassuring to have her back with us. But what a day to wake up . . . on 9-11!

There was a TV in Mom’s room. She just stared at it all day and I could see tears in her eyes. I kept reassuring her that “it” was going to be alright and that she was going to be alright. I stayed with Mom and held her hand while we both stared at the TV. As the day wore on, Mom came to understand that her condition was separate from the chaos on TV, but I am sure both were very upsetting to her. She woke up in a new world. Due to the “amnesiac” medications Mom had been given, she had no recollection of anything, even going to the ER, from the morning of her cardiac arrest and did not understand why she was in an ICU, at first thinking it was related to the 9-11 attacks.

Later, when Mom had recovered, she told me that when she first woke up she thought she had been injured in NYC in the attack. Mom had no memory of her original trip to the ER, even of being DeFibbed, or of anything else from the morning of her cardiac attack. They had been giving Mom an amnesiac in her IV’s so she would not remember all the pain and unpleasant procedures when she revived. It worked. We had friends in NYC and Mom told me her first reaction upon awakening and seeing the chaos on the TV was that we had been in New York and she was in the

Hospital because we had been caught in the 9-11 attack. Her first concern, as always was me, and she felt relieved when she saw that I was OK. It brought Mom back memories of December 7.

During the afternoon we heard a tremendous and prolonged roar as several jets and helicopters flew in very fast and very very low, right over the hospital. I looked out the window and saw a big blue and white 747 jumbo jet with a fighter escort roar low overhead. Now that usually means only one thing, but I thought, no it can't be, why would Air Force One be here? But it was. We later learned that President Bush in Air Force One with its escort had flown into the Air Force Base next by CCC as a staging point for his trip to New York City. A day to remember, Mom awake and the US at War.

Now that Mom was awake, the next trick was to get her off of the respirator and see if she could breathe on her own. The nursing staff, a wonderful fountain of information, told me this can be tricky for patients with such trauma and who have been on full ventilation for so long; their body has to learn to breathe on its own all over again.

Nurses, some of the best were male, are such great sources of knowledge because they spend 8 hours a day with the patient (intensive care patients had a Nurse for every two patients) whereas the doctors only spend a few minutes reviewing charts and examining the patient during morning and evening rounds. Also, nurses have tended so many patients they know and share things with the family that many doctors will not. In the ICU there was a huge cast of doctors, each area of the body had its own specialist, and even these changed every few days. I learned to pay close attention to the more caring and senior nurses on the staff, they helped Mom and I make it through it all.

They take you off "intubation" by turning the machine down little by little to see if your brain, body and lungs pick up the load. Three times they tried, and three times Mom had to go back to full "ventilation". Finally, on the fourth try Mom started breathing on her own. What a wonderful day! Mom had been on some form of Life Support for 10 straight days, but now she was living on her own again without assistance. Her own heart was beating and her own lungs were breathing, and her other organs, especially her liver and kidneys, were moving back into a normal, life sustaining, range of function. True, Mom was still attached to four IV's, but these were medications that could be replaced by "pills" in time. Which meant that with no further setbacks, and after some time to recuperate and rehabilitate under medical supervision, Mom could come Home!

After several more days of very carefully watching Mom on her new medications in the ICU, she was transferred to a "monitored" room. Mom had been in intensive care two full weeks. In the monitored room there was not the individual level of attention provided in ICU, but a patient's heart function was monitored 24 hours a day so that any change or irregularity could be dealt with immediately. Mom had been to the brink but now was back with us. It had been the longest two weeks of my life. I thanked God.

Permit me to digress with a few tidbits on Intensive Care. The doctors, nurses and staff were all excellent. However, as the brilliant doctor who originally saved Mom's life with the DeFib and Balloon Pump Operation later told me, all doctors are not created equal. This means that from the large cast of doctors, specialists, nurses and support staff you should select several that you like, feel are knowledgeable, that you can communicate well with, and who share your values. Seek their opinions to help make treatment decisions. These decisions can make the difference between life or death. Don't just rely on the first doctor, or first set of options, you encounter. Question everyone and everything. Be well informed when making life or death decisions.

Sharing your values is one of the most important points. There seem to be three main schools of thought among doctors. One, let nature take its course with minimal intervention. Two, treat conditions with medication unless and until there is no alternative but surgery. Three, do surgery to "fix" the problem as the fastest solution, either the patient lives and gets better or dies and it's over with, either way one avoids long treatment for chronic conditions which will probably only worsen and lead to surgery down the road. Be careful with these choices; without full Life Support, or with immediate Surgery, Mom would have died. Only the medical treatment course of action saved her life. Having key doctors, nurses and staff on your side and that share your values and choices gives you very powerful allies when dealing with life and death.

Starting several days after I had refused to let Mom be operated on, which we now know would have killed her, there began a subtle but constant pressure from a small minority of the staff to just “let Mom die”. I began to get comments like “I’d never want to be in that condition, I’ve told my kids ‘no heroic’ measures, just let me die if that’s what God wants!” Well, maybe that was their wish. But Mom had always been a fighter, and was against having any surgery. So to me the course was clear, try all medical means short of surgery. Fortunately, this plan worked in Mom’s case. Mom didn’t have a Living Will, with her husband deceased and as her only son, the medical treatment decisions fell solely to me. Although some of the hospital staff (the pro death gang) tried to tell me that without a Living Will they were entitled to make the decisions, I made it abundantly clear that Mom wanted me to make the decisions and I adopted a ‘don’t mess with me on this’ attitude. Mom would not have had it any other way.

It is worth repeating that today a Living Will is indispensible. Here is where the plethora of state laws, the kind that make national headlines, come into play. If you really don’t want heroic measures taken to resuscitate and sustain your life, then you had better make a Living Will. If, on the other hand you are pro-life and find it precious as many of us do, then you had better put that into your Living Will. There is also something (at least in NJ) called a Medical Power of Attorney, which appoints someone to make your Medical Decisions and approve Courses of Treatment if you are not able to, as Mom was not for two weeks. There are also the mundane matters, like paying the bills and feeding the pets, so having trustworthy family or friends who are authorized to attend to your affairs and enter your home are invaluable, and can make your recovery easier when you get out of the hospital. Many people fall ill and return to personal disasters at home because while they were laying in the hospital near death, outside life continued. Your landlord, your bills and your bank don’t want to hear excuses that you were sick!

When Mom made it to a regular room she weighed a 30 pounds less then she had in the ER. Some was real weight loss due to lack of food (they had been feeding Mom with an IV), but most of it was water from her CHF. They had taken over 4 gallons of water out of Mom’s lungs. Your lungs filling up with water is a classic CHF symptom and for the first time her chest x-rays looked “like a normal person”. While Mom had recovered enough to be out of Intensive Care, there were still obstacles to overcome before she could come home. Her heart would always be enlarged, with the faulty Mitral Valve, plus she had a "left branch bundle block" which meant the heart only pumped with one chamber; and her ejection fraction was now only around 20%. The immediate reason she was in the hospital was a Cardiac Arrhythmia which had caused the "Cardiac Arrest".

The shock of the cardiac attack and resulting very low blood pressure had taken a toll on Mom's kidney and liver function, but had not caused an actual lack of oxygen to the brain, nor any loss of brain function. As Mom's liver and kidneys returned to normal over time, Mom should return to pretty much a normal life if we could control her heart problems with medication alone. Mom had declined to have a pace maker inserted to control her heart rhythm and the doctors consensus now was that surgery to replace the mitral valve was not viable, even in the future. To strengthen Mom's heart, control her CHF and fluid build up, and prevent future arrhythmias, Mom would take many pills.

But the immediate problem was that Mom could not swallow, an unpleasant after effect of having been on the respirator for such an extended period. And if Mom couldn't swallow, then she couldn't take her pills or eat. And if she couldn't take her pills, she couldn't leave the hospital and her IV medications, or give up intravenous feeding.

Mom always coughed when first eating or drinking something in the morning, and as she grew older she had developed a hoarse sounding voice. She had an inflamed esophagus from something called acid reflux disease and Mom had taken large quantities of Mylanta for years. Both her throat and esophagus had been further irritated by the respirator. Not knowing Mom, her cough and swallowing difficulty seemed unnatural to the staff, so they ran more tests and decided that all of the inflammation was due to the respirator tube having been jammed down her throat for such a long time. They felt that if she was simply kept on a liquid diet for a few days it should heal. Little did I know that this foreshadowed much more serious problems to come. But that would be later. I wish they would have done more testing and made a better diagnosis at the time, but it wasn't the first time doctors has missed something.

For now, Mom was restricted to ice chips and water. No solids, which meant that she could not swallow her pills either. Now the Floor Doctor (we had left the A-Team when we left the ICU) decided that this was fine, just have Mom stop taking her pills for a few days until we resolved the swallowing issue, then she could start taking them again.

Hello? Mom was on anti-arrhythmics and other medications for a reason! I challenged the Floor Doctor, who asked me why I was getting excited? She said the average CHF patient had a life expectancy of only two or three years and was admitted at least twice a year to the hospital for treatment. In her mind Mom shouldn't expect a normal life and was going to die in a year or two and I had better get used to that idea. Bullshit.

This was my second encounter with the "Mom is old, just let her die!" syndrome. The first had been several nurses in ICU. But this was more serious, this was her "primary" doctor, the one making her medical decisions now. Throughout Mom's entire ordeal, every enthusiastic Euthanasia advocate, nurse or physician, was female. Perhaps the males related better because it was "Mom". Most men have a soft spot for Mom in their hearts. I wonder if the roles would have been reversed if it was my Dad? At all costs you must keep the "let them die if they are over 60" crowd away from your loved ones.

So I trekked down the halls back to the ICU and spoke to the doctors I knew there. Bang, Mom was on a gurney headed back to Intensive Care. There they could provide the necessary medications by IV, something that couldn't be done in a regular room. Mom was devastated, viewing this as a setback and worsening of her condition. Then one of the A-Team came by and explained that it was only to keep her on Meds until she could take them by mouth rather than risk a "setback" by taking her off of them until then. They even relaxed the tough ICU rules especially for Mom, she was allowed non-family visitors, a boom box so she could listen to her Yanni music, some stuffed animals from home, and even flowers, normally forbidden because of pollen!

I was happy that Mom was back to around the clock care from the A-Team rather than the cavalier attitudes of the regular floor staff. Later in the day after they moved Mom back to ICU the Floor Doctor called me and apologized profusely claiming "not to have known" Mom was on anti arrhythmics. To which my response was "didn't you read her charts?" Then she said "no I was too busy and hadn't reviewed them yet". Nice! So you're going to take a patient off their medications without even reviewing their charts. It's worth repeating all doctors are NOT created equal. Make sure you have a good one! And you must keep tabs on your loved ones in any hospital for every step of the way!

So by my count I was now up to 3 in 3 weeks. Three times Mom could have been done for without my proactive actions; 1st when she was feeling funny and I called 911 over her protests; 2nd when I refused the surgery that probably would have killed her on the table; and now the 3rd time when I prevented her from being taken off her medications for a few days which might have resulted in another cardiac arrest. Lessons learned.

Back in the ICU we worked Mom up from Ice Chips and Water to a pureed diet, I called it baby food. Mom called it dog food. It looked and smelled like dog food and according to Mom was gooey and tasteless. I think they make hospital food as bad as possible to get people to leave faster. I would sneak Mom in real food along with her Yanni CD's and flowers. There was this obnoxious little "speech" therapist, and swallowing was her gig. She ran Mom through any number of tests, and finally after of few days decided that Mon could swallow well enough to eat, and so it was back to a room again. It was still a monitored room where they could make sure Mom's meds were controlling heart rate and rhythm and blood pressure, but with no IV's. Mom was back on her pills.

Best of all, it was on a different floor, with a new medical team of nurses and doctors. This gang was almost the equal to the ICU Staff and the ICU doctors would stop by once a day to check on Mom. Hospitals are full of patients, some die, and many doctors develop a hard "shell" so they can function normally and deal with constant pain, death and family tragedies and not go nuts. I sympathized with them. But if you can break through this protective shell and become a real person with a real family that they care about (not just another "patient"), then you and your loved ones get the best treatment that can be had, like one of "the family". To this day I have friends at CCC.

Now being able to eat real food and swallow her medications Mom improved rapidly. They had said she had the arteries of a 40 year old, and Mom had always been a fighter. With regular food, even hospital food, and a balance of medications, we could all see the improvement day by day.

She was still on the heart monitor, but there had been no more "events". There had been one or two episodes of low blood pressure, but that was while they were adjusting Mom's medications dosages. Everyone has a slightly different tolerance to medications, and when you are using the very strong kind that regulate heart beat and rhythm and blood pressure, it is important to take exactly the right amount at the right time. Mom and I were given lessons on how to check her heart rate and blood pressure before giving them, with very strict guidelines and instructions.

The objective in treating Mom's CHF was to lower her heart rate and blood pressure to take the strain off of the heart, while giving her heart medicine a chance to make it stronger. We were walking a fine line with all the medications, keeping Mom's Blood pressure in a range of 85-90 over 35-40 which is very low blood pressure. But as opposed to Mom's low blood pressure after her Sudden Death episode, this was a medically induced low. However, even a medically induced BP of 70 over 30 will put you in the ER in real bad shape, so it was imperative not to administer the medications when Mom's BP lower than 85/35. The same was true with her heart rate, we needed to slow her heart down, it was still beating at almost 100 beats per minute at rest in bed.

Mom's new heart rate target was in the 50's at rest and 80-90 with exertion. But heart rates in the 40's are too low, even with medication, so these meds were also withheld when her resting heart rate was below 50 in the morning. Mom also took pills to control her "rhythm" and the blood pressure and heart rate monitor we used could also detect an irregular heart beat. Mom also needed a "blood thinner" to prevent the blood which pooled in her heart from forming fatal blood clots. Too much of this medication could cause internal bleeding. The final medication was a diuretic, with CHF you have trouble clearing fluids from your body, they build up in various places, most seriously the lungs, and you can literally drown, although most people usually just wind up back in the ER.

CHF patients on average get re-admitted to the hospital once or twice a year, the Floor Doctor had been right about that. The trick to staying out of the hospital and the ER is to weigh yourself every day. A weight gain of more than 2 pounds in a single day, or 3 pounds over several days, means that water is building up in your body, and a simple call to your doctor to increase the amount of diuretics you are taking can nip the fluid buildup in the bud before you wind up back in the ER. A doctor's visit is always wise, but the mistake many people make is to schedule a visit, which can be from several days to a week or more in the future depending on how busy your doctor is, and in that time the fluid buildup can get away from you. With Mom, I quickly learned that a call to the doctor, which always got an answer (even if from the nursing staff) by the end of the day, was much more effective than waiting to schedule a visit. When you are treating a serious medical condition, be the "Squeaky Wheel", it works really well!

(Note: CCC did a wonderful job with Mom's medications and treatment – Mom never had to return to the Hospital for CHF, and her EF actually improved to the mid 30's, or 300%)

CHAPTER 9

Rehab

AS MOM CONTINUED to improve, the staff and I began to make plans for Mom's release. It was apparent she would need rehab. While I was reluctant to have her leave the close care and immediate availability of the hospital staff, her lead doctor made a salient point; hospitals are unhealthy places. Most people don't realize this. In a hospital you are surrounded by sickness and disease, plus there are the psychological effects as well. So Mom would be headed to a Rehab facility. At least there would be round the clock nursing, daily doctor visits and a physician 'on call' when needed. So we thought.

Most Rehab Facilities are part of a Nursing Home. And we have all heard the horror stories. I wanted the best care for Mom, but between the limits on which Homes, sorry "Facilities", Mom's insurance would cover and which ones would accept patients with Mom's serious heart condition, the choices were very, very limited. I visited several "Facilities". What wonderful shows they all put on. You would think Mom would be staying at a local Spa in her own version of Paradise. I finally found a facility close to home which seemed to be perfect. Little did I know then what I learned later.

Call it "a facility" or whatever, Mom hated the thought of going to a nursing home, even if it was the last stop before actually coming Home. But I was quickly convinced it was necessary. Mom's ordeal had weakened her tremendously. She had had bad arthritis in both knees for the last few years, which made walking increasingly difficult. Now, not only had she suffered severe trauma from the cardiac arrest, but her heart was still very weak. Moreover, her entire body was weak from her month long confinement in bed. They say that it can take several weeks for even a normal healthy person to recover from being confined to bed that long. Mom was going to need to regain the strength to do everyday things, like going to the bathroom, getting dressed, and even walking up the five steps into our house. Only then could she come Home.

We said goodbye to the CCC and took another ambulance ride. But this one at least was toward home, and not a frightening ride into the unknown while facing death. Or at least I thought as much. However, almost immediately after our arrival at the ReHab things began to go awry. Many of the bad things you have heard about nursing homes, “facilities”, are probably true. And then some.

While Mom was ‘officially’ in Rehab, that just meant she stayed in a wing of the Nursing Home with the more sane patients and that she got an hour of therapy a day. The other 23 hours were just like being a Nursing Home patient. There were approximately 50 Patients in Mom’s wing of the Facility, which shared a single Nurse with another wing.

What this essentially meant was that the Nurse came by to give you your morning, afternoon and evening pills, and you never saw them again unless you pulled the “Nurse Call” rope. This lit a light by your bed and at the Nurses Station. They were supposed to come by ASAP to see what the problem was. And the problem could be anything, from chest pain and shortness of breath to needing a bedpan or help to go to the bathroom.

That light was a joke. I waited after Mom pulled it to see when a nurse would show up. After 30 minutes I walked down to the Nursing Station, no one was to be found, after another 5 or 10 minutes of searching, I finally found a Nurse in a room in another wing. You could die and rigor could be setting in before they responded to that light!

In fact, one day I heard a loud crash in the room next to Mom’s. The crash was shortly followed by screaming. Now I waited a couple of moments for the Nursing Staff to come running, but no one showed up. So I went and looked into the room. This was out of line (entering another patient’s room), but I was concerned. This poor elderly lady was lying on the floor under her wheelchair, crying for help. She had fallen over backward while trying to get into bed. I quickly went to the Nursing Station and asked them if they heard the lady screaming (we were told it was forbidden for us to touch any patients). The Nurse replied that patients were always screaming or yelling about one thing or another; if she really needed help she would pull the “light”. I suggested maybe she couldn’t pull the light cord because she was lying on the floor under her wheelchair!

This level of care was just not going to do for Mom. While cell phones were forbidden, the other patient in Mom’s room did not have a pacemaker, and neither did the patients in either adjacent room, and no one had IV’s which are also electronically controlled. I checked to make sure and then left Mom a cell phone. There were many times when she waited 15-30 even 45 minutes, for nursing assistance. Mom would call me and I in turn would call the nursing station and tell them to go see to Mom. Now the interesting point that I caught on to very quickly was that nurses and staff largely ignored the patients, but they responded to relatives ASAP. In most cases relatives arranged for the care and paid the bills, or at least administered finances for most of the ‘inmates’. So as long as the relatives were impressed and continued to leave Mom, Dad, Brother or Sister in The Facility, the Staff felt secure in treating their actual patients very poorly.

When the Son or Daughter stopped by for their obligatory 15 minute weekly, or more likely monthly, visit they were likely to tune out complaints from Mom or Dad. Just like they had tuned them out of their lives for years. My Mom had been right. She always told me no one wants you when you are old or sick in this country. How true. How sad.

This was in stark contrast to how my childhood friends from Europe viewed their parents and the elderly. Some parts of the world honor their elders. In the US we just wish they would pay for our college, leave us their house and their retirement money and then go quietly away. Go away and not interfere with our lives and raising our families. Given this attitude, it will be interesting to see how well, or how poorly our senior citizens fare in the coming “balance the budget” battles in Washington, DC.

On Sunday’s it was always so sad to see the rows and rows of wheelchairs come out, some patients peddling under their own power, others helped by the staff. They lined the main entrance hallways and waited like beggars in a soup line for someone to come and visit them, for their 10 or 15 minute obligatory visit from family or friends. I could have cried for the one’s whose family couldn’t spare 5-10 minutes of time for them that weekend. The Home combined all the worst features of a jail, an insane asylum and a prisoner of war camp. But prisoners serve their time and get released, the insane can hope for treatment and release, and all wars do end. The only end most of these poor people could hope for was death. I resolved to "spring" Mom as soon as possible.

We never saw the "daily visit" by the doctor either. Another myth to claim the insurance money. Doctors simply stopped by the Nursing Station and "read" each person's Chart. That was your visit. You had to actually request that they stop by your room, and if they were not too "rushed" they might actually drop by for a minute. Fortunately, Mom's regular doctor was one of the staff doctors, a key reason I had chosen this "Facility", and so she got pretty much regular visits after I requested than he be assigned to Mom. He was normally assigned to another wing and rotated with other staff doctors, but I requested him daily and the "keep the family happy" rules went into effect again.

Anything to keep the family happy. Already the staff was starting to dislike me. Good for me. Better for Mom. Squeaky Wheels upset their routine, you were supposed to stop by only once a month for your obligatory 15 minute visit, tell the staff what a wonderful job they were doing, tell your loved ones to be good and not complain so much, and then be on your way to the more important things in your life. Seeing the going's on during Mom's first day, I had vowed to spend as much time as possible with her. Events proved that was a very fortunate decision and kept Mom from becoming a statistic.

Mom was still on medications to control her Heart Rate, Heart Rhythm, Blood Pressure and fluid buildup, plus a strong "heart toxin" to strengthen her heartbeat and improve her Ejection Fraction. As we had been taught at CCC, there was little room for error in taking these medicines. For example some of the pills were very small, about the size of the old Saccharine Sweetener pills and Mom only needed ½ of one of these small pills per day. A full pill would stop her heart and kill her, but a quarter of a pill would not do any good and would delay her recovery. It was the same with Mom's BP, her target was a Systolic in the 80's with a Dyastolic in the 40's. Higher BP's meant you had to increase the dosage; however, when her BP was below 85/35, you needed to delay taking the next pill until it reached that limit, even if that meant waiting several hours. In addition, several pills worked together to produce the same effect, so you didn't want to just chug them all down at once ground up in applesauce like so many aspirin!

The proper procedure, the one we had been taught at CCC, was to administer some of Mom's pills, then check Mom's BP and Heart Rates an hour or so later and then follow up with the next group of pills. Mom was supposed to be taking her pills in several "batches" throughout the day. But Nursing Homes work on a clockwork schedule because with 60-70, even 80 patients per nurse they have to. The Nurses made the rounds to dispense medications in the mornings and evenings. All your pills were lumped together into the appropriate batch, smashed up in applesauce (Mom still had some difficulty in swallowing) to be eaten all at once. Likewise, Heart Rate and BP were only checked once in the morning. There was no time in the nurses busy schedule to be checking Heart Rates and BP and varying the times that medications were taken according to the readings. Plus, the Nursing staff each had their own idea of what was "correct procedure" and administered the various pills and medications accordingly.

This quickly caused real problems. Compared to the serious professional attitudes at CCC, the staff at the ReHab was almost cavalier in their approach to patients and administration of their medications. Perhaps that's because almost all of the nursing staff came from "Rent A Nurse", something else they don't tell you when you go on the "sign-up" tour. Perhaps predictably, "Rent a Nurse" quality ranged from poor to barely acceptable, just as you might find with any Temp Agency for clerical office help. Regarding Mom's medications, "Rent A Nurse" opinions were divided, some nurses thought that her BP was too low at 85/45 and withheld her pills. Others would freely give them at 80/35 when they should have been withheld. No time for niceties!

Since you were unlikely to see the same "Rent A Nurse" several days in a row, it was a constant battle with these nurses and the staff to get Mom's medications administered correctly. Each new "Rent A Nurse" had to be told in detail how Mom should be given her medications. It got so I would arrange to be there for the morning (most vital) and evening (2nd most critical) batches of pills, and check Mom's Heart rate and BP myself, refusing the meds if her HR and BP were out of their limits. A patient, can always refuse to take a pill, which is duly noted in the log. This avoided over or under medicating Mom and landing her back in the ER, but it did not resolve the missed medication issues.

However, I had learned a thing or two. One ironclad rule is that if it is written in “Doctor’s Orders”, the staff, even “Rent A Nurses”, will follow it to the letter. The threat of malpractice lawsuits or disciplinary action is much more in the forefront of their minds than patient care is. The stick and not the carrot in this case. So “Orders” written as “give BP medication if BP is over 85/40” (just the sort of prescribing shorthand doctors are wont to use) just will not do. Too much room for interpretation.

But if written as “check HR and BP immediately before administering medications, if less than 85/40 recheck BP hourly until 85/40 or higher and then administer”, it will get done correctly. I called my friends back at CCC and had the Head of the Intensive Care Unit dictate new instructions directly to the staff at the Facility. Of course Mom’s local doctor had to sign off, but in practice no local doctor is willing to risk going against the orders and medications prescribed by a high level physician at a major hospital. Now, finally, Mom got her pills as prescribed and her condition started improving rapidly.

On my visits to check out this Facility, everyone had been very accommodating, assuring great flexibility in visiting hours and promising lots of medical and rehab care. I had already seen the medical care, and rehab was along the same lines, an hour a day all at one time. In reality it was about 30 minutes, they counted the time from when the nurse got you out of bed, until she put you back in bed. Just enough to collect the insurance money. Now don’t get me wrong, Mom was not up to vigorous exercise or long workouts, but several short exercise periods each day would have been better.

After the first few days in The Facility, it became apparent that when a family member was present, the quality of care improved greatly. Sort of like during WWII, the Germans would hand out Red Cross Parcels and provide firewood for the stoves just before the Red Cross visited a POW Camp. So I decided to take them up on their “flexible” visiting hours and stay with Mom as much as possible. I would come by the first thing in the morning and stay through Mom’s morning meds, then go to work and come back in the evening after work. Normal visiting hours ended at

8pm, but this place was supposed to be flexible, at least that's what they said when I was checking out the various Facilities. After they made me leave at 8pm for several nights in a row, I had another chat with the Chief Administrator, and got to stay until midnight. By then Mom had had her last medications and was ready to go to sleep anyway. I'd come back at 6am when Mom woke up and cheer her up by bringing her in some real food for breakfast.

The Facility's "food" (calling it food is too generous) would gag a maggot. It was supposedly "diet controlled", which in Mom's case meant low sodium and potassium, and little or no caffeine. Sodium is a no no with CHF, because it makes the body retain fluids. Mom was limited to 2000 mg a day. To put that in perspective, a few shakes of the salt shaker can be as much as 500 mg, a Hot Dog can have 800 mg, and that can of soup or chili a whopping 1200. I learned to read labels closely. Potassium is one of those elements that the body needs just the right amount of, too much or too little can cause heart rhythm problems. Caffeine can too. Mom didn't need any more of those!

With Mom's medications in balance, and being administered correctly, plus some good low sodium food that I brought in and daily exercise, Mom made rapid progress. After a couple of weeks they would let me take her out for a few hours on Sundays. The first place we went was to our favorite local restaurant, a Sizzler Steak House, for their Sunday Brunch. True, Mom had to use a wheelchair, which took some creative stuffing to get into my car, but for the first time in two months Mom was out of the hospital!

Mom hated the wheelchair, but to me it was a mixed blessing. While I appreciated how tough and independent Mom was and how much "wheeling" around hurt her sense of independence and pride, I also understood that Mom had very bad arthritis in her knees to the point where walking was difficult even before she had CHF. In her still weakened condition we didn't want to risk over taxing her heart or having her slip and fall. The wheelchair put less stress on her heart and knees than walking did. As November and the Holidays approached, I really began to believe that Mom would actually make it home and be able to resume her life, perhaps with some activity and diet adjustments, but a long long way from the betting pool on her survival the day of her Cardiac Arrest!

Once we had Mom's medications under control, one of the keys to getting her out of rehab was stair climbing. We had five narrow brick steps at home, and Mom would have to be able to climb them to get into the house. This had been an increasingly painful process with Mom's arthritis, but now it was going to be a tremendously difficult process in her weakened condition. Climbing stairs, even a few steps, takes the breath away from people with CHF. Mom still had an ejection fraction in the 20's, and any activity, even standing or normal walking, was going to be very stressful and exhausting. The fact that Mom had spent weeks in bed wasn't going to help much either. Prolonged confinement to bed allows your muscles to atrophy. Those five brick steps began to look like Mount Everest to Mom. A very serious obstacle to going Home.

But Mom was regaining strength every day and she got to where she could climb eight steps in Rehab. It looked like we would be leaving for home soon. But not before another, stupid silly situation, landed Mom back in the ER. The routine of checking Mom's Blood Pressure and Heart Rate before administering medications was by now well established, as were the thresholds, do not administer medications if BP was below 85/40. One night Mom's BP fell to 78/38. She seemed fine, but we delayed her pills as instructed. The next morning her BP was still hovering around 80/40, and not only did we skip the pills, but the Nursing Home staff began to get worried. Mom and I were not worried, the Doctors at the CCC had been specific, keep the BP LOW, just don't give any more medication until it came back up. Period. But the Nursing Home Staff panicked and called 911, so Mom and I got treated to another ambulance ride.

We were taken to a different hospital than she had been to before because her family physician, the attending doctor at the Nursing Home, practiced there. I had learned to keep on top of things, an absolute necessity, so as soon as we hit the ER I briefed the Admitting Nurse on Mom's complete condition and medications. She made some notes, muttered something and left. Now understand, Mom was fine all this time, and I was getting worried that the ER people would precipitate some problem when there wasn't one, at least as far as Mom and I could see. A little while later, the In Charge Nurse came by, took Mom's BP, read her Chart, and turned around and asked, with a straight face, "what are you doing here?" Mom was doing just fine with the medications she was taking. Now if you or I walked into an ER with a BP of 80/40 they would probably have the Crash Cart out, which is what worried me, but the very low BP was the intended effect from all of the pills Mom was taking, and not all that uncommon in CHF patients.

The Nurse monitored Mom's BP every 10 minutes for almost another hour, and it stayed in the 80-85/40-45 range, coming up slightly as her pills wore off. These strong medications could build up in your system and the effects could easily last for a day, the Heart Rhythm pills, called Amioderone, would continue to work for over a week after you stopped taking them. The body could suddenly react to the Digoxin and develop what was called Digoxin Toxicity, which would lower your heart rate too far and could even stop your heart, a fatal interaction if you were not treated at once.

That's why the way a patient "presented"; breathing, lucidity, pallor, plus BP and Heart Rate, were ALWAYS checked before administering any of these medications. Once the Nurse had determined that Mom's BP was at least holding, if not rising, she said Mom would be released after the ER Physician stopped by. And he did just that, stuck his head in between the curtains used as a screen and said "You're Fine – Go Home".

I would be happy when we made it all the way Home, I was tiring of the Facility Staff, as I am sure they were tiring of me. I was also beginning to believe that I could handle Mom's needs and medications as well, if not better, than they could. By the end of the week Mom could do the "practice steps" in the Rehab Center twice in one session, so it was high time to go. Mom was given her own pretty new blue wheelchair, which mortified her, but which was going to be necessary for a while for all but short trips around the house. Mom would make it Home for the Holidays after all. Wonderful!

So one crisp Fall day we packed Mom and her new blue wheelchair into my car and made the 5 minute drive Home. Mom made the painful walk up the five brick steps, and through the house and into her favorite chair in the Living Room. It had been a very long couple of months since Mom last sat in that chair. It was the happiest day of my life!

CHAPTER 10

Home Again

AS HAD BEEN the pattern with our lives, good times and triumphs were followed shortly thereafter by a fresh round of disappointments and tragedies. Not that what happened next was a tragedy, in fact my friends said it was a blessing in disguise. But to me at the time it was another bitter disappointment. After years of casual relationships, I had finally been ready to make a commitment and settle down. I had a fiancé. We had been close for several years and she had helped Mom and I with the Deli on weekends.

While she had been supportive during the ordeal with Mom over the past several months, she was very upset when Mom came home. She had preferred that I just consign Mom to the nursing home permanently because home care was going to take up too much of my time and "Mom was going to die anyway", hopefully sooner rather than later. Another one. Let's improve the quality of life by killing off the old people.

My fiancé had been adamant that I leave Mom in the Nursing Home while we waited, or should I say while my fiancé impatiently waited, for her to die. Sorry, but I still believed that Mom had some good years left in her and I wouldn't consign my worst enemy to a Nursing Home if there was any other alternative. And there was. In a way it was better, I would be able to devote more time to caring for Mom without a new "wife" in the way.

You never realize what an obstacle course your house can be until you are unable to walk and need a wheelchair to get around in it. My advice to all seniors, and by that I mean anyone over 55, is to live in a one story, ground floor house that is wheelchair accessible. You never know when you are going to have that slip, fall, stroke, heart attack, or other medical emergency that makes climbing stairs difficult or impossible.

Imagine waking up one day and you can't walk, or can barely walk. I had been there for days at a time with back problems, and Mom had been having increasing difficulty for years with her knees. But that was nothing compared to the prospect of recuperating for months in our house. The bedrooms and bathroom were upstairs. The downstairs "bathroom" was actually only a spare toilet in the laundry room. All of Mom's clothes and personal things were upstairs, which in our house was two flights, and they were even narrower than the outside steps. So Mom was going to live on the first floor for a while and things would have to be re-arranged accordingly. The first thing I did was make the whole downstairs "wheelchair" accessible. I moved everything out of the way so Mom could make if from her favorite chair to the bathroom in the wheelchair. Clearing the wheelchair path also made it easier for Mom to navigate when walking.

Next, I bought Mom a new powered "recliner" armchair, the full reclining type, which was also actually good to sleep in because with CHF you are better sleeping with your head raised a little. The new recliner was wonderful. Not only did it require only the press of a button to raise and lower yourself, but it would raise you up to virtually a standing position, and from a standing position you could step back "into" the chair and lower yourself down into a sitting position. The transition between getting up and sitting down is even more strenuous than actually walking, and the power recliner relieved a lot of that physical stress on Mom's heart and knees. Mom loved it.

I put shelves up in the living room and moved most of Mom's things down from her bedroom upstairs. The living room became her new bedroom, the kitchen her dressing room and the laundry room a bathroom. For the first few weeks Mom had to take sponge baths in the kitchen sink, she still couldn't make it upstairs. We finally re-arranged the laundry room to include a stand up shower, finishing the conversion of our two-story house into a one story living arrangement. I think that all senior citizens should live in ranch houses. It is something we never think about until the day the simple trek up two flights of stairs becomes an impossible task. Food for thought.

At this point I was still working, and I needed some way for Mom to get help when I wasn't home. The daily nursing visit lasted only an hour at most and unless your insurance covers it, most of us simply can't afford all day care. Mom had a cell phone, which she carried in her pocket, but as always I wanted some backup. So we put in one of the “Life Alert” systems that are supposed to alert people if you are hurt or injured. You carry a Panic Button which activates the system, and then they speak to you over the “intercom” which supposedly works well even from several rooms away.

We put it in and tested it. On several test tries it took over a 30 minutes for the people to respond, and then you had to be right in front of the unit to hear them or be heard. We sent it back. Mom’s small, pre-programmed, cell phone proved to be the best protection. If Mom had another attack and was unconscious she wasn’t going to be able to “push the panic button” anyway. And if she was not unconscious, then she could just as easily push the one button preprogrammed Speed Dials on the cell phone! With 9 buttons we had one programmed for me, for the doctor, and of course 911, everyone that mattered. I might have been at work, but I was never out of touch.

The “in-home” nursing was a bigger joke than the Nursing Home nursing. They came by several times a week to make sure you were still alive, and check your BP and Heart Rate. Just enough to collect the insurance money for “In-Home Health Care”. I checked Mom’s BP morning, noon and at night and kept close track of her medications, how much and what effect they had (such as making Mom sleepy, drowsy, lowering her BP, HR etc) in a Log Book. I also weighed Mom daily, which she hated but which was necessary, and kept that in the log. The doctors loved it, the first thing they wanted to see each visit was my Log Book. It told them volumes about Mom’s condition, progress and the effects of her medications. As onerous as Mom found the daily checking and weighing, for almost two years she never had to be readmitted to the hospital for CHF or other heart problems. The average for CHF patients was once every six months.

I also discovered a Big Secret. Call the doctor. If I even suspected Mom was developing a problem, gaining weight (fluid retention) or not responding to her medications properly, I called the doctor. Mom, like most people, hated going to the Doctor, and it can take a few days, forever when you have CHF, to get an appointment. This delay can have deadly consequences if you are building up water in your lungs. I found that if I called the doctor, and simply stated the issues I was concerned about and relayed Mom's past few days of Log Book Data to them, they could often advise medication changes right over the phone, and follow them up with a new prescription faxed to the pharmacy. Most issues could be handled with a five minute call, and that way we avoided many trips to the doctor, or worse to the ER and another stay in the hospital.

Mom had a plethora of pills. Unlike the brain, the heart is a muscle and modern miracle medicines can actually make it stronger after trauma, infection or injury. And as we both learned the heart has built in "excess capacity". Mom would get better. How much better and how fast remained to be seen. Remember that just before her attack she was running a Deli hands-on and managing a Real Estate Office, plus trying to start a Sushi Business on the side. At 77 years old Mom never sat still. And it was not my intention to have her chair bound, or worse constantly in and out of hospitals, or even worse confined to a dreaded nursing home. We both believed she would lick this and we were both fighters. We would beat this, but it wasn't going to happen overnight.

CHAPTER 11

Finding a Cardiologist

IF YOU HAVE CHF, choosing the correct team of doctors when you get out of the hospital, starting with a crack cardiologist, is one of the most important things you can do to help yourself. We both knew that one of the key components of the healing process was going to be finding and frequenting a top notch cardiologist. While I would have preferred to continue having CCC treat Mom, they were not set up to provide primary cardiac care. That was the province of your local cardiologist. The best I could arrange with CCC was to schedule routine quarterly checkups for Mom on an outpatient basis.

I had not been overly impressed with the cardiologist Mom had been seeing just before her attack, the one that just sent her home with some pills the day before her Sudden Death episode. I'll always believe that if she had been admitted to the hospital and had had supervised medical treatment immediately as result of that visit (doctors have been known to send CHF patients directly to the ER from their office), she may never have had her attack which nearly killed her and set her back months in recovery.

That was my first experience with the cavalier way CHF is treated by most doctors, but there would be more episodes. Heart Attacks, a true Myocardial infarction or Cardiac Arrest, are immediate life threatening events that require fast medical intervention for survival. CHF on the other hand is usually a longer term process where low cardiac output causes fluid retention in the body and sooner or later in the lungs. This water in the lungs causes the chronic cough and "out of breath" symptoms so often associated with CHF. It is most often controlled by medication, diuretics to control fluid buildup and one of the digi toxins to strengthen the heartbeat, with hospitalization reserved for extreme cases of breathing difficulty and dangerous levels of fluid buildup in the lungs.

What they don't tell you, and what I found out only by quizzing doctors and nurses and research on the web, is that Sudden Cardiac Death occurs in many people with CHF due to the added stress being placed on their heart. Recall, Mom's doctor told us a few days before her attack that her condition, Moderate to Severe CHF, was "not immediately life threatening". And technically it's not, not until your over stressed heart stops beating.

A stunning fact that I learned from doing my own research was that many, if not most, people with CHF do not even visit a cardiologist, they rely on their own primary care physician (family doctor) to prescribe the right does of the blood pressure, heart rate and diuretic medications. I was shocked to learn this. The reasons for it are caused by the relative scarcity of cardiologists compared to the millions who suffered from CHF, something like 5 million people, and increasing annually as the Baby Boomers age.

The scarcity of cardiologists in this country became all too apparent as I tried to get Mom treated by one. The wait for an appointment was sometimes measured in months. And not all of them would even accept patients with Mom's complex condition. There is no glory in treating elderly people with CHF, the glory is in Cardiac Catheterizations and Open Heart Surgery. Among available cardiologists, few were experts in treating CHF.

We found three CHF "specialists" within driving range, all recommended by CCC. One refused to treat Mom, he was the doctor who originally treated Mom with the balloon pump in the local ER and saved her life. He said her condition was much too complex and she should be treated CCC, period. He pulled some strings to get more frequent visits to their clinic and taught me how to call them and work with them over the phone, resolving many problems before they got serious. A smart man, a great doctor.

But Mom still needed a local cardiologist. So on to Number Two, his attitude was pathetic, go home, take your pills, don't expect to recover and make your peace, after all you've lived a long full life at 77 right? Another one. Go die quietly. The glory was in treating babies, kids and those under 50, with a "full life ahead of them". The impact of this attitude on a patient like Mom is hard to measure. Mom wanted to get well, and the poor attitude on the part of some doctors caused mental setbacks which didn't help.

Doctor Number Three. Now here was a real gem. His practice specialized in CHF for the elderly and his waiting room was filled with senior citizens older than Mom. He started with a thorough explanation of Mom's condition and medications, not assuming Mom understood anything that any previous doctor had told her, including those at CCC. He also actually read her charts and her complete file (by this time I carried them in a briefcase with me to each doctor's office) and he also consulted with the staff at CCC.

Mom wanted to hear that she was going to be better in a few weeks. But this wasn't a cold, it was a condition and long term treatment was needed. However, it could be treated and controlled and Mom would improve with the right care, which he'd make sure she got. What a breath of fresh air. While still depressed about her situation, she caught a glimmer of his optimism and it took hold. We had a good cardiologist at last.

It was obvious that for the first few months, Mom was going to need more care than a ½ hour visit by the "Visiting Nurse" every other day. So I planned on taking Family Medical Leave (FMLA). While normally associated with maternity leave, FMLA can be used to care for a close family member as well. Up to this point, work had been very cooperative, I had put in as many hours as I could, and spent time "working from home" via PC and Internet; which was company policy and which many of the executives frequently did. I had also used up all my accumulated vacation and sick time, which was substantial since I had previously only rarely took a day off. Work had been very tolerant of my changing schedule, working at home, and taking days and time off.

Right up to the point where I applied for FMLA. I had discussed taking leave with my boss, personnel department and the owner of the company, and all had given me verbal assurances that it would be approved, and had even helped me fill out the paperwork to apply. This involved a few weeks because a significant number of medical opinions and references were needed, and the doctor's offices were not in any great hurry to fill out paperwork unless it was an insurance claim. But I figured I was all set. Dumb me.

The morning after I handed in the paperwork, I was summoned into my boss's office, to get the approved leave papers back I thought. Instead I was bluntly told that I was being fired. Your Fired. The company conveniently sidestepped the FMLA legalities by "eliminating" my position; since I was an executive in charge of four departments, that took a lot of organizational gyrations to accomplish. They temporary assigned my departments to other executives, I guess until the FMLA statute of limitations ran out.

It is a travesty to think that the FMLA Act does anything to protect people in my situation, family care situations. Due to societal pressures, pregnant women in menial jobs are protected. But if you are in any sort of senior management position, and if the leave is to care for a family member instead of yourself, forget about it. There are so many loopholes in the law it's a joke, and when the need for FMLA comes up, who has the time or money to hire expensive attorneys to fight Corporate America in court?

They fired me at the end of November, right before Thanksgiving. They even gave me the severance package we had negotiated when I started the job. That was nice, because they had a reputation of repudiating their agreements and I was in not in the financial position to take them to court. Now I had plenty of time to spend at home with Mom over the Holidays, and no immediate money worries for the next few months.

At this point I was still living day to day, and a few months seemed like a lifetime in the future. There would be time for doing marketing consulting and to work side by side with Mom in Real Estate, she as the Broker and me as the Mortgage Loan Officer making sure her deals could be financed and closed. But for now, we had a lot of time to spend together over the Holidays. Time we almost never had. Very special time.

In some ways those were the best Holidays of my life. They were extra, or as the commercial says; "priceless". Back in September I didn't' think the odds were in Mom's favor to ever see another Thanksgiving or Christmas, much less celebrate another New Year. We had fun decorating, and fixing up the house for the new living arrangements. By Thanksgiving, Mom was strong enough to make it to the bathroom without the wheelchair. And she could make it up and down the outside stairs well enough to go out for car rides. That opened up all sorts of possibilities. We were out and about again.

Mom was never one to stay at home, and our car rides became the focal point of the day. We would eat lunch out, and try to take in the boats by the water, or a sunset, as well as some shopping each day. We'd bring the wheelchair in the car, and Mom soon learned how to "pedal" herself up and down the aisles of her favorite stores. She didn't' have the upper body strength to use her arms to move the wheelchair, but we took the foot rests off so her feet could reach the floor and she would "walk" herself through the store. Sitting in the wheelchair took the pressure off her bad knees and put less stress than standing did on her heart, while the "walking" provided low impact exercise and also helped flex her knees. It worked and Mom enjoyed it. Even the doctors approved!

When we went food shopping we discovered they had powered shopping carts for the disabled. I loved them, but Mom found them frustrating. They were hard to control in both speed and steering and would often "crash" into displays some idiot had placed right in the middle of an aisle. Mom was mortified, but I loved it! We left a jumble of splattered displays down every aisle. I loved it because there are thousands of Senior Citizens in our area and nobody ever pays them much mind. For years I watched them struggle to wiggle and worm their way past these displays that turned grocery shopping into an obstacle course. Well, Mom turned their obstacle course into a Demolition Derby. After a while, I noticed that the "pathways" at Mom's favorite local food stores started to be more open, easy to navigate, and accessible. Much better for everyone!

Mom showed good improvement through the Holidays. We were able to go out and stay out for several hours at a time and she no longer needed the wheelchair to get from her chair to the bathroom. In fact it seemed that the limiting factor to Mom's walking was now more her arthritis than the weakness of her heart. They were the best Holidays of my life. As winter wore on and Mom continued to improve, she was able to do more and walk more. There was a day in late February when Mom walked into, and showed, a house, and then closed the deal on the spot with the buyer. That was one of the best days of my life and made me very proud. Mom, who was never one to quit and who sat up in the ER after having just been shocked back to life and said "Can I go now, I have work to do?" was out showing houses and making deals in spite of having nearly died.

Mom continued to improve steadily throughout the Spring. In May, her longtime friend, Pat, was hospitalized for CHF for the 26th time. Pat had both COPD lung disease and CHF and had been in bad shape for years, and getting worse. This time the doctors at the local hospital said there was nothing they could do, his heart was so weak and his lungs so deteriorated that they said he should just go home and get his affairs in order. They said he had only a few days to live, and suggested he go on Hospice for the short time he had left. Sound familiar? His wife, family and my mother were all devastated.

What a difference a few months made. The prior Fall Pat had visited Mom on her deathbed, now Mom was up and about and seeing her friend Pat on his deathbed. But my experiences with Mom had taught me a thing or two. Don't give up. And don't rely on just one medical opinion when your life is hanging in the balance, I suggested that Pat go to the same CCC that had saved Mom. Pat was convinced it was hopeless, but like Mom he was a fighter and he got a transfer to CCC. The next day he was at CCC. Wham! You have never seen such rapid action, tests, tests, tests, no "come back in a week". Get it done. Today. They worked as if a life hung in the balance because it did.

When my Mom walked into CCC with Pat, she was greeted with an ovation from the doctors and staff. Many came down from their rounds and the ICU unit to see her and shake her hand. A miracle had just walked through the door. Now it was Pat's turn.

By evening of the day Pat had checked in, they had come back with both a diagnosis and a solution. Pat's heart was extremely weak and was beating irregularly, the combination meant he was dying simply because his heart could no longer provide for his body's needs. The solution was a brand new device (at that time) which combined the functions of both a Pacemaker and a Defibrillator. The Pacemaker would make the heart beat "stronger" by getting both sides, or chambers, beating in snyc with each other, and the Defib action would shock his heart into a sinus rhythm every time is started to beat erratically. The miracle device would be implanted under the skin in his chest and the life saving operation was scheduled for the very next morning.

Immediately after surgery Pat looked pretty poor. He was in pain and the Defib kept shocking him almost constantly, vivid testimony as to how bad a shape his heart had been in. But the amazing thing was how much more alive he seemed, even right after the operation. His appetite and feistiness had returned, and within several days he could get out of bed and walk. It's amazing what a properly functioning heart will do for your overall health! Within a few weeks, after the hospital had finished adjusting Pat's medications and monitoring his recovery and the device's functioning, they sent him home. Pat ended up living six more years and died from his COPD and not the CHF.

So much for go home and put your affairs in order! To his dying day, Pat maintained that CCC saved his life as well as Mom's. And countless more. There is a moral here, if you have any sort of heart problem, don't fool around with the generalist staffs at your local hospital, check yourself into the best Cardiac Hospital you can find right away!

Birthday's had always been special for Mom and I, we liked to celebrate them together. Just like Christmas 2001 was an "extra" Christmas we might never have had, Mom's Birthday in July 2002 was very special. For Mom's Birthday her friend Jack and his wife came down to visit her. It was another one of those priceless Moments. How priceless I didn't know at the time, for it was to be our last one together. Back in September, I would have given odds against Mom ever seeing another Birthday, much less being out and about to enjoy it. Mom had been out of the Hospital and Rehab for 9 months now, and she had had no re-admittances for her CHF, and was still getting stronger.

She still used the wheelchair for long distances, but she was able to walk through houses, around the yard, into her friend's houses and even stand and fix food and her flowers. Her heart was getting stronger too and the doctors were all impressed during her quarterly checkups. So we set out to enjoy her Birthday, the four of us went up and down the Seaside Boardwalk, rode the Merry-Go-Round, soaked in the sunshine of a gorgeous mid summer's day and ended up eating at the Top of The Mast, one of Mom's favorite restaurants by the water. She had been doing so well, I looked the other way and let her have all her favorite foods regardless of the salt. But Mom suffered no ill effects from her Birthday outing, such was the progress she had made in healing.

CHAPTER 12

Living with CHF

MOM AND I had always eaten out often, both together and separately. During her career as a Real Estate Broker she specialized in selling restaurants, and knew most of the local restaurant owners on a first name basis. My job as an executive had me eating more "fast food" than I care to admit, rushed burgers between rushed staff meetings or the ubiquitous deli sandwich tray provided for the marathon executive meetings. While we had always eaten very healthy at home, eating out provided a special set of challenges. I had been aware of the dangers of too much fatty and fried food, but it took Mom's CHF doctors to also make me aware of the perils of too much salt, or sodium.

Sodium. This key element helps the body retain fluids and is vital to life and good health. The problem is that most Americans get 2 or 3 times the amount they need on a daily basis. In some people this causes excess fluids to build up raising blood pressure and straining the heart and kidneys. Fluid buildup is the nemesis of people with CHF, so they are placed on low sodium or no sodium diets. Mom was placed on a 2000mg per day low sodium diet. The doctors explained how people with serious CHF, like Mom's, could require hospitalization after eating one large Chinese Food dinner or Deli Submarine Sandwich; both are loaded with sodium. They even advised that I follow this diet as well, not because I had heart problems, but simply to avoid them in later years. Later years used to be your 60's and 70's. Now they are your 80's. As we live longer, things that you didn't think about when you were younger begin to take a toll on you.

At first, even for Mom and I, it was a challenge to stick to the 2000mg daily sodium "ration". Let's put that into perspective, those couple of shakes of salt on your morning eggs could be up to 500mg of sodium. A normal hotdog has 500-600mg, some have almost 1000. And don't forget to add 150-200mg for the bun, and another 100-200mg for those dollops of ketchup or mustard. I say dollop because some people drown them in condiments like pickle relish and sauerkraut which can total more sodium than the hotdog. One good "loaded dog" can easily provide almost a full day's sodium ration.

Restaurants are notorious for very salty foods because salt is one of the flavors easiest to "taste" in our mouths and it is used to give lots of different foods the intense flavors that we enjoy. Salt is also one quick and cheap way to make fast food taste good. It was surprising that after months on the same low sodium diet as Mom, food actually began tasting better with no salt than it had with salt! The natural flavors were not being covered up with saltiness and my mouth's taste receptors had healed from "sodium burnout". I discovered a world of other spices to add flavor to our food.

But back to eating out. A Fast Food Burger, Fries and Soft Drink can have more than 2000mg of sodium. So Mom and I learned the tricks of low sodium dining. First, forget the Salt Shaker. This was fairly easy because Mom had never been a big salt lover. It was harder for me because I used to use several packets of salt on my already salted Fast Food fries! The Fast Food chains will make your fries "without salt" if you ask. Ask. There are already several hundred mgs of salt in the basic fries before they cook them (added I presume as a preservative because they are frozen) and there is no need to liberally shake salt all over them when they come out of the deep fryer. The next things to watch are the pickles and the cheese. Pickles are cured in salt and the cheese, especially the cheap yellow American Cheese they use, is loaded with sodium, up to 400mg in a single slice. And did I mention the Bacon on a Bacon Cheeseburger?

While there are ways to cut down on sodium, you can't eliminate it entirely. Thus, in addition to reducing sodium where we could, I managed our menu over the day and tried to get the saltiest foods in at lunch while Mom's morning doses of diuretics were still the most effective. If we had burgers for lunch we had salad for dinner. We even managed to eat at our favorite places, those infamous Chinese and Japanese buffets.

Asian food is notorious for its high sodium, and the doctors would cringe every time I mentioned Chinese Food. But with portion control and by leaving the Soy Sauce alone just the way we left the Salt Shaker alone, Mom and I ate Chinese food at least once a week without any ill effects. The secret is that the daily sodium ration was just that, a daily ration, not a "by meal" ration. If we went over the allowance one day, we cut back the next, mostly by eating home cooked meals where we could control the sodium.

Shopping for low sodium food became a challenge just like eating out. We both became avid label readers. You'd be surprised how much sodium was in everyday supermarket food, especially canned foods like soup. Most soups are loaded with sodium, perhaps as much as 1000mg a serving. Mom and I used to love watching popular cooking shows. While many were "calorie" conscious and advocated use of healthy "anti oxidants" like garlic and oregano, a simply tally of sodium content in many of their TV meals came to well over 2000, or even 3000 mg. Your whole daily sodium allowance in just one meal!

If you shopped in the right stores and looked in the right places you might find a health food section with low sodium items. In general these items had less than ½ of the sodium that regular items did. Not all low sodium foods taste bad either. I learned to "doctor" up these foods with alternative spices, which made them taste quite good. And after a while your taste buds get off their sodium addiction so foods with only a bit of salt taste as good as ever, and the foods you used to eat now taste unbearably salty. Now when I get Fast Food and forget to ask for fries without salt, they taste so salty I almost gag and have to throw them out. We Americans have become addicted to salt.

I also learned the places that sodium "hides" in our diet. That hunk of pickle with your burger can have several hundred mg of sodium. Ketchup, mustard and condiments generally have several hundred mgs per teaspoonful, and some people use almost a cup load of ketchup with their fries. Bread has a fair amount of sodium 100-200mg per slice, or 300-400 mg per sandwich. Deli Lunchmeats are loaded, and while there are some low sodium brands, even they will have over 100mg per slice. So that ham and cheese sandwich with mayo and a pickle slice is going to run well over 1000mg of sodium even using the "lower sodium" products. Add salty chips and you have a day's sodium ration!

The doctors told us that not adhering to sodium restrictions was the number one reason people with CHF were re-admitted to the hospital.

And patients try every way to get around them. I know Mom thought I was overdoing it at times. I remember one doctor told us about a lady who kept going to the ER with excess fluid buildup, CHF. She finally admitted a craving for pickles, but claimed they couldn't possibly be the problem because she always washed the salt off before eating them! So we watched the sodium, and weighed Mom every day. While it was a pain, Mom never did have a fluid buildup problem and in the for what it's worth department, I lost 10 pounds over several months, due to the low sodium diet, and felt healthier and had more energy.

As Mom got out and about more, one of the challenges was keeping her medications on schedule. There were specific medical reasons that certain pills were given at certain times of the day. Heart Rate, Rhythm, Blood Pressure and Diuretics were all given in the morning, with some follow-up doses in the afternoon and evening. We both had already learned how important knowing your Blood Pressure was before taking the pills. I bought a small battery powered blood pressure machine which took readings right from your wrist. We took it to the doctor's office to have it "calibrated", and it worked just fine. In fact it was better than the "old" stethoscope method of taking BP which can be highly subjective depending on who is doing the reading, or "listening". Nurses are so used to only having to tell the difference between 120 or 130 over 80 or 90 that the nuances of 90/45 versus 85/40 are completely lost on them. So go digital.

We'd just bring Mom's little wrist BP unit along and take readings and pills as needed. Both Mom and our family doctor thought this was overdoing it. But the cardiologists were of a different opinion, taking your medications at the right time of day and in the right doses was of critical importance if you wanted to stay out of the hospital. It was even more important if you actually wanted your heart to heal. Unlike brain damage, heart damage can be healed with the proper medications because the heart is, after all, a muscle. Administering these medications, especially the Digi-Toxin family, must be very precise. Too little and they have no effect, too much and they can kill you.

In Mom's case she was taking a very low dose of Digoxin, a few mg's a day, about half of the smallest pill they made. Now that is a very small pill, smaller than an 81mg Aspirin. And it had to be cut it in half just right; take a full pill and it could be fatal, take less than 1/3 of a pill and it had no effect. You had to cut that pill very carefully! It was administered in the afternoon after all of the other medications had time to take effect and Mom's Heart Rate and BP had established their baseline readings for the day.

This sounds overly complicated, but Mom's condition was a moving target. When first out of the hospital her Heart Rate would be around 90 even at rest, and rocket to over 100 with very little exertion. Over 100 was dangerous territory and could trigger another Arrhythmia. In fact when her Heart Rate was over 100, the irregularity in the beat became noticeable, you could feel it taking her pulse and the BP machine would Error Out. The first time this happened, I almost panicked, and put in a quick call to CCC before deciding whether to go to the ER or not. They explained this was "normal" in Mom's condition and a trip to the ER was not necessary because it should subside in a few minutes, just watch it. It did, and we continued to go get Mom's hair styled.

After the strong medications began to take effect, the opposite problem would occur, one time after Mom took her pills her heart rate fell to 50. Now less than 60 is not particularly good either. So another call resulted in being told to hold the medicine, and watch Mom. How a heart patient "presents" is a key factor in evaluating their condition. The strong medicines will drive Heart Rates and BP to levels that would have you and I out cold in the ER, but these are medically induced rates, and can be tolerated by heart patients. As long as they are awake, can breathe without difficulty and are coherent, with good color and without chest pain, they are probably OK. If they have poor color, seem sort of delirious or dopy, not fully lucid, and have trouble breathing and/or chest pain, STOP, do not pass GO just get to the ER immediately! Or better yet, call 911.

I remembered back to that day in September when Mom had definitely not "presented" well and getting her to the ER in a few minutes saved her life. But now Mom said she felt great, her BP and color were fine, and she had no pain. In fact, she couldn't understand why I was concerned. She was acting a little silly like she had had a drink or two, but the doctor I spoke to on the phone had said that was a byproduct of the low low heart rate and without any further symptoms, or further reduction in heart rate, a trip to the ER was not needed. I remember we sat in the Chinese Restaurant with her heart rate slowly coming back up to the low 50's and then almost 60 by the time we got home. I'm sure I presented better after Mom's heart beat reached 60 again!

Your heart rate is at its lowest when you first wake up in the morning and highest before you go to bed at night. I remember mornings when Mom's pulse was very firm, but so slow there was a noticeable interval between beats. Thump . . . . Thump . . . . Thump . . . . on some mornings her heart rate was as low as 40 beats per minute. Now that's just not healthy, and at this point the doctors would have me suspend her Digoxin, the primary medication that lowered her heart rate. Eventually we cut it out completely, but by then Mom's Heart Rate was between 55 resting and 95 with activity, and her BP was between 80-100 over 40-50, right within the parameters we wanted.

As later events were to show, this course of treatment worked, and her ejection fraction made it up from 10 after her Cardiac Arrest, to 20 when leaving CCC, into the mid 30's. While that's nothing to write home about, it sure beat the low 20's Mom had when she left the hospital, and represented about a 50% improvement in her heart's functioning. With an EF in the 20's you're pretty limited as to what you can do, but with an EF in the mid 30's you can live a good life if you don't over do it, take your pills and watch the salt. The effort to do it right had paid off and Mom still continued to improve.

CHAPTER 13

Struggle to Survive

MOM HAD NEVER been able to re-open her Deli after she came out of the hospital, and I would have been unable to run the Deli and give Mom the attention she required. The choice was obvious if not easy. Mom closed her Deli which was a huge personal and financial loss. She had loved her Deli. That was back during the Winter. And remember I had been fired when trying to take FMLA in the late Fall. Therefore, as Mom steadily improved during the Spring and Summer, our thoughts turned back to making a living.

The only viable income we had was from Mom's work in Real Estate and my work in Mortgages since a friend of mine had singed me up as a Mortgage Loan Officer. The Real Estate business is grueling in the best of times with unpredictable and long hours and lots of driving and walking. We both realized that while this would provide some income, the constant driving, travel and hours it required meant that it was not a long term solution. In fact, that was why Mom had started her Deli in the first place. Were I to return to corporate work, I would not be available to care for Mom, I was after all her "primary caregiver" since all of her nursing assistance had long ago ceased.

We turned back to the food angle. While the food business can be grueling, there were some options. Mom's partner in the Deli, Jack, was still interested in having a Sushi Catering business at the Jersey Shore even though Mom had had to close the Deli. When Jack and his wife came down for Mom's Birthday, they made a business plan. This was when Sushi was just becoming a "rage" in the major cities on the East Coast, and down by the Jersey Shore we felt that it would also become a hot item. We planned on establishing a small "take out" Sushi Bar, and also providing catering services and Sushi Chef's for local Restaurants during Happy Hours and on summer weekends.

Mom would run the business, which was basically sit down admin work and scheduling. I would do the sales and marketing, signing up the restaurants. And Jack would supervise the Sushi Bar and the Sushi Chefs. A nice little business where we could all use our abilities to make a living. Jack would have his own business which he desperately wanted, Mom would have a job less taxing than Real Estate, and I could put my business experience to use and still be around to care for Mom. A good plan.

And we made good progress. We had several large local restaurants interested in having Catered Sushi Chefs on weekends and during Happy Hour during the week. We had found a suitable small ex-bagel shop for rent which could easily be converted to a Sushi Bar, had developed business and marketing plans, and had scraped up our part of the working capital needed to start. But at the last minute Jack backed out because his wife wanted him to live and work in New York City and not the Jersey Shore.

Now Jack had also been Mom's original partner in the Deli, until he left several month's after it opened, signing over his piece of it to Mom. Mom had really liked her Deli and had struggled with the physical efforts needed to keep it open even after Jack left. Jack's reliability had been a major concern since we first talked about the Sushi Business, but by late Summer we had been planning it and visiting local restaurants for several months. Mom was willing to risk it, trusting Jack to follow through this time.

But it blew up in our faces at the last minute in late summer when Jack took his Sushi Chef expertise and his part of the working capital and headed off to New England, even though his wife now wanted him to stay in the New York area. Bye Bye Sushi Plan and wife. I always suspected there was more to Jack's story than he told, especially since he never seemed to stay in one place longer than a few months. It had been a few months after the Deli opened that he left, and now it had been a few months since we started putting the Sushi Business together and Jack was gone again. Poof and gone.

Mom and I made several attempts to get another local partner who knew the Sushi business, but Asians in general don't want to be in business with Americans. They want to do business with Americans and get rich, but they don't want to be in business with Americans. They want our money, one way or the other, but they do not want us. Nice.

By late summer it had become obvious there was no saving the Sushi business, and Mom was getting more and more despondent. While she had recovered well during the year since her attack, she never fully recovered to the point where she could spend 12-14 active hours a day like she used to. The medications also always made her a little bit woozy, and she was reluctant to try driving for herself. She could get around the house fine, and in and out of the house to the car. And she could walk around for brief periods when we went out, but for longer hikes, we still used the wheelchair.

To top it all off, her friend Pat had been hospitalized again, this time with pneumonia. They took him back to CCC, which was also a lung center, and spent over a week treating his lungs and nursing him back to health. While he was there Mom and I went to visit often. Just as with her first visit, it was amazing and touching to see much of the staff come by, not to see Pat, but to see Mom and marvel at a living Miracle.

They all said she looked great, and she did. Just one year after having been technically dead, and having spent 10 days in Intensive Care on Life Support, she was back visiting her friend Pat. This was a case of half full and half empty. Mom was still depressed because she was not "as good as new" like she was before she developed the CHF, but the rest of us were amazed that at almost 80 years young, after what she had been through, she was alive, active, and living a life that would tire most people in their 60's!

CHAPTER 14

Mystery Illness

MOM CONTINUED TO be depressed into the Fall. With Jack's departure, our Sushi venture was going nowhere and we needed a new plan. After losing the Deli, the failure of the Sushi Plan and realizing that she was unable to continue with the rigors demanded by the real estate business, Mom was at a quandary at to what to do. We could just get by on what I made in the mortgage business, and Mom still had some income from the real estate business, but that is missing the point. Mom was an active and hard working person. She had worked non-stop since she was 16 when she edited war films during WWII, and to her there was no such thing as retirement. Mom always had to be doing something productive, something businesslike, and something useful. Working.

As Fall blew in, Mom seemed to lose much of her spirit. I've often wondered how much the triple disappointments of the Deli, the Sushi business, and her condition contributed to what came next. And in hindsight I wonder if what came next had eaten up Mom on the inside and changed her just as it had my dad decades earlier. It was hard to tell cause and effect, perhaps because there was a little bit of both. Our minds and our bodies are inexorably linked together and as our mind suffers traumas it can impact our bodies health, just like trauma to the body can impact our mental health and outlook.

After over a year of constant improvement, by Thanksgiving 2002 Mom had begun to show signs of slipping for the first time since she had left CCC. We had a great Thanksgiving, in retrospect our best ever, and went to a gourmet holiday buffet with tons of great food. I let Mom get away with all sorts of "bad" foods with no more ill effect than gaining a few pounds of water which her pills shed over the next few days.

Many heart patients can eat themselves right into the hospital at Thanksgiving, but this just went to show how far Mom had come. But I was concerned because she kept getting a little more out of breath than usual with normal activity. For the first time we were going backwards, not forwards. Mom's heart seemed ok, which was supported by my detailed daily records of BP, HR, Medications and weight. So what was wrong?

The doctors found these records extremely useful, the first thing the Nurse did was take my "log book" to the doctor which he reviewed before even meeting with Mom and I. One way to maximize your visit to the doctor is to take as much relevant, written, information as possible. They see so many patients, looking at a patient's specific history and daily progress (not just their chart from the last visit) can provide of wealth of diagnostic information.

Since Mom's heart seemed fine, the doctors ordered a complete blood work up. The results were shocking. Mom's Kidney's had almost completely stopped working, they were functioning at less than 20% capacity. This is in the range where they usually recommended Dialysis. Now Dialysis is not a simple procedure even for otherwise healthy patients. People have been known to die during the process. Given Mom's condition, they referred us a good Renal Specialist. He turned out to be one of the best doctors Mom ever had. He concurred that Mom was not a candidate for Dialysis unless nothing else worked and decided to try alternative treatments first.

The first thing he did was place Mom on a different diuretic. Mom's Kidney's had been fine when she left CCC. Why had they deteriorated so much in a year? Different diuretics place differing amounts of strain on the Kidneys, and Mom had been on consistently heavy does for over a year now. We would change her pills, watch her weight for water build up (which I did every day anyway) and see if her Kidney function improved. A related problem was that Mom had developed severe Anemia, often a side effect of Kidney failure. The doctor prescribed Iron Pills and said if it got worse Mom might have to have a blood transfusion. The anemia explained why Mom been getting short of breath and had less energy during the fall than she had during the summer. The problem now was due to her kidneys and anemia, not her CHF. Or so we thought.

If the change in diuretics and iron pills could correct the problems, then everything should be ok. We hoped Mom didn't have to have a transfusion and start having risky dialysis treatments. With a new set of medical problems to worry about, our 2002 Holidays were not as joyful as the 2001 Holidays had been. Now, with the advantage of 20-20 hindsight, looking back on the events of the next few months, even if Mom was not doing as well as she was during the summer, these were more priceless Holidays.

On New Year's Day 2003 Mom wound up back in the ER for an emergency blood transfusion. Her hemoglobin had fallen to dangerous levels from the anemia and she lacked color and was constantly out of breath. The dangers of a fluid overload from the transfusion were now outweighed by the strain her anemia was placing on her heart and other organs. The transfusion was successful and she was placed on a drug often given to patients suffering from anemia, especially those taking chemo therapy. Mom wasn't taking chemo, but the doctor thought this might help her cope with the anemia caused by her failing kidneys. He even managed to stabilize her renal function by changing her medications and adding some new dietary restrictions.

It was a long, cold winter but once again, without dialysis and against the odds, Mom started to improve. As spring came it seemed she had once again cheated death. The kidney episode had not had any impact on her CHF, which by now was very well controlled. The shots were controlling her anemia, and her kidneys were holding up without any further reduction in function. A routine visit to CCC for Mom's quarterly checkup on May 1st, 18 months after she had been released, showed marked heart function improvement. The doctors said she looked wonderful and she did. While still using the wheelchair sometimes, Mom could climb more stairs and walk longer without it. She was maintaining her weight, no water, and had even come off of some of her medications. Mom's heart was improving, she seemed in excellent overall health and the treatments for her kidney failure and anemia were working with a good prognosis.

May 1st was a great day. Mom had beaten the odds again. Her heart was stronger, and the prognosis was that she would be able to resume even more activity. True, Mom would still need to use the wheelchair on occasion, but that was mostly due to Mom's arthritic knees which had made walking painful even before her CHF. Mom was now almost 80 and some close relatives lived active lives well into their late 90's. Now it seemed the ordeal of the last 18 months had been worth it. Mom could look forward to 10, or maybe even 15 more years of a meaningful, quality life. It seemed Mom had won.

But it was the calm before the storm, or perhaps more correctly, the eye in the middle of the Typhoon. Little did we know that Mom would not live see her next Birthday, just three months away. Mom had recently started to feel sick and throw up after eating. All of her doctors, even those at CCC, had attributed this to Mom's strong medications upsetting her stomach. They suggested we vary the times she took them and the foods she ate with them to try and find a combination that caused less stomach upset.

Mom's upset stomach continued throughout May and as my Birthday rolled around at the end of the month, her heart rate was alarmingly high, she couldn't keep any food down, was very short of breath again and now even had a high fever. Time to go back to the hospital. We started in the ER and tests showed that Mom had both pneumonia and a urinary tract infection. But believe it or not, she was in good enough general health that they thought she could recover at home with the proper antibiotics. The choice of antibiotic was key because many have been rendered ineffective from over use. Also, Mom was still taking medications for her heart rhythm and there are potentially fatal interactions with some antibiotics. They checked her out pretty thoroughly, and armed with some of the proper antibiotics, we went back home.

Mom stayed at home through my Birthday, it was my 50th Birthday, and she was going to celebrate it with me come hell or high water. Over Memorial Day weekend, she didn't seem to be getting any better, but I'll always remember Sunday June 1st. Mom vomited up a huge sausage shaped piece of coagulated blood. She said she felt better right away and thought that maybe this was something that had been stuck in her esophagus all along. I was more worried though, and wanted Mom to go to the ER right away.

Vomiting blood was the one thing every doctor had impressed on us was a danger sign that required immediate medical attention. Especially since Mom was on Coumadin, a blood thinner, which could make any bleeding very serious. All the more so because Mom was still anemic. But Mom hated the thought of another trip to the ER, so we compromised and ended up going to her doctor's office, which was open on Sundays. Another doctor was covering for our family physician, but I had saved the "blood sausage" and he took one look at it and said take her to the ER, now!

Well we made it to the ER, but it was touch and go, Mom was bleeding internally and had lost enough blood to drive her hemoglobin down to very low levels, plus with the Coumadin they were having trouble stopping the bleeding. She very nearly bled to death. They gave Mom several emergency transfusions, which caused fluid overload with her CHF, but after two days in the ICU, Mom had recuperated sufficiently to be moved into a regular room. Once more Mom had cheated death, or so we thought.

Once in a regular room, Mom underwent a battery of emergency tests, including another Electrocardiogram, which showed her heart had gotten smaller (smaller, meant it was healing), almost back to normal size, her valve was no worse and her Ejection Fraction was now in the Mid 30'. Not outstanding, but more than a 50% improvement over when she had left CCC over 18 months ago. Her strong medications had worked.

All we had to do now was find out what was wrong with her digestive system. Mom was reluctant to have "a scope" procedure done where they visually inspect and photograph your esophagus and stomach, so the hospital concentrated on getting fluids into her, and treating her new urinary tract and lung infections. At this point Mom could still swallow and hold down some fluids. She had had a long history of "heartburn" or acid reflux, and had constantly swigged Mylanta from a bottle she carried around. They decided that Mom's acid reflux disease, combined with her strong medications had severely irritated her upper digestive tract. In lieu of the scope procedure they treated her with medications for severe acid reflux, hoping the damage would reverse itself.

This 10 day stay in the hospital to treat Mom's anemia, infections and run tests, was fraught with many of the same issues that had plagued Mom during her nursing home stay. Incorrect medications, improperly administered. While the quality of the attending physicians at the hospital was far superior to the nursing home, the quality and care provided by the nursing staff was not much better. I fought to spend time with Mom beyond normal visiting hours just so I could be there to make sure the proper meds were administered at the proper time and in the proper manner. Mom's meds were vital.

This caused a few run ins with hospital staff, the patient advocate and even security. But I was beginning to know my way around and had the attending cardiologist (who just happened to be the same doctor who originally saved Mom's life by putting in the Balloon Pump) write in "Orders" that I was to be present at all times when medications were given or when procedures, such as taking blood, were done. Doctors orders are gospel and supersede even hospital "rules" for trivial matters like visiting hours, and that ended my battle, save for some minor skirmishes, with the hospital staff.

It is absolutely essential for a loved one to have an adult advocate present as much as possible during a hospital stay for any acute or serious condition. I don't mean the daily 15 minute "how are you feeling" visit. I mean camped out in the patients room and watching all procedures, paying attention to what medications are given and how they are administered, and participating in the discussions about treatment options with doctors and staff when they stop by. Often the patient may not be fully lucid, but even if they are, it's comforting to have a family member just to discuss your options with.

Some facts to keep in mind. During Mom's stay in this hospital, I stopped no less than 17 instances of incorrect medications being given, or being given in incorrect amounts, any one instance of which could have been fatal. For example, since Mom had trouble swallowing, the nurses mashed up her blood pressure and heart rate pills in apple sauce. However it was a Timed Release pill (the nursing staff never bothered to read the instructions) and mashing it would have released it all at once, a fatal dosage. If you think I'm exaggerating keep in mind 100,000 people a year die from medical mistakes in hospitals, more than in auto accidents. That's the published number. Your loved ones need an adult advocate when they are in the hospital for any length of time!

After 10 days in the hospital, they felt Mom was well enough to send her home. Her fever had come down and it seemed her infections had been cured with the proper antibiotics. Mom still didn't seem right to me, and she was still having trouble keeping food down. But Mom was anxious to go home and I gave in. So they sent us off with some new pills and we went home. It was to be Mom's last night at home. She spent a restless night. When I checked in the morning her fever had returned, her BP was high and her heart rate had risen to over 100 just sitting in her chair. She did not "present" well and was having difficulty breathing. Mom never should have been sent home.

Back to the ER where they quickly determined that the high HR was caused by her UTI which had returned in less than 24 hours with a vengeance. So they immediately hung an IV of antibiotic, but before the Nurse could ever insert the needle, I read the label and told her to take it down. This was the same antibiotic that Mom's Heart Specialists had nixed several times before because it had a very serious drug interaction with Mom's Amioderone and could cause another attack of Arrhythmia. During the last 10 days in this very same hospital we had addressed this issue on several occasions, and Mom's entire medical record was supposed to be "in the computer" along with all of her medications and possible drug interactions. The incompetence was getting to be nuts. I immediately sought out the head of the ER Staff, and as it turns out they used another computer system, that was NOT linked to the main hospital computer. Unbelievable! And little wonder 100,000 people die in hospitals every year from medical mistakes!

Once again Mom made it alive out of the ER and back into a regular room, but her stay in the hospital this time was a nightmare. When we went to the ER it was originally to treat her returned urinary infection and pneumonia, but Mom was having increasing difficulty in swallowing and could not keep anything down including fluids. That meant she could not take her medications. Mom finally agreed to be "scoped" to see what the problem was. Mom needed her heart meds and was going to need another course of antibiotics to finally cure her various infections, and she needed to be able to swallow.

CHAPTER 15

Diagnosis of Death

THE PRELIMINARY EXAM went well, with Mom's stomach and esophagus looking inflamed as we had expected from her acid reflux. But I was devastated when the diagnosis of cancer came in, they called it "Linitus Plasticus". A horrible form of cancer that infiltrates the lining of your stomach turning it into what looks like a "plastic bottle", hence the name. It's virulent, aggressive and almost always fatal. When I looked on the internet for information, the prognosis was listed as grim, with a 97% mortality rate.

Suddenly all of Mom's symptoms clicked into place. Her anemia was being caused not only by her kidney failure, but by the slow bleeding from her stomach due to the cancer having "eaten" away most of her stomach lining. The blood in Mom's stool had been camouflaged by the "black tarry" stools associated with her iron pills and the normal side effects from the anemia shots. The cancer had weakened Mom's immune system and made it ripe for opportunistic infections like her Urinary Tract Infection, and finally the Pneumonia had been caused by aspiration of food particles when she vomited after eating because her stomach could no longer digest food. It is even likely that the sudden onset of Mom's kidney failure had been cancer related. While we had been so diligently working to get Mom better from her heart condition, cancer had sneaked in unobserved and put the last few nails into my Mom's coffin. The same as with my dad.

Mom was now vomiting after every meal. There was nothing left of her stomach, it was all cancer, and she could not keep down nor digest any food or liquids. Or pills. Poor Mom, after all of the good meals we had shared, and being such a wonderful cook, she ended up not able to eat or hold food down because the cancer had eaten up her stomach, along with all of the rest of her digestive tract. Even worse, the doctors believed the cancer had spread to nearby organs, like her kidneys and liver. It was certain that for the past several month's we had been treating the symptoms not the root cause. Probably just as well, the only treatment for this type of cancer was complete removal of the digestive tract from the back of the throat to the anus, and like the doctors said, most 30 year old patients in good health didn't live through it.

A few doctors said Chemo might buy Mom a few months and improve her quality of life, i.e. reduce enough symptoms so that Mom could at least eat for the few months she had, instead of starving to death in a few weeks which seemed to be a real possibility. But Mom had cheated death for the last time, this time Mom was going to die. The only questions left were when and where. The estimates ranged from days to months. The doctor that had given me the brutally honest opinion "you'll never take her home again, everything is cancer and she has less than two weeks to live", was closest to correct. From the time the diagnosis came in, Mom had just 3 weeks to live. Mom had beaten CHF against all odds, only to die from stomach cancer. That still seems an ironic tragedy to me. To both Mom and I it was the cruelest of cruel jokes played by fate.

Fate wins in the end.

For years Mom had had very bad "indigestion", and her voice had grown hoarse with age. She would always cough with the first few swallows of her coffee in the morning. Remembering back to the swallowing problem when she first came off of the respirator after her cardiac arrest at CCC, I wondered how many years this problem had been developing. With all of the x-rays, MRI's and Ultrasound tests Mom had had, first for the auto insurance after her car accident, then for her CHF, and then the cardiac arrest and subsequent visits to all sorts of specialists, it amazed me that no test, X-ray, or Cat Scan or Ultra Sound, had ever picked up any sign of this. Even the "Fluoroscope" used to check out her swallowing problem at CCC had not identified any blockage or problem internally in her throat or esophagus. It's amazing what tests can miss.

I tried to get second opinions from some of the famous cancer treatment centers, but when they were faxed her medical reports, they would not even agree to see Mom. It was that hopeless. Once I had reluctantly accepted the painful fact that Mom was going to die, the next question was what to do to make that death as painless as possible. There were several options. Go the chemo route and try what medications we could to try and prolong and improve her quality of life during her final weeks or months. Or, check her into a hospice to make her as comfortable as possible for her remaining time. Or, just withhold all of her medications and treatments and let the end come as quickly as possible. What is the best strategy in a fight that you can't win?

Now Mom and I had always been fighters and we had always fought together. Knowing there was no cure, it seemed to me there were still some decisions. We elected not to tell Mom that it was terminal. But as soon as she heard "Cancer" Mom knew the truth and sunk into a deep depression as she realized that the end was near in spite of all of the doctors trying to talk up various "treatments". She had seen too many friends and relatives, staring with dad and all her brothers, die from the dreaded Big C. Mom knew.

While Mom was not going to beat this, there were some options. Having seen the nursing homes (Hospices were just Nursing Homes by another name where they left you to die) I didn't like that option. The hospital did not want Mom to stay there, as they said hospitals are for the living and those who can get better and go home or to rehab. Besides it looks bad for your statistics when someone dies in your hospital. I thought there was a middle course. Mom had always wanted to die at home, never in a hospital or nursing home. I conferred with several of her better specialists and asked if we might get her well enough to return Home, on Hospice, even if only for a few days. For Mom's last days, she would at least be Home in comfortable and familiar surroundings.

Among the best doctors, the consensus was that with intravenous feeding and by giving Mom her other meds and antibiotics intravenously, we might be able to improve her condition enough that she could go home and onto Home Hospice. Now with no way for her to eat or take her meds at home, Mom would only last a very brief time, but she would die at home like she wanted. To even get to that point, we needed to get Mom strong enough to make it out of the hospital and back into home and able to do certain basic functions at home like use the bathroom. In her present condition, due to the internal bleeding, infections and lack of food, she would have died in the ambulance.

So I set out with a new mission, to let Mom die as peacefully as possible at Home.

There were days when it seemed like the medical and nursing staff at the hospital (the hospital resident staff, not Mom's excellent specialists who were all "in" on the plan with me) were actually trying to do Mom in and hasten her demise. Once the diagnosis was confirmed as terminal cancer, they bent over backwards trying to get Mom out of their hospital to a Hospice or to a Cancer Center, several of which actually refused her. They reviewed her records via fax and rendered an "it's hopeless" verdict, and they didn't even think Mom would survive the ambulance ride up to the Center.

Die anywhere but in their hospital. I guess they get graded on how many people die on their shift. Once it was clear that Mom would die, sooner or later, most of the hospital doctors and nurses opted for sooner. So they cut out her heart medications, cut off her food, and stopped "get well" treatments like lung therapy and antibiotics. Other doctors sided with me and thought we might get Mom well enough to spend her last few weeks at home. It became a daily battle, medicate Mom so she could go home to die, versus cut off everything now except her "happy" meds and morphine so she died quickly.

I, being a Roman Catholic, was never into euthanasia, although surprisingly all of the hospital admin staff and most of the doctors and nurses under 40 were. The staff is ever aware of the costs and the insurance reimbursement. Taking up a precious bed with a dying person for a couple of weeks just will not do financially when that bed could be occupied by several people having major surgery during the same time frame. Which was a joke since Mom's insurance was still covering everything and one whole wing of this hospital was dark and empty due to budget cuts and lack of patients.

Remember, in this country you are only a dollar sign! As for a majority of the doctors, as Mom had always said, they seemed to place a value on life inversely related to age. If you were over 50 you were not as valuable as a person who had a "life yet to live". And if you were over 60 you weren't worth their time. Over 70, and forget about it! Unless of course you were rich. King Dollar. And if you were dying, hurry up and get it over with!

Many have asked why I persisted in trying to get Mom home to die and didn't just pull the plug like the hospital staff wanted. To understand, you would have had to know Mom and had the many discussions we had had over the years. Her mom, dad and husband had all died in this very same hospital and even before her heart problems, when she had been feeling really sick with just a cold or the flu, she would make me promise not to let her die in this hospital like so many of her loved ones had. Mom wanted with all of her being to just die peacefully at home, sitting in her chair, with me by her side. Had I known where this was all leading, I might have never have had her taken back to the ER after that last night at home. That decision has haunted me.

So it became a daily struggle between the good doctors and the bad doctors to try and get Mom enough medication and intravenous nutrition to get her well enough to go home and die in a "home hospice" setting. For a while it seemed like Mom was rallying. She was awake more often, was actually hungry, and her kidneys and other functions were working again, albeit at low levels. At my request, and backed by several other doctors, they had put Mom back on intravenous food, and she seemed to be regaining strength. No wonder, at this juncture Mom had been on a liquid diet, or no diet, for over a month. Her body was responding to the nutrition, the medication and the care.

By Friday July 4th Mom was doing pretty well and asked me to get her food, I got her favorite Penne Pasta with vodka sauce, At this point they were letting me bring in whatever I wanted for Mom. Mom actually ate some and managed to keep it down, and I was wishing there was somewhere I could get her to a window in the hospital to see fireworks. We settled for the TV. Mom's vital signs had gotten much better as well, her breathing was less labored, and her heart rate and BP had returned to normal ranges. Medications had removed some of the water build up since she had been off her cardiac medications and the swelling in her hands and feet had gone down dramatically. Mom was rallying! I knew Mom would die soon, but I had hopes we could bring her home.

Being a Holiday weekend most of her good doctors, the ones fighting for her, were away. Unfortunately the ones that had been fighting against her were not. The lead “death” doctor was still there and she promptly cut off the IV food (saying that food is for people who will get well, not to prolong life of the dying) and her other medications. By the time the other specialists returned after the Holiday Weekend and I could get her food and medications turned back “on”, Mom was a wreck. Her vital signs were worse, and her kidneys had shut down. The 3-day Holiday Weekend had given the “Doctors of Death” their window of opportunity and put the final nails in Mom’s coffin.

I was under tremendous pressure to check her out to a Rehab or Hospice to die there. Everyone knew she would probably not last 24 hours, but at least she wouldn’t die on the hospitals time and mess up their tidy statistics. I was also under pressure to give a DNR (Do Not Resuscitate Order). My thoughts of getting Mom well enough to die with dignity as comfortably as possible at home were gone. On Monday Mom gave me a feeble smile, kiss and wave as I left the room while they cleaned and bathed her. It was the last little kiss and wave I ever got from Mom. We both knew the end was very near.

By Monday night Mom was in really bad shape and was not even fully conscious. Mom was now fading in and out of consciousness and one of the last things she said to me was “I want to go home!” I thought about just requesting ambulance transport to home, but she would not have survived the trip. I knew Mom didn’t want to die in this hospital, but dying in a cold dark ambulance didn’t seem to be much of an alternative. I even thought about just getting her wheelchair and trying to get her into it myself and taking her home. But what would we do when I got there? She was much too weak to make it up the stairs and I was not able to carry her. Sad. Maybe a drive down by the water where we always used to go to watch the boats? I had run out of ideas and options.

Mom seemed to realize when I was there and roused somewhat when the staff came in to give her a morphine shot, but she did not respond to conversation. If you hadn't read her charts, Mom would have seemed to be just peacefully sleeping. It wasn't obvious from looking that Mom and I had lost this fight. But we had. Mom wasn't going anywhere anymore. I found one of Mom's physicians crying in the hall because he could not do anything more for her. Having realized when the diagnosis came in that Mom was terminal, I now had to face the fact that Mom wasn't going to improve enough to spend her last days at home in familiar surroundings. Mom was going to die right there in that bed. Soon. All we could do now was to make her comfortable as possible.

I wonder to this day that if her treatment, that was helping her rally, had been continued over the Holiday Weekend, could she have been just well enough to make it home again. I think the Death Lobby had their way. And it was a shame. Mom should have been allowed the right to die at home and with dignity. Profits be damned.

With a heavy heart, I instructed the staff to focus on palliative care and gave a DNR, Do Not Resuscitate, order. No sense in putting Mom through any more to prolong her life a few hours. I just wanted her to be as comfortable as possible. Mom seemed to rally a bit on Tuesday night during one of our favorite movies, *In Harms Way*. We made eye contact, and Mom smiled and squeezed my hand. Over the next two days all, and I mean all, of Mom's physicians, specialists and nurses made a pilgrimage to stop and say goodbye. Doctors from CCC called and expressed their sympathy. Mom's closest relatives and friends, including Pat, who was still alive, and Mom's sister came by.

On Friday morning Mom and I were watching Ming Sai. I say we, but Mom was sleeping and holding my hand. Ming Sai was Mom's absolute favorite cooking show, and he was fixing Foix Gras, which Mom had always found disgusting. She gave my hand a little squeeze which I thought was to acknowledge that he was making that stuff she hated again, but a minute later one of Mom's alarms went off. I thought the heart rate and blood O2 sensor had slipped off her finger again as had happened often over the last few days, but when I turned to look at Mom, I could see the color draining from her face. She looked very peaceful and almost had a smile. It was over. Mom was gone.

Mom and I had stuck together through thick and thin for fifty years. And I had stayed by her side for almost two years as she fought and beat CHF and then fought and lost to cancer. Now I was going to stick it out with her to the bitter end. The "on call" house physician came in and "pronounced" Mom dead. The nurses came in and cleaned her up for her last gurney ride to the morgue in the basement. Several of the staff were crying as I placed Mom's favorite little teddy bear on the gurney as we left the room. I went with her to the basement and waved goodbye as they brought her into the morgue and shut the large cold steel door behind her. Clank. Mom was gone.

Try as I could with all of the doctors and specialists, this time I couldn't save my Mom.

CHAPTER 16

This Was My Mom

I HAVE NEVER felt so empty or alone. But I kept busy with the funeral arrangements. How do you make a funeral special? I wanted Mom to be buried with her parents, which was also the same Catholic Cemetery where my dad was buried, but they had no more plots, that section had been closed for years. I went to the Pastor and appealed, and because Mom had taught in that Parish years before, they relented and actually created a new plot, just for Mom, in the old section of the cemetery. It was near a magnificent pine tree with an unobstructed view of the afternoon sunsets which Mom would have loved.

I had the undertaker dress Mom in her favorite outfit and had them play her favorite Yanni music, placed some of her favorite belongings, jewelry and Yanni CD in the casket, and even arranged for the funeral procession to detour past Mom's favorite local places where we used to eat and watch sunsets on the way from the funeral home to the cemetery. What little I could do I had done. It seemed so very little and so futile.

Mom's friends did the most. Pat came, he was back on a portable respirator by this time for his COPD, but his heart was still strong. One of our closest friends, a black minister from North Carolina who had lived with us at one time, borrowed a car and drove all night to make the viewing. Jack and some of his Chinese friends drove down from New England. Most of Mom's business friends showed up and her last real estate partner delivered a eulogy and called Mom the strongest woman and best "businessman" he had ever met. One of Mom's kindergarten students from 40 years earlier, now with MS, showed up in a wheelchair to say goodbye. Surveying the crowd of relatives, friends, students, businessmen, Whites, Blacks, Asians, people in wheelchairs and Pat with his respirator, the funeral director walked over and asked me “who was this woman?”

I told him. This woman was my Mom.

EPILOGUE

It has been several years since Mom passed away, but every day I still ask myself the question: “what do you do when you have done your very best, and your best was just not good enough?” I hope my writing Mom’s Story provides part of the answer to that question. If any of Mom’s experiences reach out to someone and gives them the inspiration to spend more of that priceless time with their Mom, Dad or special loved one, then that will give value and meaning to Mom’s Story. If more friends and relatives begin to work and spend more time as a “patient advocate” for their loved ones in hospitals and nursing homes, then Mom’s pain and suffering will have new meaning. If the doctors and hospitals can find a way to stop killing 100,000 people a year through stupid, needless errors, then that will give true meaning to Mom’s life. And last but not least, if this country as a whole begins to place more value, or perhaps I should just say value, on its parents, elders and seniors, then we will discover a true National Treasure as the Baby Boomers reach their Golden Years. And then my Mom can rest in peace.

MOM'S TEN COMMANDMENTS FOR THE SICK

1. Understand your condition. Read up on it, it's your life, get second and third opinions. Demand details and treatment options from all of your physicians.

2. Choose your doctor and hospital very carefully. Remember, all doctors and hospitals are not created equal. You are making a life and death decision.

3. If you have CHF go to a cardiologist. Your family physician is a generalist not a specialist, get the best care. See a specialist for any "special" conditions.

4. Take your medications. Know all about them and take them exactly when and how prescribed. Don't just rely on your doctor, always talk to your pharmacist as well.

5. Have a Patient Advocate. Anyone in a hospital or nursing home needs a patient advocate to protect their interests, the best advocate is a close family member.

6. Have a Living Will, and a Power of Attorney prepared well ahead of time before entering a hospital or facility. Discuss your desires with attorney and next of kin.

7. Prepare your home ahead of time (when you hit 55) in case you or a loved one becomes disabled, simple things like getting to the bathroom can be difficult.

8. Throw out your salt shaker. And talk to your physician about the garlic, glass of wine a day and aspirin routines and their risks/benefits for you. Ask questions!

9. Go to the ER by ambulance. If you have heart problems and are considering going to the ER you should already be there, the time you waste may cost you your life.

10. Pro-actively participate in your own care. Demand the best care, you deserve it! Be a squeaky wheel to make sure your needs and your loved ones are addressed.

And Lee's "Commandment" . . . .

Treasure the time spent with seriously or terminally ill loved ones. It's priceless. Take time to enjoy today, watch a sunset together. You may not have many tomorrows!

SILLY LITTLE THINGS THAT CAN KILL YOU

This chapter retells some events in even more detail.
Read it. It could save your life.

Nightmare in the hospital.

Throughout Mom's final two visits to the Hospital, lasting 40 days, I logged (yes I still had my Log Book by my side) no less than 17 major medical errors that could have resulted in serious consequences up to and including death. These were not trivial incidents, and included major overdoses and/or underdoses of medications and also sheer stupidity. Since Mom was having trouble swallowing and keeping things down, the "text book" solution Nurses use was to crush up Mom's meds and mix them with Applesauce. They did this like robots without paying any attention to what they were crushing. Some of Mom's medications, like her BP pill, were timed release capsules and had major warning labels right on the bottle stating DO NOT CRUSH.

Of course the nurses never saw the bottles or the labels, the pills simply came up from the Hospital Pharmacy in little packets marked "give this to so and so at such and such time". Any of the finer details in administering the medications relied on the overtaxed memories of the nursing staff. Some nurses were better at this than others, but since they rotated every day and every shift, and included a high portion of Rent-A-Nurse people due to personnel cuts, the competency level was pure a luck of the draw.

Another factor resulting from both the nursing shortage and rotating schedules was the fact that all medications were delivered once in the morning and once in the evening, so the nuances of Mom's carefully timed daily schedule of when she got specific medications went right out the window. The nurses just took half her pills and mashed them together with the applesauce in the morning and the other half in the evening.

This was not going to do, so I requested a meeting with Mom's Heart Specialist, the same doctor that had saved her life almost two years ago with the Balloon Pump. As he told me, "all doctors are not created equal". He was referring to the fact that both medical skills and patient communication skills vary among physicians, and one needed to carefully choose those upon who you were willing to risk your, or your loved ones', treatment and life. I would find out time and again just how right he was.

We had had several discussions since Mom was re-admitted to the Hospital and I had also learned that he had a fondness for Mom and for me. For Mom because she was the first patient he had ever performed the balloon pump operation on that had lived. I'm glad I did not know that the day he operated on her! However since then he has done it successfully many times and saved many lives with the procedure. I was happy to learn that some good had come from Mom's ordeal, she was always happy to help others.

I think he liked me because I cared about Mom. Many younger people abandon their elderly parents in the Hospital the same way they do the Nursing Homes. There is the daily "are you still alive?" call and the obligatory weekly "when are you getting out" visit, but beyond that little to no involvement in matters relating to treatment. To some extent the same was true for spouses, in fact the only real involvement I saw was from mothers when their children were in the Hospital. How many more lives could be saved each year if family got actively involved in the care and treatment of their loved ones?

For my part, I had sought a conference with this doctor because I knew he was as good as they come, and was following his advice about choosing good doctors to work with. I also chose him because he was a Cardiologist. There is a very definite "professional pyramid" among doctors, nurses and staff. Surgeons seem to occupy the top spot, but you never get to see or talk to them except on the way to the OR. Cardiologists seem to be next. And this man was not only an Attending Physician at this Hospital, but he was the head of the "Cath Lab" at another major hospital. Now Cardiac Catheterization, or "Cath" Labs are huge revenue generators for Hospitals, and the top Cardiologists that specialize in this procedure are among the most prized of Physicians, they are like the original Seven Mercury Astronauts were to regular pilots. They had The Right Stuff.

So the head of a Cath Lab was second only to God for the rest of the hospital staff. And when he spoke, or wrote, the staff listened, including the other doctors. Part of this was the ever present fear of Malpractice. Everything is written in Doctors Orders, by every doctor, every day, and supposedly reviewed by every doctor treating a patient every day. If it is not written, it does not exist. But if it is written, it is an important, indelible paper trail, the kind that provides fuel for the fires of malpractice suits.

And if it is written by a famous cardiologist who is head of the Cath Lab, it is obeyed. Period. No doctor, not even your primary physician, or nurse or member of the hospital staff, is willing to take the career risk of ignoring or contradicting something written by God. if you want something done, or not done, to your loved one, have the most senior or important Attending Physician you can find write it in the Doctors' Orders. If you are lucky enough to have a famous surgeon or cardiologist on your side, have them do it.

In Mom's case, after I discussed the serious daily problems in administering her medications with this superb and famous cardiologist, he actually wrote in the Orders that I, alone, was to administer all of her Heart Medications. They were to be dispensed to the In Charge Nurse by the Hospital Pharmacy, and then given to me by the Nurse. Period. I could then give them to Mom in the proper way and at the proper times.

His reasoning was sound. As Mom's primary caregiver I had been administering her medications, as so carefully prescribed and adjusted by the CCC, for almost two years. During this time she had never had to be re-admitted for CHF and her heart had actually strengthened and improved. It if ain't broke don't fix it. So we had no more problems with Mom's medications. I also seemed to gain a bit more respect from the hospital staff, and stopped being treated as another annoying, meddling family member. They said they had never seen an Order like that, so I guess it set them to thinking.

Insurance & Financial Issues

Mom had normal “over age 65” MediCare and also had AARP’s supplemental policy plus a PAD Card; a NJ State Prescription Drug Card which helped with her prescriptions. All of this insurance fully covered the hospital and rehab costs. Mom only had to pay $5 for her prescriptions, or a $20 Co-pay for doctors visits, including specialist and lab work. Even so, there were real financial impacts. Mom lost her Deli, and much of the income from her Real Estate business. As her primary caregiver I lost my job when I applied for FMLA, a fate that befalls many primary caregivers. Caregivers can be as significantly impacted as the person they are caring for, often leading to personal bankruptcy.

If the true costs of all the “free” healthcare provided by friends and family were calculated, national healthcare costs would amount to additional billions of dollars annually. For the individuals involved, this is a real loss in time and money, and to the economy as a whole it is also a loss. If you are not working because you are caring for a friend or relative, you’re not making the money to go out and buy things, the so called “Consumer Spending” on which our entire national economy depends for its health.

But you’re just a faceless statistic that is not shown in any government data such as “Unemployed”, and the costs and losses are not even tax deductible. The rich deduct millions in phony paper losses, but there is no relief or assistance for carrying for a loved one. In fact, as in my case, your company is likely to fire you when you attempt to apply for FMLA. When Mom died, we were both down to our last few thousand dollars in the bank. I estimate that my personal losses were well in excess of $500,000, and years later, I’m still paying off the thousands in debt that I ran up while caring for Mom.

I was not looking to “make money” by caring for Mom, and gladly incurred the financial hardships so that I could be with her. However the ability to collect unemployment or to deduct some of the losses, like rich people and corporations do, would have helped. As the Baby Boomers age, we are all going to share the burden and costs of their care. If our government would pay more attention to “senior policy” than it does to “foreign policy” perhaps solutions could be found. There is a battlefront right in this country.

Salt—The Silent Killer.

As a result of our many cardiologist visits it became apparent how much these doctors knew about good health and how little of what they knew and took for granted was ever passed along to the general public by the news media. We do have our own brand of censorship in this country, make no mistake about it. Our brand of censorship revolves around King Dollar. If it makes money, or is politically correct (earning "goodwill" for the right business lobby) then it gets printed, televised and advertised. If it is bad for the bottom line, we never hear about it. Issues of health and morality take a back seat to profits and prosperity. If you don't believe that just look at how long the cigarette manufacturers lied to everyone. Or more recently the debacle of certain "famous" prescription drugs which killed and injured hundreds of thousands. One of those big secrets is SALT (sodium) and the Fast Food industry in particular, and food processors in general, have long lobbied government to ignore the annual toll from too much SALT.

Too much SALT. The culprit is actually the sodium, and too much of it is apparently bad for almost everyone regardless of their current health or condition. For those who are susceptible to it, it can cause high blood pressure and other problems. For a person with CHF it can kill you, or at the very least put you back in the Hospital (the average person with CHF is hospitalized frequently for fluid build-up). About 2000mg of sodium a day is sufficient for the average person, and is the upper limit for people with CHF. But the average American gets way more than that, perhaps as much as 4000mg or more.

I became an avid label reader. Even before you reach for the salt shaker, there are 1000's of mgs in your food. Your basic can of Chili has over 1000 mg *"per serving"*, and that can contains 2 to 2 ½ servings. Gotta read the labels! Sodium is measured "per serving" and an industry trick is to claim a small can of food contains three or even four servings to hide the real amount of sodium you are eating. A Hot Dog has 350-700 mgs depending on the brand, the hot dog roll another 150 mg or so, and all the condiments 100+. So a person can easily consume a half day's ration of sodium by eating a single Chili Cheese Dog with all the fixings. Sub sandwiches loaded with lunch meats, even "low sodium" brands, are another huge source of sodium. At the Big Hospital they told me stories about people who ate large sub sandwiches and wound up back in the ER.

Fast Food has horrible amounts of sodium. A Burger and Fries, with salt and ketchup of course, can top 3000-4000 mg in a single meal. The major chains have started putting out data that list fat, carbs and sodium for those on diets. Do yourself a favor – read them! And remember the huge sodium contents listed are before you add more salt (those little packets), ketchup and pickles on your burger and fries! Skip the Fast Food?

Actually Mom and I ate Fast Food, two of Mom's favorite treats were hot dogs and hamburgers. We also ate lots of other "forbidden" things. The secret was moderation and it worked. Mom never had to be hospitalized for her CHF and that condition was actually improving when she died from cancer. When at a Burger King or McDonalds we ordered fries without salt, not only healthier, but cooked fresh to order. Don't add salt to your burger and go easy on the ketchup and pickles, use other spices like pepper.

Proper planning can avoid sodium pitfalls. If we had a high salt lunch we had a low salt dinner. I also read labels when shopping, as mentioned before. Hot Dogs vary widely in salt content, and some of the better brands have LESS salt than the cheap brands do. Companies use salt as a substitute for flavor and good quality hot dogs and processed foods like deli lunch meats have less salt because they use better ingredients to start with. Many brands actually make "low (er) sodium" products and while these still pack a salt wallop, they do have less than normal brands have. The same with soups, most are loaded with sodium, but there are now low sodium varieties, and the selection is increasing every day as the problems sodium causes make the nightly TV news. Don't just buy Low Sodium items, you actually have to read the sodium content labels! That's because FDA rules let companies label items as Low Sodium even if they are not.

We also ate lots of Chinese and Japanese food, but we always went easy on the Soy Sauce and used the low sodium "lite" variety whenever available. Yes there are differences. And your local Chinese place can reduce the sodium in meals for you if you ask them to. Don't be afraid to ask. Bottom line is that Mom was able to enjoy her favorite foods, albeit it with some moderation, right up until the time she died without ever having made her CHF worse. That made me very happy. I started eating the same diet as Mom, and found that I had more energy, fewer colds and actually lost weight at first and then maintained a steadier weight, within 2 pounds plus or minus, for years.

More than one cardiologist told me what to do if I wanted to live to be a hundred:

1. Throw out the salt shaker.
2. Take an Aspirin every day.
3. Use lots of Garlic in your food.
4. Have a glass of Red Wine each day.

If you have CHF go to a Cardiologist not your family physician!

At the time Mom was diagnosed with Congestive Heart Failure, I thought CHF was a death sentence. So did Mom. Everyone we knew that had had CHF filled up with water and died, including my grandfather. And we had yet to learn about Sudden Cardiac Death, which none of the doctors thought to tell us about until it happened to Mom. However, it turns out that with proper medical care, medications and dietary restrictions, many people can now live for quite a number of years with a reasonably good quality of life. There have been, and continue to be, major advances in treatment.

You should understand them all.

To research CHF I looked up all Mom's medications and diagnosis's online and in available medical books such as the Physician's Desk Reference. I also found my local pharmacists possessed a wealth of information and were much more willing to share it than most doctors were. My research at the time found that 5 million Americans, most over the age of 65, have some form of Heart Failure and the numbers grow each year as Baby Boomers become senior citizens. Note that Heart Failure is not the same as a Heart Attack, or Cardiac Arrest. It would behoove anyone over 60 to talk to their doctor and go online to learn the differences. In addition to problems like Mom's mitral valve, High Blood Pressure, Obesity and Diabetes all play a serious role in your heart health.

For the record, Mom had Congestive Heart Failure (CHF), which when left untreated caused a nearly fatal Cardiac Arrest (Sudden Cardiac Death). She never had a "Heart Attack", also called a Myocardial Infarction, a Stroke, or any problem with her arteries or circulation, which is sometimes called "hardening of the arteries". Many people who have Heart Attacks, suffer heart muscle damage which can also lead to CHF. People need to understand the difference between Heart Failure (CHF) and a Heart Attack.

Some of the treatments for CHF are dependent on the root cause. In my Mom's case, she had a bad Mitral Valve from an undiagnosed case of

Rheumatic Fever when she was a child. Her sister had in fact also had it, and now also has a weakened Mitral Valve. Sometimes siblings passed it among themselves and in the 1920's and 30's it went undiagnosed. Except for Mom's weakened condition after her Cardiac Arrest, the preferred treatment for healthy patients is often to repair the mitral valve. Since surgery was not an option for Mom, we looked at other courses of treatment based on medication and dietary changes. Much can be accomplished with medications and diet.

The knee jerk reaction among doctors treating CHF is to give diuretics to reduce the fluid level in the body. With CHF fluids build up in different places in different people, ankles, wrists, sometime the stomach and abdomen, and in Mom's case her lungs. When you get enough fluid in the lungs without treatment you sort of drown in your own juices, assuming the strain on your heart doesn't cause Cardiac Arrest before then.

Therefore, one of the key objectives of standard treatment is to reduce fluid levels by restricting fluid intake and sodium levels and increasing fluid output by giving diuretics. The next common medication, especially for people with weakened hearts, is digitalis or digoxin, which is poison given in small doses, extremely small doses, and which cause the heart to beat stronger compensating for the root cause of the heart failure.

While family physicians can prescribe many of the common medications used to treat CHF, I wanted Mom to have the best care available. So we sought out a cardiologist. Most people with CHF are only treated by their family physician, NOT a cardiologist, because there are not enough to go around as the population ages. Some of the cardiologists I tried to hook Mom up with simply were not accepting new patients, others had over a six month waiting list. If a loved one of yours has CHF, I'd suggest you move mountains to find the best cardiologist you can and start routine visits with them right away. All doctors are not equal. A person with CHF needs a cardiologist.

Notes Added After I Received Mom's Medical Reports

I had lingering doubts about the way Mom's care was handled during her final visit to KMC and during her final days of that visit. I believed that the actions of some of the medical staff hastened her demise and prevented her from getting well enough to come home to spend her last days and peacefully in familiar surroundings as she wished.

So I decided to get her medical records from the Hospital, all 1200 pages of them. It is amazing the latitude doctors have in treating patients. They can kill you, but if they write it up correctly, they can escape repercussions and even criminal prosecution.

Shortly after Mom's death I had looked into a "wrongful death" suit, but no lawyer would take the case, Mom was old and terminally ill, and the fact that she died several months ahead of schedule in a hospital instead of at a later date at home or in a hospice mattered to no one but me. My own research had confirmed that Mom could not be saved this time. However it was Mom's sincere wish and my wish as well, that she be gotten well enough to return home to die, and failing that to at least spend her dying days in a hospice setting as comfortable as possible. Mom had been getting better, well enough to transport, and was close to being able to come home, before the hospital pulled the plug on her medications and IV feeding to speed up her death.

They wanted the bed freed up. Once expensive surgery or chemo treatment options had been ruled out, Mom didn't make any economic sense to the hospital. Better to free up the bed for patients who would generate more income for the hospital, surgeons and physicians. It's all a numbers game. King Dollar. They didn't care whether Mom was dead, alive at home or in a hospice. Just so she didn't die in their hospital bed. It's bad for business. It's worth noting that it wasn't because they needed the bed for other patients, there was an entire empty wing and the wing we were in was only 50% full.

If it wasn't so tragic, it would be comic. Half of Mom's Medical Team was pulling out the stops to get her well enough to go home, or to hospice, while the other half was DC'ing all of her meds, including her IV feeding (one doctor told me "food is for the living") in an effort to end things quickly. Before her food and meds were cut off, Mom was on oxygen and slept a lot, but she was lucid, coherent and conscious. It wasn't as if she was a comatose vegetable. But Mom was denied a chance to die with dignity.

Mom's primary physician (unfortunately) was also the prime mover in "let's get this over with" movement. I was constantly pressured to give a DNR (Do Not Resuscitate) Order, to take her home, or move her to a hospice, even knowing that home and a hospice were not equipped to provide her current IV medications and that she would probably die on the way in the ambulance. The primary physician would just come in during morning rounds and cancel all of her meds, and I would have to scramble to find one of Mom's other Attending Physicians to re-write the orders to re-start her medications. All of this back and forth didn't help Mom, and I believe prevented my bringing her home.

The morning she died, I think one of the younger nurses took it upon herself to "load" Mom's shot of pain killers with a lethal dose of "happy juice". Mom had seemed to be doing somewhat better that morning, we were watching Ming Sai, funny but that was her favorite TV food show, except that she hated when he prepared Foix Gras, which he was doing that morning. The nurse came in and gave her the shot and a few minutes later the pulse monitor alarm went off and Mom died. She died within five minutes of that last shot. To me that was very suspicious. The hospital and insurance company had had their way in the end, but to me Mom should have been allowed to die at home.

I am certain this episode will spark furious debate as it always has when I have told this story to people in person. Some think that Mom should have been given the "happy shot" when the initial terminal cancer diagnosis came in. Others believe that we all have the right to die with dignity in the manner and surroundings we chose to the extent that's possible. As the Baby Boomers, of which I am one, age and as we move inexorably toward Nationalized Health Care, this will become a key topic. So let the debate begin. That's why I have included it here. Mom would have wanted me to.

I can admit to much soul searching myself. Mom's last night at home haunts me. Had I known then that she had terminal cancer and that she would be dead within a few weeks, I would not have taken her back to the ER. True, she would have suffered for a few days in her favorite chair, but absent the hospital care, physicians and IVs, she would have probably died, as she wished, at home. The trouble is that I did not know that then. Mom seemed to be fighting an infection which could be easily cured with a course of treatment and she had beaten the CHF and had, if not beaten, at least held at bay, renal failure and anemia. In the end Mom died sitting next to me watching Ming Sai much as if she had been in her chair at home. I cherish the several weeks we had, and many of her friends and relatives cherish their last visits with Mom. And maybe, just perhaps, some of the hospital staff also gained a new perspective on life and love.