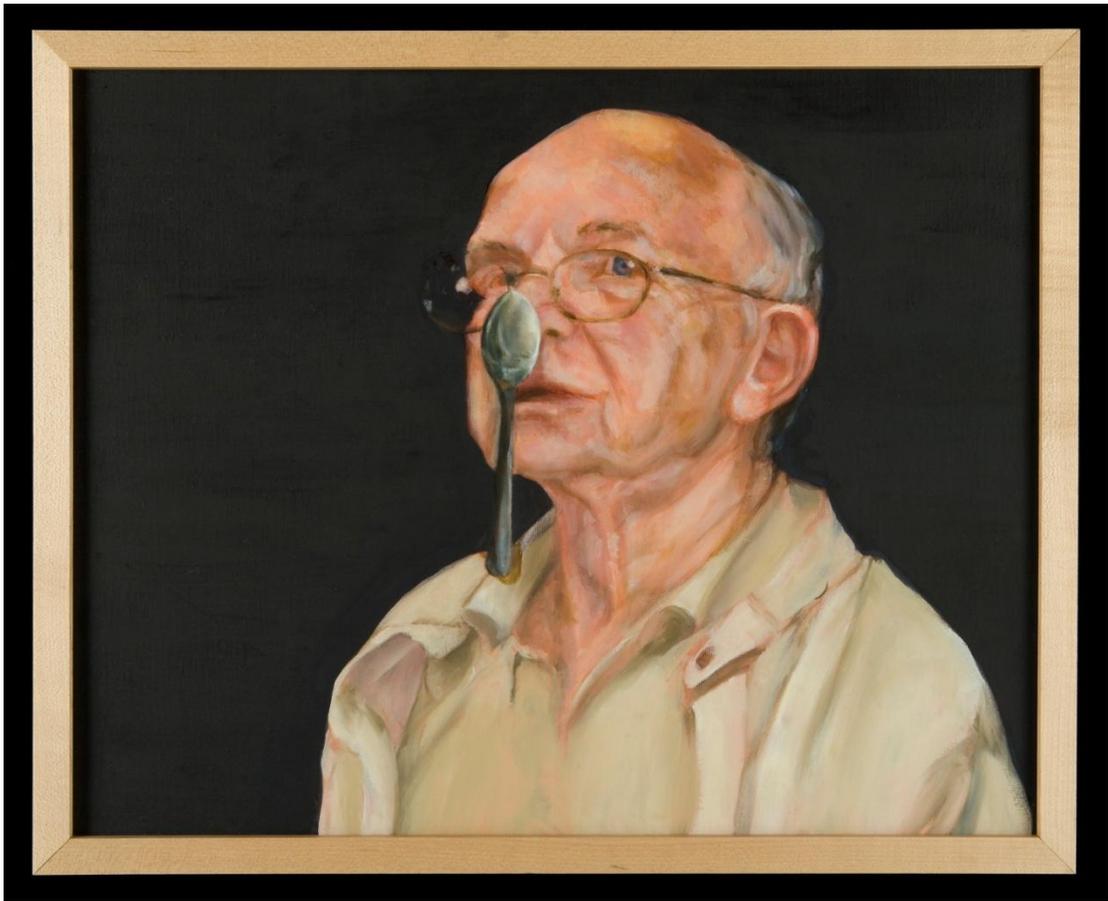


*Sharing the Journey:  
Becoming a Caregiver for Your Parents*

by

**Jody Catlin**

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# *Sharing the Journey:*

## **Becoming a Caregiver for Your Parents**

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## *Dedication*

To my daughter Yvie and all the daughters and sons who will become parents to their own moms and dads.

Especially to Yvie who is already planning to honor my wishes when I am frail and can no longer speak. I tell her, “Not yet...not yet.” I like that she will plop me on a beach where she knows I will be a happy clam.

Yvie created the oil painting on the cover of this book, *Spoon Trick*, of her grandfather, my dad; and photographed the hand portrait, on the Section One title page, of her grandmother, my mom, and me. She also gave me writing tips and edited three versions of this book.

I am also thankful for other family who advised me and supported me in this endeavor: especially sister Janny who partnered in caregiving and supplied two chapters for the book, my brother Jim, his wife Kim and their kids, Jessica, David, Amy and Jennifer, Janny’s son Nik, Aunt Betty and Uncle Roy, and cousin Bobbi. Supportive, dear friends Cathy Jo Corso-Plank, Lynn Stewart, Jill Eshenbaugh, Scott Ross, Diane Cutler, Marcia Fram, Joan Bennett, Shelly Chandler, Bonnie DuBois, Ann Marie Monahan and Susan Shofner who gave me tips and moral support, and Violet Theogone, professional caregiver extraordinaire who was a marvel at tending to Dad. I am grateful for the top-notch health care professionals who generously contributed their support and time for interviews: Norma Brownell, Executive Director, ActivCare; Vivian Wohlwend, M.S.W., LCSW; Mary Unterwegner, L.M.F.T.; Lima Taiti, CNA; Juanita Lewis, LVN; Cherrie Wagner, LVN.

Some names and places in the book have been changed to honor personal privacy.

## *Preface*

This is my chronicle of caregiving. I'd like to share it with you for two reasons. One; it helps me. Two; if you are becoming a caregiver, it might help you, too.

As a daughter, I learned the hard way how to care for my parents in their not so golden last years.

In the beginning, my nose dripped droplets of sweat as I strained to maneuver Mom into her wheelchair while my left eye kept watch on my restless Alzheimer's-stricken dad. Strangers smiled. I swelled with pride as I mopped my brow. Surely, these witnesses of my efforts were amazed at my selfless tenacity. Not really. Most of them smiled because they knew. They were, or had been, caregivers, too. Someone would say, "May I help you?" I would reply, "No, I'm fine. I'm fine." Pretty soon, I wasn't. Caregiving takes its toll. After awhile, I meekly, wisely, answered, "Yes. Thank you."

Miraculously, a whole world of family, friends, support groups and health care professionals appeared, at the ready to answer our needs. I had been trying to reinvent the wheel and it was exhausting and lonely. When I began to share and ask for help on difficult daily duties, quality time with my parents became possible again. When other caregivers shared their stories with me, I felt lighter. We carried our troubles together.

This is a personal case-study, from a daughter's point-of-view. I hadn't a clue what I was in for at the beginning and, even with helpful resources, I made many mistakes along the way. A caregiver is a resilient phoenix, yet oh so fragile. We must endure anguish and tragedy, yet somehow maintain joy and find the glory.

Caregiving is a lot of trial-and-error. Diagnosis and treatment are likewise trial-and-error. In order to give the best care for our loved ones we need to create compatible teams with family, friends and compassionate professionals. Not an easy challenge.

Each person, each family, is unique. At the same time, we may have a lot in common. Perhaps you will relate to certain of my mistakes, or discoveries, or tantrums. Maybe you can adapt or improve on some of my accumulated caregiving tips.

Most of all, I want us all to know we are not alone. We can share.

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### Section One: Discovering the Need

*I would not exchange the sorrows of my heart for the joys of the multitude. And I would not have the tears that sadness makes to flow from my every part turn into laughter. I would that my life remain a tear and a smile.*

*---Kahlil Gibran*



Hand portrait photo by Yvie  
(Mom and Jody)

## Chapter 1

### **Is This Her Last Christmas?**

I remember exactly where I was and what I was doing when I was hit with the grim probability of Mom's mortality. It hadn't yet dawned on me that I would become a caregiver, but this may have been the beginning. It was 1995.

Just before the holidays, I approached my boss about holiday PTO (paid time off). He was in his office, and my fellow account executive, Lauren, was sitting across from him. He nodded it was ok to interrupt, so I began: "May I..." Out of my mouth, instead of words, came a guttural "Arrrrrghourgh..." I tried again. "I'm afraid it's.....arrrrghourgh..." Again, and again, I tried to speak, but from the pit of my stomach kept coming only primitive sounds. Lauren said, "Should I come back later?" "No, I'm ok...aaaarghourgh..." I felt like I was a seal in the seal show at the San Diego Zoo. Again, I tried, but couldn't speak. I was trying to say that we thought it might be Mom's last Christmas, and might I have time off from Christmas through New Year's Eve? Eventually, I got the words out, and got approval for time off. But I was totally surprised at myself. Where did that come from? I had often thought I was good with crises; that I could handle anything. I guess I was scared. Evidently, it is not wise to suppress and deny powerful feelings.

Like fear of death. It was 1971 when Dad had a heart attack and wasn't expected to survive. We kids were weak in the knees to see our robust dad lying there frail and white as a sheet. But, he recovered. The parents were still young. We kids were, too. Life went on.

This time, Mom was seventy-four, over-weight, and still fragile from knee-replacement surgery. Now she had uterine cancer and faced surgery, radiation. We were frightened.

I recall a disconnect between my body and my mind. Dad and I weakly waved to Mom as she was wheeled post-surgery back into her hospital room. We both grinned widely trying to show game faces, but we had tears rolling down our cheeks.

The surgery and radiation were a success. Amid flowers, cards and gentle hugs from family and friends, Mom steadily regained her strength.

Mom survived that Christmas. Life went on, with gusto. Family reunions; travels; parties. But, in between family outings and celebrations, Mom's and Dad's health problems began to escalate. I hadn't even heard of the term "caregiver." But I knew I needed to start driving down to San Diego to help out the parents.



The whole motley crew, Christmas morning, 1996

## Chapter 2

### **We Are Not Alone**

Many of us today find ourselves caring for aging and infirm parents. It brings both challenges and blessings. As children, we seldom consider that one day a parent might become the child to the parent in us.

All over the world, there are families clinging to varying degrees of togetherness in the face of crisis and incapacity. There are multi-family, multi-generational homes; root-bound, close-knit nuclear clans; far-flown, nest-flung, web-connected relations; other-descendant, self-chosen, creative-styled communities. Family—how can we stay together in trying times? Do we want to? Who will care for our parents if not us? Will trauma tear us apart or bring us together?

In the 1990's, I found myself unexpectedly caring for both of my parents. Mom walked weakly with two titanium knees; had uterine cancer; then, end-stage renal failure. Around the time Mom's kidneys began to fail, Dad was diagnosed with Alzheimer's disease.

It was, and is, difficult to watch Mom and Dad endure physical pain; and to imagine their emotional suffering. My mother passed away in December of 2004; and, at this writing, my father is in the far side of the moderate stage of Alzheimer's. He resides in an Alzheimer's facility, a few minutes away from me.

Grief, I learned, doesn't just happen when someone dies. It happens when your dad can no longer hear the mocking bird scold in the back yard, or when your mom can no longer see her Lawrence Welk on TV. It happens when someone you love can no longer walk to the bathroom, or feed themselves turkey/avocado sandwiches, or recognize you.

There is anger, too, and exhaustion, and feelings of helplessness. You get frustrated when Dad asks for help and then screams at you for taking over. You get drained from cleaning toilets and floors and bottoms. Maybe you lose your job because you just can't do it all.

There are stages of grief that come lickety-split and unexpectedly. Health in body, mind and spirit, is a fragile commodity not only for the infirm, but for the caregiver as well.

What a relief, then, to have family. Someone who has known you and loved you for years is irreplaceable, especially during trying times. Family may live far away and financial constraints and work stress may preclude frequent visits. Despite the challenges of communicating, there are many creative ways for family to unite for a team of care.

I know some families who see each other every day; others hardly at all. Our family falls somewhere in-between. Over the years, one or the other of us three kids lived relatively near the parents. Sis Janny had the best job ever as a flight attendant for flying to the rescue if needed, or just for fun. She worked for the airlines and could hop a plane, stand-by, at a moment's notice. My brother Jim and I, plus our families, rendezvoused with the parents once or twice a year, as well as joining up for special adventures and reunions.

By the time the parents' health began declining, it happened that I became the on-location caregiver, with Janny flying out frequently to help, and Jim continuing his bi-annual visits. The trial-and-error teamwork commenced.

Whatever its configuration, content or dysfunction, family can provide a wondrous team for caregiving. Sharing of responsibilities empowers family members and allows them to experience new depths of family connection. Consistent efforts at communication can help to dissolve dysfunction. Our family disagrees about a lot of things. But do we have to be disagreeable?

We keep trying to choose to focus on what works--what makes us happy; what is healing; what we want to last forever. In our efforts to care for the parents, we have seen each other more than ever before in our adult lives. The closeness--both contentious and loving--has prompted us to search our memory banks for treasured moments to share with the parents to lift their spirits and help heal their hurts. If we spend our time talking about the fun and loving things, there is a good chance we will laugh and sing a lot. Nanny used to say, "If you don't feel like smiling, smile anyway, and pretty soon the feeling will follow." Everyone knows that laughter and music are great medicine.

Thus, we share the albums and the movies, videos, DVD's of Christmases past, graduations, grandchildren, and the picture of the fish Janny caught and kissed at sunset. Jim and Dad ooh'd and aah'd at that big ole fish sticking out of Janny's creel, and Mom cooked it right up. It has become a frequent family lore remembrance.



There is help to be found in community, too, I gradually learned. Even with family help, when the caregiving crises escalate, it is so easy to run like a crazy person trying to do everything by yourself, until you collapse from exhaustion. I thought I could do everything. Until I couldn't. It sort of crept up on me when I wasn't paying attention to myself—my body turning to mud—very fat mud...not being able to lift the wheelchair out of the car. Loneliness and isolation. And then I learned I was not alone.

There is help out there. Lots of it. It is easier than one thinks to find it.

Myriad professional resource agencies, such as the Alzheimer's Association, AARP, and the National Association of Area Agencies on Aging are at our internet fingertips, as well as local conferences, support groups and printed materials. Support Groups provide both professional advice and opportunities to connect with others who share similar heartaches.

This has been a journey home for me, in more ways than I can count. By sharing the ends of our parents' journeys, our family has grown closer. Returning to the city of my youth I rediscovered friends of long ago.

I never expected to be caregiver. Now, I wouldn't give up these precious caregiving moments for anything.

I know that aging is inevitable. I know that change happens. I keep trying to remember to be in the moment and to enjoy the journey. And yet, I keep finding myself startled and unprepared at new turns in the road. Just as mommy and daddy nurtured a new-born, toddler, pre-teen and young adult me, the day came when I would become their parent, and offer my comforting arm to them.

This narrative chronicles my story and their story. It is a story about change and a story about coming home.



Dad and Mom--Larry and Patty, 1950's



Patty in skilled nursing home; Larry in Alzheimer's facility, 2004

## Chapter 3

### **Just Say Cheese**

Mom was the instigator. I think she was masterminding festivities at every opportunity long before I came on the scene. Back in 1944, during the war, Mom and her friends made aluminum Christmas tree ornaments from chewing gum wrappers for their scrawny little tree. Their pilot husbands flew home with corsages for their brides and gathered 'round their little tree to sing and celebrate. Mom would face life's adventures and adversities with the same festive gusto and positive outlook all her life. My sister, daughter and I got it from her.

I think our proclivity for scavenging and hoarding and liking too much mayonnaise are all related to Mom's mind-mode of abundance and joy and saving anything that might be used for fun, entertainment or anything else; empty boxes for trains, clothes pins for dolls or ducks or nose pincers, the garden hose and sprinkler for water fun, of course. There had to be plenty of food for everyone, over-stuffed Christmas stockings, one present on Christmas Eve, tents and castles and dolls and coca-cola machines and trains spread half-way across the room on Christmas morning.

The party-at-the-drop-of-a-hat attitude followed me into my adulthood. Even during times when I didn't know if I could pay the rent, I felt abundantly celebratory of this or that. My daughter and I made newspaper mache ornaments glued with glitter, home-made presents decorated with fall leaves and seed pods gathered in the park, matching pants and skirts made from old curtains, and gingerbread houses with removable roofs that would reveal little people, mice and furniture inside. At Mom's, sis's, daughter's or my place, one never knew what long-forgotten goodies could be found stashed in nooks and crannies.

Not to be daunted by infirmity, Mom in her waning years had me push her in her wheelchair to shop for Christmas presents at Macy's. We piled the presents high on her lap; two singing moose, several sets of furry slippers, candy and kissing fish ornaments, all the way up to her chin. She giggled all the way to the cash register.

Early one morning before work, I drove over to peek in and check on my increasingly fragile parents. Up Mom sat, and handed me the front page of the *Union-Tribune* Food Section, all folded carefully to frame a picture of an elaborate feast of brisket, glazed carrots and carved peppers with colcannon (a yummy Irish potato dish).

"Oh, is this what you would like me to fix for your birthday?" I inquired.

Mom nodded an impish grin.

Mom's positive attitude and sense of celebration would come in handy when disease and disability presented. Thank goodness, too, for Mom's and Dad's stable careers and pensions, and their planning ahead. The plan-ahead part was a good lesson for us kids for our own families, as we struggled in subsequent years with our own jobs in an increasingly unstable economy.

We weren't living in the midst of war, famine or hurricane devastation, and we had a roof over our heads and food to eat. We were lucky. Yet, whether living a life of riches or bare subsistence, death and decline are common denominators, and anyone may suffer anguish when a loved one suffers.

Then there is family dysfunction. Does anyone not relate? After the I-do's, there often exist the I-don't's and I won't's. One may wonder from time to time, who is this alien living in my home? Baby boomers like me can be heard reminiscing about our post-war happy days, but just how happy were they really?

Once upon a time in 1992, a baby boomer friend and I sat around a kitchen table recalling what we used to think of as our fairytale youth. All of a sudden, she spoke words that have stuck with me ever since. She said, "Isn't it nice to now know that all families are dysfunctional?" I let out a whoop. "Yes!" My friend's observation may seem obvious to many, but to me, a stubborn graduate of the happy days school, those words were a revelation and a relief.

One of my favorite movies of all time is *Home for the Holidays*, 1995, directed by Jodie Foster. A family gathers for Thanksgiving; family dysfunction is rampant and hilarious; bickering and miscommunication escalate, and a turkey ends up in someone's lap. Our family, like so many others, can relate.

On a particular Thanksgiving, our whole family is gathered at Mom and Dad's. It is early morning and the smell of Mom's sizzling bacon tempts us to the kitchen.

"That bacon is mine," I declare, pointing at a particularly crispy bit. "That one—nobody eat it, okay?"

"Hey—that was mine! I wanted that," I screech, as my daughter Yvie grabs and gobbles it right up. "You ate my bacon," I wail. My mother—the sweet grandmother—rushes to the defense of her little girl—me—and suddenly becomes cold and mean to her own granddaughter. Yvie thinks the whole thing is hilarious and silly, mainly because there is an entire skillet of bacon still cooking, so she laughs...which, of course, makes it worse. Uh-oh—escalation.

An undercurrent of past misdeeds, mistrust, betrayals and abuse, both real and imagined gushes forth. Hurt feelings. Old wounds. It is no longer about bacon. A frost falls on the land for many days. Absurd? Yes. Typical? Perhaps. We are all such complex creatures. Anyone watching from the periphery would surely protest, "Why don't they just talk to each other?"

Flowing through our memories of dysfunction over the years are multitudes of hurts both said and unsaid. Little girl me overhearing Mommy and Daddy fight: "Are you going to get a divorce, Mommy?" Accusations and innuendoes quickly pushed under the carpet. Mom replies, "Oh no, dear, Daddy and I are just having an argument. Everything is fine." Or, years later, "Why did you stay together all these years, Mom?" "For you kids, dear, for you kids." No one knows the true ups and downs of anyone else's relationship. Infidelities? Abuse? Then; "I love him," "I love her." I look at a snapshot of Mom and Dad at their 50<sup>th</sup> Anniversary Party, and I know those words were true, too. It's all true, the goodness and the bad.

Dad called Mom "morbidly obese." He ridiculed relatives for disagreeing with anything he said. Mom was the old school proper wife; "Say nothing; just smile." Maybe there should have been more arguments, more honest expression—more communication for sure. One of the grandchildren asked his mommy, "Why does Gramma look so mean?" Despite Mom's usual positive attitude, I think she paid a price for keeping anger and frustration pent up inside. Sometimes her smile turned stern and froze, and it looked like a mean face to a little boy.

On the other hand, my daughter and I could be annoyingly out-spoken rather than silent like Mom. We strutted our bossy, sassy selves, convinced we knew everything about anything because we were New Yorkers. I lectured my parents on alternative medicine until they demanded, "No more." I interrupted sentences and dove in to problem-solve before a problem was even identified. One day, Yvie barked at me, "Mom, stop trying to fix everything--sometimes I just want you to listen."

Soon we all would need to start listening to each other better, every member of the family.

My brother is a fundamentalist Christian who supports the pro-life movement, and my sister, a Unitarian, marched in the front lines of pro-choice marches. They set aside their differences when they had kids and decided they wanted their kids to share aunts and uncles and cousins. One time my brother and I talked until 4 in the morning comparing Biblical interpretations until we agreed to disagree and go to sleep. When my gay daughter was about to graduate from UC Berkeley, my brother Jim sent her a generous check, which she sent back, saying, "I appreciated the check, but to be fair, if you saw some of the subject matter of some of my paintings, I don't think you would be comfortable about it." She still gets tears in her eyes when she recalls that he sent the check back to her, writing, "We love you, Yvie, and we support you." We all at some point agreed that family is about love. There would be ongoing efforts to get along.

Maybe there could be happy days if we would embrace diversity and multi-layered facets of ourselves and everyone else, past and present, and just be kind. Not always that easy. We did have fundamental differences in our beliefs and often felt we had to walk on the proverbial egg shells around each other. While it is refreshing to admit dysfunction and discuss differences, it is an ongoing challenge to maintain constructive, compassionate communication.

It was our parents' decline that brought us together in ways we hadn't anticipated. The common purpose of caring for them challenged us to share responsibility and to seek ways to bring them comfort. We searched our family archives, discovered ancestors we never knew about, and treasured shared memories of our grandparents.

Nanny, our grandmother, was an Eastern Star president and "Daily Word" reader and called me Miss Kafferty. She was a positive thinker, like Mom. We discovered a love letter Nanny wrote to her beau Leroy (Bampa) as he was returning from WWI. Read to us all by sis-in-law Kim at a family gathering, it was written on an entire roll of adding machine tape. Nanny's maiden name was Clark. Who knows if it is true, but one of our Great Aunts said that we are related to Clark of the Lewis and Clark Expeditions. We all promptly checked out books, DVD's and History Channel stories about our Clark ancestors.

Bampa, who became Nanny's husband and our grandpa, was a pharmacist, smoked sweet-smelling cigars, studied religions, quoted French poetry, and was a tease. He pinched us and told us Johnny Greeno did it.

Mom's brother, our Unke Roy was and is a magician. He and our Aunt Betty were teachers; Roy, a principal, and both have been magicians for many years. They performed card tricks and multiplying bunny tricks for us and our friends. They even levitated me and sawed Janny in half in one of their stage shows when we were in the first grade. They still bring light and levity to us and to patients in hospitals where they volunteer.

The photo that Dad remembers best, even as his memory fades, is one of his parents in front of Grandpa's bee hives. Dad grins and points, "My mom...my dad..."

Grandpa was a beekeeper and a minister, and Grandma helped tend to the ministry and made us German cookies. Grandpa always smelled of cigars and beer, and his cellar smelled of wine because he made his own. As a kid, Dad sang in Grandpa's church services, both in German and English.

These memories brought the past alive for Mom and Dad, and for us, too.

As for myself: I was born with a pointed head.

On that momentous morn of my birth, the nurse said, "Patty, squeeze your thighs together—the doctor is not here!" Ow.

The doctor had said to Bampa, "Le Roy, let's go have coffee, this baby isn't coming for a long time."

Finally, the men returned, and the nurse said, "Now, Patty!" Out I popped, and Mom gasped at the sight of me...I am told.

"Don't worry, Patty, your baby's head will go back to normal." I guess she had seen pointed heads before.

Maybe my pointed head experience contributed to a "let me live; never say die" attitude. Maybe it's also why I sometimes try way too hard. Ahhh, the clues one can gain from sharing. Note to myself again to listen better.

Every family has some kind of fish-kissing story that can lift the spirits of a loved one. The picture of Janny kissing the big ole fish at sunset never fails to make Dad smile. Levity can often make us forget the aches and pains of infirmity. I am reminded of the ubiquitous parable of the twin boys, one an optimist, the other a pessimist. A psychiatrist tries to temper their extreme attitudes by advising the parents to give the optimist a pile of manure for Christmas; and the pessimist, a pile of toys. The little boy optimist is revealed digging through the manure on Christmas morn, insisting, "There must be a pony in here somewhere!" But the pessimist won't even play with his toys. He can only cry and wail, "I would only break them."

The sad little pessimist was determined to be unhappy. If we can choose optimism we can relieve a great deal of stress for ourselves and everyone around us.

As our parents' health declined, they managed to help finance us kids to fly home for visits. When Mom or Dad was seriously ill, or a big change in their lives was looming, here we came. The family all squeezed into Mom's tiny hospital room to plop flowers and furry toy spaniels on her fragile lap. We would trip over kidney-dialysis cords on the hospital floor giggling, and aghast--hoping we hadn't disconnected a life-line. After Dad's heart attack, we all flew in to be by his side; then flew in again for his traumatic move into an Alzheimer's facility.

Some of the family gatherings would be for fun times rather than crises--Christmas, birthdays or summer visits to Sea World and the beach. One time, sis Janny arrived for Mom's birthday at the nursing home bedecked in a hundred Mardi Gras beads for us and the staff. One Easter Yvie camcordered Mom and Dad talking about their life adventures, as they munched away at their chocolate bunnies. Sis-in-law Kim made computer generated books about family Christmases and travels.

Standing at Mom's and Dad's hospital and nursing home beds, we spent hours singing *My Blue Heaven*, the *Doxology*, the raunchy *Little White Mouse*, and *I See the Moon*. We watched many an hour of *Lawrence Welk* with Mom. When she was weak and could hardly keep her eyes open, we had her hair and make-up done, sat her at the decorated nursing home table, and kept propping her vertical for her birthday party. She could barely eat, but she smiled an askew lipstick grin. I'm not sure whether she enjoyed that celebration or if she just wanted to sleep, and if I should feel guilty.

It was only fitting and quite normal, considering Mom's teachings, that on Mom's last day on this earth, we would all be singing and laughing and telling stories. The only reason we didn't all watch *Lawrence Welk* from her bedside that day is that he was pre-empted by an Andre Rieu concert in Tuscany that Mom and I had seen before. I squealed to my unresponsive Mom, "Ohhh, Mom, this is so perfect—we loved this concert, didn't we, and now we get to share it with Dad and Janny and Jim!" We all figured that deep inside somewhere, she was hearing our lullabies and sassy songs and Andre as well.

Even as the mortuary van drove Mom's tenderly wrapped lifeless body from the nursing home, we kids waved like we were wishing her bon voyage. Janny said "Let's sing *Aloha Oe!*" So we did, and waved some more. Months later when we scattered Mom over the Pacific we sang and told stories and Janny flung her hand-made daisy lei to Mom and the sea.

Mom taught us to celebrate life and survive her death. Her teachings became ingrained. It's a good thing, because when the caregiving part happened, when I was overwhelmed and exhausted and didn't know which way to turn, I sometimes fell back to Mom's default program. Her positive, constructive, celebratory modus operandi sustained me many a time. Whether it was the photo albums, the videos and DVD's, the TV shows, the family, there were ways to maintain some kind of equilibrium and lightness. It didn't cost a thing except love and care to provide some comfort and joy. Even when Mom couldn't see or speak any more, she was still sharing valuable lessons because they had become a part of us.

When I sit with my declining Dad these days, I invite ancestors long gone as well as the living to our imaginary party. Time is shorter. There are choices to be made. I envision us dancing the polka at Little Bavaria in Del Mar with Nanny and Bampa as we did many years ago. I want to savor Grandpa's honey and Grandma's Springerle cookies again. I want to walk on the stilts that Daddy built and wear the tutu that Mommy sewed and watch my baby Yvie sit on her grandpa's shoulders. There are other memories, darker ones, but if I choose wisely, will there be resolution...comfort...healing tears...joy? It's a good choice, I think to sing and dance and laugh.

After Mom died, I compulsively wrote about her last days, and eventually about caregiving for both parents. I realized how therapeutic it was to write stuff down. Hospice letters that continued for awhile after Mom's death were comforting because they told me that writing things down was one of the ways people grieve. Hallelujah, I thought, I'm normal. Even if once I did have a pointed head.

It is difficult not only to figure out how to be a caregiver; it is challenging to learn how to cooperate with family. It is also difficult to learn how to take care of myself, the primary caregiver. Mom taught me that it is nice to share and that the best way to not be alone is to celebrate life with others.

Of course, with Dad, it would sometimes be a whole different ballgame.

## Chapter 4

### **Never Say Never**

When I wasn't barking like a seal at my first glimpse of Mom's mortality, before Yvie and I moved West, I was merrily living my own life in the far-away land called New York City—the place to which my daughter and I had sworn undying allegiance. Never. Never would we leave. Until we did.

My young adult years were spent as an actress in the Big Apple and at regional theaters around the country. Yvie swears now that she liked our bohemian life, as she called it, but she pretty much raised herself and I was often just glad to be able to afford toilet paper. Yvie left before I did. After high school, she went to live in Japan for two years and then became a pilot and flight instructor in Mt. Airy, North Carolina. When a casting director friend suggested I move west, I decided the time was right. I persuaded Yvie that the West Coast had better weather for flying, so we drove cross-country together.

I actually had said to my friend, “Well, the time is right—I just finished a project; got new head shots...and I would like to be closer to my parents.” Of course, I had no idea my parents were really going to need me, I just hadn't seen them much over the years, and thought it would be nice to visit.

I got older. That was unexpected, too. The roles became fewer. Never. I was never going to give up acting. Until I did. A playwright friend, who was making ends meet by working as a director of sales for a skin care company, suggested I might like to work there, too. Of course, I thought I could do it all—act and sell, but it didn't work out that way. I accepted the job as an account executive, discovered there was no time for acting, but marveled that I could buy all the presents for family I wanted, contribute to charities, and never fear going without toilet paper. To satisfy my suppressed passion for entertaining and applause, I wrote rap songs with funny words about skin care, and lo and behold, the CEO liked them and insisted I perform them at conferences, regional meetings and restaurants.

My daughter sent me a card for my birthday with a quote by Madeleine L'Engle which read:

*The great thing about getting older  
is that you don't lose all the other ages you have been.*

I have the card taped to the corner of my bathroom window so I ponder its message as I brush my teeth.

A gung-ho, post-war baby-boomer, I learned a can-do attitude from my parents. Dad was a Navy pilot, captain, and mom was a Navy wife, school activity supporter, Red-Cross swim instructor, and Padres ticket sales employee. Dad would proudly say "Patty works for the Padres," waiting for people to ask what she actually did, whereupon he would merrily fib, "Third base."

Mom discovered Dad was constantly underfoot after he retired, so she got out of the house to preserve her sanity. Her part-time work at the Padres turned into an 18 year second career.

The two of them divvied up the household chores, traveled together, partied together, worked through relationship ups and downs, and, miraculously, managed to stay together for over 50 years.

They were each other's ears and eyes when Dad needed hearing aids, and Mom's eyesight was impaired by macular degeneration. After Mom's knee surgery, there appeared grab bars in the bathrooms, night lights in the bedrooms, and non-skid, good grip rugs on the floors. Routine doctor exams for both parents were up-to-date.

They would drive up to Los Angeles to visit Yvie and me, and we would drive down to San Diego to visit them. We had fun times—lunch in Topanga Canyon, trips to San Diego Zoo (where the seals and I exchanged knowing glances). Pretty soon, though, I began driving down most weekends to help out.

There were numerous physician referrals for Mom and Dad for various medical conditions. Dad had two prostate surgeries. He had recurring chest pains and back surgery. Mom's uterine cancer was resolved, but now a nodule appeared on her lung. She began to experience incontinence. The frequency of doctor appointments increased. I tried to monitor and assist.

However, my efforts at parent-care were not always appreciated. They needed me, but resented my interference. This was not going to be easy.

“Stop telling us what to do! Enough with the alternative medicine advice! Don't criticize our doctor; he's my golfing buddy from way back!”

“Don't ask so many questions, Jody,” they would bark. “You embarrass us. The doctor knows what he is doing.” Mom stewed in silence over the stove, giving me the cold shoulder. Dad stormed out in a huff.

I was a bulldog. I persisted in bringing my lists of concerns and all their related medical information. When doctors asked for concerns, symptoms, medications and medical histories, Mom and Dad finally relented and learned the value of having a list-carrying, note-taking, questioning advocate on their team.

The number of prescribed medications for the two of them now took up a whole shelf in the kitchen. Back at work in LA, I designed a chart that would help Mom and Dad check off each time they took one of their medications. A co-worker who was proficient in Excel created and printed the charts for me. My parents started using them right away. The charts made it easier for them to take the proper medications in the proper amounts at the proper times. In addition to providing the doctors with updated medications lists, I asked a pharmacist to review the lists for contraindications, duplications, correct dosage.

Dad and I attended our first caregiver conference in 1998. We were in for a surprise. We thought we were going to learn more about diapers for incontinence, preventing bedsores, grab bars and elevated toilets and other ways to be a good caregiver. It turned out the conference was also about how to take care of ourselves—the caregivers. We looked at each other with tears in our eyes. We didn't realize we needed help, too. The whole first part was about us. We learned many things that day.

We were told that denial can be your friend...for a time. Sometimes denying a crisis or pain can allow us time to adjust. Just for a time, though. Eventually it helps to face the facts. We found out that anger is normal, too. One speaker suggested buying a cheap set of dishes and finding a safe wall to throw them against. The audience laughed, sort of. We found out we were not alone in our fear and worry.

Despite my help, Dad was getting overwhelmed. He was now doing all the house and yard work and cooking and extra laundry that both he and Mom used to do. They had a gardener and finally hired a once a week house-cleaner, but Dad was swamped with all the work and all the doctor appointments. He said, "Patty raised you kids while I was at sea. She cared for me through my heart attack and stroke. Now it's my turn to take care of her." But it really was too much for him.

My drives down to San Diego increased.

I didn't know it at the time, but the stress was getting to me, too. My cortisol flight-or-fight survival hormones must have kicked in, because my stomach began to expand. "What is this!" I exclaimed one casual Friday, as I tried and couldn't button my jeans.

Working for the skin care company, I "repped" salons and spas and beauty supply stores on the East Coast by phone and I would fly East for seminars, events and conventions. I was up at 5:30 am and home by 7:30 pm. It was a good job, but intense. The stress sort of crept up on me.

One day, on my drive to work, I accidentally caught a glimpse of myself in the rear-view mirror. What I saw startled me. Thinking myself a positive person (a co-worker once sang "Cock-Eyed Optimist" to me on my birthday), I felt that I always had a natural and perpetual smile on my face regardless of stress or illness of any kind. But the face I unexpectedly saw in the mirror was not smiling. What I saw was a grimace—a pretentious grotesque mask. It was as if I was trying to morph a facade of serenity to cover the stress and anxiety inside. Red flag. I needed to find a better way to deal with both my job and the parents' needs. I needed to move down there. I concocted a plan for telecommuting.

My manager declared, "It isn't done, Jody. You will not get approval. Our CEO wants to keep his employees here in LA." Then she added, "But, go ahead and try."

That kind of business boldness was out-of-character for me. I don't know where I got the guts to do it. It was necessary, so I guess it made sense. I forged ahead with a proposal, collecting data on my performance record and on cost-effective statistics for telecommuting. I wrote and re-wrote, and paid Kinko's to professionally format and print six copies of my proposal. The Board of directors and CEO approved it unanimously.

In February of 1999, I moved to San Diego, and began telecommuting for my sales work from an apartment four minutes away from Mom and Dad.

Two years later, the company restructured and employed only on-site-local-sales reps, instead of in-house cubicle-based reps. My new manager told me, “We happen to need a rep in San Diego. If you want it, fine. Otherwise, you’re out.” So, I became the San Diego account executive (instead of handling East Coast accounts), with 120 local clients whom I would visit in person. What a fortuitous turn of events. If I hadn’t moved down to San Diego, I would have been out of a job.

Yahoo, this would solve all our problems! Now I can rush over to my parents’ at a moments notice. Jody to the rescue, I thought naively. Little did I know I would soon enough need rescuing myself.

Odd, how things happen. Or is it? Somehow, I had followed my own little yellow brick road back home. I began my caregiver 101 education in earnest. Of course, Dad was already a full-time caregiver. Now we had each other.

A little note: My sister Janny is from Kansas. My favorite work of art by Janny is an etching she created and gave to me in 1985. It is a self-portrait, with a little bit of me in it, too. The inscription reads:

*Alice remembers wonderland  
and tells Dorothy who relates.*

I wish always to have wonder in my life, I muse to myself--even if I can’t foresee what lies ahead, or what changes may come, or where my path may lead.

Therefore, the best place for Janny’s etching is on my bathroom wall next to Yvie’s Madeleine L’Engle card. Ensclosed in San Diego near my parents, I establish my morning routine: open eyes; stretch; brush teeth; try to remember what I’ve learned, never say never, and be ready for the unexpected. Ha!

## Chapter 5

**Peter Pan Pop**

Why didn't I move in with my parents? I figured if I did I'd be dead in two weeks.

Mom was a sweetie, but Pop was a pill. Ever the Peter Pan, Dad could be a fun play-mate when he was home from military duty, teaching us kids how to fish and camp and tell jokes, but the man did not want to grow up. Little boys from the neighborhood knocked on our front door, "Can Larry come out and play?" We thought that was cute at first, but Dad wanted to be the cute center of attention all the time. While an oft-requested talented master of ceremonies, singer and jokester, his temper could flare if you didn't follow his rules, cater to his needs or laugh at his jokes. Protesting his bossiness or trying to share attention could result in angry outbursts. It was fruitless to attempt to read a book if Pop was in the house.

When kept waiting for his appointment at the doctor's office, Dad would exclaim loudly to the entire waiting room, "How rude of the doctor! I would never keep *him* waiting like this!"

I would drop Dad and Mom back home after an appointment, give them a kiss, and tell them I had to get back to work. Dad was miffed that I had to go, "Well! You don't care about us! You don't have time for us? Go ahead! Go back to work. Don't even bother to come help us anymore!" His Peter Pan could be entertaining, but his impatience and tantrums could exhaust the rest of us.

One day, my aunt gave me a newspaper article on "people with toxic personalities." That would be my father, I thought. If I don't figure out a way to deal with him, I will have my own heart attack or stroke. In order to prevent my own demise, I determined to know my own limitations and attempt to help the parents from a safe distance. When they asked me to move in, I thanked them for their invitation, but explained that I needed a separate work space for my job.

Of course, none of us realized that Dad would later be diagnosed with Alzheimer's. It would dawn on us much later that some of his erratic behavior may have been symptomatic of his dementia, depression and Alzheimer's. It didn't occur to me until after Mom had died, that it must have been so incredibly difficult for Dad to function as fully as he did, while his own abilities were declining.

Dad's need for attention, his insistence on entertaining, his temper tantrums, and his depression would all intensify as his mental abilities declined. Yet, he could turn on the charm if he wished and there were those who thought us the crazy ones for suggesting he needed help. Our cousins and others rebuked us for even hinting that Dad was anything but sweet and entertaining. "Not my Uncle Larry! He's never mean or cruel!"

We tried to be supportive, and to find ways to avoid, tolerate or deflect his variations of temperament. He still was in charge, and still very capable, and still full-time caregiver for Mom. We wanted to respect and support him.

As kids, and for years as adults, we naively believed in our happy days existence. Indeed, there were many idyllic moments. We played outside 'til dark; cheered while the bands played as Dad sailed in on the giant carriers; we were ferried to gymnastics, dance and karate by a doting mom. But there were the fights behind closed doors, the tee-many-martoonies, intolerance, repression and instilled fears. Back then, we didn't talk. It just wasn't done. Whatever went on behind closed doors, we all put on a happy face to the world. Then, we grew up and realized there were multi-levels of discontent both within and without the family and no one told. I felt it was only us—everyone else was just fine. It became important to face reality.

The words of my friend around the kitchen table back in 1992 echoed often in my mind: "Isn't it nice to now know that all families are dysfunctional?"

What a surprise to realize it wasn't just us. At reunions of old high school friends, the truths came pouring out. Childhood had been tough. The cool model-type who seemed so sophisticated was really painfully shy. My really smart and confident friend told no one back then that her alcoholic father was killed in a DUI car crash. The witty writer for the school paper later told me those were the worst days of her life. Most everyone suffered from low self-esteem or jealousy or a sense of failure. There were hidden scars from divorce, abuse or death in the family. There was race, religious, cultural, political turmoil in the world and many of us hadn't a clue. I thought I was the only ignorant one until our 40<sup>th</sup> reunion when classmates, one after another, spilled the beans. We were no longer trying to hide or to impress. We just wanted to connect.

How refreshing to now live in an age where sharing is valued; communication and problem solving may be brought to the table, the circle, the psychologist's couch. We can try to bring the skeletons and blame and guilt out into the open, and by sharing begin to heal. Learning to accept one's own failings and limitations, of course, is a lifetime challenge. But talking about them; sharing challenges--about caregiving, for instance--is a valuable and constructive beginning.

Easier said than done. Stress is omnipresent. My dentist made me buy a night guard.

Just a few years ago, sitting around the dining room table, Dad was pining for the good old days—the camping, the fishing, our cocker spaniel, Taffy, who sang Hey Diddle Diddle... Everyone was grimacing-and-bearing Pop's on-and-on rantings, when, suddenly, Janny threw up her arms and declared, "Daaaaad! The good old days are NOW!" Hmmm...what would Peter Pan say?

After that, Dad frequently quoted Janny, proud of her spunkiness and wisdom. He would quote Janny's words to many a family member or friend, and than laugh uproariously at the memory of his daughter putting him in his place.

It is ironic that one of the symptoms of Alzheimer's is one of its greatest blessings. The person with dementia progresses from loss of short-term memory to loss of all memory. He is unable to contemplate the future. He can only live in the now. How many of us often remind ourselves to be truly present in every moment? Is it possible that we can be wise and responsible adults caring for our ailing parents, struggling day-to-day to pay the bills and maintain our homes and still savor a child-like joy in the moment? While we may emulate the courageous adult who strives boldly toward the future, we may also appreciate the Peter Pan who has his day.

## Chapter 6

### Cat to the Rescue

“No more pets,” Mom sobbed after Angel, their second Cocker Spaniel, died. It was too hard to say good-bye.

We all grew up as dog people...with a few turtles, rabbits, guinea pigs, birds, fish, lizards and horny toads...but never cats. It had been years since a furry creature had graced the parents' house.

One day at work, a friend approached me about adopting her Maine Coon cat, since, it turns out her husband was allergic to felines. “Oh, no,” I replied, “two cats are quite enough for me.” Then I had a crazy idea.

“It’s only on a trial basis,” I told my friend. “We’ll try it for two weeks.” She agreed. With my cats Tiger and Gypsy in tow, I drove down to San Diego and presented Mr. Steinbeck to Mom and Dad. Steinbeck promptly treed my cats on the branch-like support beams under Dad’s pool table and proceeded to drop little cat turds in a perfect oval all round the table to trap my cats there and claim his territory. Evidently, Steinbeck settled in just fine, but the parents were mightily skeptical about him.

Dad treated him like a dog (which was all he knew) and complained when Steinbeck would run away instead of roll on the floor and play fetch with him. “Hmph. He’s a scaredy cat,” Dad scoffed.

But Maine Coons are very smart cats. Within a short time, Steinbeck was indeed acting, in many ways, like a dog. Dad barked, “Roll over...roll over...see—Steinbeck does roll-overs on command...when he wants to.” Steinbeck would come running when Dad whistled, then followed him around the yard as he did his morning chores. At night, the two would run back and forth through the house playing hide-and-seek and “catch-em.” Mom adored Steinbeck and would lean for ages over the bathroom sink, stroking her cat as he lapped water out of the faucet, which, of course, Steinbeck had trained her to let him do.

That cat tamed them both and won their hearts. It was my first personal experience with pet therapy for the elderly. Steinbeck was a caregiver, too. One day soon, he would even be a rescue cat.

Mom took to falling frequently. She scared us a lot. We had heard many stories of elderly folk falling and breaking hips and limbs, and their health then declining rapidly. Amazingly, Mom always seemed to land on her well-cushioned rear, without hurting anything. She would sit calmly and wait for someone to pick her up. By this time, I was living in San Diego, and Dad could call me when he couldn't get her up by himself. One time, she sat on the floor of the bathroom, grinning like a mischievous little girl who knew she was making trouble. I had to giggle. "Mom, you are such a graceful fall-er. How did you learn to fall so well?"

"Amy Gilbert taught me," she grinned. "Amy Gilbert was my high school drama teacher, and she taught us all how to fall." We giggled together and then I managed to get her up on her feet.

One time, Dad called me over in the night. Mom had fallen and was wedged on the floor between the bed and the wall. Together, Dad and I couldn't get her up and we were afraid she might have broken something. Not wanting to risk further injury, we called 911. The nice men got her up, and to our relief, she could walk. Having experienced the Emergency Room several times by now, Mom pleaded not to go to the ER. We worriedly decided she was ok; the medics walked her around and sort of concurred without officially telling us. We thanked the medics on their way and tucked Mom in.

Often, at night, Dad would shuffle off to bed before Mom. Mom would doze in front of the TV in the living room, then make her way to bed where Dad had fallen asleep reading. On this particular night, she had slid off one of the chairs and there she sat on the living room floor. The bedroom was all the way at the other end of the hall. Dad could not hear her calls through his snores, and his hearing was not so hot anyway.

Steinbeck came running. He meowed at Mom repeatedly, but she wouldn't mind his entreaties to get up. So, off the cat ran to Larry; jumped up on his chest and meowed loudly. Whiskers tickling his nose, Dad startled awake with a cross-eyed stare at the Maine Coon two inches from his face. Steinbeck jumped down and entreated him to follow. Dad sleepily followed Steinbeck down the hall, with cat looking over his shoulder, Lassie-like, to make sure man was still there.

Success. Dad comforted Mom; called me; I drove over; we picked up Mom, and all was well. Steinbeck was king cat of the day.

Animals can be therapeutic in so many ways, whether bringing comfort from cuddling; laughter at antics, or support as search and rescue critters. Steinbeck certainly brought joy, laughter and comfort to my increasingly ailing parents.

\*P.S. It is best to not just rely on the cat for rescues.

Caregivers should be sure to safety check your house to minimize risk of falls. For example: remove dangerous scatter rugs, install grab bars by toilets, tubs and showers; clear walkways of debris, and make sure the walkways have sufficient illumination. (Review Household Safety Tips, Chapter 8).

Plan to have a relative or neighbor visit, or just check in, when you need to go on an errand, rather than leave a frail loved one alone.

Many people really want to help an ailing friend, but don't know what to do unless something specific is suggested. If they know when would be a good time to stop by and give the caregiver a break; or a good time to bring over a meal, it would help to put their minds at ease, as well as help the caregiver. The family member or friend will feel empowered and grateful for being able to help; and the patient will know she/he is loved.

And, of course, who doesn't like a hug and an occasional warm furry creature?



## Chapter 7

### Watering Hedges

“It’s only going to get worse, Jody.” Dad was watering the backyard hedges with Mr. Steinbeck close at his heels. I was following him, too, trying to get an idea of his routine, in case I had to start doing it for him. I certainly didn’t want to admit that’s what I was thinking—to him or to myself.

“There are some things I need to discuss with you,” he continued.

“Nooo, Dad, we don’t have to talk about that.”

“Yes, we do, Jody. It’s going to get worse”. Dad had told us that his mom, our Grandma, had died of Alzheimer’s, although in those days they didn’t call it that. It was senility, or hardening of the arteries. Occasionally, Dad worried aloud that, someday, he would lose his mind, too.

Dad, the pilot, negotiator and nuclear weapons inspector was used to facing and dealing with challenges, and completing crossword puzzles. He calmly proceeded to inform me that he would be taking me to see his and Mom’s lawyer and bank representatives. He wanted me to be ready to take care of them and their finances when it became necessary.

Oh no, he was going to talk about the death word.

We sat across from the lawyer who reigned at his polished mahogany desk and we signed lots of papers. Dad and the lawyer put me on the parents’ Trust as co-trustee, gave me Durable Powers of Attorney and Powers of Attorney for Health (which included Advance Directives) and confirmed that I would be listed on their bank accounts. Then Dad told me that when he dies, he wants his ashes scattered at the 4<sup>th</sup> hole on his favorite golf course.

No nonsense on my part, Dad, I decided. I became my dad’s calm wing-woman. I listened and dutifully took notes in my first of many spiral mom-and-dad-decline notebooks.

The cat and I trailed Dad at his chores the next week, too. “You’re taking notes so you can take over for me when I forget how, aren’t you!” I winced; then noticed he had a mischievous twinkle in his eye. I feebly protested, “No, no, no, Dad...I just figure I oughta know how to do this stuff...”

A few months later, “Someone stole my check out of the mail box! I can’t find my car keys! I can’t balance my checkbook! Help!” Dad would call, and I would come running. Followed by, “Why are you writing my checks, and fiddling with my checkbook? I have taken care of that for years! I can certainly take care of my own business! You’re trying to take over, Jody! You’re going to take all our money!”

Okeydokey, time to shift gears. Frustration. Repetition. Arguments. Defensive posturing. Tempers. Both of us. Dad was right. It was getting worse.

It was time to learn about dealing with dementia and agitation. Time for referral to a neurologist.

Fear of death—of the unknown. A person can relate at any age; even more so, I expect, when one hits the golden years or is diagnosed with a terminal illness. Death will happen, but wouldn’t it be nice to be prepared? To make our own decisions about our last days? Is it possible to have the tough decisions out of the way so we can savor some serene moments with our loved ones? Do we want our kids to quibble about what they think we want? And then feel guilty about the decision? Or end up hating each other?

I would be eternally grateful to Mom for the words she said one day, “I don’t want you kids to feel guilty about anything.”

Years later, in March of 2005, When Janny and I were returning from scattering our mom’s ashes over the Pacific. The captain of our little boat confided that his dad’s health was declining, and that his dad refused to write a will. The Dad would not tell his kids how he wanted to spend his last days; if he would want to be kept alive by tubes and machines; what he wanted them to do with his remains when the time came. Our captain was dismayed because he and his brother only wanted to do as their dad wished. The dad would only say, “Well, if I write my will, then I will die.” Now, that’s logic.

Okay, I must be honest. I will reveal that while attempting to be efficient on my parents’ behalf, I was negligent for myself—dragged my own heels for a long time at the prospect of completing my own legal end-of-life documents. I don’t think it is easy for anyone to plan for their future demise.

One of the most comforting gifts a parent can bestow upon a child is the gift of sharing with their kids their plans and wishes for the time when they can no longer care for themselves. As disconcerting and painful as discussing these issues can be for parents and children alike, parents set good examples for their kids when they plan for their own decline and their own deaths. The child can reciprocate by paying attention to their parents' wishes.

Vivian Wohlwend, MSW, a proficient and compassionate social worker, worked at the center where Mom underwent kidney dialysis. Vivian offered support, not only to the patients, but to the patients' families as well. Vivian read to me words from a San Diego Hospice class transcript that went something like this:

*To love a person is to learn the song in her heart,  
and to sing it when she has forgotten it.*

When I asked Vivian what she treasured most about her job, she said she wanted to help people not be afraid when they came to the end of their lives. She wanted to "help them be honest and clear about what they wanted, and to help them with communication." Vivian said, "That's my favorite thing to do."

Every resource I came upon stressed the importance of listening and sharing and preparing. Caregivers owe an eternal debt of gratitude to Dr. Elisabeth Kubler-Ross for her many books that demystify and share the processes of death and dying and the complicated feelings surrounding death. In her book *On Death and Dying*, she takes us through stages of grief one may face when diagnosed with a terminal illness: denial and isolation, anger, bargaining, depression, acceptance. She adds,

*The one thing that usually persists through all these stages is hope.*

Further, Dr. Kubler-Ross says,

*Though every man will attempt in his own way to postpone such questions and issues until he is forced to face them, he will only be able to change things if he can start to conceive of his own death...we may achieve peace—our own inner peace as well as peace between nations—by facing and accepting the reality of our own death.*

Dad was right, I mustn't be afraid to discuss the scary things. Sure enough, the more we talked, the less afraid I was about talking.

I was grateful that the parents prepared as well as they did for their waning years. Now, it was my turn to pay attention and learn their songs.

## Legal Document information

**\*Advanced Healthcare Directive**

**\*Will**

**\*Revocable Living Trust (and appointment of successor trustee)**

**\*Durable Power of Attorney**

**\*Conservatorship**

**\*Family Medical Leave Act**

1. **Advance Directive.** Many states offer an Advance Directive, which combines a living will and a durable power of attorney for health care in one form, called an Advance Directive. Almost every state has suggested forms you can get through your doctor's office or local hospital.

You can also download for free state-specific forms from **Caring Connections**. [www.caringinfo.org](http://www.caringinfo.org) 800-658-8898.

**AARP** Foundation offers free booklets titled "planning for Incapacity," which are tailored to each state and include all necessary forms. 202-434-2118.

(Karen Hube, "The Will to Die." From July-August *AARP* magazine article [www.aarpmagazine.org](http://www.aarpmagazine.org) )

2. **Will.** Declares distribution of assets upon one's death. Can be written, signed and dated by an individual. Forms available at stationery stores. Lawyers can prepare. Multiple on-line resources. Elder Law and Advocacy's Senior Citizen's Legal Services programs may offer free assistance for qualifying seniors.
3. **Revocable Living Trust.** Called "living," because is established while individual is still alive. The grantor can manage his/her own account, or have an outside person or organization act as trustee. A successor trustee should be appointed to manage the trust if the original trustee becomes incapacitated. Since assets are in the trust, probate court may be avoided.
4. **Durable Power of Attorney.** (works same as general power of attorney, but does not lose power after someone loses capacity). Gives an agent the financial rights of the person signing the document.

**5. Conservatorship.** A **probate conservatorship** is appointed by the courts if it determines a person is unable to provide for his/her personal needs and/or financial affairs. A probate conservatorship can be a conservatorship of the estate, of the person, or both.

**Lanterman-Petris-Short Conservatorship.** Provides short-term treatment in a care facility for persons who have serious mental disorders, or who are impaired by chronic alcoholism or drug problems. (Little, if any authority to handle finances). Must be authorized and initiated by physician, police, or authorized mental health personnel. LPS Conservator may be a relative, friend or a representative from Department of Social Services.

**6. Family Medical Leave Act (FMLA).** Sponsored by U.S. Department of Labor. [www.dol.gov/esa/whd/fmla/](http://www.dol.gov/esa/whd/fmla/) “Covered employers must grant an eligible employee up to a total of 12 workweeks of unpaid leave during a 12-month period for one or more of the following reasons:

- For the birth and care of the newborn child of the employee;
- For placement with the employee of a son or daughter for adoption or foster care;
- For care for an immediate family member (spouse, child, or parent) with a serious health condition; or
- To take medical leave when the employee is unable to work because of a serious health condition.”

The web site above offers fact sheets and further instruction and info.

**\*\*\*Most states have support agencies for senior legal resource info.**

**\*\*\*Southern California has many valuable resources, among them:**

\***Elder Law and Advocacy** organizations to offer free legal advice to seniors.

\***Aging and Independent Services.**

\***Southern Caregiver Resource Center (SCRC).**

\***AARP.**

### Section Two: Becoming a Caregiver

*Health is based on happiness—from hugging and clowning around to finding joy in family and friends, satisfaction in work, and ecstasy in nature and the arts.*

*~~Gesundheit!*

*Patch Adams, M.D., with Maureen Mylander*



Amy, Jim, David, Patty, Jessica, Jennifer, Kim



Kim, Janny, Larry, Jim



Nik, Larry



Larry, Yvie



Roy, Patty, Betty



Jody, Larry

## Chapter 8

### What to Do

How to go about being a caregiver? What comes first? It is easy to feel pulled in all directions and not know where to turn.

An important first step: medical evaluation. Many symptoms can be treated and cured. Even dementia. There are many kinds of dementia, I learned. Perhaps a loved one has a dementia caused by medication or medication interaction; or by anesthesia during surgery; or by a physical chemical imbalance---all of which may be treatable. If dementia is developing, early diagnosis is important. Proper treatment can be prescribed that may resolve some issues, or delay the progression of Alzheimer's or other neurological diseases. The primary physician may perform a "Mini-Mental" exam, or the primary may refer to a neurologist or a geriatric specialist. Or the patient may request the referral.

Following are some of the steps I learned to take.

#### **Communicate~~~Evaluate~~~Act**

1. Communicate with the parents. Ask them questions.
  - a. How are you? How do you feel? What are you thinking about?
  - b. What medicines are you taking? Do you ever mix them up, or forget to take them? Does your doctor or pharmacy evaluate for contraindications?
  - c. Is your home safe and efficient? Do you need grab bars, elevated toilets, non-slip carpeting?
  - d. Are you up-to-date on all your medical check-ups?
  - e. Are all your legal documents regarding health and finance in order?  
How can I help?

2. Communicate with all medical personnel who care for parents.
  - a. Do the doctors have your parents' comprehensive medical histories?
  - b. Does the primary physician communicate with your parents' specialists?
  - c. Has the primary evaluated all meds for your parents lately?
  - d. What specialists have your parents seen? What is the history?
  - e. Is the primary a geriatric specialist, or have your parents seen such?
  - f. How are your parents' mental health? Any dementia? Mini-mental test performed? Neurologists consulted? Medical causes for dementia considered?
3. Communicate with family.
  - a. Share all information, questions and concerns with siblings and other responsible and concerned family members.
  - b. Create a means of continuing communication for monitoring the health and welfare of your parents: phones, cell phones, email, family blog etc. Make sure all responsible family parties are on the same page regarding parents' health and financial concerns and end-of-life choices.
  - c. Designate a person who can be in charge of parent care. If possible, assign parent care responsibilities to family members, so that care is shared. (This is not only helpful to the primary caregiver, but rewarding for each family member).
  - d. Plan ways and means to have fun, laughter and adventure. For example; photo albums, DVD's, family reunions, cards and letters.
4. Create a community network of assistance. Access resources.
  - a. Communicate with local relatives and neighbors. If someone offers to help, suggest specific ways they can help. For example; "It would be wonderful if you could bring Mom and Dad a hot meal on Wednesday." Or, give them a choice: "Would you be able to take Mom to her hair appointment on Friday? Or, would you have time to sit with Mom for two hours so I can run some errands?"
  - b. Acquire the Red Cross Emergency Checklist and prepare your plans for medical emergencies and possible disaster or power outage. Post emergency phone numbers and enlist neighbors to call for back-up.
  - c. Do your parents attend a church or other spiritual organization? Contact them for possible outreach programs that might be helpful to your parents.
  - d. Check online for eldercare resources. Southern California has a free Eldercare Directory. The Southern Caregiver Resource Center has many valuable and many free services for eldercare. Consult helpful sites such as The Alzheimer's Association and AARP.

- e. Consult any social workers or case managers who have contributed to your parents' care, as to recommendations for improving your parents' situation and health.
  - f. Participate, when possible, in local Support Groups, Conferences, Town Hall Forums on relevant caregiver topics.
  - g. Consult printed articles, pamphlets, books on your caregiving concerns.
5. Create tools for consistent parent care and communication.
  - a. Make a chart for meds. Prepare a chart for each parent; listing days, times, frequency, dosage of meds to take, doctor prescribing and purpose.
  - b. Create a comprehensive medical history for each parent.
  - c. Prepare a notebook to carry to all doctors' appointments. The notebook should include medical history, questions to ask doctors, notes on all appointments, to-do list as prescribed by doctors and other medical personnel. A doctor may ask about allergies, what tests have been done, what other physicians have been consulted, etc. Having medical info at hand can save time and lives.
  - d. Have at the ready a bag with the medical history/appointment notebook, along with up-to-date list of meds.
  - e. Perhaps the "bag" could be a kind of adult diaper bag, if necessary, including such items as pull-ups for incontinence, anti-bacterial wipes and hand wash, small first-aid kit, Kleenex, water, snacks, reading materials, notebook and pen, and family photos in albums or plastic sheet protectors, extra sweater or back-up clothes items.
  - f. Create 3-ring binder for home that includes all essential medical information and important contacts for the parents. If an in-home caregiver is acquired, this book can serve as your Caregiver Resource Booklet. You can insert daily or weekly personal notes to caregiver that can update or remind them of current concerns.
6. Visit a Senior Day Care; a Skilled Nursing Facility; an Alzheimer's facility. The time may come when your parent may need one of the above. If you have visited at least one of each, you will not be overwhelmed at the prospect. Select places near to you so that transportation and visitation are convenient. Keep your list of these places on file, with phone numbers, addresses, contact personnel, and your personal notes.
7. Research professional in-home care personnel. There are private contractors and there are agencies which provide caregivers. We interviewed many individuals, and were most satisfied working with an agency which screened their employees for records, health, licensing and work history. The agency would supply an alternate caregiver, should one become unavailable or unacceptable.

The agency we chose required log books of care and other means of accountability, and agency owners were available for questions and concerns. Certainly, I always appreciated a personal referral from family or valued friend.

8. If you are doing the caregiving, contact an Eldercare Attorney to research possible reimbursement for caregiving expenses.
9. Support the dignity, self-respect and self-reliance of loved ones. For example; what kind of grooming or personal habits are special to them? Such as—Mom likes to have her hair styled. Dad always likes a handkerchief in his back right pocket. Are their clothes clean and mended? Do they feel like they look their best?
10. Play; laugh; sing; dance; read; watch and listen to nature; be still together.
11. Communicate gratitude. Most nurses and caregivers we met were under-paid and over-worked. Verbal and written notes of thanks mean a lot. Many facilities have special thank-you-grams or pat-on-the-back forms for you to say thanks to a particular nurse or caregiver. They will post, and place in personal files. Chocolates, flowers, produce from your own garden or baked goods are awesome tokens of appreciation. For holidays or special occasions, or just-because, I liked to create thank you baskets filled with candy, protein bars, packets or mini-bottles of moisturizers, hand-sanitizers, face and body products, and jokes, cards, etc.
12. Pay attention to your own respite needs. Make appointments for yourself to relax, go to a movie, find spiritual sustenance and re-energizing. Plan for family, friend, or person from respite organization to give you specific hours to yourself. Your respite provider will be grateful for specific assignments. Breathe.
13. As friend Jill's aunt used to say:

“Have as much fun as you possibly can, every single day.”

## Forms for Monitoring Medications

Whether the patient is administering his or her own medications, or if the medications are administered by a family member or professional, a medication form with physician and prescription information, dosages of medications, and times of day to take the medications can be very helpful. This is one of the records that should accompany patients and patient advocates to medical appointments and treatment facilities. The Alzheimer's Association, AARP, Healthcare Group, and various other organizations provide a variety of useful forms for helping to monitor medications.

When I first began assisting my parents, Dad was handling his own organization and administration of medications, and Mom's as well. I designed a separate form for him, and for Mom, to help prevent their inadvertently taking each others' medications (which did happen as Dad's short term memory diminished). I wanted Dad to manually check off each time he took or administered a medication, to give him concrete verification of having taken a medication, or not, if he became forgetful. Even if one is not memory-impaired, it is easy to become preoccupied with daily tasks and wonder, "Did I take that already, or not?"

Dad was not thrilled that I was giving him more work to do, and initially resisted using the forms, but once I explained how user friendly his customized forms were, he readily accepted and dutifully utilized them. The forms became a comforting support for him and gave him confidence that he was taking good care of his wife.

Many forms you will find are medication records, logs, lists for reference. The first form I have provided on the following page is an example of just such a form. It includes physician information; medication identification; dosage; times per day for administration; whether or not to take with food; what the medication is for; and a space for notes, side-effects, etc.

The second form is similar to what I created for my parents, with boxes to manually check-off when a medication has been taken.

When I began as a caregiver, I didn't know such forms were available to me; thus, one of the instances when I tried to recreate the wheel. On the other hand, sketching out our own forms helped me realize the practicality of customizing the forms for our own needs.



## **Household Safety Tips for Physically and/or Mentally Impaired**

### **Bathroom**

- \*Install handrail and grab bars around toilet and tub
- \*Use skid-resistant floor mat or carpeting to soak up water and avoid slipping\*Apply decals or other non-skid applications to tub and shower to prevent slipping
- \*Remove door lock (persons with dementia can lock themselves in)
- \*Lower temperature of hot water to prevent scalding
- \*Per physical condition of patient, consider elevated toilet seat, bath and shower seats, as well as canes, walkers, wheelchairs (consult insurance if applicable)

### **Kitchen**

- \*Use plastic rather than ceramic dishware
- \*Remove knobs from gas stove and keep in locked drawer
- \*Keep medications in locked drawer or cabinet
- \*Forego waxing kitchen floor
- \*Store countertop appliances (toasters, food processors) out of reach
- \*Install childproof latch on refrigerator
- \*Install on-off switch in back of electric stove

### **Bedroom; other rooms**

- \*Display emergency numbers and home address by all telephones
- \*Hide a spare house key outside in case person with dementia locks you out of house
- \*Install night lites
- \*Keep unsafe items out of sight: Iron, knives, car keys, hair dryer, matches
- \*Eliminate throw rugs or tack them down to avoid slipping
- \*Secure or remove decorative knick-knacks
- \*Cover sharp corners on furniture
- \*Tuck away extension cords
- \*Be wary of tipsy furniture like rocking chairs
- \*Install handrails on stairs, anchored in wall studs, not sheet rock
- \*Use child-proofing gates at top and bottom of stairs
- \*Make sure draperies and upholstery are flame-resistant
- \*Identify poisonous plants and eliminate them (consult Poison Control Center)
- \*Install security locks on windows (these leave a 3-inch opening)

**Outside**

- \*Install outdoor lights
- \*Install railings where useful, at least waist high
- \*Clear away debris, toys, tools
- \*Disconnect a gas grill, and never leave unattended when is use
- \*Fill in holes in ground
- \*Install security fence around pool or pond
- \*Check rickety lawn furniture

**Excellent resources for safety concerns:**

The National Institute on Aging has a 21 page booklet, available on-line. They offer general safety concerns: “Think prevention,” “Adapt the Environment,” “Minimize danger.” National Institute on Aging; [www.nia.nih.gov](http://www.nia.nih.gov)

AARP; [www.AARP.org](http://www.AARP.org)

Alzheimer’s Association; [www.alz.org](http://www.alz.org)

Southern Caregiver Resource Group; [www.caregivercenter.org](http://www.caregivercenter.org)

## Chapter 9

### **Naked Parents**

I'm a child. Am I six; or am I twelve? I remember it well. Sweating, big-bare-bottomed Mama bent over, cleaning the bathtub. Sis recalls demure Mom vacuuming in the buff so she didn't have to re-iron a sweat-drenched dress. Even Aunt Betty, miles away, heard about the vacuuming vision the mailman saw through the screen door. Family legend also has it that our milkman, on a routine delivery to our frig, nearly dropped the glass milk bottles when he spied Mom racing naked to answer the phone. Mind you, Mom was a very shy, conservative gal.

About the same pre-pubescent age. Early morning. I approach my parents' room for a wake-up hug. The bedroom door, open a crack. I peek. Dad, the man of the house, on the way to the bathroom, in full bobbing majesty. My child's mind has vivid recall.

I'm an adult. I'm sort of in charge. How am I going to deal with giving my mama a bath? What if I have to wipe my daddy's bottom?

How 'bout that—when the time comes, it is kindness and common sense that take over.

Now that Mom has two titanium knees and is generally in fragile condition, her bath time requires a new contraption. She sits gingerly on her sturdy professional chair which extends from inside the tub to the floor outside of it. With my help, she can safely swing her legs around and into the tub. Wanting more than anything to preserve Mom's sense of dignity, I wash her fragile body ever so carefully, all the while chattering away as if we're sharing a lunch on the plaza. When my washcloth approaches her breasts and armpits, I burst into mock opera arias, to see her smile, and to attempt diversion from embarrassment. When I get to her privates, I ask if she would like to wash that area herself; and she does, until, after awhile, she can't very well. By that time, I have become used to being gently thorough, and we are sweetly used to each other.

When Dad unexpectedly messes his pants on the way to brunch at Denny's, I grab an extra pair that I am now thankful I had put in the car trunk, just in case. I usher him into the men's bathroom, smiling at a couple of men in there, explaining, "We'll just be a minute." Dad stands dutifully in the stall as I proceed to clean his rear. He says to me, "You shouldn't be doing this. I'm the father, and you're the daughter." "Oh, Dad," I say to him, "You took care of me all those years—changing my diapers and everything. I can certainly help out a bit, now." He grins, and seems just fine about the whole thing. The patiently waiting gentlemen had finally left. Maybe they used the women's?

Amazing how the fear of dealing with the nakedness of my parents could blur my mind to common sense.

By caring, and focusing on the task at hand, I learn as I go, that a loved one needing care will respond to the caregiver's state of mind. If I am calm, smiling, and practical; they will be, too. Or, perhaps, they are the practical ones and are grateful for the help.

I marvel at how necessity makes it all so simple. Health and cleanliness. Dignity and respect. Love and kindness. After all, nakedness is so natural. And, bodies are incredible creations.

## Chapter 10

### Facing Physical Decline

Seriously—the health care industry ought to try to keep people healthy. I'd like to see more emphasis on preventative care. Aren't there more ways we can avoid hospitals, surgery and drugs? Seriously--for my part, spending so much time in hospitals as a caregiver is making me wake up, eat my broccoli and do more sit-ups.

There are germs in hospitals—I guess that is unavoidable since that is where people go to get rid of the germs. But many of us seldom think of it that way—we go to the doctor or to the hospital to get well. And the staff is exposed to the germs—something else I seldom think about. They are brave. Let's all wash our hands. It's scary. There are health risks associated with surgery; therapy and drugs to recover from surgery and anesthesia; exercises and therapy for muscle atrophy from inactivity due to surgery, more medicine and more doctor visits as follow-up to surgery. The doctor may prescribe new drugs to alleviate side effects of others. How do we keep track of so many drugs, especially when some of them don't get along? Plus, prescribing and dosage requires a delicate balance. There was a time when we almost lost Mom because an overdose of a blood-thinning medication caused internal bleeding.

That wouldn't be the only time Mom almost slipped through the cracks. All the noble hospital people who courageously choose this healing profession can't know each of their myriad patients personally. They are trying to do their job and help every patient in their charge to get through and go away. They are treating symptoms and diseases, not people, much of the time, even though they may try hard to get to know their patients. It's a good thing when there is a family member/patient advocate to fill in the blanks, add a little TLC—help with little things like lotion on hands, chapstick on lips, brushing of hair—not to mention keeping any eye out for a food tray that never arrives, a pillow fallen on the floor, a cord unplugged, a suspicious rash or bed sore or other discomfort that might have been missed.

It's no wonder that Mom didn't want to leave the comfort of her own bed and expose herself to the hospital environment again on this particular day in question. Dad and I were worried. Shall we take her to the doctor? ER? Call 911? She wasn't holding down her food or liquids. We kept trying. Maybe she was right. Maybe not.

Mom always had pretty good common sense. She spent all those years tending to our colds, flu, strep throat, mumps, measles. She made it fun, too—Janny and I gave each other bubble bath faces when Mom plopped us chicken pox kids into a special bath. Mom knew when to feed us chicken soup and popsicles and keep us home from school. She was also good at knowing when it was time for the doctor. Same for herself and Pop. They were conscientious about all their check-ups and necessary doctor visits. What about now? Was she too weak to know better? Mommy knows best, doesn't she? Did I really want to put her through nine hours in ER and maybe even days in the hospital? How to know what to do?!

We did call a doctor's office—the nurse said to keep an eye on her. Brilliantly, I drove to see the pharmacist—explained her symptoms—vomiting, diarrhea, weakness. He said, “BRAT—feed her BRAT—bananas, rice, applesauce and toast—or a variation thereof.” Adding to what we already had at home, I tossed into my shopping cart anything else I had heard might help—juices, Gatorade, Ensure, more applesauce, chicken soup, jello.

Still worried and floundering, I asked the pharmacist, “How will we know if it is time to take her to the hospital?”

He said, “If she gets cold and clammy and unresponsive, then take her to the hospital.”

The rest of the day and evening, we kept watch, tried to feed her little nibbles; to give her little sips. She seemed to be resting peacefully when I left that evening. I had just fallen into bed when Dad called me about 1:00 a.m.

“She's cold and clammy, Jody. She's unresponsive.”

“Call 911, Dad. I'll be right over.”

Was it ever the right thing to do.

A doctor would later reprimand us for not bringing Mom to the hospital earlier. “Dehydration is a serious concern, especially in the elderly,” he scolded. “When an elderly person has considerable vomiting and diarrhea, you need to call the doctor right away.” I thought I did. I felt so ignorant. I recalled that when Dad had his stroke, way back when, the doctor had determined dehydration to be the culprit. I kicked myself. Maybe I was missing a few screws. It was my first time at caregiving and we were learning by trial and error. It turned out we made it just in time.

The paramedics whisked Mom right into the ER. After a few tense moments, the ER nurse further validated the trip. She whispered to me, “You know, your mom almost didn’t make it. The doctor took one look at her, and said, ‘bowel obstruction’. He was right. So far, they’ve drained over eight liters of backed-up bile, and they’re still going.” There’s no telling how long fluids and toxins had been backing up in her system. No wonder she couldn’t keep foods down.

Everyone would be astonished at how many liters of bile they would eventually extract from Mom’s tummy. Suddenly, there were IV’s; an NG tube (nasogastric); an EKG, CT scan, stomach x-rays. Dr. Mike, ER doc extraordinaire, asked Mom her name—no answer; did Mom know where she was?—no answer; did she know who was president?—no answer. Dr. asked me if this was usual for her, and I said, “Worse.” The ER team was remarkable in their efforts to stabilize her and determine how to address her blockage and dehydration. One CT scan of her head was unclear, but possibly indicative of her having had a small stroke at some time.

On August 16, 2000, surgery commenced: an entero-enterostomy, by which the blocked intestine was by-passed (no colostomy!); and a repair of an incisional hernia (which had occurred beneath Mom’s hysterectomy scar). We later told mom, “You got a 2-for-1! What a deal!”

Speaking of doctors, this visit to the ER provided us with an opportunity to acquire a new primary physician, since the parents’ existing golfing buddy doc did not have privileges at this hospital. The doctor recommended by the attending ER doc was younger, healthier and more up-to-date. I was glad I had backed off earlier and decided to respect their decisions and their loyalties to their friend. This time, they acquiesced to a permanent change to the highly recommended new doc. I was beyond relieved.

Mom’s and Dad’s good buddy doctor was a dear man---I had not wanted to hurt his feelings or anyone else’s. But, I kept repeating in my mind, “health and safety, first.” From the first time I witnessed one of their appointments with him, I had felt that he was past ready to retire, and that he was not giving my parents quality, comprehensive treatment. He cleaned a wound here and there, prescribed multiple medicines, but didn’t seem to evaluate the whole person or question all those meds. Change was necessary.

Weeks later, while Mom and I were sitting in our new primary doctor’s office for a follow-up, a nurse, who was bringing her mom as patient, said of the doctor, “Oh, he is the best! I have been trying to get my mom in to see him for years.” I also later learned that some doctors thought that my parents’ previous primary had been retired for years. That helped me feel validated for my concerns.

The suspected causes of the Mom's bowel blockage were radiation scarring from her uterine cancer treatments and a hernia and complications from a fall onto her hysterectomy incision scar. Her calcium level was high, and her creatinine level was the highest it had been. She had pancreatitis and a uterine infection. Her nephrologist was brought in, and she would have her first kidney dialysis; then, three more. We were told that if her kidneys didn't come back, that dialysis would be on-going. Happily, her kidneys would regain function, and on-going dialysis would not be required until 2002.

Mom also contracted MRSA (methicillin-resistant *Staphylococcus aureus*) in the hospital. This meant she was resistant to a broad spectrum of antibiotics and would have to be prescribed stronger and stronger ones. Eventually, nothing would work. This also meant Mom had a private room, with a warning sign on the door, and staff needed to take extra precautions with gloves and aprons, so as not to spread the very contagious infection. Many a time they did not and just shrugged their shoulders.

Brilliant, I thought, when I saw that the hospitals have anti-bacterial hand cleanser dispensers in each room. Hopefully, everyone uses them.

Mom's skin became paper-thin fragile due to her illnesses and the medications she took for them. Hopefully, attentive nurses would change Mom's position every two hours so she wouldn't be uncomfortable or get bed sores. Sometimes, both at the hospital and the SNF (skilled nursing facility), they seemed too busy. Several times at the SNF, she would have to be treated for painful open pressure wounds on her rear. Any repositioning of Mom had to be done with great care so that her delicate skin would not tear. I felt so bad for her.

Back at home, I squealed, "Oh, Mom, I am so sorry" when I accidentally punctured the skin on her fragile leg with my thumbnail while I was trying to maneuver her leg onto the wheelchair. Another time, leaning back into her electric recliner, she rubbed a layer of skin right off her arm. Each time, I hurried to stop the bleeding, disinfect and bandage, and utter soothing words of comfort as best I could. We kept first aid supplies handy, both in the house and in the car.

While she was in the hospital, both Dad and I would visit Mom daily, as would the other kids and grandkids when they flew in. When it came time for Mom to transfer to a skilled nursing facility for the first time, Dad said "I'll tell her." He had always said, "We'll never put you in a nursing home, Patty." Janny and I, who were both there at the time, thought he was going to be sweetly gentle and reassuring. No. He bluntly said, "Patty, we're putting you in a nursing home." Janny and I fell over each other trying to buffer Dad's blunt words to mom. We explained gently that the SNF was only temporary—Mom would do rehab and then come home.

Dad and I were a darn good team while Mom was in the hospital. I think we were in crisis mode, because it really was touch-and-go for awhile. Our mission was clear, when we were researching the SNF's. It had to be done, and we methodically surveyed our options. We wanted the best possible skilled nursing facility for our mom/wife. We compared staff-to-patient ratios, the cleanliness, the smells of each place. We wanted sunshine, proficiency and kind staff. We had narrowed it down to two. When the athletic male Physical Therapy manager was the only person to actually look my hard-of-hearing, impatient Dad in the eye and talk to him instead of me; that was it. Dad said, "This is the best place. This is where we will put Patty."

Thus, I re-learned what we were taught in kindergarten: it is important to look a person in the eye and communicate clearly and respectfully. Nurses usually remembered this, but doctors and administrators often spoke just to me (since I was the one asking questions), and ignored my elder, hard-of-hearing father, whose dear wife was the patient needing a room and medical care. Giving my dad respect was clearly what did it. Many a time in the future, I would make a point of directing conversation to Dad, explaining surreptitiously to people that Dad is hard of hearing ("Please speak loudly and clearly to him."), and making sure Dad was always included in discussions. It also turned out that, despite the dubious criteria for this selection, this SNF did turn out to be the best around. I told the staff so, praising them in Care Conferences for Mom. The head nurse would grin and reply, "Oh, yes, we do have a good reputation. City dignitaries send their loved ones to us."

After the bowel blockage surgery and the rehab, Mom would endure continuing decline in multiple areas. Despite the cat Steinbeck's vigilance, Mom continued to fall frequently. She tried several medications for her incontinence, to no avail. We bought cases of adult diapers from the medical supply and purchased a bedside potty for when she was too weak to make it to the bathroom. Dad did a lot of laundry. Doctors did not see indication of any significant stroke. But, Mom would experience dementia episodes from anesthesia, or medication contraindications, or from uterine infections. The dementia would diminish as the effects of anesthesia wore off, or as medications were adjusted. It was not easy to figure out why she was hallucinating.

Yvie suggested we explore Mom's nonsensical wonderlands with her. Maybe her reality was more real than ours? So, when Mom told me there was a little girl at the end of her bed, I asked her who she was and what did she say? I asked Mom who that man was standing in the room. Doggone, she didn't offer any answers.

Several times, Mom told us she was "in her other house...it was like this one, but had another room, or a spiral stairway and different neighbors." One day I arrived at her nursing home and she giddily exclaimed, "Ooooooh, you are on the space ship, too!" We called her "our space cadet." Her bouts with dementia were short-lived and she would regain her lucidity. (Dad's dementia would be a whole different story).

Mom would end up in the ER eight times in the next two years, plus three additional hospital stays to relocate or repair her kidney dialysis catheters. Two more times, she would spend rehab time at the SNF and then get to come home. In 2003, after a hospitalization from the blood thinner overdose, she was admitted yet again to the SNF. Eventually, her condition would become too medically complex to be handled at home, and she was moved to the long-term wing of the SNF.

At three different ER visits, her nephrologist took me aside, so that Mom could not hear. Each time, he gently whispered, "I'm afraid she's not going to make it." When she seemed comfortable and well-monitored, I would steal away and, with a lump in my throat, call family to give them the sad update. The siblings would begin preparations to fly down.

Mom rallied each of those times. The third time, I sneaked a look at the doctor's chart and saw scribbled there in doctor scrawl: "Remarkable recovery!"

Despite my misgivings about hospitals, the doctors and staff sure did some bang-up jobs on Mom, saving her life numerous times. Mental note to me: try not to be afraid of doctors and hospitals, just be vigilant and help when I can.

"Mom, you have 947 lives", I told her, "and you've only lived 534." Or, "...and you've only lived 535...536..." On it went. We giggled together. After all, she had survived two-new-knees surgery, uterine cancer hysterectomy and radiation, and in-the-nick-of-time bowel blockage surgery. During these times, she would also endure various surgically implanted kidney dialysis catheters in her arms, legs and chest. She would contract pneumonia, MRSA, dehydration, cellulitis, blood-thinner over-dose, catheter infections and sepsis. "Mom, you have many more cat-lives to go," I would remind her.

What an education: dealing with the ER and each hospital arena, and nursing homes. We learned about the good the bad and the toxic. Hospitals and nursing facilities are replete with both opportunity and danger. They may be understaffed and underpaid. There are kind, compassionate, proficient professionals; and there are others who seem disinterested, complacent or under-educated. There may be state-of-the-art equipment, tools and techniques meticulously applied toward your loved one's care and cleanliness; but there are also deteriorated machines, out-dated computers and germs lurking everywhere.

I learned there are good reasons not to rush to the hospital unnecessarily—people can get sick in hospitals—or fall through the cracks. On the other hand, highly trained medical teams saved Mom's life multiple times. Part of our personal education was figuring how to navigate the systems and be supportive.

## Chapter 11

### Communication...Gratitude...Teamwork

Just getting into the hospital can be daunting. I became frustrated when I would be required to fill out multiple admission papers every time Mom was moved to a new room. Fortunately, I always carried my “essential papers bag” with me. I sat at Admissions for some time, providing all Mom’s medical history, meds lists, insurance info, Advance Directive, Power-of-Attorney, and other pertinent info for computer in-put. Then, in ER, I had to repeat it; then again, in ICU (Intensive Care Unit); in TCU (Transitional Care Unit), and again when she was moved to the third, and then the fifth floor. I thought to myself, “This does not compute!”

Don’t hospital computers communicate with each other?!” I exclaimed each time. “No, you need to provide all the information again--every time your mom moves,” I was told. I resigned myself to just being thankful that I had the info at my fingertips, and reminded myself that the human touch is more important than technical mechanical protocols, so I should just take a breath.

In 2006, money was voted for upgrades to the hospitals in my area, and eventually patient records have begun to be digitalized. Yay! Nevertheless, technical upgrades have still been slow in coming. I find it befuddling that consumer retail technology becomes obsolete and replaced with new inventions in the blink of an eye; yet technological improvements in both the health and education arenas lag so far behind. The other day, three different technical support people from India told me to get a new computer. I ought to forward that recommendation to the hospitals. Certainly, with baby boomers turning 50 at the rate of at least 8,000 per day, it is imperative for hospitals to get a move-on with upgraded communication.

Miscommunication, or no communication, is always a possibility. Accidents can happen. Medical staffs have so much to deal with, I wonder how all pertinent info for each patient gets communicated (or not) between each shift change; between each medical development; between each emergency; between each family request; between each transfer to a different rooms or facility.

“What’s this?” Janny asked, on one visit to Mom, when she was in the nursing home. It turned out that Mom had cellulites on her arm that, left unattended, could have turned into a serious infection. Another time, Mom had pneumonia, and no one at the SNF had noticed until Janny said, “Mom sure is coughing a lot.” Other times, Mom would have skin tears, or skin infections that went undetected, until a family member would say, “What’s this?” Sometimes it is the faraway sibling on a visit who notices what the everyday caregivers, and even local family, have missed.

One time, when Mom was in the hospital and Dad was in the Alzheimer’s facility, Janny flew in to take over caregiving duties, so I could go visit my daughter in Berkeley. I gave Janny a typed to-do list, including questions to ask of the doctors, social worker and nurses. As the surgeon was signing Mom’s release papers, Janny asked, “Did Mom have a physical therapy assessment? Does she need any PT before going home?” Janny told me the doctor looked at her quizzically, cancelled the release, and ordered the PT assessment. It turned out that Mom, indeed, needed two days of rehab before she should have been released.

Another time, I noticed the surgeon’s release form for Mom didn’t include any home health care. I quickly asked the doctor if Mom needed it. The doctor, in response to my inquiry, told me that, indeed, she needed “home health,” and that it must be prescribed by him. He then wrote the prescription for a nurse, PT and OT to visit Mom at home.

A couple of years later, at the end of yet another hospital stay, Mom was about to be transferred by ambulance to her SNF. I had been chatting with the medics, and jokingly told them “Now, don’t get lost on the way to La Mesa.” The medic joked back, “Ha—very funny—we’re going to North County.” I suddenly stopped laughing and realized he was serious about taking her to the wrong place! I said, “Let me see your orders...” Indeed, there had been some mistake, and, hallelujah—another “in the nick of time.”

Every patient can benefit from an advocate, a family member or friend who can speak for them when they are woozy from anesthesia, weak from being ill, or just for a second set of ears. When a family member is present and has a good rapport with medical staff, the patient/loved one gets more and better care. We are all on the healing team, I figure. I wish to help, but, certainly, not hinder the work of the professionals.

Without a doubt, good and consistent communication with health care staff helped Mom to survive her hospital and SNF stays. Most important were Mom’s nurses, the ever-present angels who tended her day and night. They were Mom’s healing hands, eyes and ears when she was unresponsive.

Because staff is always changing, I made sure I contacted the charge nurse and the attending nurses every time I visited, and that I left my phone numbers at the nurses' station, and sometimes on the board in Mom's room every time I left. They agreed to call me if there was any change, and I called to check in periodically when I had to be out in the field visiting clients. I learned that the case worker assigned to Mom's case was a key person who knew much about Mom's progress; and who would coordinate Mom's transfers to rehabilitation facilities, or to home.

Sometimes I was lucky to catch and communicate with the doctors who were fleet-of-foot between surgeries and patient care both in-and-out of the hospital. At times, when a doctor wanted to give us info, we were able to page him or her. Other times, if I had difficulty connecting, I would leave a message and specific question with the doctor's office staff, and they, or the doctor, would return my call.

My daughter, having worked in hospitals and nursing homes, suggested bringing "savory treats" of appreciation for the nurses, so I brought chocolates or baskets of goodies many a time. I wrote care-grams or other letters of appreciation to the staff who took exceptional care of Mom.

Yvie told me, "Mom, professionals at the nursing homes may need three jobs to survive. They are often understaffed and underpaid. You must be your Mom's advocate. And you must show them your gratitude." Yvie told me about the time when she was working in a nursing home, and noticed one of the CNA's nodding off. Yvie asked the woman if she was OK, and the lady said she was working three jobs; taking care of her family, including her ailing mother; and had only been getting an hour of sleep a night for over a year. Yvie's words encouraged me to be empathetic and supportive of the hard-working staff. The challenges they face make it even more incumbent upon family to help with their own ailing loved ones as much as possible. Despite the difficulties of health care jobs and life challenges; most of the nursing staffs we encountered were truly caring and exceptionally proficient. We're all human, and we all need to support each other.

I learned to double-check that the day, afternoon, and night staffs were apprised of Mom's condition, and any changes. At first, when I brought candy or a basket of goodies, I would only bring one, and put it at the nurses' station. Later on, when Mom was on the "east wing," for long term care, I learned to take three baskets, one for each shift, and I would check to see if certain especially attentive nurses were on duty that day.

Mom was always grateful. She thanked the nurses for their care, and was way too reluctant to ask for help when she needed it because she didn't want to bother anybody. We tried in vain to tell her to push her remote nurse call button. Her meekness made it all the more important for us to pay attention to her needs.

The family advocacy vigilance necessarily continued. The requisite paper work, staff meetings, post-op care and meds communiqués were all addressed. We placed family pictures on the walls, flowers and cards where allowed so as not to interfere with medical care. I would attend periodic care conferences with Mom and staff members. When possible, we (and sometimes kids and grandkids) would wheel her around to the corner restaurant for lunch.

The day after Mom entered the nursing home the first time, I began to realize that the strain of it all was beginning to affect Dad. It must have been difficult for him to not be able to fix things; to not be able to be in charge. Dad would make decisions based on only partial info. He would ask Mom what she thought, but he would hear only what he wanted to hear. Then, he would insist that he knew what Mom wanted. For example; he maintained that Mom did not want us to bring Steinbeck, the cat, for a visit. Then, the next morning, he would call me and ask when we were taking Steinbeck to see her, and did I have the halter? (Prior to bring a pet to visit the nursing facility, the SNF required certificates of vaccination and good health from a veterinarian.)

One morning, after visiting Mom at 6:30 a.m., I called to check on Dad and he was depressed. I filled him in on Mom's schedule: doctor visit; RNA training; Case Meeting at 10:30. I told him I was going back for the 10:30 a.m. meeting; that I was trying to stay positive, even though Mom seemed to be doing poorly. Dad said he was sad, but that he'd go over after he did his chores. I said maybe we'd run into each other. He suggested brunch. I said that I had to work. That started a ripple effect of resentment and anger. Dad sputtered, "OK, I'll take care of Patty; you work!" "You're probably talking on the phone too much...better get to work!" The tension of wanting to be in several places at once was mounting.

Mom improved over the next couple of weeks; family flew in for visits; we took Mom for a four hour home visit; then, after another week, she was ready to return home.

Dad and I trained with PT, so that we could safely help Mom with transfers and exercises. The speech therapist gave us some practical suggestions for home rehabilitation. The goal was to help Mom regain mental and physical abilities. Some of her suggestions for Mom:

- large print crossword puzzles
- large piece jigsaw puzzles
- discussing a movie after viewing
- having Mom be part of planning for events; being an active participant
- large calendar displaying special events; crossing off of days,
- having daily "routines," i.e. Mom's Friday hair appointments

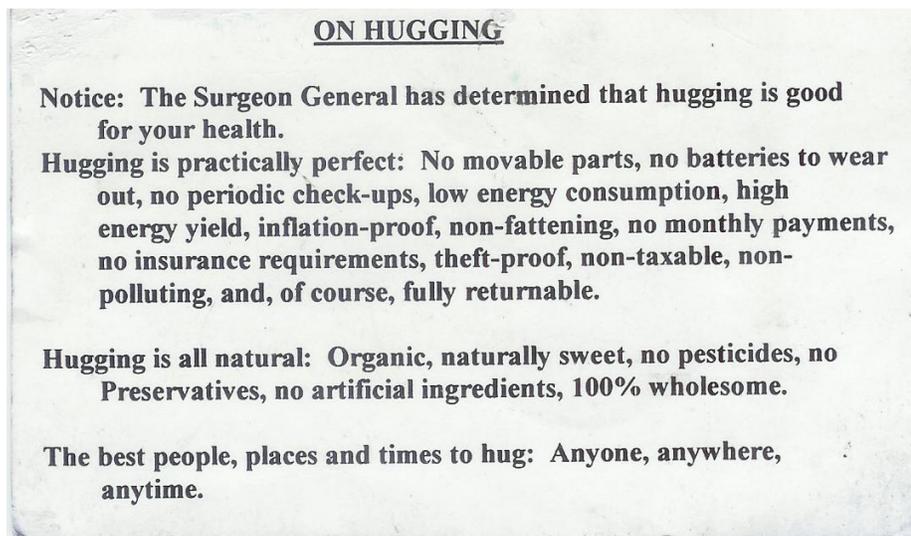
Home Health provided a Case Manager, PT, OT, nurse and home health aide for the next two months. I would try to help Mom repeat the arm and leg exercises that home health taught us. We would sort of enjoy using the “Thera-band” elastic to do the arm exercises. but, it was difficult to get Mom to do them, and Dad didn’t have much patience for helping. Mom would endure an infection at the incision site, elevated calcium, continued incontinence, investigations for further malignancy. Her developing macular degeneration meant she could see little out of her right eye, and the left was not 20/20 either. Along with frequent visits by home health, there were appointment follow-ups with Mom’s primary physician, nephrologist, radiologist, oncologist, surgeon. She would also see her dentist, ophthalmologist and urologist.

On the day before Mom was to be discharged from the nursing home, I took Dad for a check-up to the doctor who was now the primary for all three of us. The doctor pronounced Dad, “in great shape.” I wondered, how accurate an analysis could the doctor make in ten minutes?

Poor Dad was increasingly frustrated at the seeming crowds of people invading his space at home. Home health assistance ended, but Mom would still need lots of care. Dad became more confused and overwhelmed. There was a lot to be confused about. He expressed a “growing helplessness.” The doctor agreed to refer Dad to a neurologist.

Our ongoing education regarding physical decline was about to include challenging courses on mental decline as well. I began checking out elder day-care centers, and, especially, in-home caregivers. I was getting better at researching team options. Neither Dad nor I could handle all this alone.

Here is Dad's "Hug Card." Dad carried this as a 3x5 card in his wallet. Whenever he spied someone in need of a hug—someone he thought might be receptive—he handed them this card; waited for them to read it, then proceeded to hug them. He had a 100% success rate.



## Chapter 12

**Blondes with Big Diamonds**

“We do *not* want a stranger to move into our home!” Dad was adamant and Mom seemed to agree. Again, they asked, “Jody, why don’t you move in with us?”

“Dad, I need my job, my 401k, my health insurance. And what about my cats? I need my own place. I’m taking over organizing the meds for you both. I’ll drive you to doctor appointments. I can be there at your house in four minutes if you need me.”

I was determined to avoid my own heart attack.

“Dad, Mom will be starting kidney dialysis soon. We will need a trained caregiver to learn and prepare renal diet menus for Mom. That is why we must interview some caregivers.”

Truth was, Dad was wearing out and his temper was wearing thin. He would bark at all of us; be rude to relatives; forget he’d had two cocktails and have two more; forget he’d had a chocolate sundae and have another. His mind was deteriorating more than any of us knew. He needed help as well as Mom. Either Dad or I could probably have studied renal diets and learned to measure liquids and calculate other renal needs, but my sister and I seized upon this slight ruse that we must have a trained pro for Mom. Any attempt to tell Dad that he was overworked and beginning to forget things was futile and invited verbal explosions such as, “I’ve taken care of Patty all this time. I can do all the laundry and the cooking and the cleaning and the yard work just fine!”

Two previous efforts at bringing in caregivers had resulted in prompt firings by Dad. This time, our tactful trickery worked. We set up an interview at home with two women who owned an in-home caregiver agency. One focused on the business aspect; one was a medical doctor. Both were experienced and compassionate.

Dad turned on the charm. He welcomed these women into his home as if he were greeting them at his cocktail party. He offered them something to drink (they declined). After telling the ladies a few of his jokes, Dad sat down to hear what they had to say. As soon as one of them suggested that Mom and Dad would benefit from an in-home caregiver, Dad was angrily up and pacing. The two capable women took turns calmly addressing Dad's concerns. The attention made Dad very happy.

His composure regained, Dad flirted. "That is a beautiful diamond ring you have on there." "Why, yes it is. Thank you very much," the doctor replied. "Someone must love you very much," Dad coo'd. The in-home care ladies had charmed the charmer. We all agreed to interview and hire one of their caregivers. For days after, Dad would explain to people that he was persuaded to hire a caregiver by a couple of "blondes with big diamonds."

As they left, our lovely, smart blondes with big diamonds gave Janny and me a very important paper. It listed ways to deal with agitated, memory-impaired behavior. "Oh, for heaven's sake. Why didn't we think of that? Of course. Well, that makes sense," Janny and I exclaimed to each other. It was as if the ladies were sharing deep dark secrets with us, so revelatory did these common sense tips seem to us. We hadn't really acknowledged to ourselves that we were dealing with impairment. We thought it was just Dad. We leaned over the kitchen counter devouring every word.

The paper is available from the Alzheimer's Association. It was written by a volunteer for the Association, who was a former caregiver. It is called "Passionate Communication with the Memory Impaired." Here are a few of the tips:

Don't:

- \*Don't reason.
- \*Don't argue.
- \*Don't remind them they forget.
- \*Don't question memory.
- \*Don't take it personally!

Do:

- \*Give short, one sentence explanations.
- \*Repeat instructions or sentences *exactly* the same way.
- \*Allow plenty of time for comprehension.
- \*Eliminate ‘but’ from your vocabulary; substitute ‘nevertheless’ (or, ‘however’).
- \*Agree with them or distract them to a different subject or activity.
- \*Accept the blame when something’s wrong (even if it’s fantasy).
- \*Respond to the feelings rather than the words.
- \*Be patient and cheerful and reassuring. Do go with the flow.\*Remember, *you* are the rational one, and you can be generous of spirit (even if you don’t feel rational or generous).

This important paper lists examples, too. For the “Don’t reason” tip, for instance:

Patient: “What doctor’s appointment? There’s nothing wrong with me.”

Don’t: (reason) “You’ve been seeing the doctor every three months for the last two years. It’s written on the calendar and I told you about it yesterday and this morning.”

Do: (short explanation) “It’s just a regular check-up.”  
(accept blame) “I’m sorry if I forgot to tell you.”

Later on, when I took my increasingly impaired Pop to a doctor, and he protested that he was just fine, I would recall his Naval experience aboard ships. I would tell him, “This is a regular check-up. We are keeping you ship-shape.” He would grin, and repeat, “Ship-shape.”

Back then, though, when Dad’s dementia was new, we were all confused and frustrated. We did our best to absorb and apply the compassionate communication techniques.

Driving was about to become an issue. The diamond-wearing blonde that was a medical doctor had another revelation for me. She told me that driving with dementia, such as Dad now has, is like driving after drinking four martinis. I had never heard that comparison before. It was pretty vivid.

I scooped up “Talking to seniors About Driving” articles from AARP, Alzheimer’s Association, Southern Caregiver Resource Center and attempted to prepare myself for future challenges, but we could not anticipate what was coming. We really didn’t have any diagnosis yet. At least we thought we had achieved consensus on hiring a caregiver.

## Chapter 13

### Let's Go to Tahiti

Talk about a charmer. Dad used to stand on his head on the piano bar, and sing “Oh, Lord, It’s Hard to be Humble.” (From Mac Davis’ *It’s hard to Be Humble*). But he could show another side. He could keep his friends entertained; then nastily berate his golf or card-playing buddies when they didn’t exactly follow *his* rules. He could ask me for help on a chore; then scream at me for trying to take over. He might fix Mom his famous Caesar Salad; then belittle her for being fat. After pouting and bullying at home; when he went to the doctor, he became suddenly articulate, entertaining and cute (except for waiting room rudeness if the doctor was late). After two visits to our first neurologist, with Janny, the doctor declared to our deceptively adorable Dad: “I think you are a highly functioning gentleman, with two very over-protective daughters.”

Was the doctor in denial? Nevertheless, after several appointments and mini—mental tests, the neurologist prescribed dementia medication for Dad: one, then another, when the first irritated his stomach. These drugs would hopefully slow down the progression of dementia. The mini-mental test results could be repeated and monitored for mental decline at subsequent visits.

Not every doctor/patient relationship is a heavenly match. The highly regarded new primary doctor we acquired when Mom was in ER in 2000 had always been thoughtful, patient and responsive. He was vigilant and meticulous about every aspect of Mom’s care.

One day, though, I may have caught him at a particularly stressful time. I think he needed to get to his hospital rounds. Or, maybe dementia wasn’t his cup of tea. I requested a reevaluation Dad’s mental status and a review of his multiple medications (he had been on some of them for a very long time). The doctor grew impatient and said there was nothing to be done and nothing to change for my dad. Uh-oh. I later learned that many primary doctors are not trained in geriatrics, although this is beginning to change.

Dad's first neurologist was very young; perspired profusely; seemed inexperienced. With him, Dad became frustrated because he couldn't understand the young man's English and because the doctor didn't speak loudly and clearly to him. Of all people, shouldn't doctors know to speak loudly, clearly, and directly to a hearing impaired patient?

Another neurologist screamed at me for interrupting her with questions and stormed out of the treatment room, slamming the door behind her. I was mortified and profusely apologetic. Is it professional for doctors to throw tantrums? Aren't doctors the ones who are there to answer our questions? If not them, the experts, then who? I respect and appreciate the stress and time-constrictions doctors face, but none of the above doctors was addressing our problems. Despite an ingrained reluctance to contradict or question authority, I kept seeking direction and solutions. There had to be a pony in all this manure. Over the next years, there would be a parade of proficient, indifferent, compassionate, Napoleonic, communicative, or not, psychiatrists. In a few years, there would be an explosive confrontation between me and one of them. For now, my own listening and communication skills needed work, and I also needed to learn when and how to speak up.

In the meantime, I tried to think outside of the box in terms of parent-caregiving.

In November of 2001, I made a suggestion that may have been indicative of my eternal optimism, or maybe it was more an indication of my own dubious mental stability. At the time, there had come a lull in Mom's physical decline and Dad's mental confusion. They were both doing well, and pretty much back to their regular routines. Everything seemed under control. I seized the opportunity to celebrate.

"Let's go to Tahiti!" I proposed. I knew that Mom had always fantasized about going to that tropical island. To be honest, Dad was not so inclined. "Dad, you traveled so much with your career in the Navy... Mom didn't get to as much..." I sort of bullied him into agreeing to the trip. Of course, they asked me to go and help take care of them—and Janny wanted to go, too. I was sensing the march of their mortality and wanted one last best fling for Mom especially.

Well, I tried. Two months later, Mom's nephrologists told us she would need to start kidney dialysis soon. The fantasy trip was cancelled. In retrospect, I wonder, what was I thinking?! Dad might have known best in this case, not only about Mom, but himself as well. His condition was more fragile than I thought.

It was the blondes with big diamonds who recommended the competent and compassionate gerontologist we finally went to see. He would take time to evaluate Dad and would respectfully speak directly to him. He would eventually diagnose Dad with Alzheimer's Disease.

“Doctor...doctor, are you sure? Alzheimers’? Shouldn’t we perform more tests?” I implored. “What about SOCARE at UCSD? (I had learned along the way about this excellent resource). How can this be? There must be something else we can do.” I was beside myself—Alzheimer’s seemed so disastrous and terminal.

The doctor quietly, kindly, said to me, “Jody, your Dad has had blood labs, stress tests, EKG’s, x-rays, MRI’s, CT scans—every physical and mental test available to evaluate his condition. This is how we diagnose—we rule out other possible causes for dementia. I can say with all probability that your Dad has Alzheimer’s. I recommend that we treat it as such.” I wilted and concurred.

Life went on. I helped Mom and Dad organize and correctly take and check off all their meds. I took them to their doctors’ appointments and helped out when needed, while attempting to meet all my sales job requirements. When I accompanied the parents to doctors’ offices, I would computer-key client orders in the waiting room, or schedule appointments over my cell phone. I never noticed the No Cell Phone signs. I traveled to Los Angeles for regional and company meetings, and to other cities for seminars and conventions. I nervously kept my cell phone glued to my palm during the day, and beside my bed at night (and even turned-on in movie theatres), in case any parent emergency would occur.

Accomplishing my work duties and caring for the parents at the same time became increasingly difficult. I’m not sure, but it could be that my stress led to me falling and breaking my wrist, twice; once while gleefully hiking down a cliff, and the other time while speed-walking at 5:00 a.m. before a Regional Sales Conference in LA. I needed to get-a-grip and take deep breaths.

Several times, Dad would call in the wee hours. “I’m having chest pains.” Calls to doctor. Nitroglycerin. Doctor appointments. Janny was visiting and went with us when Dad’s cardiologist performed an angioplasty and inserted a stent in one of Dad’s coronary arteries, on July 6, 2001.

A serious red flag: Dad didn’t feel like golfing. He was devoted to golfing, twice a week. “I’m too tired. I have a cold. I’m staying in bed.”

Sometimes he was smelly—he wasn’t his usually fastidious self—wasn’t taking showers.

In the evening, his having “two more” bourbon and waters made him more belligerent and he would again berate Mom for being overweight and not exercising enough. He would call her “morbidly obese.” I gritted my teeth at his rudeness, but he would not be stopped. He would join Mom to watch Lawrence Welk, her only favorite TV show, but, high on all those cocktails, he would sing loudly and holler derogatory comments at the performers on the screen. Then he would huff off to play poker on his computer.

He became a danger to the cat when he would put his mostly eaten double doses of ice cream with chocolate on the floor by his bed for Steinbeck to slurp—oblivious to the fact that chocolate is toxic to felines.

It was during one of these alcohol/chocolate induced moments that Dad's paranoia erupted: "Jody, you are trying to control us. Patty, she is trying to take all our money. She is using us and will leave us penniless!"

Another time, I discovered he had taken Mom's meds instead of his own.

One day, sweetly doting on Mom, Dad wanted to warm her fragile cold feet. He put her slippers in the microwave to make them toasty.

Smoke filled the kitchen and floated down the hallway into the bedroom where Mom's alert caregiver sniffed the air, even as she was attempting to lift Mom off her porto-potty and put her back into bed.

"Fire!" the caregiver screamed, as she plopped Mom back down on her pot. The caregiver raced down the hall; flung open the microwave; courageously extracted the smoking culprits; ran outside and threw them into the pool.

Several red flags. Did I take the helm? Not yet. Did I take his liquor away? No. Certain events were about to catapult me to the caregiver fore. Dad's dementia was accelerating. What was I going to do? Sailing off to a tropical island was probably not the answer.

### Section Three: Caregiver Stress

Where are my car keys? Where is my car? Where am I? And who are you?



Kim and friend

## Chapter 14

### **About That Traffic Ticket...Mine**

There I was, worrying about Dad's driving. Would he space out and accelerate when he meant to put on the brakes? Would he forget where he was going or where he was? He had already put Mom's slippers in the microwave. Would he crash and injure himself or others...or worse? Dad's dementia made it unreasonable to try and reason with him.

We could have gradually chronicled driving deficiencies and discussed options for safe driving at times when everyone was calm and lucid. We could have researched local driving assistance programs, taxi vouchers, routes for buses and trolleys, grocery delivery services and senior assistance plans. Did we? No. Relatives, friends and neighbors might have helped, too. Maybe the car would need repair and have to be at the dealer for a very, very long time (while really being parked at my place). Of course, Dad could say, "I'll call the dealer myself." As it turned out, upcoming episodes would determine Dad's driving status for us.

In my own haphazard way, I was focusing great attention on Dad's driving--but was I paying attention to my own?

Stress, fear, worry, lack of sleep, distraction can cause anyone to be a danger behind the wheel. Becoming a caregiver for one's parents—just worrying about one's parents—qualifies for red flag alert. I tried to tell myself that I needed to concentrate doubly hard during those days. I was lucky that things didn't get worse than they did.

I must tell you that some of the tickets and accidents were not my fault! Really. I recall from early adulthood being told that we must drive defensively and watch out for *other* drivers and distractions, as well as watch ourselves. *I* know that.

I was still working in Los Angeles, when the first ticket...and the second one, happened. The first one was the fault of the fleas. Unbeknownst to me, a momma cat had birthed her kittens in the tuft of grass leading to my parking garage, and fleas had set up residence in the cute kitty fur. When I passed by, the fleas jumped onto me, then into my car, and reestablished their cozy residence in the soft floor mat beneath my steering wheel. When the policeman stopped me for driving through a red light, that was definitely yellow when I crossed the white line, I protested, but didn't tell him that I had been preoccupied with scratching the multiple flea bites on my calves. At traffic school, the teacher said that I should have told the officer of my extenuating circumstances. "Would he have let me off?" I asked. "Maybe," said the instructor. Go figure.

The second ticket was definitely not my fault, and the rule book said so! The light turned red while I was still in the intersection, but had been green when I entered. Heavy traffic prevented my backing up. I considered my options, and felt that it would be safer for people and cars if I carefully continued through, since I was sitting smack dab on the crosswalk and halfway into the intersection. The officer did not relent when I tried to explain, so, off I went to traffic school again. (You could go again if it has been at least 18 months since your last traffic school). When we came to the part in the rule book that exonerated me, I asked the instructor if I should have contested the ticket, instead of coming to school. He told me that school was probably the best option, since it would have been "the officer's word against mine," and I very possibly might have had to pay the ticket and have it put on my record. Now, I am told that this type of incident can be ruled either way. The injustice of it all!

Then, there were the three accidents in parking lots while I was still working in Los Angeles. First, I thought I had looked both ways, and again behind me on the right, before I backed out of the parking space. And that young driver *did* suddenly zoom in too quickly behind me. Alright, it was clearly my fault. I had even cautioned myself that I was very excited about my daughter coming to visit, and that I must be extra careful. That was in the mall parking lot, across from work. It was after this one that my daughter gave me a plastic angel for my dashboard.

The next one was in the parking garage for the industrial complex which housed my sales company. This time, I cautioned myself to be very careful, because I was getting ready to drive down to visit my parents again, and I was full of excess energy. I had driven ever so slowly around each curve—so carefully, that, on the last one, I got too close, and hit the column. I was beside myself. When my dear co-worker, Minetta, materialized out of the elevator, I asked if she would just hug me for a moment. There was no one to blame but myself, and I felt really silly. After this one, my daughter refused to talk to me on the cell phone when I was driving.

When my sister came to visit me, it was such celebration. We had an ocean view table at the restaurant, and sipped our cocktails as we marveled at a pod of dolphins. Uh oh. After dinner, I backed right into the red convertible in the parking lot. My entire family began to pray for my safe parking.

I must say, I have really enjoyed all my traffic school experiences. Some have been humorous-entertaining; some inspirational; all informative. Of course, I was none too happy that they had to happen at all.

There's more. The same year, someone ran into me as I attempted to park in my own apartment parking lot. Oh my. It was clearly his fault, but I did sustain a neck injury, and those things can come back to aggravate. The sound of the crunch when the metal collapses upon impact stays with one for a long time, doesn't it?

Yet another time, a kind, elderly man ran into my parked car in a Target parking lot. He was writing me a note when I returned to my car.

Except for a smashed window from a vandal spree in San Diego (the vandals were caught, after several years of drive-by bb gun shooting into parked cars), I have been ticket-and accident-free since the Target episode. ...Holding breath...

Clearly, it wasn't just my dad's driving that needed to be scrutinized. We all need to try hard to be alert and careful. I finally admitted to myself that caregiver stress can have a heavy impact. Nowadays, when I see myself inching over the speed limit, I say to myself, "It's not worth it." I frequently flash back to the sound of metal and glass crunching. When I am in a parking lot, I go verrry slowly and carefully, and say to myself, "Parking lot." Even so, once, when I drove from the hospital to the nursing home, late at night, the driver next to me told me that my lights were not on. I guess I needed yet another wake-up reminder. I am aware that any of my incidents could have been worse. I remind myself that stress and weariness can impair judgement. I consider the fear of getting a ticket or having an accident to be a healthy fear.

## Chapter 15

### **Blowin' Smoke Rings**

Gotta go, gotta go, gotta go, gotta sit.  
I think I can, I thought I could, I wanna cry, I wanna quit.

What'll I do? Where'll I go? Where're my keys, my car, my brain?  
What will happen to my parents if I croak or go insane?

I'm a mess, I'm stressed, unruly, unpresed--  
Can't button my jeans, can't touch my toes.  
I'm 200 pounds—no way I'll buy clothes.

Hey now, hello—I used to be svelt.  
Caregiving is stressing, I'm beginning to melt.

Chocolate-on-ice-cream, yum, I love cheese.  
My tummy's so big I can't see my knees.

Here's my Benson and Hedges, I take a big drag,  
Sip lime with my gin, read People magazine.

Oh, nice, my breath stinks; my gums are receding,  
I'm shrinking, I'm thinking I'm turning to mud.

Oh crud.

Catlin; Sharing the Journey

My heart goes a-patter; something's a-matter  
I break my wrist twice, then I fall off a ladder.

Red flag.

Red flags--quite a few. Quick, pick up the phone.  
What was I thinking to try this alone?

Ahh, the smoke clears, there's respite in sight,  
There's Janny and Yvie and Aunty and Jim  
The neighbor next door and the groups and the gym.

I can't do it all, I have to confess.  
Sharing the messes, the stresses are less.

I take a deep breath. I take a first step,  
Every little bit helps. I'm not burned out yet.

With a team we take turns in our work and our play,  
There is time to stand still and to savor a day.  
Every once in awhile, anyway.

## Chapter 16

### Help

“Do you need me, Jody? I can fly right out.”

“No, Janny. Thank you. I’m fine.” Whatever my caregiving stress, Janny made it better. She would offer to fly out, or simply say to me, for the umpteenth time, “You’re doing a good job.” That was all I needed. (When Dad first started getting confused, Janny was the one who flew out and spent days reorganizing his files).

Thanks to her being a flight attendant, Janny flew to see us a lot—meeting Mom and Pop for an airport cocktail on her lay-overs, zooming in for family fun, or arriving to help out with parent medical challenges. I don’t know how she did it—always flying stand-by, dealing with delays and flight changes and odd hours. When she arrived, she must have been exhausted, but there she would be, at baggage curbside, a bouquet of flowers in one hand and her trusty roll-aboard in the other, her long salt-and-sandy hair blown about by a San Diego Santa Ana and a big grin on her glowing face. It was always easy to pick Janny out of a crowd at the airport. She wore her characteristic travel-anywhere-in-the-world layers of clothing—elastic leggings, flouncy skirt, silky blouse, versatile vest, linen jacket, all-weather coat, and hand-crafted multi-colored scarf. One time she had on a Dr. Seuss-like spiral Santa’s elf hat. Another time, when Mom was in the SNF, Janny wore 100 Mardi Gras beads around her neck in honor of both the holiday and Mom’s birthday. Years before, my teeny daughter Yvie called Janny “My exotic auntie” because of all the international gifts Janny came bearing—dollies from Japan and Brazil, chocolates from Germany, tulips from Amsterdam.

I didn't want to cause my sister financial stress—flying out often meant she had to lose work. I didn't want to burden her—she certainly had her own full life back home in Baton Rouge--son Nik, her art, her church and myriad other activities that she somehow managed to squeeze in between flights. Besides, I wanted to be responsible and successful with my caregiving duties on my own. One day, though, my “I'm OK” world went topsy-turvy.

Mom went to the hospital to have her kidney dialysis graft surgically implanted. She would soon go on dialysis. This meant big life changes. Mom must have been apprehensive about what she could and couldn't eat and drink--she loved her bananas, her champagne-filet mignons and her manhattans-on-the-rocks. Now she would have to be more careful about what and how much she ate and drank, especially liquids and potassium and phosphorus. How did she feel about having a tube implanted in her already delicate fragile arm with paper thin skin and brown and purple bruises everywhere?

Was she anxious, I wondered, about the impending four-hour dialysis sessions she would endure three times a week, as soon as the graft site healed? What about her hair salon appointments; her birthday group parties; her shopping? What a way to crimp her style. What a bummer.

One step at a time. We consulted with the nephrologist, a dialysis social worker and a nutritionist. Mom and Dad, the newly-hired caregiver and I studied renal diet restrictions. We scheduled the at-home caregiver for after Mom came home from the hospital.

Mom seemed to take it all in stride, but I knew this had to be awful for her and I just wanted to hug her tight and not let go—I mean, I wanted to hug her gently. I so wanted to make it all better. I know, I know—fear of the unknown is almost always worse than the real thing, and one can learn to adapt, but it's easier said than done to let go of anxiety for a loved one.

As always, when Mom was in the hospital, Dad and I spent hours with her. We kept tuned in to her care through the nursing staff and did our best to maintain positive rapport with them. I kept family members informed via my cell phone, and managed to make work calls as often as I could.

I would key orders for my job each night when I got back to my apartment. It was always difficult to leave Mom, but I kissed her good-bye, and made sure nurses had my phone number before I left each night. The third morning, about 5:30 am, Dad called me from his home.

“Jody, I’m having chest pains.”

“Did you take a nitroglycerin?”

“Yes—three.”

“Are you still having pains?”

“Yes.”

“Dad. Call 911... I’ll call 911.”

“No.”

“I’ll be right over.”

Dad had dealt with a creaky heart for some time and seemed to be diligent in his own care. Anyway, he was the captain. He was a type-A personality and anyone trying to tell him what to do did so at their own risk. I tried to respect his sense of dignity and control. It wasn’t easy to figure out what to do or how to countermand him when he gave a misguided order. That would be mutiny. And mutinous behavior might cause him to really crack up.

I arrived at Dad’s bedside that morning, about six. “Are you still having chest pains?” “Yes,” he said. “We need to call 911, Dad.” “No.” He became more agitated and resistant. Oh dear. We went back and forth as I tried logic, cajoling and pleading to get him to call 911, to call a doctor-on-call, to let me drive him to the hospital. “No, no, no.” I resorted to trickery. “Ok, let’s go visit Mom.” (We were planning that anyway). “We can get you some breakfast there, too.”

“OK.”

We got him dressed and in the car...into the parking lot...into the stark stainless steel elevator that took us up to the lobby level of the hospital. It was early and there were few people around. No one noticed that I had in tow a petulant puppy threatening to collapse into my arms at any moment. I kept in relatively calm crisis-mode, trying to prop up this rag doll little boy who kept groaning and pouting and leaning against the wall railings along the way. He let me swerve him toward the cafeteria. “We should have a bite to eat before we go see Mom. Okay, Dad?” The ER happened to be a few steps away from the cafeteria. He was weaker than ever and fell against the wall. “Dad, let’s just stop in the ER—it’s right there...” Maybe he didn’t realize what he was agreeing to, but he let me guide him a few more steps into the ER, where orderlies, apprised of his condition, whisked him right onto a gurney and into a treatment room.

Dad was spitting mad. “You tricked me. I don’t need to be here. I’m fine. What are you doing to me?!”

He really did need to be there. He was admitted to the hospital.

That day I ran back-and-forth between Mom’s room on the 2<sup>nd</sup> floor of the west wing, and Dad’s room, fourth floor, east wing. Dad was furious, and wanted to leave. The doctor said he could leave, “AMA,” (against medical advice), but he might need to come back. The doctor advised he stay in the hospital and be put on a heparin drip. Dad must have had another weak spell, because he acquiesced. The doctor scheduled an angioplasty for two days later.

After consulting with the nurses who would be caring for each parent, and making sure staff had my phone numbers, I proceeded to make family and work-related calls; take one of Dad’s hearing aids to be fixed; feed the cats, and buy chocolates to bring back for the nurses. By 10:30 p.m., when I returned, Dad was on the heparin drip, and had been given a sleeping pill. Since my cats were fine, and they had each other’s company, I went to my folks’ place to sleep, so Steinbeck wouldn’t feel lonely.

For almost a year, now, I had been a San Diego “outside sales rep” for the skincare company, whereas before, I had worked out of the main offices in Los Angeles, calling East Coast clients in the phone. This meant I had about 120 clients in beauty salons, spas and beauty supply stores, whom I was supposed to see in person each month. I would drive up to LA for regional meetings, and drive or fly to other cities for seminars or conventions.

A regional manager would occasionally visit, as she did with all her reps, to monitor and coach me. There was constant pressure to create more and more reports, take classes in Excel, meet higher and higher sales goals, and prospect for new clients.

I wasn’t getting exercise and was continuing to gain weight. My body felt like it was turning to mud, so I started getting up and walking the nearby lake at 5:30 a.m. That helped a little. Since I started having trouble getting the wheel chair in-and-out of the car trunk, I started lifting weights. That helped a little, too. One day, I lay on my couch and thought I felt heart palpitations, so I reminded myself to “breathe,” like Aunt Betty always said. Another day, I said to myself, “I need socialization.” So I tried out a couple of support groups. That helped more..

Now, though, with both Mom and Dad in the hospital, two cats at my place, Steinbeck at Mom’s and Dad’s, and work deadlines to face, I wasn’t sure how I was going to be everywhere at once.

I awoke the next morning in a panic and began walking back-and-forth down the hallway, into every room, and in circles. Steinbeck meowed his concern.

I kept saying to myself, “What’ll I do first? What’ll I do now? I have to call Janny. I have to call Janny!”

Janny had already visited about every other month for a day or two. She had Family Medical Leave papers, in case we needed her for an extended period, but I only wanted to use that as a last resort.

I was frazzled and exhausted from running between the parents’ hospital rooms. I was worried about both of them. The doctors said Dad hadn’t had a heart attack...yet. Mom would shortly be coming home with a new graft in her arm. She would need lots of attention. And--what about the laundry; cooking proper renal meals; watering the hedges and the philodendron and the dracaena? Maybe I’d better vacuum—go grocery shopping—pay the bills...

My wrist was hurting from my fall in LA. I hadn’t had it checked—not smart—to see if it was fractured—I later found out, it was.

I had a little talk with myself. Calm down, I said to me.

I began putting one foot in front of the other. I called the hospital to check on the parents...they were okay...I said I would be there soon...I fed all the cats...began making plans. I reassured myself that putting one foot in front of the other was all I needed. Everything was under control. I was fine. I didn’t need to call Janny, after all.

Aunt Betty and Uncle Roy stopped by for a visit. They both wore their Disney shirts, since they were on their way to perform their monthly volunteer magic show at Children’s Hospital. Betty brought some of her famous fudge for me to take to the parents, and Roy showed me one of his new tricks. He had been a magician since the age of six, and the two of them still performed.

They had both been teachers and Roy had been principal of the school where I went to fourth grade. I was quite proud that my own uncle was principal, and insisted he come to my rescue the day I skinned my knee. Aunt Betty and Uncle Roy even used Janny and me in one of their magic shows at the grade school. They levitated me, and sawed Janny in half! Janny was so scared, they had to tell her the secret, and she has told no one, to this day.

Betty and Roy asked me how things were going, so I told them.

“Call Janny right now,” they ordered.

Obediently, I did so.

“Hi, Janny. I need you.”

“I’ll be right there.”

Thank heavens for Aunt Betty and Uncle Roy. Thank heavens for flight flexibility. This time, I really did need Janny. She would be here the next day.

I thanked Betty and Roy; went to check on the parents; then, downtown to the Navy Exchange to get prescriptions. (Fortunately, Dad and Mom and I had previously gone through the red tape required to get me and my car properly authorized to go onto the base and get their prescriptions).

It took several hours. Finally, prescriptions in hand, I was making my way to the car, and I got a call on my cell phone. It was a nurse. She sounded frantic. “Where are you?! Your dad is agitated. He tried to pull out his IV’s. He almost hit a nurse. We called Security. When can you get here?!” I told them I was on my way, and, would be there as fast as I could.

When I arrived, I saw five hospital staff surrounding my belligerent Dad in the hallway all talking at once, and a security guard at attention. They were trying to persuade Dad to get back into his bed. I joined in the fray.

A lovely redheaded respiratory nurse was in the process of tapping Dad’s arm, and saying, “Mr. Baumgaertel? Mr. Baumgaertel?” Then, to anyone and everyone, “I went to school with his daughter...”

The nurse next to her said, “...and there she is.”

It was one of my dearest friends from the 60’s. We embraced and laughed and shared memories. It was one of those moments where time stands still—everyone around us was frozen in place—and the two of us jabbered on like we were back in 1964. Bizarre. Suddenly, time came back to normal; my friend proceeded with her duties, I grabbed Dad and led him back into his room.

“You are not to hit people!” I exclaimed. Dad protested that he wouldn’t have hit her, and demonstrated by swinging at me. He barely missed and boasted how he had pulled his punch an inch away from her face.

“Nevertheless....” I continued. He was grinning from ear-to-ear, clearly delighted to be a center of attention.

After awhile, the meds took effect and Dad was effectively sedated. Hopefully he would sleep fine through the night.

A security guard would remain posted at his room for the rest of his stay.

Mom was released, and I brought her home. She was so happy to settle into her own cozy bed.

The next day, Mom and I visited Dad in his hospital room. He seemed to be behaving. I took Mom home for a rest. I picked Janny up at the airport and we went right to see Dad. We chatted with all the attending staff, thanked them for taking care of our feisty father, and gave them chocolates. Then, we came home to spend time with Mom.

That evening, Janny and I returned to the hospital, and were told by the surgeon that Dad was confused and not capable of signing his own consent forms for angioplasty or other treatment, should it become necessary. The RN explained Dad’s condition to Jan and me. It was more serious than we had realized. We were asked to sign permission for open heart surgery, just in case. That frightened us. We knew Dad was fragile, due to his previous heart attack and stroke and his deteriorating mental condition. It was not an easy decision. We thought about getting a second opinion. We discussed and thought, and asked many questions. We finally agreed to trust the surgeon and hold our breath. As Power-of-Attorney for Dad, I signed.

Dad was wheeled in for surgery early the next morning. It was a long and anxious wait. The doctor finally came into the lobby.

“Your Dad has had two heart attacks in the past. Two arteries are still blocked. His heart is severely depressed.” The doctor said they tried many times to at least do an angioplasty and implant another stent in Dad’s artery, but the blockage was too severe. One of the two arteries was still functioning fairly well. They decided that Dad was not a candidate for open-heart surgery, due to his other complications. The decision was made to attempt to alleviate the blockage through medication: beta blockers and ace inhibitors. We were advised to have his primary doctor address his depression, obsessiveness, paranoia and weight loss. They would keep him in the hospital one more day.

By 10:05 am, Dad was back in his room, on the fourth floor. The nurse said Dad had had chest pains after the procedure, so they kept him a little longer; did an EKG; and gave him sub-lingual nitro. Jan and I joined Dad, and sat with him for awhile.

Dad was sent home with his occluded arteries and directions to attempt to treat his heart condition with medication. Pretty soon, he seemed to return to his old self and resumed his regular activities—laundry, yardwork and golf.

Janny settled our new caregiver into the “yellow room” (so called because of the yellow bedspreads and furniture that used to be Janny’s). The caregiver was up-to-speed on Mom’s renal diet restrictions and care of her dialysis graft. I prepared a “purple binder” for her with all pertinent meds, renal diet instructions, contact lists, and other various directions for Mom’s care. A home health nurse would visit to monitor the healing of the new graft.

Janny and I performed catch-up around the house. We got the car serviced, filed insurance papers, updated bank books, purchased diapers, bandages and other medical supplies. Janny updated her forms for Family Medical Leave with the doctor. I hustled to keep up with my sales quotas. We had an appointment scheduled in a couple of weeks for Dad with the gerontologist that the blondes with big diamonds had recommended. We figured we had everything under control.

What a help and a comfort to have Janny here. I’m so glad she planned to stay at least a couple more weeks. The parents were both fragile, one way or another. There was a stranger living in the house; there were home-health care workers coming and going—it was a zoo, and Dad’s territorial angst was brewing. We had no idea what was coming.

### **Notes to Myself and Other Caregivers**

*Caregiving can be an emotional roller coaster. On the one hand, caring for loved ones demonstrates our love and commitment. On the other hand, exhaustion, inadequate resources, and continuous caring can lead to burn out, stress and depression.*

*---Southern Caregiver Resource Center Fact Sheet*

#### **Normal Caregiver Feelings**

\*Guilt—the most pervasive feeling for caregivers. There is always: I should do more. Why can't I fix it? Why do I get impatient? What have I done to my loved one? Why can't I bring them home?

\*Anger—sometimes at yourself for not being able to do more and for not getting a break; sometimes at other family members for not doing more or for not understanding how you feel; sometimes at the infirm loved one for needing to be cleaned and fed all the time and for not getting better; sometimes at all the red-tape involved in the financial, medical and business aspects of caregiving.

\*Fear—at what will happen to your loved one and to you—the future and the unknown are scary. Are Mom and Dad afraid? What if I can't handle things? What will become of me?

\*Anguish and Grief—it is terrible to leave a loved one in the care of strangers. Does Mom or Dad hate me for leaving them there? Sometimes it is almost too much to bear to leave them and imagine how they must feel. Every lost function, physical or mental, brings grief...sadness that they can no longer feed themselves, or see, or hear or walk...sadness that you cannot share things you used to, like going to the beach...eating Mom's home-cooked pot roast or Dad's famous ceasar salad, or just sitting and talking.

#### **Caregiver Burn-out Warning signs**

\*Sleep Deprivation

\*Poor eating habits

\*Forgetfulness

\*Weight gain and lack of exercise

\*Not taking care of yourself when you are sick

\*Depression

\*Self medication with excessive use of alcohol, tobacco, drugs

\*Isolation—not connecting with family, friends

**Tips to Prevent Caregiver Burn-out**

- \*Take responsibility for your own care: physical, mental, emotional, spiritual.
- \*Connect with family, friends, support groups and professional care.
- \*Accept your personal limitations and set boundaries.
- \*Create resource lists and use them.
- \*Accept what you cannot change and be gentle with yourself as you put one foot in front of the other to help change things you can.

A portion of *The Serenity Prayer*, by Reinhold Niebuhr:

*God grant me the serenity  
To accept the things I cannot change;  
Courage to change the things I can;  
And wisdom to know the difference.*

- \*Take breaks from caregiving. Make specific plans for someone to take over for a meal, a weekend, an evening, an appointment.
- \*Exercise.
- \*Write. Keep a journal.
- \*Call a friend.
- \*Assess your blessings and feel gratitude often.
- \*Laugh, sing, dance whenever possible.

## Chapter 17

### **While We May...**

Have you ever said...if I can just get thru this...this can't be happening...

The secret is not only to survive, but to savor along the way. Not just to rise above the challenges, but to thrive, alive within them. To love what we have, while we have it.

If we are laughing or weeping hysterically; if we are striking out in frustration and anger; if we are afraid and tired and just want to sleep—

We are still alive...to breathe, to kick, to scream. To weep, to sleep, to laugh, to sigh.

And if we pause within the eye of our anguish, we remember that all things change. And we want to forget not an instant.

### Section Four: Major Changes



## Chapter 18

**Who Took My Gun?**

Evening. Mom and Dad cozily recline in front of the TV. The caregiver's presence has been tolerated for several days now. We feel it is safe to leave the house. "Let's go have our hair cut, Janny." Off we go to the salon.

Janny sits next to me, sporting her new layered hair cut and reading *People* magazine. My stylist is half-way finished with my spiky cut. My cell phone rings.

"He hit me—twice." The caregiver is crying and nearing hysteria. "Then he hit your mother—twice—right on her dialysis graft—so hard I could hear it across the hall in the other bedroom."

My hair half-cut, I race with Janny to the car, calling the doctor on my cell phone as we run.

I recently learned that Dad kept a shotgun behind the curtain in the far corner of the bedroom, within feet of where he slept. "If someone tries to break into my house, I'll be ready for him!" Dad boasted.

"Get the gun out of the house," the doctor orders. "Double his agitation med, and, by all means, agree with him!" Janny engages Dad and Mom in the living room. I creep around the back of the house and into the bedroom to retrieve the shotgun. Finding it behind the curtain next to Dad's side of the bed, I tip-toe to my car and gingerly stash the gun in the trunk. I join the parents and Janny in the living room. They are the picture of normalcy, watching TV together. But there's electricity in the air. It doesn't occur to me there might be another weapon in the house.

Earlier in the day, the caregiver's log indicated a pleasant morning: Janny reading the newspaper to the parents in bed; breakfast; meds. About 10:00 a.m., the caregiver wrote that Dad became very angry that she was staying with them, so she stayed in her room for three hours to "avoid contact with Mr. B." She emerged to make them lunch, then stayed in her room again while Dad's friend came over to play cribbage, shoot pool, and putt golf balls in the back yard. We later read in her chronicle of the evening that after Janny and I left for the salon, Dad started drinking bourbon and continued to do so. She says that at "approximately 8:00 p.m., he became enraged... wanted me out of the house. He hit Mrs. B. x 2. And also hit me x2."

Now, with Janny, Dad and Mom in the living room, I seek out our caregiver in her bedroom, where I had asked her to remain while we dealt with Dad. I thank her for her vigilance. "Are you sure you're ok? She insists she's fine, "I'm experienced with agitated clients," she insists. "You're sure? Then, go ahead and go home for the evening. We'll take over. We are so sorry." Off she goes, saying to us, "I'll be back in the morning."

We turn our attention back to Dad.

As if nothing had happened, Dad nonchalantly announces he's tired and is going to bed.

We decide to keep Mom in the living room for the night. She can sleep in her recliner chair and we'll doze on the couches.

I whisper to Janny, "I am not going to call 911," "We can't do that to Mom and Dad."

"I agree," she whispers back.

There is a doctor's appointment scheduled for Monday. This is Wednesday night. We'll be fine until then. Surely.

About an hour later, Dad returns to the living room.

"I want my Patty to come to bed with me," he purrs in a baby voice, as he raises Mom's electric chair to its upright position. Janny and I exchange glances.

"Mom," we ask softly (Dad has taken his hearing aids out—hopefully he doesn't hear us), "Mom--what do you want to do?"

Mom is clearly shaken, but she meekly, weakly, says she'll go with Dad. We are treading on egg shells here and don't want another violent outburst, so we follow the doctor's orders and just agree. Off they go. Janny and I sit wide-eyed.

A little while later, I make a trip down the hall to the bathroom, and lean my ear to their bedroom door. This is what I hear Dad saying:

“I’ll get my shotgun tomorrow and take care of it...they don’t know where it is...if they took it, they’ve been plotting it for a long time.”

He must have looked behind the curtain, because then he said:

“Patty, Patty—they got the shot gun. You knew about it all along. You’re a traitor. I’ll just file for divorce—sell the house—I’ll take my part. You knew about the gun—what did you think I would do—kill myself—when I could kill them and you, too. I’ll kill them tomorrow if not sooner.”

Swiftly, I return to the living room to tell Janny what I have heard. No, we still will not call 911. We won’t do that to our parents. Knowing our Dad’s devotion to protocol and chains of command, we hope he will dutifully keep his scheduled Monday appointment. We just have to hold on until then.

“Let’s both stay the night in the blue room across from Mom and Dad’s bedroom, Janny. You take the bottom bunk. I’ll sleep right here on the floor so I can move quickly if need be.” I sneak out to the garage and grab a fire extinguisher and a rubber mallet. I reason, cleverly, I think, that if I have to defend us, I don’t want to hurt Dad, just deter him. If he comes at us, I figure I can spray him with the fire extinguisher or clobber him with the rubber mallet and stop him, without inflicting any permanent damage. So, now I have my cell phone, flashlight, rubber mallet, fire extinguisher at the ready. We doze intermittently, trying to stay alert for any ominous rumblings.

I overhear Dad tell Mom, “You know I also have a rifle. Did they get the rifle?”

I didn’t know he had another weapon. Now we’re wide awake. In the next few days, I will discover and extract the rifle and several hunting and fishing knives, hidden all over the house. That’s later. For now, we’re poised like meerkats on high alert.

Who knows who’ll sleep tonight. Not us.

The next morning, the caregiver returns. The parents merrily munch their cereal and blueberries in bed. Janny reads them the morning paper. It’s Valentines’ Day, and weirdly idyllic. Dad asks Janny to run out and buy some flowers for him to give to Mom. Janny comes back with roses and candy and we all eat chocolates. All seems normal.

I call the doctor to give her an update and ask what next. I tell her we'll be taking Dad to see the gerontologist on Monday. "Take all the alcohol out of the house," she says. (We do not). She prescribes more anti-psychotic medications. We include them with his regular medications.

By mid-day, the agitation returns. Dad suddenly upends his TV tray, picks up his plate of tuna sandwiches and throws it at Janny. Lurching toward her, he pushes her so hard she falls back on the couch, narrowly missing the pointy brass tip on the corner of the glass coffee table. His face beet red, he keeps poking at her, sputtering, "You leave me alone! All of you get out of here!"

"Stop poking me in the chest," Janny hollers back. "Don't touch us!"

Suddenly, it's calm again. I'm reluctant to leave, but I have to go get new prescriptions, and I must get back to work. Janny and the caregiver are in charge. I hope there will be no disaster.

Back at my apartment, my cats Tiger and Gypsy doze in the sun streaming in through the Eastern-facing picture window. In the distance I can see my old high school make-out mountain. I step out onto the balcony, take a deep breath of fresh mid-morning air, and return to my work station. Twenty-two calls await my replies. Orders from yesterday are scattered over half-written advertising proposals and seminar requests. Everything is due. I feverishly attempt to call my clients, set appointments, place orders, compute reports and communiqués.

In between work projects, I call my parents' lawyer to update him on the previous day's events. He tells me what I would need to do if it happened that Dad became mentally unable to handle his financial affairs. He tells me a story of what happened to one of Dad's golfing buddies—how the buddy flipped out and was placed in a hospital for observation and the County initiated conservator proceedings. The daughters of Dad's golfing buddy had to take charge. The lawyer told me that if I need to declare Dad incompetent, I will need two doctors to issue written statements declaring his inability to handle his affairs, and then I will need to assume my role as Trustee for the Trust. If Dad becomes violent, the lawyer continues, it is possible I might need a court order to place Dad in a locked facility so that he will not be a danger to himself or others. If that happens, a court order will be necessary to appoint me as "Conservator of the Person." I thank the lawyer for his advice. Surely, I think, none of this will ever apply to us.

I complete my workday as best I can and rush back to Janny, the caregiver and the parents.

Janny intercepts me at the curb in front of the house. She has followed the doctor's advice and is trying to keep Dad from driving. Dad storms out after her. He's livid. "Where are my car keys? You've hidden my keys," he screams at her. "That's ok, I called a locksmith and he will be here any minute. You're gonna be sorry." Back into the house he goes. Janny and I stand our ground next to the car to await the locksmith. I check in with the doctor by cell phone. "Give him another agitation med." The doctor confirms that the DMV has been sent a letter stating reasons why Dad should not drive. Having just purchased new meds, I take a breath and approach Dad who stands fuming on the front porch.

"Oh, here, Dad," I say, attempting non-chalant, "Here is the pill I forgot to give you this morning." He takes it. (I was planning to put it in ice cream if he wouldn't).

Dad backs into the house. The locksmith never materializes. We make it through Thursday.

I attempt a full work day on Friday, leaving Janny and the caregiver to weather the tantrums. After work, I return to the house.

Oh, no. Dad had found the car keys and managed to drive Mom to her hairdresser. Janny is in a panic because she just gave Dad another agitation med. "Holy cow," she says, "I've just sedated my Dad and allowed him to drive away with my Mom."

The parents make it back from the hairdresser just fine. Dad smugly struts his stuff.

Our caregiver is off for the weekend, and Mom, Janny and I anxiously endure more bouts of agitation, tantrums and paranoia. We're hanging in there, just waiting to see the doctor on Monday. Surely, he will make everything right.

Now it's Monday, February 18, the day of the doctor's appointment. Once again, I'm thankful that Janny can be here. Janny is keeping a journal, too. She writes about the morning

"Dad came into my bedroom as I was combing my hair—to say calmly and firmly—'if the gun does not show up that must mean it is stolen. If anything happens with the gun; if anyone is hurt, I will be liable. So I intend to report the gun missing to the police, today at 12 noon. So if you are leaving soon, you might want to leave before I report it because the police are going to want to talk to you. If Jody tries to claim that I would be violent, I will deny it and say it is a lie...I've been a good father. How can you do this to me after all I have done for you? You are breaking up our family. I'll have to take you out of our will and leave everything to Jim. You don't love me anymore.' I knew by then to say, 'OK, Dad, if it will make you feel better.'"

We make it to the doctor's office. Sure enough, Dad is good at obeying protocol and rules, and we arrive right on time. The doctor asks Dad; "So, what's been going on?" Dad replies, "Oh, nothing."

The doctor turns to me. "What's been going on?" "Well....." And I proceed to recount the events of the past few days.

The doctor abruptly stands and leaves the room. Returning, he tells Dad he needs to go to the hospital for observation; that he can go on his own, or he can be escorted by the police."

Dad puffs out his chest, and says; "Well! I've never been escorted by police, before. That would be an adventure."

"May we speak to you in the hall?" Janny sweetly asks the doctor. Out of Dad's earshot, she continues. "I don't think Dad realizes what is going on, and he is very hard of hearing. Will you please explain again to him?"

The doctor kindly takes his time with us. First, he explains that, due to Dad's agitated behavior at this point, no Senior Center would take him; that, because Dad has hit someone, "it is law" that the doctor must call Adult Protective Services; and that Dad must be checked into a psychiatric hospital for observation. Dad has the choice, the doctor tells us, to go willingly, on his own, or to be escorted by the police. We go back into the room where Dad sits. He is fuming and ominously agitated.

The very patient doctor sits directly in front of Dad, looks him in the eye, and explains again that he needs to go to the hospital for evaluation, and to see what medications are right for him. "Larry, would you like to go willingly, or would you prefer to be escorted by police?" Dad says that he will go willingly. Whew. We agree to drive him.

What are we thinking? It crosses my mind that driving our agitated dad to the psychiatric hospital might be unwise, possibly dangerous. Janny and I are really nervous. Dad's mental state is unpredictable and we don't know how much he really understands about where we are taking him. We don't know if he will become violent. Will he strike us? What if he tries to grab control of the steering wheel and swerves us off the road? My own emotions are roller-coastering through fear, determination, guilt, hope, love, frustration, uncertainty.

Ten minutes into our drive, Dad says, "You gals have had it—you're trying to put me away." I am so freaked out that I get lost three times. Janny and I keep exchanging frantic glances and giggling inanely as we try to read the map.

“Here, let me help.” Dad takes the map and attempts to help us get back on track. A fine how-do-you-do: here’s our demented dad unwittingly trying to help his increasingly agitated daughters deliver him to lock-up.

Somehow, we arrive at the hospital. Dad calmly walks in; signs the appropriate papers; meets the medical staff; and is admitted. I provide the necessary forms that I always carry with me: insurance, medical history, list of meds, Power of Attorney for Health, Advance Directive. How odd. Janny and I exit the building; walk to our car; climb in. We collapse in a kind of manic euphoria. “We did it. We got him here, Sis.”

There’s our dad in a psychiatric hospital. A mental ward. A looney bin. Our dad. We don’t know whether to yahoo or cry. Must get home to Mom. What must she be feeling? Better drive carefully.

### **A Little Honesty**

We had experienced numerous close calls. We had not paid attention to multiple red flags. Someone could have been hurt. We were lucky.

- \*We didn't prevent him from driving when it was advised.
- \*We did not call 911 when he hit people and threatened to kill us.
- \* We did not take the alcohol out of the house. (We reasoned that if we did that, he would become more agitated.)
- \*We did not find and remove all weapons right away.

There were some things we did right, or tried to.

- \*Dad kept up with all his primary doctor exams (and we helped).
- \*We took him to three neurologists.
- \*He was prescribed a medication for dementia that caused stomach discomfort, so then he was prescribed another. He took his meds dutifully.
- \*We drove him to a gerontologist who prescribed and performed additional tests.
- \*The doctor diagnosed him with Alzheimer's disease, having ruled out other possibilities, and proceeded with recommendations.
- \*The doctor sent a letter to DMV with a diagnosis of dementia, advising DMV rescind Dad's drivers' license.
- \*Private home assessment suggested in-home care, not only for Mom, but for Dad as well.
- \*Caregivers were hired. Medications and doctor visits continued.

Still, we did not see it coming.

The doctor helped guide us. He helped us get help for Dad.

\*\*\*\*\*

Some resources to call when adult mental illness threatens:

Adult Protective Services for your state

NAMI—National Alliance on Mental Illness. 1-800-950-NAMI (6264) [www.nami.org](http://www.nami.org)

National Mental Health Association. In crisis? 1-800-273-TALK

## Chapter 19

**What Will Happen to Dad?**

It is twilight as I drive slowly around and down the gravelly driveway, approaching the home for elders with dementia. In the half light, I can make out an old-fashioned two-person swing creaking in the breeze beneath embracing pine boughs. I see his silhouette, framed by the light of the office behind him as the director makes his way toward my car. He taps on my window, motioning for me to roll it down. An exchange of pleasantries. I tell him I need a place for my Dad. He says:

“About Alzheimer’s: the first rule is there are no rules.”

I would repeat those words over and over in the days, months, years to come—to myself and to family. Every person is unique. One never knows in what ways and how quickly this insidious disease will manifest.

Then he says, “Sometimes with Alzheimer’s, a person can decline very gradually for a very long time”—he inclines his hand like a children’s slide with a very gradual slope—“then, suddenly, there is a giant step downward”—and he gestures his hand at an abrupt right angle. The child falls. I can see it. That was exactly what had happened to my dad. Or so it seemed.

The cricket chirps and soothing pastels of the sunset sky lull me with hope that this might be a kind and caring place for Dad. I know I must start searching for the right place, just in case Dad does not get well enough to function safely at home. The director invites me onto the rustic porch and into the cabin-like home.

It reminds me of summer camp. Happy memories. The toasty kitchen has a cozy family table in the center where residents and staff alike eat and even share some chores of cooking and washing dishes. There are five bedrooms, two folks to a room, and a living room with overstuffed chairs and TV, right out of the '50s. It is quiet and comforting. I want it for Dad...it looks like a safe haven for him. A couple of days later, I bring Mom and Janny to see it. They like it, too. The director agrees to follow us to the hospital to interview Dad. Wow, that's really nice, I think.

Mom, Janny and I hold our breath as the director and Dad chat. In just a few minutes, as Dad looks over his shoulder, the director looks me in the eye and pantomimes a cutting off of the head gesture. My jaw drops. Out in the hall he tells me, "We cannot accept your dad at our residence. He is far too agitated. I am sorry. It would be too dangerous for him. Our doors are not locked. Right over the fence is the freeway. He would escape; wander; not know where he was. It would not be safe." My heart sinks.

I had not anticipated this. A revelation. I must focus on what would be good for Dad, rather than what I would want, were I in his place. I need to assess Dad's needs and wants and conditions; to choose from his point of view and not from my own.

Summer camp sounded so good to me. But it's not what Dad needs. Not only does he need a secure facility, he needs activity, lots of people, lots of attention, constant supervision. A valuable lesson for me, indeed. So we will keep looking.

For now, Dad must endure a "72-hour mental health hold" (often called a "5150"). He is observed by doctors, nurses, social workers. His medications are being adjusted and evaluated. Every morning there are group sessions for Dad and five other patients with a psychologist and intern. There is occasional entertainment such as an afternoon three-instrument concert for patients. In the evening there are games, karaoke and TV.

We are surprised when Dad "signs himself in" to the hospital; then unsurprised when he becomes contentious again. He is alternately charming, forgetful, agitated and paranoid. Janny and I are concerned that Dad's ability to turn on the charm might disguise the symptoms that brought him to the hospital. Will the doctors be fooled, and think that Dad is just fine, and, consider what is wrong with his daughters? But the doctor responds that Dad is "so forgetful, that he is probably not putting on an act." The doctor continues that it "would actually be good if he were sane enough to 'put on an act.'"

“Your dad may be calming down from his at least two drinks of alcohol a night—that’s a lot,” the doctor says, and suggests that perhaps some of Dad’s symptoms could be caused by alcohol. He states that Dad’s paranoia is severe and is the main concern at the time. He prescribes anti-psychotic meds, to be carefully, gradually administered.

Janny needs to return to work. She flies home. Mom and I, or Mom and her caregiver visit Dad every day. We usually play Uno. What a lifesaver, that card game. It keeps us all engaged. We chat with other patients. We discover that one veteran shares his cigarettes with Dad (Dad quit twenty years ago). We struggle with the anguish of Dad’s condition and commitment. We try to be supportive.

I make notes on some of Dad’s comments. He calls the hospital a “mercy home.” Regarding driving a car, he says, “When the DMV tells me not to drive, then I’ll stop. Until then I plan to continue driving.” The doctor at the hospital says he will send another letter to the DMV, to supplement that of the previous doctor.

It has to be a terrible ordeal for Dad. It’s painful for all of us. Dad always wants to know when he’s coming home. He calls home to advise Mom that the hospital will be keeping him longer for evaluation. Most of the time, when he calls, we have to keep saying, “...a little longer...to see how the new meds work...” When with him, we try to occupy and distract him.

The social worker comments that Dad is “very sweet...that...often, patients start doing better in a structured environment.” That’s hopeful.

Dad becomes very agitated and starts calling people, “asshole.” Dad tells me, “I am who I am—outspoken—I say what I want and call people what I want—nobody ever got anywhere by being ‘milk toast’.” He says that if he wanted, he “could be nice and mealy-mouthed.” He gets nasty while saying these things. He doesn’t comprehend when I try to remind him of his “best loving self.” “I am who I am.” he repeats. He does respond, somewhat, to the memory of Bampa, my grandpa, and Dad’s father-in-law. Years ago, when Dad was growing up in Scottsbluff, Nebraska, Bampa owned a local drugstore and soda shop. Leaning over the soda fountain counter, Bampa was friend and counselor to the kids of the neighborhood. He was a kind and gentle soul, and Dad knew and loved him before he even met Mom. Dad reluctantly concurs that Bampa’s gentleness was “not a weakness,” but, “a strength,” and “a good thing.”

When Janny calls from Baton Rouge to check in, she learns that there was a search on for Dad’s hearing aid batteries; that Dad couldn’t sit still long enough to participate in group sessions; that he asked the same questions over and over, and that he wanted to call Mom and ask the same questions again. Janny is told that Dad “has to have supervision; needs trained people in a structured environment; has short term memory problems and angry outbursts.”

Mom hardly ever shares her emotions. I wish she would. I know she hurts and is full of contradictory feelings. She loves Dad and misses him and worries so.

It must be a relief for Mom to be able to sleep without fear, though; to walk without egg shells underfoot; to watch Lawrence Welk on TV without Dad's rude comments or tantrums.

She is facing her own frightening diagnosis, end-stage renal failure, and will begin kidney dialysis soon. She needs her uninterrupted sleep. She needs to allow her dialysis graft to heal.

I know this is really hard for Mom because of what happens next.

By the end of the 72 hours, a certification review hearing (a "Probable-Cause Hearing") is scheduled to determine whether Dad would be held against his will for another 14 days. If it is deemed necessary for Dad to remain longer at the hospital, he will then be evaluated by the Conservator's Office in order to determine the best place for his treatment; the appropriate level of care.

To prepare Mom for what's coming, we talk about what is happening to Dad. We share how agitated and potentially dangerous to himself and others he has become. He has become not only verbally, but physically abusive.

"Mom, remember when Dad put your slippers in the microwave?" She nods. "Mom, you know how it's hard for Dad to do simple things now, like--take his medicines...dress and eat properly. Mom, sometimes he won't take a shower and gets smelly...that's not like him."

"I know, Jody," Mom whispers.

"Mom--the doctor and the nurse and the social worker all agree that Dad is too unstable to be sent home at this time. You don't want him to hit you again, do you?" Mom doesn't answer.

It is painful to discuss, but I keep at it until I think Mom and I are on the same page regarding Dad's condition and necessary treatment. We will each be interviewed at the hearing. We need to be clear that Dad meets the criteria for further observation, the probable cause being that he is still:

- \*a danger to himself;
- \*a danger to others; or
- \*gravely disabled (unable to provide for his basic personal needs for food, clothing or shelter).

Upon being informed of the hearing, Dad says, “I know exactly what to do. I’ll do what they say. I’ll be real nice and then I’ll come home.”

On the appointed day, we all sit in a conference room around a large oval table: the Superior Court officer (acting judge) at one end; Dad at the other. Dad’s Patient Advocate is on his right, and Mom on his left. I sit next to Mom. The hospital nurse (representing the doctors) and the social worker sit on either side of the table. Dad’s best friend sits behind Dad, to be supportive. Dad glares at me and Mom. His anger is palpable. The court officer interviews the nurse and the social worker.

When Dad hears the social worker’s testimony, he replies, “I would detain that patient, too.” But, after I testify, Dad stares at me, saying, “How could you do this to me?” Dad also says, “I am not willing to go to a retirement home.” The session interviews are nearly over. It is clear to all who have spoken that Dad needs more observation and treatment. The court officer turns his attention to Mom.

“Mrs. Baumgaertel? Do you have anything to offer?”

A long pause. Dad’s eye’s lock on Mom’s.

The Patient Advocate asks Mom, “Do you feel safe with him?”

Very softly, Mom says, “I did...until now...”

The Advocate offers, “You don’t have to answer.”

Dad inserts an unintelligible gruff comment here. He is seething.

The acting judge speaks, “Do you want to answer?”

Mom looks at Dad, then back at the court officer.

She says meekly, “I feel safe.” She continues in a very soft voice, “Larry is not a danger to himself or anyone else, and he can take care of himself, and I want him to come home.”

The court officer slams his book closed; Dad passes on all three criteria; the judge declares the hearing over, saying, “The patient is free to return home.”

All hell breaks loose. The nurse is shocked. She calls the doctor on the phone immediately. The doctor responds that this is a huge injustice. He threatens to bring the court officer up on charges. I am later told, though, that there are no appeal rights for a certification hearing. A member of the medical staff whispers to me that if Dad becomes agitated in the parking lot that I can call out to them immediately and Dad will be readmitted. Thinking that they were suggesting that I intentionally provoke Dad, I tell them no way--I could never do that to my dad. Everyone is talking at once. That’s it—court’s adjourned—Dad’s coming home.

Someone tells me things may have to get worse before they can get better, that I may have to let things fail. I hope beyond hope that maybe things will just get better. Maybe Dad is ok. Maybe it is good and for him to come home. Maybe this is wishful thinking...

We collect Dad's things and we drive home.

I deposit Dad and Mom at home with the caregiver. All seems well. Mom and Dad are happy to be home. I leave to go pick up new prescriptions from the local drug store, stopping at my place to feed my cats. I leave a phone message for the doctor since I have some follow-up questions. (This will be a good thing).

I arrive back at the parents'. Bedlam. The caregiver is crying. "He hit me—twice—hard—on my back." My cell phone rings. It's the doctor. I tell him what just happened. He insists, "Call 911."

"I can't," I tell him. "I can't do that to my dad."

"You do your dad an injustice if you don't call 911. He could hurt himself or someone else. How could he live with that?"

"But I can't do that to my mother. She loves him. It would hurt her."

"You do your mother an injustice if you don't call 911. How would she feel if he hurt himself or her or anyone?"

The doctor is adamant. He won't let me off the phone.

At that moment, Jim calls on the house phone. "Here, Mom, talk to Jim." I give Mom the phone.

The doctor implores me to call 911. He advises me to tell them that I suspect there is another gun in the house. He tells me to clarify that Dad is being aggressive, coming closer and we are fearful, even if he has calmed down. The doctor tells me that when the police arrive, to have them bring Dad back to the same hospital that just released him. If they hesitate as to where to take him, I am supposed to have them call the doctor. When the doctor feels he has persuaded me that I must call 911, he lets me go. Shaking, I retrieve the house phone and tell my brother, "Jim, I think I'm going to call 911." Jim says to me, "Jody, you must call 911."

To my astonishment, when the two police officers arrive, they are kind and respectful. It turns out I had worried unnecessarily about how my parents would be treated. (Remembering perhaps news stories I had heard about terrible abuse in other areas of the country).

The female officer steps right into the living room to speak with Mom and comfort her. The male officer shakes hands with Dad, who is now on very good behavior. Dad proceeds to give the officer a tour of the house, proudly showing him pictures of his kids and grandkids on the wall. The officer also searches the house for other weapons, and when he is unable to open a house safe, Dad readily obliges and opens it for him.

When the police officer keeps insisting he wants to take Dad to a different county facility, I repeat what the doctor told me and I entreat the officer to call the cell phone number the doctor gave me.

After the doctor finally persuades the officer to bring Dad back to the same facility, the officer tells me he is relieved to do so. He says that if they take Dad where he had intended, Dad will be incarcerated amongst murderers, drug dealers and psychopaths. The officer says that when someone is elderly and frail, they are glad to have somewhere else to take them.

Dad goes agreeably with the officer into his car. They follow me back to the hospital, and the officer escorts us into the building. I ask what he and Dad talked about on their ride.

“Oh, we talked about fishing and playing pool, and baseball,” the officer tells me, “Your Dad was cooperative.” He leaves us. I want to call out, “Don’t leave!”

Dad starts to get antsy. Finally, someone handles our paper work. Back into the hospital Dad goes.

The doctors’, nurses’, social worker’s observations and medical evaluations continue, along with the group sessions and daily family visits.

Then, a second certification hearing is scheduled.

In the meantime, I step up my research for the best possible place for Dad. I think I have found it. It has the activities and stimulation that Dad needs. It is a beautiful golden stucco Spanish-style building with lush landscaping and a huge skylight in the center Great Room. I bring Mom to see it. Parked in front of the building, we sit in silence for a long time.

“I’m scared, Mom.” “I am, too, Jody. Let’s do it.” In we go. We tour and interview. Mom and I agree it has enough activity, a good staff-to-patient ratio, cleanliness, kindness, security. We talk to family on my cell phone. Mom and I sign the papers and make a deposit.

Back at the second hearing, all who are interviewed this time, including Mom, concur: Dad needs to be placed in a secure facility. He is deemed gravely disabled, and a danger to others. The court deems it necessary for Dad to be placed under conservatorship, and the county conservator’s office will evaluate Dad and agree to appoint me as his LPS (Lanterman Petris Short—\*see index) Conservator. It is a good thing we have already arranged for a quality secured facility.

I don't even remember Dad's response. Taking him away from his own home is major, and shocking and upsetting to every member of our family. I believe this is right, but it doesn't diminish the anguish for any of us.

It is time to call the siblings home; time for us to band together as a family and support Dad and each other for this painful transition. We have a short time to prepare.

What happens next I leave to Janny to relate, since she was in the living room when the phone call came.

## Chapter 20

### **Daddy's Escape, by Janny**

My sister and I shared guilty glances of dread when the attending doctor released Dad from the psychiatric hospital to enter his new home, an Alzheimer's facility, because he exclaimed, "This guy's going to live forever!" The low blood pressure and other vital signs he measured showed Dad to be so...vital. After the three months of drama and trauma we had just endured with Dad, the last thing we wanted was more; and certainly not forever.

We were so grateful that our brother Jim and his wife, Kim, had left their four kids and come from Seattle to help us transfer Dad to the new and possibly permanent facility. We had scoured the community for the right place for our Dad to live. With Yvie, Jody's daughter, visiting, and with Mom in her wheelchair and me following Jody's lead, we researched and visited place after place. The very name of this place seemed to support our formerly mentally and physically active Dad as he faced his new reality. The energetic and thoughtful, caring staff displayed a calendar of stimulating activities to give their charges as full a life as possible and to entice family members to visit. We were glad Jim and Kim agreed with our choice.

Jim and Kim helped us label dad's clothing and furniture as the day of the move drew near. We all went together to the hospital to help Dad say good-bye to the friends he had made at the hospital, especially "Tex," a fellow patient Dad seemed to believe was one of his old Navy buddies. Tex reached out from his wheelchair, they shook hands and cried and wished each other well.

The day was carefully orchestrated at the suggestion and request of the facility administration. They had suggested that only one or two of us accompany Dad to the facility and that none of us should visit him for at least a week to let him settle in. Jim was disappointed with the no-visit clause as he and Kim were set to return to their kids in two days, but we agreed. Jim and Kim took Mom home.

Jody and I, in our car together, followed the van carrying Dad in the required wheelchair. Jane, the admissions director, was there as planned, to greet Dad. She had obviously carefully listened to our family stories. As Dad was wheeled up to the door, Jane said, "Well! Is this Captain L. F. Baumgaertel?" "Yes, it is," said Dad, standing. She saluted him! He walked forward and, as she had explained she would do, did not take his hand in a childish gesture, but wrapped his arm around hers and ceremoniously led him into the facility. "Bye, Dad. See you soon," we called as we backed away, wide eyed. It was accomplished. We had just placed our Dad in a secured home for people diagnosed with dementia.

Jody had another daunting task she regularly accomplished: filling Mom and Dad's prescriptions at the Navy pharmacy. She dropped me off at home. We knew she would be gone for several hours.

I joined Jim and Kim and Mom as we collapsed in the living room with the emotional exhaustion and temporary glee that the difficult day had gone as well as it had. We sat chatting and enjoying the support of each others company.

I do not remember how long we sat there but we had not moved from the living room when the phone rang. I got up to answer it.

"Hi, Janny. What cha doing?"

"Daddy! Hi!" I said, looking over at Jim to see his quizzical expression. "Where are you?" I began repeating, out loud, everything Dad said. "You're at BJ's having a beer?" Jim shook his head saying silently, "No, I don't believe it."

"How did you get there, Dad?"

"Oh, I was with a class and I decided to walk home and I got thirsty and stopped here for a beer. Wouldn't it be nice if you got Mom and you all came to join me? Can I talk to Mom, please?"

I gave the cordless phone to Mom and picked up the cell phone. While Mom spoke to Dad and he asked her to please bring a jacket as he was cold, I phoned the facility. The clerk at the front desk answered. I said, "Hello, this is Janny Baumgaertel. I just dropped my Dad off this morning to be a resident there. Can you tell me if he has access to a phone?" "Yes, he does." "I'd like to hold on here, please, while you go check to see if he is on the phone, now, because he is on the other phone now, here, speaking to my mother, his wife..." She came back soon to say that, no, he was not on the phone now. "Could I please speak to Jane, the administrator?" "Yes?" "Jane, my Dad is speaking to my Mom now on our other phone. I don't think he is there now." "Oh, yes, he is. I just saw him a few minutes ago."

She went to find him. She was away from the phone for what seemed like a long time. By the time she came back, she was breathless. Jim was sitting on the edge of the couch, rolling his hands, as if to get her to respond faster as I repeated everything she slowly, breathlessly said. "I ... would... like to say..." Jim's rolling his hands, "your Dad... is right here... but he is not!" Pant, pant. I quieted her and asked, "Would you like me to tell you where I think he may be?" "Yes!" "I think he is at BJ's having a beer." "I'll go get him!" she said.

Jim and Kim jumped up to drive there, too. I looked at Mom. "Mom, I can't think of anything I'd rather do right now than to have a beer with Dad." "Me, too," she said. We both nodded our heads gently. "This sounds just like my Dad, our Larry, doesn't it?" "Yes," we both giggled. "I think I will have a beer right now." "OK," said Mom, "and I will have a vodka tonic!"

It is my understanding that two cars left Dad's new home to drive to BJ's, one with Jane and a caregiver and one with the director, and a caregiver. I am not sure what transpired but it went something like this: Jane found Dad and said, "Larry, hi. How did you get here?" "Oh, I took a taxi." "Well, you don't have to get a taxi to go back. I am here to take you." "Not until I finish my beer!" He finished his beer. Someone paid for it. They drove him back. When Jim and Kim arrived at BJ's, Dad was gone so they drove to the facility. They were led to watch Dad through the one way mirror. He did not seem agitated, they said, but sat calmly at a table with others.

They came home and we collapsed again, this time a little less gleeful... and in wonder. We were wondering, "What next?!" We couldn't wait for Jody to get home. Little did we know we would later become "famous" on the Alzheimer's Support Group circuit for being "the ones" whose father had escaped the first day in a secure facility. We would never know how he did it.

The date was March 16, 2002. Dad's new residence had been decorated with shamrocks to celebrate St. Patrick's Day. We believed Dad would notice and realize the importance of the day: St. Patrick's Day, his wife, Patty's, birthday! Suspecting they would relent, under the circumstances, and not enforce their "no visit from the family for a week" policy, we asked to celebrate Mom's birthday with Dad the next day. They fell over themselves accommodating us. We gathered in the Family Meeting Room with lemonade and tea provided and plates and silverware. We brought a cake and Mardi Gras beads and presents and had all set up and ready when they brought Dad in. "My family!" he said. He walked over to Mom, in her wheelchair, and kissed her. "Patty, Happy Birthday!"

I love my memory of asking my sister, "Jody, I'm sorry all this has fallen into your lap. Do you ever resent the fact that you're the one doing all the work caring for our sweet Mom and difficult Dad?" "Oh, no!" she said, "It's my joy and my honor! You're not jealous, are you Janny?" Ho, ho! What a great response to make a sister and daughter relax. Yes. I am jealous for all the special moments my sister has had with Mom and Dad. But, mostly, I am so grateful that my Mom and Dad are so well cared for. I have told my sister, "Jody, because of you, Mom and Dad, in what otherwise would be considered tragic situations, are still having quality lives." Thank you. Thank you. Thank you.

So now I travel "home" whenever I can to live in Mom's and Dad's house with my sister and to jump into the routines of their lives: to pick Dad up; call first to make sure they have him ready; to go to a movie and lunch; to see his joy as he greets us..."My darling daughter, Janny!" To enjoy the fact that he still recognizes us. To hug and kiss him and thank him for his loving support as a father and all he has done for us. And to be amazed that his sense of humor and zest for life still crop up as he "reviews" a movie or critiques a meal and its cost. To soak it up as he zaps off a hilarious zinger. We sing at the top of our lungs in the car together as we drive. And I thank my sister, Big Time! And I say to myself, "I wish Dad could live forever."

## Chapter 21

### **Strange Places, Strange People**

Ten times a day, he wailed, “Come get me! I want to go home!” How could we do that to him—take him from his home and leave him in a strange place with strangers? He must have felt alone, abandoned, trapped. Gradually, the frantic phone calls subsided. Miraculously, the chest pains did, too. Dad was getting the help he needed. The structured, daily routines, the consistent nutritious meals, the assistance with medications, bathing, dressing--24/7 care from professional and compassionate staff soothed him and comforted him. He was safe from accidentally hurting himself or others. The stress of feeling overwhelmed at all the things he could no longer accomplish at home was gone.

Mom’s anguish, guilt and sadness at being a part of what seemed like incarceration of her dear husband began to subside, as well. One day, she said to me, “I know he’s where he needs to be. I didn’t before, but I do, now.” Still, we knew it had to be lonely for Dad, even if he was starting to forget his old home. It was awful for all of us.

After a while, we were able to take Dad out to lunch or movies, but it was difficult to get him to return to his strange new place. It was hard on us to leave him there. It often took patience and guile to get him to go back.

“Hi, Larry,” a caregiver would greet him with open arms and take his hand firmly, “Let’s go get some ice cream.” Sometimes, if that didn’t work, I would enter with him and try to help divert his attention to an activity. When he wasn’t looking, I would guiltily sneak away. I would watch him through the one-way mirror to make sure he was okay and that his attention was refocused.

One time, Dad was extremely agitated, “Where is my car? I want to know where my car is! Where are my credit cards? I want to see my credit cards! My money is not safe!” He whirled around and around, his arms flailing, as four caregivers and I tried to calm him. Nothing worked. Then a tiny little woman sidled up behind Dad and tugged on his sleeve. She quietly slipped her hand into his and sweetly cajoled him into sitting with her at a table. Dad and his new girlfriend became totally engrossed in their own little world.

Did I say girlfriend? Oh, yes. Evidently, one day, this sweet little lady who also had Alzheimer’s took Dad’s hand. She was high-functioning, like Dad. They had much in common--military backgrounds and travels abroad and golf and sports. They became inseparable. I kid you not.

I found out about it one day as I lingered at the one way mirror, feeling sorry to be leaving Dad after a very nice trip to visit Mom in her nursing facility.

“Jody...I don’t know how to tell you this...” the Program Leader, who was head of all the caregivers, tentatively addressed me. Then she just said it, “Your dad has a girlfriend.”

.....“Really?”

“Yes. Now, we know he has a wife and that this might be difficult for you to hear, but you need to know this is very comforting to your dad. They watch out for each other. They eat all their meals together.”

“That’s nice.”

“We know you don’t want your mom to be hurt. But, Jody, this is different. Your dad is not the same. We think this is a good thing. I hope you will be supportive.”

Oh...my...goodness.

Yes. I was supportive. When I explained it to the siblings, they were, too. We decided not to tell our physically fragile Mom. I had been forewarned by my cousin that this sort of thing happens. Her dad, who had Parkinson’s had taken a girlfriend, too, and it had torn her mom apart, even though she said she could understand. I’m sure every situation is unique. We were adjusting the best we could. A few times, Dad called his girlfriend by his wife’s name, but I don’t think she ever noticed. Only once, during Mom’s last days, did Dad actually call her by the wrong name, but Janny and I overlapped his words and I don’t think she heard. If she ever knew, she didn’t let on.

Dad and his girlfriend were two increasingly physically fragile, mentally impaired, child-like sweethearts, aging-in-reverse. They had been taken away from their own homes and were isolated from their families. I was thankful they had each other. They were so cute to watch, toddling down the hallway, hand-in-hand. She would be alternately bossy and little-girly flirt with Dad. He would look bemused and just sort of follow her lead.

The second June of Dad's residence, the facility hosted their annual Seniors' Senior Prom, replete with burgundy table cloths, flowers, starbursts and rainbows hanging from the ceiling, and sparkling cider freely flowing. The residents were dressed in their finest—fancy gowns and classy suits, provided by family. Lots of family members came to party and dance with their loved ones. I donned the full-length silver beaded gown I had bought for Yvie's wedding. Dad and his girlfriend were crowned King and Queen! They were so cute, dancing the first dance, sequin and rhinestone-studded crown and tiara atop their heads.



Dad's suitemate, who had also been in the Navy, stood and saluted Dad as the couple made their way back to their table.

Was there sex? Now, this is a very touchy subject, but I must say, I hope so. When I finally got the courage to ask, one caregiver, who was wary of answering, said, "Well, one time we did find them naked in the bed together." That was all I could handle. Oh my.

Even after his girlfriend passed away, caregivers would wonder where Dad was, and then find him asleep in what used to be his girlfriend's room.

I am thankful for any and every moment of sweetness that Dad could enjoy.

Dad's memory of many things began to fade. But, as long as Mom was alive, his affection and love for her never wavered. His very last words to Mom on the day she passed away were, "Patty, you have been a wonderful wife and mother and I love you."

While they were both alive and alert, we would pick Dad up from his place, then Mom from hers, and we would all go to lunch and a movie. If Mom was too fragile, we would party with her at her facility. Dad could still be pushy and ornery. He would push food into her mouth too quickly. “Dad, Mom will aspirate—slow down!” Or, he would still berate her for her weight and try to make her exercise. In some ways, he couldn’t help it. He didn’t understand she had to be treated very gently. Mom loved Dad a lot, but early on, she let me know that she was very relieved that I couldn’t find a place where they could live together.

I had tried. Many continuing care facilities have sections for independent living, assisted living, skilled nursing care and dementia care. Of all the many places our family researched, none at the time fit the needs for both our parents. We were able to keep Mom in her own home with live-in care for a long time; then, in a skilled nursing facility just minutes away from home. Dad’s facility was also seven minutes away. This made it easy for family to visit often. When I felt the pangs of guilt for not caring for the parents at home, health care professionals would remind me that full professional staffs were doing what I had exhaustively tried to do all by myself. With Mom’s and Dad’s most difficult medical and mental problems cared for by staff, I and my family were now free to spend quality happy time with them.

It is one thing to be rational and accept what must be, but caregiver guilt is omnipresent. I feel guilty for not making everything all better and for allowing strangers to take care of Mom and Dad. I feel guilty for them not being in their own home all the time. I ask myself, who would want to allow strangers into their home? Who would want to leave their home and allow strangers to take care of them? I can just gurgle away my breath in guilt. I can feel guilty at any given moment about any little thing. Okay, enough tantrum. Actually, sometimes some people are ready for change and change can bring comfort. I first learned this from a stranger.

The receptionist at the third caregiver agency I researched told me her story. Her aging mom lived independently in her very own trailer. As the mom’s health diminished, she and her daughter researched assisted living residences and nursing homes and even put the mom on a waiting list, thinking it wouldn’t be needed for a very long time, if at all.

One day, the chosen residence called. “A bed has become available. If you want it for your mom, you need to commit now. There are many others waiting for it. It will be gone by tomorrow.”

The daughter wept as she signed on the dotted line. Wiping her eyes as she drove to her mom’s trailer, she composed herself and put on a happy face. Upon hearing the news, the Mom burst into tears.

“Oh, Mom, I’m so sorry,” the daughter said.

“Oh, no—I’m so relieved!” exclaimed her mom. “Can we start packing? When can I move in!”

The daughter was stunned. Her mom was ready for change. Need had eased the way for acceptance. How often do we allow fear of what might happen blind us from seeing the good that could happen? It makes no sense to assume we can know the future. I made a mental note to resist unfounded fear; to never say never; to continue to plan ahead, enjoy the moment, and face the future when it comes...and to banish guilt from my mind. (The latter would be impossible, but it was a good idea).

I did not initially realize how many community services are available to the home-bound person. Not until much later did we take advantage of some of the invaluable services such as: in-home medical, dental, cosmetic, or grocery delivery, volunteer transport, or free senior telephone assistance. There are many senior day-care centers that offer supervised care, activities, entertainment and socialization. By the time I took Mom and Dad to check out one delightful day care program, Mom’s physical and medical needs were more than the day-care staff was equipped to manage (and Dad’s journey followed an entirely different path).

The moderator of Alzheimer’s Town Hall Forums (which offer awesome education about dementia) suggested an important assignment for all would-be caregivers: before it really becomes necessary, he recommended, we must visit at least one each of the following care options: senior day-care, assisted living, skilled nursing, dementia care facilities. What a comfort it can be to be prepared instead of pressured.

While Dad endured adapting to his new home, Mom and I continued to tackle the challenge of welcoming strangers into her home.

It is helpful if a close friend can personally recommend a good caregiver. We checked out a variety of resources for in-home care services; made a list of duties and requirements for new caregivers. We specified Mom’s unique needs and made sure to ask if the prospective caregiver was experienced with those needs. From the many independent contractors and caregiver agencies we interviewed over time, we were very satisfied with agencies that employed several screened, licensed caregivers and provided professional and personal reference checks, orientation and training, criminal background checks, and bonding and liability coverage of their caregiving staff.

It was while Dad was still living at home that we attempted to hire our first caregiver, whom he promptly fired at the front door. Somehow, we convinced him to tolerate a caregiver for a few hours a day, and when it became clear we needed live-in care, we were grateful that the “blondes with big diamonds” helped us to persuade Dad. Sadly, the Alzheimer’s decline accelerated shortly thereafter.

Fortunately, with the caregiver agency we hired, if one caregiver didn't work out, the agency could supply another. The owners themselves stepped in to assist us from time-to-time and monitored the caregivers. The caregivers maintained caregiver logs which we could review.

Mom and I trained each caregiver regarding routines and needs for Mom and her house. Janny prepared the yellow room and I provided the purple binder (with: telephone and address contact list, medication charts, renal diet resource information, other medical requirements, legal documents, activities-of-daily-living instructions, cat and house-care instructions; plus a cover letter with updated info and any special reminders). I would have weekly "reviews" where I could ask the caregiver what was working and what wasn't, and we would share and compare notes. I had adapted a "caregiver performance review" that was given to me by an owner of one of the facilities I had explored.

Whether in the hospital, the skilled nursing facility, the Alzheimer's facility, or at home, it is important to monitor care. Consistent communication, good rapport and care updates were a necessity. It would have been naïve of me to expect all these people who just met each other to automatically know each others' needs and routines, and to perform them perfectly all the time. It is also normal for someone admitting strangers into their home to wonder, "will they steal from me?...will they like me?...will they ignore me?...will they show up?"

The women who were our main caregivers were angels in many ways. We tried to employ the same caregivers even when our employment of them became interrupted by Mom's stays at the hospital or SNF. Luckily, they were usually available when we needed them. They lived in Mom's house five days a week. I stayed with Mom on the weekends and visited/monitored during the week as my work permitted. These remarkable caregivers studied Moms' renal cookbook and cooked up delicious dishes according to medical specifications. They measured her liquids. They never complained about her incontinence care, her wound care, bathing, transferring, driving her to visit Dad, doing light cleaning around the house. We were a team. I would stay friends with one of these lovely ladies long after Mom became a long-term resident in the SNF.

There were also issues. It was Mom's hairdresser who alerted me to one of them.

"I don't like the way that caregiver speaks to your mom! She pushes a cookie into her mouth and commands, 'Eat!' She is mean to your mom."

I did not know this—the caregiver had been sweet and attentive to Mom when I was around. Mom was too meek to complain. I questioned Mom and watched more closely. This same caregiver had changed her address to Mom's. Next, she started moving her son's plants and belongings into Mom's house when he lost his job. She asked to borrow money from me. I was still pretty naïve and wanted to be helpful.

Fortunately, I did speak up and shared this information with the agency owner. None of this behavior was condoned by the agency. The owner admitted they had been short of caregivers at the time we needed a replacement, and this new caregiver had just arrived and had not been fully screened. The owner immediately terminated the caregiver's employment with us, after which the caregiver became antagonistic, and the owner stood witness at our house while the caregiver moved her and her son's belongings out.

Some moments were bizarre. We had another caregiver who was lethargic, and when I suggested she be a little more energetic with Mom, she donned a headset and danced outside, all around the back yard, hands waving to-and-fro in the air, while Mom sat unattended and confused in the house. I explained that was not appropriate. This same caregiver also brought her nieces and nephews to visit. Aside from a few behavior issues, we adored that caregiver—she was otherwise conscientious and very good with Mom. What to do? Happily, conferencing with one of the the agency owners proved constructive. She was able to clarify working parameters with the caregiver, who continued to work with us.

When Janny flew in to visit and help out, another unexpected conflict arose. The caregivers ran to me in tears, complaining, “Your sister is trying to take over. She's putting your mother at risk. We can't work with her in the house.”

“Good grief—she's family, for heaven's sake,” I told them. “Janny has been taking care of Mom long before we hired any caregivers.”

The caregivers stood their ground. “We're trained in health and safety techniques, and your sister is preventing us from doing our jobs. We can't just sit by and do nothing.”

All this after Janny had helped celebrate the caregivers' birthdays and cooked a special dinner in their honor. Janny was hurt and offended. This was not good. I called a meeting of all concerned.

After putting Mom down for a nap, we convened in the patio. It was a lovely sunny day. I asked each of them to tell me what had happened and what their concerns were. After each spoke, two things became clear. One: that I could have better prepared the caregivers for my sister's arrival—clarifying to them that “family comes first.” I could have let them know that my sister will be “in charge, the same way that I am.” Two: that the caregivers felt the health and safety of Mom would be in jeopardy, as well as their own jobs, if they were prevented from following the protocols they and we had established. They felt confused and thwarted by my sister who was just doing what she always did, but now seemed to be interrupting their routine. Everyone had the best of intentions.

We made it clear, then, Janny and I, that we appreciated how conscientious our caregivers were, but that when family is here, the professional caregiver duties will be redefined, and we will let them know when it is ok for them to relax and take a break. We would certainly consult each other about health and safety concerns. We learned yet another lesson in effective listening, communication and mutual respect.

Somehow, we had to make the best of a difficult situation. I had to work. Mom was physically incapacitated in several ways. Dad was off his rocker. We had to have help. And we might as well learn how to do it with a smile, and find ways to have celebratory moments like Mom taught us.

### Resources for Home-Bound Patients

How can an elder/impaired person stay independent and self-reliant at home, despite infirmity? There are more options for assistance than we can imagine. We need only to look, listen, ask.

Many resources may be found in the local telephone book. Key eldercare resources are AARP, National Association of Area Agencies on Aging, Southern Caregiver Resource Center, Alzheimer's Association.

Would any of these following resources be of help to you?

- \*Elder day care/senior centers
  - \*Physician house-call services (1-800-CALL DOC)
  - \*Community medical pharmacies that deliver to your home
  - \*Dental house-call services
  - \*Hearing-aid in-home tests and fittings
  - \*Mobile eye services
  - \*Podiatrist home health care
  - \*Grocery shopping and delivery services
  - \*Mobile Notary Public
  - \*Hair stylist and nail home services
  - \*Elderhelp community programs offering volunteer services
  - \*Telephone programs such as San Diego's T.A.P. (Telephone a Partner) who will call free of charge daily to check on a homebound senior
  - \*Telephone Access Assistance for free, such as California's CTAP (California Telephone Access Program) that offers to qualifying individuals telephone products and services for free
  - \*Volunteer food mobiles and transportations assistance groups
  - \*Volunteer organizations that bring animals to the elderly (pet therapy)
  - \*Veterans services (check government Section of the phone book)
  - \*Local ethnically-specific elder day programs
  - \*One-piece outfits for the agitated or incontinent
- An example: [www.buckandbuck.com](http://www.buckandbuck.com)

### **Hiring Professional Caregivers for the Home**

Sources for independent contractors: Recommendation from a relative or friend; church, synagogue, senior center, nursing or social work programs at colleges, Independent Living Centers, Senior Day Care Centers, eldercare publications. Some communities have attendant registries. Be sure to ask if they are free or charge a fee.

If you or another family member are doing the caregiving, inquire whether you may be eligible to receive payment through Medicare or Medicaid.

If hiring an independent contractor, ask for employment history, training, social security, previous employers. Ask for two work-related and one personal reference. Follow-up references with phone calls.

If hiring from an agency, consult the agency regarding the caregiver's background, security check and training, previous employment history and any other pertinent information and recommendations.

Before the interview, prepare a job description itemizing your particular needs, and a list of duties that will be required of the caregiver. Be sure to include duties related to the patient, appointments, light housecleaning, pets.

Examples of questions for the prospective caregiver:

- \*Where have you worked before?
- \*What was your most recent job? How did you like it?
- \*Have you had experience with caring for an elder/disabled person?
- \*Have you had experience dealing with dementia?
- \*Do you have training with transfers? Incontinence? Bathing?
- \*Do you have experience cooking for others? With special needs diets?
- \*Do you smoke?
- \*Do you have any allergies?
- \*Do you drive? Are you comfortable with driving your client to appointments?  
Do you have a car?
- \*What is your availability? Do you have any family or other job time commitments to consider for scheduling purposes?

Be sure to write down impressions after each interview; check the references; discuss your evaluations with family and friends.

Determine legal requirements for employing caregivers according to current state and federal guidelines.

Sign a contract and make sure employer and employee have a copy.

Provide the caregiver with a resource binder with pertinent patient and contact info. Have the caregiver maintain a written caregiver log. Have regular care meetings.

**Some of My Favorite Caregiver Resources**  
(Besides Family and Friends)

- \*Support Groups sponsored by facility where my parent resides. It is comforting to share with other sons and daughters, husbands, wives who have loved ones at same place as my dad or mom.
- \*SCRC. Southern Caregiver Resource Center Fact Sheets. They provide a myriad of services, including many short, concise publications that address practically every caregiver challenge you can think of. [www.caregivercenter.org](http://www.caregivercenter.org) (800) 827-1008.
- \*[www.healthcaregrp.com](http://www.healthcaregrp.com) Health Care Group provides a variety of helpful resources. They manage several levels of senior housing; retired or independent living, assisted living, skilled nursing, Alzheimer's care. They also sponsor informative Town Hall Forums on dementia, that my neighbor and I attend. I love their yellow laminated sheet *Ten Ways to Effectively Communicate with Alzheimer's Residents*.
- \*Alzheimer's Association. [www.sanalz.org](http://www.sanalz.org) 800-660-1993. Local offices, too.
- \*AARP. [www.aarp.org](http://www.aarp.org) Extensive information and resources for caregiving.
- \*[www.caregiverplanning.org](http://www.caregiverplanning.org) provides a wonderful, free DVD called *Your Future Now: A Practical Guide to Communication, Legal issues, and Financial Strategy*. This DVD is entertaining and touching as well as informative. They also offer a free DVD: *Yoga for Caregivers*.
- \**Eldercare Directory*. Free local publication. Invaluable resource which I consult often. [www.signonsandieg.com](http://www.signonsandieg.com) Click on Caregiving.
- \**Taking Care of Aging Family Members*, by Wendy Lustbader and Nancy R. Hooyman, The Free Press 1994. I heard Wendy Lustbader, M.S.W., speak at a conference and immediately bought 3 of these books; one each for me and my siblings.
- \*[www.thehartford.com/alzheimers](http://www.thehartford.com/alzheimers) The MIT AgeLab and the Corporate Gerontology Group at the Hartford produce research that expands the understanding of older drivers and their families as they deal with changes in driving abilities. I appreciated their free pamphlet, *At the Crossroads Family conversations about Alzheimer's Disease, Dementia and Driving*. They treat the aging driver with respect and support the elder driver's dignity.

- \**Caring for Your Aging Loved One*, by Sherry Peacock, Infinity Publishing.com 2005.
- \**On Death and Dying*, by Elisabeth Kubler-Ross M.D., Macmillan Publishing company 1969.
- \**Heartsongs*, by Mattie Stepanek, Hyperion Books 2001.
- \**You're Only Old Once*, by Dr. Seuss, Random House, New York 1986.
- \**Tear Soup—A Recipe for Healing After Loss*, by Pat Schweibert and Chuck DeKlyen, Grief Watch.
- \*Gesundheit!, by Patch Adams M.D., with Maureen Mylander, Healing Arts Press, 1993.
- \**Food is the Frosting; company is the Cake*, by Maggie Marshall, Author House 2007.

## Chapter 22

### A Personal Reckoning

In the pre-dawn dusk, I step away from the grassy flats and tip-toe softly down the sage-embraced sandy path toward the lake. I see him, 20 feet away. I freeze. His ears perk. He turns to face me. We stare into each other's eyes.

"You are magnificent!" I whisper to him—not wanting to wake the neighbors in the darkened apartments behind me. What a beautiful coyote, yes you are. Just look at that fluffy coat and tail! Oh, you are so gorgeous!" I am enthralled to be so close to this wild creature—my adrenaline is pumping. "Bye-bye, now," I whisper. "You go ahead...I'll go this way."

But he doesn't turn back; he starts to follow me down the trail.

Now I'm getting nervous. "No, no—you go that way...I go this way...bye-bye...bye-bye..."

Would you believe it; he turns and continues the other way. I am very full of myself.

As the first rays appear in the East over make-out mountaintop, a thousand birds burst into song.

I think to myself—I can do this. I can take care of myself. I can walk the lake to get some exercise before work. Just think of that magnificent beast. I shall be like him—bold and bushy-tailed and strong. I must put one foot in front of the other and start to lose this stress-induced caregiver weight gain.

My new mantra is "a little bit at a time."

I waddle my way around the lake, winking at rainbow-hued wood ducks and pausing to watch sleek black cormorants effortlessly slide into the water and re-emerge, fish-in-beak.

Nature revives me. I have to do something. I am falling apart. The chest pains I felt the other day gave me a scare. Just gas, I'm sure. Stress, undoubtedly.

My daughter tells me over and over, "Mother, you've got to spend a little time with people under the age of 75."

Aunt Betty calls every other day, "Take a deep breath, Jody."

I know I'm pushing the envelope. I am not heeding the advice of support groups and publications that warn about caregiver burn-out. They tell us to take care of ourselves...put our own oxygen mask on first.

I make my way back home.

It's time to take a good look at what's happening with me: weight ballooned to 200; no exercise; not getting my proper allotment of veggies, fruit, lean protein and fiber. I too fondly recall my favorite fast food spots strategically spaced along client routes where I eat my Santa Fe chicken on the way to check inventory at a Murrieta spa, or gulp down my bacon cheese burger after sales updates at a Palm Springs beauty supply. I grimace at the thought of all the times I survived dozing at the wheel driving to Los Angeles for regional meetings or over the mountains to Palm Desert for client appointments. The pudgy sweaty little face in my mirror stares wide-eyed back at me. I ponder my work challenges.

Managers monitor outside reps and routinely come down to coach and support us in maximizing our work efforts. One manager even helped me set up my San Diego work space. I am sent to classes in Excel (what a great opportunity). Despite this support, I am getting overwhelmed and my job performance is flagging. More reports are demanded. Sales quotas go up. My manager demands, "Jody, You've got to open more accounts! Go check out Coronado, downtown San Diego--there are some great spas in North County." I want badly to succeed in opening new accounts. I am starting to drown.

The company keeps down-sizing—the way of the corporate world these days, I muse. I read the comic *Dilbert* avidly. Client territory, quotas, paper and computer work increase. A new-hire manager comes in with a vengeance. She focuses more on bottom line profits and less on client rapport or sales rep support. She's a whiz at crunching numbers and devouring people. Dressed to kill in her designer togs, she is keen, competitive, ambitious. She has an archaic management style based on fear and humiliation rather than the more humane methods that embrace encouragement and empowerment. She puts my positive attitude to the test.

She humiliates reps in front of their peers, sending several of them running in tears to Human Resources. She tells me I am failing and that I am the only one. That hurts. I am devastated and angry. But I also know she's right that I'm falling behind.

Doggone. This is an excellent job, despite corporate downsizing and work overload. I don't want to admit failure—that maybe I can't be a caregiver and carry my work weight, too. I want to continue to excel and contribute. But caregiving for my parents is also a fulltime job. I can't do it all anymore.

Onward with my self-and-situation-evaluation.

Mom is full-swing into her kidney dialysis, and my monitoring is necessary both at the SNF and the dialysis center. I try to spend time with Mom one-to-three times a day, especially since the nursing home keeps forgetting to send her blanket, her pillow, her sweater or her breakfast with her in the transport. I remind every new nurse of Mom's needs. I remind the staff to put her breakfast in the frig at night, since Mom leaves for dialysis in the early morning before the kitchen staff arrives. I put signs on the wall at the head of Mom's bed to remind the caregivers to dress her warmly. I tell them, "Mom gets very cold at dialysis...she needs her pillow...would you please put the fuzzy little blue bear in her purse, too?" I worry about Mom's comfort, and I worry about her feeling lonely.

I spend time with Dad one to three times a week—taking him to visit Mom or on some other outing. Once, I brought him to dialysis, but that was a bad idea because he got restless and couldn't sit still for more than a few minutes. I try to keep a close watch on him as well as try to give mom some loving attention.

Surely, there are constructive options for helping me alleviate my work load. I consider Family Medical Leave. I speak to Human Resources, previous managers—what about reconfiguring my job or taking a pay cut for a different position? Job headquarters is too far away for me to take a different position there. For one reason or another, I discard several options. Should I hang on until my work output declines such that I will be fired, and eligible for unemployment?

"Jody, you don't want that on your record—being fired," a sensible previous manager coached me. I want to take the high road and do the right thing. But what is the right thing?

I submit my resignation. The thoughtful owner of the company orders me a giant cake at my last client educational seminar. He gives me a big hug at my last holiday company dinner and tells me, “Who knows, Jody, in a few months things may change, and you can come back and work for us.” At the dinner, he insists I read the poems and company rap song I had written and performed at his request for previous company gatherings. There is warmth and support for my parent care efforts. I am glad I didn’t get fired. I feel validated for my work and for the choices I have made.

Finally, I have a plan that seems workable. In exchange for caring for my parents and their home, they will cover my expenses. My savings are nominal, but their home is paid for and they both have pensions and retirement to cover our needs if we are careful. We are very lucky to be able to make this happen. Counting blessings.

Stuffing most of my belongings into storage, I and my cats move into the parent’s house. Talk about memory lane. I never expected that I would have a chance to sort through and share long-lost, or never-seen by most of us, family treasures while Mom and Dad are still alive, rather than facing estate challenges after they have both died.

Odd, how things turn out. I learned how to function on a computer through the job I just quit. Now, I can put my new, albeit still rudimentary, tech skills to work creating family memory books for all the family to share. I can even scan and enlarge pictures so Mom can enjoy them despite her failing eyesight.

It’s a whole new chapter for me. Sanity somewhat restored, I retrace recent events: 1999, I move to San Diego apartment to be near parents and telecommute; 2002, Dad enters his new home at the Alzheimer’s facility; February, 2003, Mom becomes a long-term resident at the skilled nursing facility; April, 2003 I leave my job and focus on caregiving; May, 2003, I move into the family home. I believe (and hope) I made the right decisions. I am thankful to be in my new home.

It’s a good thing, because Steinbeck has been by himself in the house for awhile, even though I visited twice a day and stayed over on weekends to help him not feel so lonely. It wasn’t enough. Aunt Betty noticed he was losing weight. As soon as I move in, he regains the lost weight and his spunk. He makes friends with my cats, Tiger and Gypsy. Steinbeck is the prince of the domain and surveys his kingdom in the backyard and in the front, delivering presents of mice and lizards, and an occasional humming bird, which I am able to rescue right out of his jaws. Steinbeck teaches my cats about the wild creatures, too. The cats and I take care of each other. I always keep them in at night, though, lest a fluffy-tailed coyote wants to eat them.

### Section Five: Dealing with Death

Elisabeth Kubler-Ross, M.D., from her book, *On Death and Dying*:

*...we may achieve peace—our own inner peace as well as peace between nations—by facing and accepting the reality of our own death.*

*When anger, resentment, and guilt can be worked through, the family will then go through a phase of preparatory grief, just as the dying person does. The more this grief can be expressed before death, the less unbearable it becomes afterward. We often hear relatives say proudly of themselves that they always tried to keep a smiling face when confronted with the patient, until one day they just could not keep that façade any longer. Little do they realize that genuine emotions on the part of a member of the family are much easier to take than a make-believe mask which the patient can see through anyway and which means to him a disguise rather than a sharing of a sad situation.*

Patch Adams, M.D., with Maureen Mylander, in their book *Gesundheit!*

*Medicine practiced as a business hurts everyone. The true rewards of medicine come from helping others and from self-discovery....Service is essential to healing and the pathway to inner peace.*

## Chapter 23

### **Treasuring Time Together**

Never in a million years did I imagine this is what I would be doing in my late fifties and early sixties. Surprising to me as well is how much I will treasure these caregiving memories. I am grateful for the most challenging times--relieved and yes, proud, to have endured (and still be enduring) them. But what I love the most are the sweet interludes when Mom or Dad felt some kind of relief from their ailments and shared moments of joy or gratitude with me.

I know that some of the best times were possible because we asked for help. When we had momentary respite from the most grueling of tasks-that-seemed-to-never-end, then we had time and energy for quality sweet times. If one is constantly scrubbing poop and pee from floors and walls and emptying port-o-potties and washing sheets and cleaning bottoms; if one is on constant high-alert to prevent falls, treat wounds and deter a wandering agitated Dad from putting slippers in microwaves or dismantling whatever you've just done; and also, of course, if you're preparing pills, making meals, spending hours in hospitals and doctors' offices—when is there time to share a hug, appreciate the humming birds, take a drive along the beach, have a laugh or sing a song?

Even with Mom in a skilled nursing facility and Dad in an Alzheimer's secure residence, I can be an incorrigible micro-manager, trying to monitor and control parent-care to the point of interference rather than support. Let them do their jobs, I say to self. I need balance, perspective, trust. Ha! I need to monitor myself. Sit, I say. Be still. I talk to myself and am delighted when I listen.

Dr. Elizabeth Kubler-Ross helped many of us when she opened dialogues about death and dying and helped patients and families talk about feelings and let go of fear. It is comforting to contemplate Dr. Kubler-Ross's stages of grief and to know we are normal when we feel denial, anger or depression, or want to bargain and question, and then hopefully come to an acceptance of whatever our lives have dealt us.

Right off the bat, Dad was a Dylan Thomas' poem incarnate. I read Thomas' "Do not go gentle into that good night," and I think of Dad. Dad did not accept his state readily—he would "Rage, rage against the dying of the light." He fought hard through the denial, anger, bargaining, depression and even foggy acceptance of the radical changes in his life. We weathered those stages with him. Mom really did seem to go with the flow, but it had to be hard. During one of her pre-emergency room ordeals, in between retching and projectile vomiting, Mom wailed, "Oh, Janny, when will this end?"

Yet, when she first received her cancer diagnosis, and Mom's hairdresser asked if she was worried, Mom replied, "Oh, no, I'm more worried about my daughter who is going through a divorce." Mom kept her grace and empathy for others in the midst of her pains.

I still remember Mom saying, "I don't want you kids to feel guilty about anything." We wanted so badly to do right by her and Dad and it would never seem enough to us, but her words would bring us ongoing support and comfort.

On the day of Mom's memorial in 2005, Mom's best friend shared with me words Mom had spoken way back in 1988. The ladies were lounging around a pool discussing the ongoing financial woes of their kids. Mom turned to her friend and said, "I know that when my time comes and I need her, my Jody will be here for me."

With Dad and his Alzheimer's-damaged neural pathways, we never knew what inappropriate things he might utter. We were told not to take his rude comments personally, but what would unsuspecting strangers think? "Look at that ass!" he might say...or, "What a pair of knockers!" Oh dear. When Dad said to me, "You are destroying me and our family...you are trying to take over...I'll kill you...why are you doing this to me," it still hurt, even though I told myself it was the disease speaking. Of course, now, he speaks very little.

The calm that emerged for Dad when he settled into the safe structure and routine of his Alzheimer's residence allowed opportunities for gentler moods and less-stressed moments. Sometimes it takes more than one person to bathe or dress him; medical nurses administer his meds; different caregivers lead various activities; an entire staff must be alert to the mood swings and needs of their residents—all the things I, or Janny or one single caregiver tried to do for Dad all on our own. With so many needs cared for, we had and have some sweet and memorable times with Dad. His words of appreciation have often taken me by surprise.

“What would I do without you, Jody? You are a gem,” Dad said to me as we drove off for lunch and a movie. He toddled after me as we approached the movie ticket office, saying, “We like to go to movies, don’t we, Jody?” I replied, “Yes, we do, Dad.” “Can we do this again?” “Oh, yes, Dad, we sure will.” After mom could no longer go with us, Dad and I went to a movie and lunch practically every week for a long time. We took the rest of the family when they visited. As we rounded a corner in the car, Dad would squeal like a little kid, “Wheeeee...”

On the way to the ticket booth, one day, I saw him look up toward the sky, and say, “Life is good, isn’t it?” I just about fell over.

He became a movie critic. Regarding the movie, *A Beautiful Mind*, which I absolutely loved, Dad critiqued, “That’s the stupidest movie I’ve ever seen.” *Hero*—“Unrealistic, but good photography.” *Vanity Fair*—“Good movie; too long.” Critiquing *Pirates of the Caribbean*, Dad declared, “We’ve just seen a masterpiece.” *Master and Commander; Far side of the World* brought, “That was a shoot ‘em up on a ship.” When I tried to take him to see the real ship, his response was, “See a ship? Big deal.” (He’d rather see a movie, I guess. He had certainly seen plenty of ships in his career).

He didn’t like animated films. “That’s for kiddies.” One time when I took him to see *Madagascar* because I wanted to see it, it occurred to me that, being hard-of-hearing, maybe he reads lips. So I asked him and he said, “A little.” I think reading lips on cartoon characters must be difficult. During the animated film, he said, “This isn’t the movie, is it?” Then afterward, when asked how he liked it, he said, “I won’t be seeing it again.”

During *Wedding Crashers*, he thought a particular line was a hoot. He quoted, “Kiss my left nut,” threw his head back and roared. In the middle of another movie, he leaned over to me and whispered, a little too loudly, “They said ‘fuck’ eight times!” Every time a four letter word was repeated, he’d lean over, up the count, and giggle.

My favorite movie critique by Dad’s was for the movie *Babel*. As we emerged from the theatre I was thinking that everyone should see this terrific film! I asked Dad for his thoughts. He looked up at me from his wheelchair, and said, “Save your money; buy good liquor.”

Another day, as I was squishing Dad into the passenger seat of my vintage plum Honda Civic for an outing to see the seals at La Jolla Cove, he told me, “You are a shining star, Jody. Yessir, a shining star on the horizon.” Is that not music to a daughter’s ears?

Later on, when he was speaking very little and would strike out at anyone who startled or confused him, he would still have sweet moments such as beckoning a caregiver with, “Hon...hon...” and then point to his cheek for a kiss.

Odd, I thought—after Mom and Dad were ill and living in two different places, I spent more one-on-one time with them than ever before, and enjoyed it immensely.

Take Mom’s dialysis time, for example. I spent a lot of time there partly because I wanted to make sure the SNF sent Mom’s blanket, pillow and purse with her and needed to monitor her care and note any changes that would be prescribed, since communication between facilities sometimes didn’t happen. I didn’t want Mom to feel lonely, plus, she became my best confidant and friend.

I tried to share all the world’s events as well as my own activities with her all at once. I was a little kid again, telling Mommy all about my day. “Mom, am I tiring you out?” I inquired. “Yeeess,” she replied. After that, I tried to slow down a bit. Dialysis is tiring and she needed to nap.

These days trapped at dialysis provided opportunity for broaching delicate subjects. We used Aunt Betty’s and Unke Roy’s gift subscription pamphlet, *The Daily Word*, by Unity, to segue into meaningful discussions about life and death. Mom and Dad had been devoted church goers most of their lives, but their commitment to structured church-going diminished with their ailments. The *Daily Word* presented a daily succinct one-page dose of spirituality that could be uplifting, inspiring, humorous, comforting. It had a topical subject, an engaging anecdote and a related Bible verse. I read it sometimes to Dad when he could relate. I read it every day to Mom. It prompted me to bring up important issues about feelings, fears and faith with Mom.

One segment prompted me to ease into the question of funeral wishes. At the time, she was weak and not talking too much, so I offered suggestions and she shook her head yes or no. She surprised me. “Mom, how about a lovely service at the Presbyterian Church where we all went and where you were an elder and Dad sang in the choir?” She shook her head, “No.” When I asked about a service/celebration of life in the back yard of their beloved home, she clearly nodded “Yes.” She and Dad had already specified their wishes for disposition of their cremated remains. I knew Mom wanted the Pacific Ocean; and Dad wanted the fourth hole of his favorite golf course.

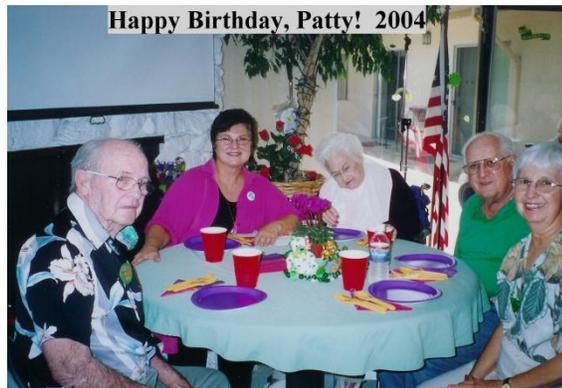
Some *Daily Word* chapters addressed fear or hope or suffering or worry. I said one day, “Mom, is there anything you worry about?” She nodded. “What, Mom?”

She looked into my eyes and said, “I worry that Larry will die unattended.”

“Oh, Mom,” I said, “I will always be there for him. I will hold his hand. I will never abandon him, as I will never abandon you.”

Another page, titled, “Praying for others,” prompted me to say, “Let’s pray for... (everybody we could think of)!” Mom and Dad and I proceeded to pray in a hootin’ and hollerin’ way, giggling “amens” and “hallelujahs” after each one. We called it our “prayerfest hootennanny.”

Then, “Lo and behold,” as our minister Grandpa used to say, there was the discovery of Mom’s journal *My Trip* that was hidden away in their house and had never been seen by any of us kids. Mom had hand-written a single page for each of the twenty-eight places our family had lived in twenty years. I read it to Mom and Dad, cover-to-cover. Janny and Jim each got to read about the day of their births. Janny read about her first airplane flight, when beautiful actress Loretta Young held tiny baby Janny in her floral shawl and voluminous skirts, so Mom could feed two year old Jody.



We did our best to make Mom’s room at the Skilled Nursing Facility seem homey. Janny provided the “wall of daisies,” and Jody made a moveable gallery of large family photos. On the right is Mom’s birthday party in the SNF dining room. Mom is pooped after having her hair and nails done.



Larry's room at Alzheimer's residence.



A birthday party for Larry in Great Room.

One photo collage (on the right) for Dad has pictures with names of each family member. The other collage includes photos of Larry through the years—flying an F-J4B over Mt. Fuji, his barber shop quartet, his all-star basketball team, fun family photos.

Health permitting, there were many visits home, or movie and lunch adventures, or celebrations in the parents' facilities. Thanks to supportive staff, the parents had fine care at their respective residences, allowing us kids time to play and share unforgettable moments with Ma and Pa. We had many a chuckle in between the challenges, but, as always, I kept my cell phone close-at-hand.

**Family Photo Gallery**



Larry and Patty, 1950's



Patty and Larry, Mardis Gras, 2004



Larry, Patty 1980's



50<sup>th</sup> Wedding Anniversary Party 1994

Siblings; Jody, Janny & Jim,  
with Mom and Dad and Critters



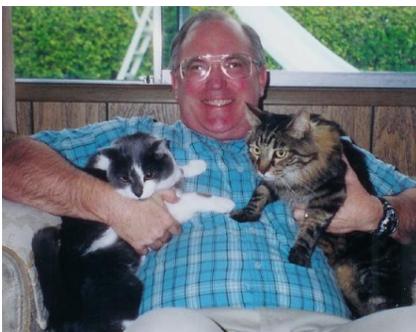
July, 1955



1970's



2003



Around 2006--Jim with Tiger and Steinbeck; Janny and Jody with Alligators

Fun with Grandkids and Roy and Betty, Too



Kim, Janny, Larry, Jim—Miniature Golf, 2004

Roy, Patty, Betty, Home Visit 2003



Jody, Nik, Larry, Janny at Alzheimers' Home

Jim and Family at Mom's Skilled Nursing Home



Larry and Yvie



Larry and Jessica



King Larry, Sr.'s Sr. Prom, 2003



Larry, Yvie, 2003



Patty's Room at the SNF



Jody, Patty's Room, Lunchtime, 2004



Patty at Dialysis, Halloween 2003



Larry at His Place, Halloween 2003



Local Restaurant; Trying to keep Mom upright; Dad a bit surly; Janny and Jody smiling widely.



Halloween 2006, Dad's Place



Jim and Larry, 2006



Larry and Mr. Steinbeck



Larry, Jody, Janny at the Beach 2007



Janny and Larry Kiss Hello



Jody and Larry Dance at a Sr.'s Sr. Prom



Christmas Morning, 1996—Patty, Larry, Their Kids and Grandkids



Celebration of Life party for Mom Patty March, 2005 (Larry not pictured)  
Back Row: Nik, Jessica, Amy. David, Kim, Jim  
Front Row: Janny, Roy, Yvie, Cousin Carolyn, Betty, Jennifer, Jody, Cousin Bobbi



## Chapter 25

**The Sky is Black; the Ground is White**

In 1988, it really did snow in San Diego. Mom saw it on her way home from work at the Padres, and we kids saw it in the back yard. I'm not joshing. It was glorious.

Things are often not as they seem. It is now October, 2003, and the fluffy white flakes of the Cedar Fires blanket the front yard like snow, enticing us to frolic. I thought soot was black. These flakes don't melt and they don't taste good either. The white fire flakes cover the windshield, clog our throats and sting our eyes. We wear masks when we venture outside.

Around the corner and up the hill, cars line Navajo Drive and passengers crane their necks to see the flames lashing down the valley not so very far away.

"Hey, neighbor, I see you've got your car packed, too, just in case. Well, I figure we're not in danger unless the fire jumps the highway and crosses the river." He agrees. I return to my living room and plop myself in front of the TV.

The news commentator says, "Well, the fires have jumped the highway and crossed the river." I race back outside. My neighbor gestures to the left and to the right, "Well, they've left; and so have they; we're ready to go, too."

Betty and Roy have already agreed to house me and the cats, should we need to evacuate. It occurs to me that they might appreciate our arriving early in the evening as opposed to, say, 3:00 a.m. Oh, yes.

I call Janny to clue her in. “You do have my paintings packed, don’t you?” She swore afterward she was just kidding, but—ha—I know better. I rush back in and collect both Yvie’s and Janny’s art work from the walls and find exactly the right amount of space left in the back of the car.

Cats all secure in their car carriers, I return once more to say good-bye to this dear house. I survey each room. I verge on maudlin. Good-bye, room. I look at all my stuff and think, they are only things; we will always have our memories. Or will we? Of course, I think of Dad. Going through family albums for the umpteenth time just days before, I asked myself, do I really remember any of this, or do the pictures conjure a memory? Good-bye albums. I tell myself I have been very lucky to have been here, and now the cats and I will get a camp-out adventure at Betty and Roy’s. Mom and Dad are safely ensconced at places far from the flames.

The cats indeed have a fine time exploring, and Gypsy becomes black with soot when she tries to hide in Roy and Betty’s fireplace and effectively cleans it for them.

The Cedar Fires have destroyed 280,278 acres, 2,820 buildings and killed 15 people. San Diego mourns, remembers, and focuses on recovery. Our family is lucky and we are grateful to have another hello.

When we have tossed our masks and the grass is green again, I revisit all the rooms of our house and promptly order new ovens and a cooktop.

Halloween happens. Mom and I wear silly cat ears and eat candy at her dialysis session. Dad and I wear fuzzy spider feelers, applaud the Rhinestone Cowgirl singers, and eat candy at his facility’s Hoedown.

I ponder, after the fact, how both Mom’s and Dad’s health crises seemed to take a pause during the Cedar Fires. One thing at a time is merciful. Life can seem so normal even if it isn’t. What is normal?

Both before and after the fires Mom used up a few more of her cat lives. In July, she was taken by ambulance to the hospital, unresponsive, and with a temperature of 103.1. This was the first time Mom’s nephrologist pulled me aside and said, “I’m afraid your mom’s not going to make it.” Right away, I called Janny and Jim. Mom was given strong antibiotics through IV’s; a lumbar puncture failed since her spinal bones were too fused to release any fluid; she had a staph infection and contracted scabies. She rallied, and was sent back to her nursing home.

Following the fires, we resume seizing healthy energy opportunities. I arrange medical transports to bring mom home for lunch visits several times; Dad and family visit her at her SNF; Dad’s best friend comes every week to Dad’s place to play cribbage.

In November, ER happens again. The doctor tells me that Mom is "...not doing well. We'll know by this afternoon if she's going to do better, or not." Mom's chart reads "End stage renal failure with sepsis." The diagnosis: "Eschemic colitis." It is explained to me that blood is not getting to Mom's colon; there is necrotic tissue; she is septic—has a strong infection in her blood; her bowel is thick and could burst at any time; the blood culture shows pseudomona bacteria; a lung biopsy may have shown cancer, but was inconclusive. It is recommended that Mom undergo no new treatment. They will treat her conservatively.

Up until now, I have resisted placing Mom on DNR (Do Not Resuscitate), but now, the doctors are recommending it. It is suggested that I contact Hospice.

As Mom's and Dad's Power of Attorney, I and my siblings are aware of our parents' wishes concerning life-prolonging treatment, services and procedures, and, as their appointed agent, I will honor their wishes to the best of my ability. Each of their documents reads, "I do not want to receive medical treatment that, although sustaining life, has the effect of prolonging my inevitable death if the burdens of such treatment outweigh the anticipated benefits." This document, which also appoints me as their agent, goes on, "...my agent shall consider the quality and duration of my remaining life if such treatment is provided or continued and the relief from pain if such treatment is withheld or withdrawn." Further, the document states, "I request that my agent refuse or require discontinuance of any medical treatment or artificial nutritional support or hydration which will only prolong the process of my dying or my irreversible coma." Clearly, there may be some decisions up to me (and Janny and Jim, since I always consult them, too), even though Mom and Dad have documented their desires.

Forms and information about Powers of Attorney, Advance Directives, Living Wills, DNR's can be accessed from various health care and legal sources, and online. The wording may vary from state to state; from lawyer to lawyer; from person to person. It is important to discuss and formulate all the necessary decisions for each person and each family. I know I have said this before, but each person's wishes are valuable and we caregivers need all the help we can get in order to implement those wishes.

When Dad was admitted to his new secure residence in 2002, I, as his Conservator, was required to decide whether or not to sign a DNR for him. It was an awesome responsibility and it frightened me.

The daughter of the woman who would later become my dad's girlfriend happened to be in the lobby when I was discussing the pros and cons of DNR with the director and the nurse of the facility. The daughter said to me, "When my mom moved in here, she was adamant about my signing a DNR for her. She said, 'I do not want to suffer the way my husband, your father, did when he was dying and the doctors would not let him go, despite his protests!'" The daughter urged me to sign a DNR for my Dad.

I spent many days anguishing over this decision. Mom told me, "Oh, Jody, stop stressing about this." I considered Dad's heart condition and his deteriorating mental condition. I thought about how CPR might impact his already fragile body. I questioned doctors and searched the internet.

One psychiatrist said to me, "You must consider his quality of life. If his heart stops and he stops breathing, the lack of oxygen will further impair his brain. If he is somehow resuscitated, will his quality of life be better? No. How is his quality of life now? What do you think he would want?" I decided to sign the DNR for Dad, only to rescind it at least once when, on one of Dad's trips to the ER, a doctor asked me if I wanted to keep the DNR in place and I panicked and said, "No no—if there is any chance of recovery, I want you to try anything and everything."

Fortunately, Dad perked up; all the tests done on him at the hospital that time were normal. There were some slight medication changes, and Dad resumed his normal activity back at his residence. I had a second chance at sanity. I think I was acting out of fear and not out of realistic assessment of Dad's condition. I am aware that every person is different and that perceptions can change. The challenge is to keep looking and trying to see clearly and to listen very hard. I reinstated a DNR on Dad's behalf. That was some time ago.

No, no, though, not for Mom. I did not consent to signing a DNR for her until now. She has 947 cat lives, as you recall, and over 500 left. No matter what ailment befell her, she always seemed to make a miraculous recovery. Her heart is as big as the world and very healthy, and as for her breathing, she was one of the first ladies in La Mesa of the 1950's to study Yoga (however briefly). This time, medical staffs surrounding Mom are unanimous in their recommendation. Mom is really fragile and declining.

On November 16, at twelve noon, I sign a DNR for Mom.

On November 30, she rallies again. "Mom, you scared the patooties out of us!" Mom grins and responds in a mock-shocked tone, "Nooooooo!"

Sensing this to be an appropriate time to discuss the future, I continue; “You’re doing so much better, Mom. You’ll be going back to your room; then some visits for lunch at Casselberry...but, Mom, when it is your time to fly away, what would you like? When the time comes; do you want to be on Hospice at home with a hospital bed and us, watching family videos and stuff; or at the SNF; or at the hospital?” She thinks, but will not answer. She just grins at me. So I ask, “Or do you just want to trust our judgement?” She nods.

I’m still not comfortable using the words death and dying. I need to read some more Kubler-Ross.

Wanting to be sure she understands, I ask again, “So, as long as we’re with you and our love is all around you—is that what you want—and to trust our judgement?” She nods and says, “Yes.”

“Mom, you’re amazing. Out of your 947 lives, you’ve now lived 537, so, would you believe, you now have 410 left!” I would count her cat lives several times in the coming months with Mom giggling every time I cheered her remarkable resilience.

Dutifully following the doctors’ recommendations, I call Hospice for an appointment. The calm, gentle, empathetic, capable Hospice nurse sits at Mom’s side and explains her medical condition to her in great detail. The nurse tells Mom what would happen if she should decide to forego all medical treatment and go on Hospice. To our surprise, Mom is lucid and quite clear that she wants to continue treatment. Mom gives the OK to dialysis; the OK to access (maintenance of the dialysis graft); the OK to the hospital; also, the OK to the DNR. The Hospice nurse and I look at each other. The nurse says, “She is not ready for Hospice.”

Once again, Mom let her feelings be known, and I am grateful.

The next day, Mom is well enough to be transported home for lunch. A friend visits, too and we chuckle over lunch and holiday “Poppers” that pop out funny hats and little toys.

The very next day, though, it’s back to the ER. Mom has an aneurism; a kind of abscess, in her graft.

Jim provides valuable support from afar when we have to decide whether to authorize surgery for Mom to repair her aneurism. The surgeon tells us that without surgery, they could “guarantee a few days” for Mom, and that doing surgery “could mean a few weeks.” Jim asks pertinent questions when I call him: “Is there pain and discomfort due to the abscess? If she does not have the surgery to repair it, would she have to stop dialysis? If so, why?” It is so good to know I am not alone in considering these options for Mom, who is not in a condition to decide for herself.

We kids together decide to authorize the surgery, but when I return to Mom's room, I am informed that Mom's aneurism got bigger and that the surgeon "yanked her into surgery right away."

It is comforting to put our trust in our quality medical team, as well as to have family who can share the worry.

There are many grey areas. We can only do the best we can. There is so much happening that there is no time to obsess or equivocate. We must simply try to make each moment the best it can be, and trust.

Would Mom have wanted to have the surgery? Would she have wanted to be intubated when she was in critical condition in ICU following the surgery?

With the tube down her throat, she gags and looks wide-eyed and frightened. "Do something, Jody!" her eyes plead. I hold her hand, "It's OK, Mom, relax; let yourself breathe through the tube—just a little while longer—it's OK."

Sure enough, two hours later, the tube is out and Mom and I are chatting softly and people-watching in the ICU.

When the family arrives for Christmas, we watch *The Nutcracker* with Mom in her hospital room, share presents and help her eat her dinner. Hooray, recovery; back to the SNF.

Another day, Dad's facility nurse calls me to let me know Dad has pink eye and that they will treat it there, and that it would not be wise for us to bring Dad to see Mom until the pink eye clears up. Later that day, the program leader calls me to tell me that Dad had another "territorial skirmish" (Dad socked another resident), but that "both men are OK." As Dad acts more and more like a little kid who protects and defends his own toys and space, staff and family must repeatedly remind ourselves to focus on simple direction and simple activity. We work on redirection and diversion and, when necessary, how to avoid Dad's swinging fists. I give the caregivers chocolates to keep in their pockets for Dad, too.

On the days that Dad is in good enough shape to visit Mom, we learn that an hour is plenty of time for them to visit. While they are both happy to see each other; so cute holding hands and kissing, Mom tires easily, and Dad gets restless. He tries to boss her and make her eat, or he keeps shoveling food into her mouth faster than she can chew it. We enjoy whatever photos, stories, or goodies that are at hand. Then, Dad says, "OK, let's go," or, "I'm ready to go." Or, he might say, "Mom's tired, let's go." If we sit too long, he has to get up and walk around, and I must scurry after him to make sure he doesn't get lost.

Mom endures another surgical procedure in the hospital; a stent, or “endograft” is surgically inserted into her left leg artery. Her nurse draws me a diagram of the procedure and I ask her to autograph her art work. She complies, telling me, “Your mom is the best patient I’ve ever had. She had no sedation, no pain med, only a local shot at the femoral artery.” I go downstairs to chat with the hospital chaplain. She and I discuss DNR, hospital care for the elderly and care for Jody.

Later on, I read Mom a page from the *Daily Word*, entitled *Harmony*. I tell Mom it reminds me of a story Bampa once told Janny about Nanny. Bampa said that, after Nanny had died, she appeared to him. He said she was standing in the hallway of their home; young again; her brown curls flowing over her shoulders. She was showing him her feet, that had been gnarled and painful during her last years of life. She said to Bampa, “See, they’re perfect, now!” I then say to Mom, “When your time comes, will you communicate with me and tell me what it’s like? OK?” She smiles at me and says, “OK.” I say, “I truly believe we go on—do you?” She says, “Yes.” I ask if she believes in a specific place. She says “No.” I say, “Me neither.”

We do our best to help Mom feel comfortable and good about herself. She really misses having her fancy hair, having gone to Christina, her stylist, every Friday for so many years. We schedule weekly hair appointments for her at the facility, but showers wash out her new coifs. I try to tell her how French and sleek is her new “do.” But she looks at me like I’m crazy. We arrange for manicures and pedicures, too. Sometimes, though, nurses in the hospital say the polish on her fingernails prevents them from getting a “reading” on her oxygen saturation.

Mom always loved cinnamon candy and cinnamon gum, so I bring cinnamon gum to dialysis. She is delighted and chews away. When it is time for her to eat, I ask her to spit out the gum into my hand. She grins at me; sticks the gum between her teeth; and, when I try to take it; she pops it right back into her mouth, and grins even wider. At first, this is funny, her acting like an impetuous and teasing little girl. But after numerous times, pretending to spit out the gum, and then mischievously resuming her chew-chew-chewing, it’s not so funny. The nurse is now trying to retrieve the gum, too, and we are both getting frustrated. Our frustration turns to concern when Mom’s blood pressure drops, and we really need to lower her head, but we can’t until Mom spits out that gum. We certainly don’t want her to aspirate it. We keep trying to stick our fingers in her mouth to get at the gum, but we don’t want to get bitten, either. We coax and cajole her. It is dangerous and hilarious all at the same time. She finally calmly spits it out.

Maybe we sometimes try too hard to give Mom a good time. Dad, Janny and I wheel Mom around the corner from the SNF, to Baker's Square for lunch. We know she is weak and tired, but when asked, she says she'd like to go. She can barely eat, and she can barely sit up. We feed her a bite and encourage her to chew. She keeps falling over in her chair, and we prop her upright. At one point, Janny says, jokingly, "Is this elder abuse?" The woman at the next table says, "Yes!" We laugh, but we're not so sure the woman at the other table is kidding.

Talk about elder abuse: for Mom's birthday, March 17, 2004, I arrange for her to have her hair and nails and make-up done so she will feel really good about herself when we wheel her into the SNF dining room where Dad and Betty and Roy and I all sit around the festive table filled with party napkins, sparkling cider and presents. She is so tired, she looks like a wobbly wax museum mannequin that keeps falling over and is oblivious to all the hullabaloo around her. I push her upright and we cheerfully sing *Happy Birthday*. I push a little piece of cake into her mouth and tell her, "Chew, Mom, chew!" Poor Mom. Who knows if she senses the celebration at all. I think so. But there I go again, trying to plan too much for my frail little mama. And she is so cooperative and doesn't complain. Remind me to be the adult here.

So much is going on with Mom. She endures not only the dialysis three days a week, repeated ER and Hospital and Access visits; complications from surgeries and grafts and various wounds; she is often symptomatic with effects of the dialysis and all her medications; not to mention the end-stage kidney disease and probable cancer recurrence. I am doing my best to facilitate communication between all the different doctors, nurses, facilities and changing staffs. We all want to help her be comfortable and to help lift her spirits, even though she is often the one to lift ours. She always greets me with a smile and often asks a staff member, "How is your family? How are you today?"

Mom is increasingly confused. I am told that is common with dialysis. One thing that really drives her crazy is frequent itching, which is also a symptom of dialysis and trying to maintain correct phosphorus and potassium levels. We constantly put lotion on her arms and legs and urge staff to do the same. Mom is not pleased when she has to wear cotton fingerless gloves all the way up to her elbows, to keep her from scratching. I tell her, "Mom, they look like opera gloves." She isn't buying it.

In early 2004, two of Mom's roommates pass away. I sit by Mom's side and hope she isn't too upset. A couple of Mom's and Dad's friends die in 2004, also; and then Dad's suitemate passes away, too. I worry about Dad's feelings. When I sit with him, he doesn't remember who his roommate was. Instead, he turns to his girlfriend who sits beside him, and tells me, "She's my sweetheart, you know." Mom and Dad both seem to accept the dying of their roommates and friends as simply part of life. They are both fine. I marvel.

This will turn out to be quite a year. I am busy dealing with challenges and frustrations, and yet, there are moments of lightness and calm. When there isn't an emergency, I blissfully go about Mom's and my routine of chatting away at dialysis or the SNF. I feel like these sweet days will go on forever. Then reality or fear will jolt me out of my reverie and I think, I couldn't bear losing Mom! But, of course, I know I will, and I can, when the time comes. It's just that these beautiful moments seem eternal.

## Chapter 26

### Feed the Birds

How do I tell him? Or, do I? No one knows for sure when it will happen, that's for sure.



I take Dad to the lake so we can feed the birds and be at peace with nature all around us. I take a breath.

“Mom’s not going to live forever, you know, Dad.”

“Neither are you or I,” he says.

It is just the response I wanted.

Little by little, I try to let Dad know that Mom is declining. He asks me several times, “Now, what is wrong with Patty?” Each time, I explain, “Mom’s kidneys are failing, Dad. She has lots of things wrong with her.”

I tell him about the time I asked Mom how she could deal with so many difficulties—needles and tubes and aches and pains—and how she said,

“Oh, I just go with the flow.”

That brings a smile. I struggle to say the right things, just enough, not too much, knowing Dad’s decline in comprehension.

I recall the time we were in a hospital elevator with dear friends Cal and Patti, on the way to visit Mom. After explaining Mom's kidney failure to his old buddies, Dad turned to me, asking, "And what's wrong with me?" That was the only time I ever answered, "You have Alzheimer's." Dad looked startled—or confused or scared...and so did Cal and Patti. I quickly explained, "You have short term memory loss, Dad." That he understood. He nodded and turned to his friends, "I have short term memory loss."

I would say from time to time in the coming years, "Everyone has something wrong with them, don't they, Dad?" He would nod.

Then, I would say, "Getting old's a pisser, isn't it?!"

He would laugh and laugh.

## Chapter 27

**Fragile Butterfly Mama****Day 1**

“Hi, Mom, I’m early.” There’s no reason to expect anything awry. I am blithely savoring our sweet crisis-free days. We can handle anything and we do. It’s true that Mom is so frail that she can’t walk and has to be hoisted by Hoyer Lift from her wheelchair to dialysis recliner, or to her bed. She’s bent over in her wheelchair as I greet her this day, Wednesday, December 8, 2004, but her spirits are high.

“They’re going to get me hooked up, but they haven’t done it yet,” she says, smiling up at me. Her macular degeneration causes her to see me with one eye only peripherally, and not at all with the other, but her eyes twinkle, just the same. She even speaks in a full sentence instead of her usual partial phrases. She is so cute and spunky.

I chuckle and say, “I know. I’ll go run an errand while they’re hooking you up—then I’ll be back. OK?”

She smiles again, “OK.”

When I arrive back at dialysis, nurse Carla intercepts me before I get to Mom, and says, “There you are. I need to tell you about your Mother.”

In her professional yet gentle voice, Carla clinically itemizes Mom’s morning incidents. Her words run together in my mind as I begin to realize what they mean.

“Your mom’s blood pressure kept going down into the 60’s...the dialysis catheter would not work...she was unresponsive. We can’t put more saline in her to raise blood pressure—her body couldn’t take it.” They had talked to the nephrologist. “He said that they could no longer do dialysis here,”...that, “if you want her to be dialyzed, he will admit her to the hospital. He told us there really were no more viable dialysis sites...they possibly could try the vein currently in use, but there was a likelihood of the whole area being infected, so that vein really is not feasible. Your mom is resistant to most antibiotics, and infection is already existent...decubiti, sores on her legs are getting worse and will not heal...the circulation in her legs is very bad. Sepsis is a painful way to go—system failure is happening. We are sending your mom back to the SNF. You need to make a decision.”

I am stunned. A crisis-mode adrenaline rush keeps my fear in check. I tell her, “I will speak with Mom.”

Then I ask, “Is the social worker, Vivian here? After I speak to Mom, I would like to speak to Vivian.” I lean down to address my fragile little mom who seems so cozy all enveloped in her soft green blanket. She is reclined in the big blue chair and tubes have been unhooked that ran from the dialysis catheter just below her clavicle bone to the looming light blue machine on her left.

“Mom they’re going to send you back to the nursing home, and I will follow you there.” Seemingly unconcerned, Mom smiles at me. My heart aches. I can’t believe what seems to be happening. I give her a kiss and gently touch her face. “I will see you shortly, Mama, my beautiful Mama.”

In her office, Vivian greets me with embracing grace, along with the compassionate administrator, June, and dear nurse Carla. As busy as they must be, they give me all the time I need to talk about what is happening with Mom, about our choices—whatever I want to discuss.

Everyone explains to me, very clearly, that it is my and Mom’s decision, whether or not to send Mom to the hospital and try to get her back on dialysis. I realize they have liability reasons for not telling me what to do—but I can tell they feel that it won’t work; that we should accept that it is Mom’s time. They sort of do a bad cop/good cop routine, gently showing me the realities of hanging on or letting go. They carefully guide me toward realizing what is best for my mom.

I ask a zillion questions; repeat many; even get testy; and I sputter, “But, if she goes to the hospital, maybe they could fix it, and then she could go back to her room, then she could have dialysis again...” They kindly, patiently, let me repeat my equivocations, my denials, my resistance, until, gradually, acceptance comes, and I hear myself saying, “But, if we send her to the hospital, what would they fix? They wouldn’t be able to fix it. She has an Advance Directive...they wouldn’t do different from what you’ve done here...”

Vivian says, “Jody, we are glad you ask lots of questions. We appreciate that you leave no stone unturned. I sense that you have some anguish about letting go.”

“No,” I protest. “My only anguish still is about wanting to bring her home, maybe, for her last days...even though I know we wouldn’t be able to find a 24/7 caregiver who has the expertise and experience with Mom as they have in the SNF...” I start again, as I had many a time before, to explain to myself all the reasons why it didn’t make sense to bring Mom home...” I know she has complicated medical issues; she is comfortable at the SNF; they have three trained staffs--people who know and care for her; access to meds and care right away.” I am having trouble.

June says, “Jody, remember what the doctor said?” I don’t exactly, but I know that he had said Mom is definitely better where she is. Vivian says, “Your mom is not aware of her surroundings here, now; she doesn’t have much quality; her circulation is bad. Hospice would start to administer morphine for pain.” (I’m making sure to keep notes—I scribble...hospice will try to rate pain from 1-10...). “They will do palliative care—comfort care. They’ll balance her lucidity with pain control—and when the family says, ‘we’re done saying our good-byes,’ they’ll make sure to keep her comfortable.”

I grapple with all these things, trying to hold on. Finally, I know. I let go. I let myself feel content that Mom is in good hands at the nursing facility, and knew that with her well-tended, I can arrange for Dad and my siblings and me to spend loving time with her. I also know I will call hospice, and this time they will stay.

I ask how long they think Mom has, and they say, “Maybe two days.”

Wow. That shocks me all over again. I say, “I thought sometimes it’s five weeks after stopping dialysis.”

“But, there is so much going on with your Mom, Jody. She is older. She is very frail.”

I say, “Well, maybe two weeks?” They shake their heads. “We don’t think so, Jody.”

I ask Vivian to read me the quote she had read to me before, and she does.

*To love a person is to learn the song in her heart,  
and to sing it when she has forgotten it."*

Most of all, I want to follow Mom's wishes. I want so badly to understand what they are. June also says that if Janny or Jim or I want a meeting with the doctor, she will be happy to set it up. Vivian says to give Mom "permission to let go." Vivian then coaches me on some things to say to Mom, which I will thankfully remember and faithfully quote to both Mom and Dad later.

I go to hug Mom again—the transport hasn't picked her up yet. "I'll pick up Dad's hearing aids, and see you there, Mom." "OK," she says, intently watching all the goings-on, not seeming upset at all. I wonder if she understands.

Back at the SNF, I can't wait to speak to my favorite nurse, Phil. He is really experienced and Mom and I both adore him. I speak to him before I do anything. I think I am still hoping beyond hope for I don't know what. Phil confirms Mom's fragility and tells me he almost didn't even send Mom to dialysis that morning. She had been very weak; but then perked up, so he sent her. He tells me her "BP was 100" when he sent her; that he had done the "sternal rub, and she responded, and came out fighting." (He explained that a knuckle pushed into the sternum really hurts and someone will start and respond with an "Ow!" if they are capable of being responsive). Phil also tells me that he was wondering if Mom's general unresponsiveness was her subconscious way of wanting to "let go." Bless his heart; he says to me, "Jody, if she were my Mom, I would let her go."

He says more, too. He tells me that Mom's problems "will only get worse; the bed sores will not heal—will get worse; she must have a UTI—always does with a foley catheter...we're running out of antibiotics for her." I ask if she could have antibiotics if she is on hospice. He looks up another person's form, and shows me; yes, she can, if she needs them for comfort. Phil is the final person I feel I must consult. OK, now I am OK, I think.

But then, later that day, I remember that I forgot to ask Phil, "Do you think she might have longer than two days?"

"Well, maybe a little," he says, "it's hard to tell."

I go to join Mom in her room. Her roommate is not in her bed—probably in the dining room. "Hi, Mom. How're you feeling?"

She doesn't speak, but I can tell she's sleepy.

“Mom, you’re a fragile butterfly, aren’t you?” I had said that to her a couple of times before. She nods her head.

I say to her, “I think you’re about to change your butterfly energy. Is it ok to go see Nanny and Bampa now?”

Before, when I had asked her that, wanting somehow to learn her thoughts and wishes, and needing to be sure that she wasn’t holding on just for me or for the rest of us—then, she had clearly shaken her head, “No,” she wasn’t ready. I also felt that, before, dialysis was helping her maintain her quality of life and her shared time with family. Now that had changed.

This time, Mom nods. Yes, she is ready to go see Nanny and Bampa. Ahhhh.

Softly, I tell her, “They are stopping dialysis. Is it ok to stop dialysis?”

She nods, “Yes.”

“Do you want to go to the hospital?”

She shakes her head very clearly, “No.”

That is how I know she is understanding what I am saying...she understands the butterfly; Nanny and Bampa; no hospital.

I think to myself, thank you, Mom, for letting me know what you wish. She doesn’t look in pain; she looks comfortable. “Are you hungry, Mom?” She nods. “Shall I put your head up and feed you?” She shakes her head “No.” She’s too tired.

“You have a good sleep now, and eat a good dinner later?” (She hadn’t eaten all day). She nods, “Yes.” I ask if she worries about us. Nod, “Yes.”

So, I quote as verbatim as I can, what Vivian, the dialysis social worker, had coached me to say. I say, “Mom, we will love you forever, and we will be sad, and miss you...we will join you when it is our time...but, Mom, we will be OK because of your great love...And I promise that I will take good care of Dad. We will all be OK.”

I tell her, “I will make a bulletin board for Dad with pictures of all of us--with our names, because he’s a bit more confused these days.” I also tell her, “Mom, these times with you and with Dad have been sooo precious to me. What a wonderful blessing. Also, Mom, if I hadn’t been her taking care of you, I wouldn’t have re-connected with all my old high school friends.” I know she likes that.

I sit with her for some time, saying this-and-that. Putting lotion on her face. That's one of my favorite things, because she always smiles as I lovingly moisturize, nourish her delicate skin. I got better at it over time, and I could always tell that she relished it, especially when I went over and around her mouth—making sure all the dryness and flakiness disappeared into soft silkiness. I put soothing gel on her mouth, and her face gives a happy look.

After a while, she's clearly sleeping, so I talk some more with the staff. I go to the car. I come back. It is difficult to leave. I keep thinking of more things to say or ask the nurses. Time to go.

The house seems lonelier. I'm glad our cats, Steinbeck, Tiger and Gypsy are there to greet me. I grab a snack. It's time to make important calls. I try to digest all that is happening. I want to talk to family before I called Hospice. I get Roy and Betty on the phone right away; Jim, after he gets home from work; and Janny (at work on a London flight) via airline emergency hotline around 7:00 p.m. my time, and 3:00 a.m. London time. Jim is prepping for a colonoscopy the next day (good boy), and will fly out the day after his procedure. Janny's airline employers help her to arrange a flight here to San Diego for tomorrow. My daughter and Janny's son offer to fly out, too. Janny and I make a decision and carefully choose what to say.

“You are such dear kids. But all of us kids and grandkids just recently spent good times with Grandma and Cooga, and said our good-byes as we always do, just in case. We will fly you all out here in a few weeks so we will all be together at Christmas. We hope that is OK.” Right now, the three of us kids needed to be with our Mom; the six grandchildren had all just seen Mom when she was lucid and smiling; we felt the kids would understand. They do. They understand and sweetly remind us they are available if we need them. Whew.

It's getting late. I'll call Hospice first thing in the morning. Time to get a good night's sleep.

With my cell phone by my bed, I fall into a dreamless sleep.

## Chapter 28

### **Fragile Butterfly Mama, Day 2**

“I’m flying blind here, Phil,” I say to our favorite RN the next day. “I’ve been researching several Hospices—I know they are all good, but I’d love it if you could give me a recommendation.” Phil tells me about one that interacts well with staff, as well as with patients and families. Miraculously, they are able to schedule us, as I had hoped, for 10:00 a.m. this very day.

Phil tells me, too, that they will have to send Mom to Access to take out the line (the dialysis vascular catheter). Removing the catheter is a fairly simple out-patient procedure, he assures me. Phil tells me I may ride in the van with Mom, too.

“Hi, Mom,” I greet, as I enter her room. I tote watermelon, berries and grapes, in case she’ll eat something, but she’s eating and drinking very little at this point. Once again, I ask if it’s OK for her to go see Nanny and Bampa. She nods, “Yes.” Encouraged by her lucidity, I tell her the hospice nurse is coming to join us, and I try to explain everything that is happening to her. I’m still uncomfortable saying the word “dying.” Maybe that’s OK.

Enter a nurse from hospice, wearing a feather boa. I like her instantly. She has such flair and pizzazz and I’m disappointed when I find out she’s the Admissions nurse and not the nurse who will tend to Mom. “Poopy,” I say. I soon found out that all the folks from Hospice are delightful and very special people. I will love them all.

Unfortunately, upon her arrival and seeing Mom, the Hospice nurse exclaims, “She’s a mess!” I am appalled that she says this within Mom’s earshot! I whisper to her, and to anyone else who comments on Mom’s poor demeanor in front of her, that while “Mom can’t see very well, she can certainly hear!” I concur about Mom being a mess, though, and explain that Mom has a lot of things going on.

If Mom heard, she didn’t let on. The nurse sweetly introduces herself and proceeds to educate us about the details of Hospice care. She explains that Mom’s doctor and the Hospice physician will “partner” regarding pain-and-consciousness balance. It is explained that oxygen is a great comfort measure, in case Mom starts having trouble breathing. Medications will to be given sub-lingually (under the tongue)—Mom can swallow, or, if not, the meds will be absorbed. She’ll receive medications for agitation and anxiety (which could start to happen, especially if Mom has trouble breathing), and morphine. We talk about family health—the importance of washing our hands frequently. When dialysis stops, toxins build up.

This first day of Hospice, Mom will have continuous care; Hospice will re-evaluate and schedule accordingly. A non-denominational Chaplain is assigned. We are informed that all the medications for Hospice comfort care and special equipment will be covered by Medicare. I request to be informed whenever Hospice is in attendance and as to all details of my mom’s care. I am glad to learn that I may make comfort requests, too, such as asking them to put lotion on her, and to use swabs for oral hygiene.

By 11:15 am, I’m ready to go pick up Dad. This will not be easy. I want to explain things to him in person. I want to be rested and calm and to choose the best possible way to prepare him—to find the right words to comfort him—to tell him that Mom is dying.

Dad is in an agitated and delusional state when I arrive.

“My car was stolen! Jody—somebody stole my car! Where’s my car!” He is obsessed.

In the recent past, Dad would sometimes fixate not only on his car, but on his credit cards, his Navy uniform, his Navy orders. “Where is my credit card?” “Where is my uniform? I need my whites!” “I must get to the bridge! A pilot is in trouble!” Dad would frantically try to get out the front door and find a way to get to the bridge of his aircraft carrier. It was a challenge for the staff and for me to figure out ways to divert Dad’s attention and to calm him.

Sometimes, writing an explanatory memo and handing it to him or taping it on his door could be very useful. The receptionist once wrote this note: “Larry, your uniforms are at the cleaners.” Another time, the Program Leader wrote a note and read it to Dad: “Larry, all your money is in the bank. It is safe, and Jody is taking care of it.” I brought copies of Dad’s retirement papers to him and explained, “Dad, you are foot-loose and fancy-free. You are retired; in your golden years. You don’t have to worry about a thing.” I made copies of Dad’s career history, too, so staff could talk to him about his exemplary career as a “hot-shot pilot” (Dad liked that) and Navy captain. These techniques often worked to placate Dad. Not this time.

I attempt to guide Dad out of the facility despite his being inconsolable and talking non-stop about his car being stolen. It’s almost funny, but this just will not do. I muster my most authoritative manner, “Dad, sit. I have something very important to talk about.” Wonder of wonders, he settles down. I take a deep breath.

“Dad, Mom is gently fading away. They’ve stopped dialysis. Hospice will be giving her comfort care. We’re going to go see her now... we will tell her we love her.”

Dad says, “Well. We’ve known it was coming...”

Surprised and relieved, I start up the car. We drive in silence the rest of the way.

Dad quietly enters Mom’s room. Morning light streams in through the hanging strands of artificial pink daisies that Janny lovingly hung over Mom’s window. The scent of fresh gardenias, always at Mom’s bedside, fill the room with her favorite fragrance. Against the far wall stands the giant billboard displaying enlarged family photos—always at the ready to be transported to within Mom’s eyesight.

Mom stirs as Dad gently speaks, “We love you, Patty.” He kisses her several times. Mom smiles. “You have been a wonderful wife and mother,” he says, leaning into kiss her cheek again.

Dad is remarkably lucid and focused. We three talk with Mom about their cruises to faraway places; of the family’s living in 28 places in 20 years; of all the kids and grandkids. We read from Mom’s journal, *My Trip*; and laugh about the big fish Janny caught at sunset and Mom then fried in the RV kitchen. We sing *My Blue Heaven*, *I See the Moon*, and more. Dad asks how long they have been married, and I remind them, “60 years!” We talk about their 50<sup>th</sup> Wedding Anniversary when eighty-eight friends filled their backyard to celebrate them. Kisses.

“Patty! Open your eyes!” Dad implores several times, nudging her shoulder.

“Dad,” I tug on his elbow. “Dad,” I whisper, “even though Mom’s eyes are closed; even if she doesn’t seem to respond, she is hearing every word you speak.” This calms him. He holds her hand. She smiles up at Dad and nods off to sleep. He kisses her one more time.

As we leave Mom’s room, Dad says, “I have been so lucky in a wife.” I tell him, “Yes, Dad, so many wonderful years.” I take him back to his residence, where I know he will be in good hands and they will feed him the nice lunch they had saved for him. I tell him, “Dad, we will go to see Mom every day. She loves you very much.”

I am counting blessings and praying a blue streak. Everything is going so serenely and lovingly. Miracles seem to occur at every turn. I wish I could see a certain doctor and he suddenly appears. I hope for a nurse to come check in on Mom, or a friend to call, and they do. It seems we are in a state of prayer and grace. Late at night, when I worry about what to do next and how to do all the tasks at hand, I say prayers for family and for all the medical staff and for everything else I can think of...with a bunch of thank you’s tossed in. In the morning, it will be clear to me what should be done. I remind myself to trust.

Checking in with Mom’s nurse later this second day, I learn that the doctor has stopped all Mom’s vitamins. Mom can’t swallow them, and they are no longer necessary.

Betty and Roy arrive to see Mom. They speak their loving good-byes, but Mom does not stir. Just as they are about to leave, Mom’s hand reaches out from under her blanket.

“Uncle Roy, Uncle Roy,” I call to him, “Mom wants to hold your hand!” Roy, Mom’s little brother, quickly turns, sits back down, and takes Mom’s hand in his. They sit for a while like that. Aunt Betty and I know that meant a lot to Roy. Later on, he would say, “And she really had a firm grip, too!”

Janny flies from London, via San Francisco, to San Diego. I pick her up at the airport at 4:34 in the afternoon, and we drive directly to see Mom. Several nursing home staff members join us with hugs and sweet words for Mom. To one of the CNA’s, we ask, “Are you the one responsible for Mom looking so comfy and cozy?” “Yes,” she beams. Others remember Mom from when they cared for her two years before on another wing, and come to hug, too. We call Jim and hold the phone up to Mom’s ear. His colonoscopy went well and he will see us soon.

We schedule our plans for the next day: Janny will pick up Jim at the airport while Jody accompanies Mom to Access. Janny and Jim will pick up Dad. Then we will all rendezvous in Mom’s room.

Janny and I spend more time with a weak but pretty alert Mom; we kiss her nightie-night; take ourselves to Outback for big steaks; drive home to call our kids and Betty and Roy; then conk out for the night.

## Chapter 29

**Fragile Butterfly Mama, last days****Patricia Ellen Armstrong Baumgaertel, March 17, 1921~December 11, 2004**

A frenetic adrenaline fueled energy propels me to action from the moment I awake...things to do...people to meet. What happened to the serenity of yesterday? We arrive at Mom's. I am a rhinoceros on speed as I stumble headlong into Mom's room, snorting high decibel introductions as I charge. I do not endear myself to the new Hospice nurse.

I turn around and enter again. I speak softly, slowly. "I am so sorry. Please, let me start over. Hello...my name is Jody...thank you for taking care of our mom...how are you?" The nurse grunts a "Hmph," and resumes feeding Mom her breakfast. It is the morning of December 10.

Janny is on her way to pick up Jim at the airport, and then Dad. I jump into the van where Mom is secured in her wheelchair for the drive to Access.

The transport driver promptly begins railing about his multiple government conspiracy theories. This has an oddly calming effect on me.

Mom and I steal glances at each other as the driver proclaims that we are in dire and immediate danger of conspiracies toward "one world;" that there are "plots afoot to put microchips under our skin...to create internationally uniform monies, to euthanize the elderly and infirm...religious fanatics are bringing about Armageddon and we'd better bow and pray and mind our P's and Q's!"

With mom sitting back there, hearing all this, I feel I must respond—not just sit there like a ninny. I also do not want to agitate the fellow further; I wanted him to keep his eyes on the road. “Aha,” I say. “That is very interesting...I will certainly do my part to do more research on the subjects...uh...I realize that...uh, it is true that statistics can certainly be used for many purposes, on all sides of an argument...things can be taken out of context...you know, I am skeptical about some of this...hmmm... I do believe there are also people who are working for humanistic purposes...who support and respect diversity...I do feel it is important to keep one’s mind open and keep learning and asking questions.”

Finally, we pull into Access. Mom is grinning at me from the back seat.

Ensnared in the Access waiting room, Mom suddenly is very alert. She eats the snacks I brought. She listens to me read Mattie Stepanek’s poetry; then says, “That’s enough poetry, now, Jody.” A little later, while the doctor is pulling out the catheter, the nurse tells me, “A person often gets real alert just before passing.” She tells me about her Dad, who had been real forgetful, but, two days before he died, he suddenly had great recall, and told his doctor all about his flying, his planes, and so forth.

“Ouch. Ow!” Mom calls out from the room where the doctor is extracting the catheter. “I’m sorry, Patty,” the doctor says. “It’s so infected...it’s almost out.”

The pain is gone once the tube is out and the wound bandaged. I think to myself, again, though sadly, that we made the right decision to halt dialysis.

There are instructions. The nurse tells me, and agrees to write all the instructions for the SNF nurse, as well: “Remove the dressing Saturday, the next day, and leave it off, unless it’s draining. If it is draining, put a little dressing on”. Mom “should sit up for three hours. If it is bleeding, put direct pressure.”

This time we have a different transport driver. He’s a dear fellow who has often driven Mom home for lunch when she was in better shape. We hug and engage in our regular, “How are you? How is your family?”

We pull into the SNF parking lot just as Janny, Jim and Dad are walking up to door.

We enter Mom’s room, via the next room, to avoid a huge hole (for plumbing issues) that workers are repairing right outside Ma’s door. Mom is tired but still able to nod and be somewhat responsive. She is glad to see all of us.

We sit a loving vigil that day, singing our favorite songs, chatting and telling stories until Mom and Dad are both plum tuckered out.

Janny, Jim and I, back at home, eat lots of ice cream; call the nurse one more time to check on Mom, and hit the hay.

**Saturday, December 11, 2004.**

In the morning, a calm one for all of us, I ask Jim and Janny to help me with a “Memory of Mom” card that I had started drafting the day before. Jim’s computer expertise and Janny’s artistry help to create a lovely card to send to family and friends when Mom’s time comes. We talk about necessary things—Mom’s cremation wishes; her scattering over the Pacific.

Knowing that Jim has different religious beliefs from Janny and me, I have been praying often for guidance, and for a loving communion amongst us. My prayers are answered. We three siblings simply, lovingly, share and support our mom’s wishes. We meander together through the rooms of Mom’s and Dad’s house, sipping our coffee, laughing and sighing as we relive our days with Mom.

After picking Dad up, we descend upon Mama about 11:30. The sharing of life stories resumes; then Mom naps, while we kids and Dad are off to lunch.

The mood is not one of sadness. We are celebrating Mom and our being together for this important; this momentous transition. At the same time, I think maybe we are in a kind of shock or adrenaline spurt; plus, we probably need food and a break. I think this because at the restaurant we make a mess.

We are at one of our parents’ favorite seafood restaurants, eating serenely by a window with a view of waterfalls and ducks on a pond. My cell phone rings and we startle into action. It could be something important about Mom! I pull my phone out of my bag; Jim’s water goes flying; I retrieve a soggy placemat to write on; Janny knocks over the salt and pepper; Janny and Jim’s arms go flailing, grabbing napkins, patting Pop, mopping the table, the floor and each other. They are all giddy, falling all over each other. Jim exclaims, “Look, Jody’s oblivious—she’s just calmly taking notes through all of this.” More peals of laughter from the peanut gallery while I glare at them and try to concentrate on what the nurse is telling me. Piling plates and still wringing napkins and patting each other dry, they come to their senses, “Omigosh, we’re the three Stooges—but--Jody—oh my—were you able to get down what the nurse said? How’s Mom? What happened?”

It turns out the nurse was just giving me an update...nothing urgent. She may not have realized we were coming right back. She told me all was ok with mom— kidneys were still putting out urine and there was no edema yet in her legs. The nurse was assuring me they would be keeping Mom comfortable and giving her medication as needed for comfort, and that we could let them know if we noticed any changes or discomfort. I told the nurse we would be seeing her shortly.

As we depart the restaurant, after devouring Dad's requisite giant chocolate mud pie, a fellow customer, who had been observing our antics, remarks, "You didn't leave any for us!"

I think our giddy episode is just what the doctor ordered. Fed and refreshed, we rejoin Mom.

We know her time is coming. We don't know when. I want to know what to watch for. I want to understand what happens when someone dies. I have never seen it before, and I feel at a loss, not knowing. I ask the Hospice nurse to fill us in on what to expect. She had said she would. It turns out that when she gives us each the Hospice blue-colored papers that explain what happens when someone dies, it is just the right time.

Dad looks down at his copy and says, "Patty's dying, isn't she?"

"Yes, Dad, she is."

It is the first time any of us has said the words "Mom's dying." It is a relief to share the reality. It's not scary or painful. Dr. Elizabeth Kubler-Ross and Vivian Wohlwend both talk about how healing it is to share feelings and fears about death. The way Dad says it; it is a matter of fact. Dad helps us see death as a part of life.

The invaluable two-page blue papers from Hospice tell us how to help the patient who is approaching death; what symptoms might occur; and how to know death has happened.

We learn, for instance, that hearing is the last of the five senses to go, and that we shouldn't say anything that might distress mom in front of her. We learn that there will be a decreased need for food and drink and that it is ok for Mom not to eat or drink if she doesn't want to. We read that we should provide a quiet comfortable environment with filtered light and talk calmly and soothingly. I am glad to know about physical changes that might occur, like blood pressure changes, skin discoloration and blotchiness, difficulty breathing and congestion. Understanding the natural processes involved with dying help to demystify what is happening and to allow us to not be alarmed—rather to accept the process and stay calm and supportive. We let Mom sleep when she needs to, and we engage her when she seems alert, just as we are coached.

As Mom drifts off to nap, Dad says again to her, "You are my wonderful wife, Patty. You are such a wonderful mother. We have had so many wonderful years together, haven't we?"

What a special loving afternoon we had had with Mom. We took Dad back to his place. I think he was ready for a nap, too.

We kids drive home for a couple of hours; then go back in the evening to watch “Andre Rieu Live in Tuscany” with Mom. We would be watching her favorite show, “Lawrence Welk,” of course, but Andre Rieu pre-empts it.

“Mom,” I squeal—Andre Rieu is on again—you and I saw it before! Terrific—we can share it with Janny and Jim, now.” I’m sure she hears me.

We try to feed Mom some dinner, but she is unresponsive, has actually been pretty unresponsive all day, hasn’t eaten, and that’s OK. We hold her hands, put on lotion, speak to her, share with her. We are all comfy and cozy. Many friends from the SNF stop by; say “Hi,” and share. One sweet lady, whose father is in a room down the hall, stops by, as she always does, and waves. I find Mom’s roommate in the dining room and explain what is happening. I hold her hand and thank her for her support and patience with all our family members going in-and-out of her and Mom’s room.

After the concert, we check with the nurses again; go back to make sure Mom is comfortable; give her our kisses, and say, “We’ll see you tomorrow...love you, Mom.” We leave, looking forward to our next day with Mom.

Back at home about 9:30 p.m., we collapse on couches, munch, make calls, talk of important things, of Mom.

At 10:00 p.m., the nurse calls; “Jody, your Mom is going. She will probably be gone by the time you get here.”

“We’re on our way,” I tell her. Janny and Jim, and I in my pajamas fly out the door and drive as fast as we safely can, back to our Mama.

We rush to her room and enter on tiptoe.

There she is, very still; peaceful; jaw slack; mouth open. She looks comfortable, just as we had left her. We touch her beautiful face, still warm.

For so long, I thought I had to be holding her hand when she died; that she and I would be devastated if that did not happen. Thank heavens the social worker and the nurse told me that many people want to die alone. Mom has done just that. It seems she waited for us all to say our good-byes, and then she died peacefully, in her own way. Later, Yvie would remind me that “Honey,” as she called her grandma, was a very private person, really. And, too, we had been saying good-bye for some time now.

“For ten years,” Jim said, “We’ve been saying good-bye for ten years. “No, ten years?” I say. “Yes,” Janny says, “For ten years now, since Mom’s cancer, we’ve been saying our good-byes.” “I guess she’s finally used up all those 947 lives,” I say.

We three stroked her face again and again, and take turns holding her hands.

I look up at Jim who stands across from me, on Mom’s other side; Janny is next to him, and Jim has this big beautiful, loving smile on his face. He was to leave the next morning, and it would have been hard for him to leave, not knowing what and how and when she would die. Now there is completion, and he has shared this with Mom and us. He is grateful. We all are happy to have been with our mom this day.

The Hospice Chaplain joins us. It is a happy coincidence that she was around the corner at a coffee shop when she got the call to come see us. She was about to make the long drive to her home, but instead is now with us, just minutes after getting the call.

She reaches her hands to us to form a prayer circle; then pauses.

“Um...you’re not Catholic?” she asks. Then, diplomatically, “Are you comfortable with ‘God’?” I answer, “God is good.” Janny says, “I am comfortable with God.” Jim nods. We don’t have to go into detail that we have differing beliefs. God is good for all of us. So, then, we all hold hands over Mom.

As the Chaplain begins a beautiful prayer, I suddenly hear a soft intake of breath.

I am shocked. It seems to be coming from Mom! I look quickly at Mom. No movement. No one else heard it. All eyes are closed in prayer. Must have been my imagination. I refocus my attention on the prayer in progress.

Again! Another breath! I look intently at Mom. Maybe she isn’t really dead! They misdiagnosed death! My heart is beating hard. No, I must be mistaken. I calm myself in prayer.

No. Again! I’m getting frantic. I can’t stand it anymore! I’m going to stop the prayer.

All of a sudden, a big snore/snort!

Oh, for heaven’s sake, it was Mom’s roommate all along, breathing and snoring. I totally forgot she was there.

I let out an involuntary “Whoop,” and all heads turn toward me. I have to explain, “Omigosh, I thought Mom was still breathing...it came from Mom’s roommate...sorry.” We resume the prayer, as if nothing had happened. The prayer is wonderful, and when the Chaplain asks if we kids would like to say a prayer, we each of us say our own prayer with Mom, too. My insides are still doing the St. Vitas’ dance from the “Is She Still Alive?” snorting episode. We sing *My Blue Heaven* again. Janny sings a beautiful song from her Unitarian church about spirit. We celebrate Mom for some time. We stroke her face again as it begins to cool.

At some point, the Chaplain turns to me and asks, “What will you do now? You’ve been taking care of her for a long time.” She catches me off-guard.

The ground falls away beneath me. Inadequacy, guilt, fear rise up. I sputter. “Yes, I’ve been caregiving for a long time.” I babble, “...with my heart and soul...110%...with every fiber of my being.” I stare into the eyes all around me, Maybe I should get a job now? But I need to take some time...I will need a little time...but then, I will look for work...I will...a new career.”

Janny, Jim and the Chaplain soothe, “Yes, Jody, yes, you need to take some time...”

I say, “I worried...imagined...that everyone expects me to get to work right away.”

Janny says, “Listen to that word, Jody: imagine. No one expects you to get a new job right away.”

I apologize for my outburst. Janny and Jim both said, “No, Jody, you didn’t get defensive at all. Yes, Jody, it’s okay. No, Jody, there is no pressure on you to get to work right away.” They finally convince me and I calm down. I do still have Dad to look after, too. We sit for some time.

After awhile, we all three pack up Mom’s stuff and take it to the car. It is so comforting, all three of us together.

Speaking of Dad! I turn to the Chaplain and Janny and Jim, “I should go get Dad, shouldn’t I?”

It’s around midnight. We mull for some time and finally decide it would be kinder to Dad if we waited until the morning when he would be well rested, fed, less likely to be in an agitated state, and more likely to comprehend what we were about to tell him. We would all get some rest and be prepared to give all our focus to him. It would turn out to be a very good decision. Anyway, our evening was far from over.

Where is the mortuary transport? A comedy of miscommunication ensues. We think the SNF nurse had called them. The nurse thinks the Hospice nurse had called them. Everyone thinks they are on the way.

Turns out no one had called. Calls and follow up calls. Someone thinks the dispatcher is really mad; the dispatcher says, “No,” she was just startled “to be awakened. Wait...” she says, “He should be arriving right now.” It ‘s a good thing we finally connected with the mortuary, because we’ve been waiting over two hours, and while we have enjoyed every minute with Mom, we’re nodding and bobbing onto her bed.

I walk to the nurse’s station to greet the transport fellow, who is very sweet. He apologizes about the miscommunication. He’s young, tall, burly, in white shirt and tie, goatee. He and the SNF nurse are doing paperwork.

I ask, “...Only one of you?”

He replies, “Oh, yes, I can handle it fine. If we go to residences, we send two people, but at facilities, one is enough.” The nurse adds, “At facilities, they can always get help.”

I respond, “Well, she is dead weight, you know.”

They look aghast. Then they laugh and explained how difficult it is during the holidays, to have enough staff at the ready.

“I can imagine,” I say, “They are dropping like flies, aren’t they?”

“I’m sorry,” I say, “I’m a little giddy.” One caregiver later remarks, “You certainly are a well-adjusted family.”

We kids kiss and touch Mom’s cool face some more; repeat our love you’s; then, step into the hall so the nice transport fellow can proceed to wrap Mama.

Jim says, “Come on.” He beckons us out into the hall and motions for us to look away.

“No, Jim, we want to see every little thing.” Janny and I and the Chaplain stand right at the door and observe. The dear big burly guy delicately wraps our sweet Mama in a white sheet.

“It’s like a cocoon!” I exclaim.

“And, you know what comes out of a cocoon?!” the Chaplain answers.

Janny and I look at each other. “Yes!”

Then, our dear fellow covers Mom in a beautiful velvet green blanket and wheels her gurney into the hall. We kids want to kiss her again.

“That’s OK,” he says, “but it is law that I have to cover her before I take her outside.”

“OK ” we say, and kiss her one last time.

With Mom all cozy in her lush green blanket, the transport fellow wheels her out into the beautiful fresh air of the starry night.

“Ohhh, the van is a forest green! It matches her velvet green blanket! It’s like she’s going on an adventure!” I exclaim. “Shall we run along the van like we used to as kids?”

“Yes!” Janny says. “And let’s sing, *Aloha Oe!*”

So we do. We sing *Aloha Oe* as we wave the van and Mama good-bye. We look up and around at the beautiful crisp night, and we three kids hug like crazy, there in the facility parking lot.

A nurse runs out to hug us, and says, “Your Mama was really something. She would look after us and her roommates. Yesterday, she smiled like herself.”

Upon returning home, Jim flops himself down on the floor with the kitties. Janny and I plop ourselves down, too, and all three of us roll around and around on the floor with the three cats, laughing hysterically.

Then we’re up at the kitchen counter, gathering some munchies and still giggling, and Jim says “You know, this is the first time it has ever been just the three of us all together.”

“Oh my goodness, that’s right!” Janny and I say. Then Janny says, “Let’s call our kids,” and we do.

Yvie later says, “Nik and I both thought y’all had gone ‘round the bend, because you couldn’t stop laughing.”

All the crazy energy finally spent, grateful for our time spent with Mom these last days, even after she was gone, we turn ourselves toward bed and thoughts of how best to comfort Dad.

## Chapter 30

**Comforting Dad**

We arranged to meet Dad in the private family dining room of his residence. It was warm and homey with its rich mahogany table adorned with ivory tablecloth and a bouquet of silk lilies and chrysanthemums. We greeted him with hugs and smiles and we all sat around the table. We chose our words carefully.

“Dad--Mom, very peacefully and gently, passed away last night.”

“Oh. I didn’t get to say good-bye!”

“Oh, yes, Dad,” we exclaimed, “you did. We all said our good-byes yesterday. You kissed her many times, and told her that you loved her. You said such wonderful things to Mom, Dad. You told her what a wonderful wife she has been; such a wonderful mother. We shared many wonderful memories. As many people do, Dad, she passed away quietly and peacefully, after we had all left. You said wonderful good-byes.”

Dad got up and paced and said, “Patty’s gone...” He began to sob. Jim got up and held his Papa. Father and son sobbed together. Janny and I cried and held Dad, too.

After awhile, Dad said, “What shall we do, now?”

We said, “Would you like to go with us to take Jim to the airport?”

“Yes.”

Off we went, with Dad and Jim in the back seat. Jim spoke to Dad and consoled him as they grieved for Mama. We hugged and kissed at the airport and waved Jim off.

I said, “Dad, would you like to go to a movie?”

“Yes,” Dad answered. Janny and I took Dad to see *Ocean’s 12*.

During the movie, Dad remembered. “Patty died...when is the funeral?”

I whispered, “We’ll find out next week.”

Then he turned to Janny and said, “Patty’s gone...when is the funeral?”

Janny whispered, “We’ll find out next week.”

Again, he asked, and Janny said, “Ask Jody.” I said, “We’ll find out next week.” We both said, “Shhh, watch...” I was getting ready to take Dad out to the lobby, but he calmed down, and we thought he enjoyed the movie, though he never gave us his critique. Next, we took him to lunch at BJ’s across the parking lot, and sat outside. The warm sun was comforting, and we smiled at each other a lot. By the time we took Dad back to his place, he seemed to be doing fine.

Janny and I took him to lunch next day, too, and he was OK.

Janny and I went to the mortuary and made sure all the arrangements were taken care of. We ordered the correct number of Death Certificates for legal and financial institutions. We made plans for the disposition of Mom’s remains over the Pacific. We chose a simple container that we would use for the scattering. It meant a lot to me that we did it together—it was comforting.

I took Janny to the airport the next day. Buoyed by sibling support, I now felt fine to handle the rest of the calls, cards, obituaries and business stuff. I looked forward to creating thank you/Christmas baskets for the three facilities—Mom’s SNF, her dialysis unit, and Dad’s place. I called frequently to check on Dad.

A few days later, I took Dad a little Christmas tree for his room. He was sleeping, so I gently woke him and told him we were going to decorate his tree together.

“Where will you put it?” he asked.

I placed his little end table in a perfect spot for his tree. “Mom painted this little table years ago,” I told Dad.

Oops, I forgot that the Chaplain had recommended that I not bring Mom up unless Dad brought her up first. If I did, he might grieve over and over again, because of his lack of short-term memory. If he brought her up on his own, it meant he was remembering and processing.

I was relieved when Dad did remember that Mom had painted the end table, but he didn't remember that she had died. He seemed sad, though—lethargic—not his usual self, though he didn't seem to know why. So, I just let him lie on his bed for awhile and I just sat with him.

After a bit, I said, "Come on, help me decorate."

He started to get up, and then said, "Shall we go visit Patty? Ohhh...she's gone."

"Yes, Dad."

He lay back down, and I sat next to him.

"Dad, we all got to say our good-byes. You kissed her and said wonderful things to her." I told him all that we had said before.

Then, I said what Vivian had coached me to say: "Dad, we told Mom that we will love her forever; that we will miss her, and we will be sad; but that we will be OK."

His lower lip trembled.

"We will be OK, won't we, Dad?"

He nodded yes, his lip still quivering.

Worried, I went on. "Dad, it's important to Mom that we all will be OK. And we will, won't we, because of her great love. We will join her when we are ready, and we will be OK, now, because of her great love, won't we, Dad?"

He nodded.

After awhile, I said, "Dad, let's decorate your tree. Here are the ornaments. You pick and tell me where to put them. It's a little tricky, attaching them."

So, we did. The tree was beautiful.

Then, we pressed the on-button on his Dancing Santa, and I said, "Let's dance with the Santa." So, we danced the silly Santa dance together, hips twisting, and arms chugging back and forth like a choo-choo.

Then we went out to the Great Hall, and we both ate lunch with the rest of the residents. We marveled at the big Christmas tree, and I reminded Dad that he, Jim, Jan and I had helped decorate it together on Dec. 10, for the Christmas dinner and party.

Whenever someone would pass by and say “Hi,” Dad, like a little kid, would say, “I have my own Christmas tree! My daughter brought me a Christmas tree!”

The gentle oblivion of Dad’s dementia served him well for some time regarding Mom’s passing. We chose not to take him on the boat *Fancy Pants* when we scattered Mom’s remains over the Pacific. We did bring him home for Mom’s Celebration of Life and Dad was pleased to spend time with family and friends. While we told stories and prayed and sang and toasted Mom, Dad sat side-by-side with his best buddy cribbage partner and grinned. He liked being the center of attention, just like old times. I wondered how much he comprehended.

The comforting forgetfulness was not to last.

It was the Valentines’ Party at Dad’s place. Dapper in his blue pin-striped suit and wing-tips, Dad was sitting with me, front and center. Giant red hearts and stars hung from the ceiling, flowers adorned every table, the band was tuning and the rest of the residents were toddling into the Great Room.

“Where’s Patty?” Dad grinned at me, clearly expecting her to join us at any moment. He brought it up.

Okay; the big question: to tell or not to tell? Counselors suggested diverting attention, changing the subject or lying. One of my favorite speakers at a conference on dementia, Wendy Lustbader, M.S.W., spoke of the comforting and productive use of “fibulets.” I heard from numerous sources the question, why would we subject our forgetful loved ones to repeated grief every time we reminded them their loved one has died? On the other hand, Dad has intermittent lucidity, and selective memory. If I lie, will he quiz me relentlessly and then catch me in my lies, and be more upset? If I said, “She’ll be right back,” he might ask, “Where is she?” If I say, “She’s at an appointment,” he might query, “She’s at a doctor’s? What doctor? What’s wrong with her? After the appointment, then she’ll come here?”

I know, with Alzheimers’, there are no rules. What to do?

I recalled an episode from a few days before the Valentines' party. The Program Leader was observing Dad's obsessive behavior with another caregiver. "Where's Patty? Where are my car keys? Where is my car? Where's Patty?" Dad was getting more and more aggressive and the caregiver was getting red in the face. The Program Leader decided to intervene. She always had good rapport with Dad. She took him by the hand, guided him to his room and they sat upon his bed.

"Larry," she began. "Larry, I am going to tell you the truth." That got Dad's attention.

"Where's Patty?" he demanded.

"Patty is with God."

Evidently delighted to hear this, Dad exclaimed, "I want to go be with God. I want to go be with Patty and God."

"Well, Patty and God are in Heaven, and Heaven is a very long way away."

"Well, I want to go there, too. I want to go to Heaven and be with Patty and God."

"Larry," the Program Leader told him, "when it is our time, we will go to Heaven and be with God and Patty. Larry, it is not our time."

A pause. Dad looked into her eyes and said, "Thank you." That was that. Off they went with the day's routine.

Buoyed by such a success story, I resolved to try the truth, too.

With Valentine stars and hearts bobbing above our heads, I looked into his eyes, "Dad, Mom died..."

"What! Patty died? Why didn't anyone tell me! When is the funeral? Why didn't you tell me?!"

"Oh, Dad. We had a lovely celebration of life for Mom. We were all there. We were with her the day she died, too. We sang and said prayers and shared beautiful stories of our lives. You were wonderful. You kissed her and told her what a wonderful wife and mother she was."

Dad was sad and sat very still. The band played *My Wild Irish Rose*. Then the song caught his attention and the pain was gone...until the next time.

This scenario of frustration and grief would repeat itself many a time to come. Sometimes I would be able to just change the subject. I tried it all—distraction, diversion, lying, the truth, fibulets, chocolate. Chocolate usually worked the best. It made me sad not to bring Mom up, but I wanted to be kind and not cause Dad anguish.

Eventually, he ceased talking about Mom. Later on when I showed him family pictures, the ones he remembered most were his parents. I needed to find new adventures for him. Life had changed for us. Dad existed in a different reality. It was up to me to step into his world.



**Section Six: Life Goes On**

*If you don't learn to laugh at trouble,  
you won't have anything to laugh at when you are old.*

~~Will Rogers



*Breathing in, I calm my body.  
Breathing out, I smile.  
Dwelling in the present moment,  
I know this is a wonderful moment.*

~Thich Nhat Hanh, from

*Living Buddha, Living Christ*

## Chapter 31

### Seeking Quality of Life for Dad

I tell myself that change happens and I must be ready for anything. I also know that some things never change: the needs of everyone for health and safety, food and shelter. Doesn't this usually take a village? I am comforted to know that where Dad lives now he can't rush out the door looking for the plane that crashed on the bow of his carrier decades before. He is safe, and there are people who will pick him up if he falls. Someone makes sure he eats his meals and takes his pills. They shave him and bathe him and tuck him in at night. It is other changes that make me go bump in the night.

Like this: The phone rings and I tumble out of what used to be the parent's bed, grateful for the fall prevention grab bar that Dad installed for Mom. Knocking my glasses off the night stand and fumbling for the phone, I breathe a quick prayer, "Please help him to be ok."

He's fine. It's the other person...again. This time, it's the daughter of Dad's girlfriend calling, "Your dad was trying to get my mom to wake up and eat. She wouldn't, so he clobbered her. My mom was so irate; she stormed out to bang on the door of the staff nurse who told her, 'Sit down! Sit down!' Mom backed up and sat fast on her wheelchair and injured her thumb, which swelled up, and another caregiver screeched, 'Call an ambulance!' Someone had the sense to take a breath; things calmed down. My mom and your dad are both ok." After much discussion, we agree not to try and keep them apart. The daughter says, "My mom would just shrivel up and die if she couldn't be with Larry."

Peering through the one-way mirror at Dad before entering the Great Room, a caregiver watching with me points to Dad's girlfriend and says, "Oh, she will taunt Larry from time-to-time, by flirting with another man, coo'ing and stroking his hand, all the while keeping her eyes on Larry. Larry will sit there getting madder and madder." "Oh, no," I exclaim, "he might hit someone!" "No," the caregiver replies, "She knows exactly when to stop." What a remarkable little microcosm of elder-world adolescent behavior. For a long time after his girlfriend died, Dad would wander into her room and nap on her bed.

I marvel that I can view this world unseen, and then enter and wander at will, chatting with the fascinating and eccentric inhabitants. The residents and their family and friends, the staff, the mobile medical professionals and practitioners, even the visiting entertainers and animals are all integral, interactive members of this amazing team. I strive to engage with many of them. I am part of their world.

As I mingle amongst the residents, I spy Corey, a happy chatterer and quite literary—his favorite author is Bernard Shaw; then Penny who was at Pearl Harbor; and the judge who is always astute; or Ian, who's mad because Dad hit him, but Ian smiles at me anyway. I compliment Cindy on her fancy hair and the purse she always carries, and I'm pleased to see she still wears the Mardi Gras beads I gave her. The opera singer periodically lets out a few high notes, and the lady in the corner screeches at anybody and everybody, while the other residents roll their eyes. Practically everyone responds to a smile and a "Hi! It's good to see you!" Some just sleep or stare. I am careful not to touch Micky because when several of us visited the Hotel Del Christmas Tree, I tried to put a kind hand on his shoulder and he swung at me, hollering, "Don't touch me!" Always more to learn, I muse.

I spy several lovely and patient wives who tend to their Alzheimers'-stricken husbands every lunch. One husband is in a geri-chair and no longer speaks. His wife feeds him. She has made friends with other wives who sit and socialize with each other and their semi-communicative mates. One hubby resident is far more functioning. He meanders from table to table and tries to slip out the locked door when staff opens it, but much of the time he sits with the wife he knew as she chats and strokes his back. This little congregation of ladies laugh and have their own support group as they tend to their husbands day-in and day-out. They comfort them in invaluable intangible ways that only they know how to do. And they always look so nice.

Most of the time when I enter, there is a calm, relaxed atmosphere. There is the odd time when I can tell that it has been a really hard day; staff might be a little curt or dryly professional as opposed to their generally sweet embracing way. There may have been a death or two, compounded by several residents having aggressive and belligerent behavior.

One day, after Dad has had a particularly combative day, I wail to the director as I depart their world, “Is Dad the only one who acts like this?!” “Oh, no, Jody,” she says, “This is just part of dementia. Your dad is doing OK.” I praise the staff repeatedly for their persevering serenity and their kindness to my father.

I resolve to calm my own hyperactive inner beast and mimic the slow serene walk of the caregivers. I marvel at how they gently nudge a stoic resident to rise and be guided to the bathroom or the activity circle. I try to be careful that my sometimes frenetic energy doesn't bring a discordant note to the melodious flow the caregivers are trying to maintain. I tire myself out, too, if I don't slow down, too.

Lots of family members visit when the Humane Society brings animals for pet therapy, or for the Valentines' Day Dance, or for the Seniors' Senior Prom. We get dressed up and laugh and chat and clap for every song the band plays. Sometimes we dance with our loved ones. One time I showed no shame at all when I responded to the band leader calling me “Josephina! Josephina! Come and singa witha me!” “Oh, Luigi, I couldn't.” But I did—I pretended like I could sing in Spanish; like I could sing opera; ; like I could harmonize and scat sing and all sorts of stuff. I couldn't do any of it—I sounded like a howling cocker spaniel, but I did it with great gusto. Oh my. Everyone applauded, and Dad even said, “Good, Jody.” “Noooo, Luigi...no more...” I said when he gestured for me to join him again. I still have no idea how embarrassed I should have been. I hope the residents weren't the only ones who probably forgot my caterwauling.

The family members who visit frequently get to know many of the residents and interact. I am so grateful when the wife or daughter whose loved one is a resident says to me, “Your dad did really great at bowling the other day,” or, “Your dad took my hand and smiled at me yesterday.” It is heartwarming to see Corey's or Cindy's or Amy's face light up when I or anyone greets them with a big smile and a handshake or gentle touch. (Of course, it is not fine, but worrisome, when a resident scowls at me and his daughter says, “Your dad hit my dad the other day and my dad is mad.”)

There are ways to help make this home-away-from-home homey. When Dad's girlfriend was still alive, her daughter (who became my friend) decorated her mom's room with flowered fluffy quilts and bouquets and draperies and frilly chairs. The room had all the comforts of her bedroom back at home. The daughter even did laundry for her mom so the delicates wouldn't get frayed and grayed or lost (I don't do that). One of the pretty lunch wives has photos and TV and stuffed animals and elaborate seasonal décor all 'round her husband's room. I imagine that anytime a caregiver needs to tend to him, she enjoys being in his lovely room, too.

I wish there were more friends who came to visit both Mom and Dad. Cal and Patti were two rare friends who joined Dad and me to visit Mom whenever they brought Cal to town for his own cancer treatments. All four of them had been vibrant and active, laughing and golfing and partying together for many years. Cal and Patti cried after seeing Mom so frail and Dad so spacey. Aunt Betty shared with me how hard it was for Uncle Roy to see his sister declining. It finally dawned on me that I need to be sensitive to the feelings of others. People have their own busy lives and health issues and worries about their own mortality. I have to open my heart and adjust my expectations.

Still, with high hopes that someone would come to see Dad, I gave his residence a list of who was authorized to visit or take him out. One golfing buddy took Dad out to lunch a couple of times. I know Dad got restless a few times at their lunches and that can be scary. Dad's friend told me after one lunch, "Larry doesn't remember who Patty was." When I ventured to ask if he might take Dad to hit a bucket of balls, he told me he didn't think Dad was strong enough. I don't think he visited or took Dad out any more after that.

I will forever be thankful for Dad's best buddy, Sel, who came practically every week to Dad's Alzheimer's place to play cribbage. "We're pretty evenly matched," the fellas said, as they reported their close scores to me every week. He stuck by Dad for years. When he could no longer drive to visit Dad, nor play a full game of golf because of his own ailments, I took the two of them to putt a couple of holes and to ride around their old favorite course in a golf cart. Dad swung his fist at me when we chatted too long in the cart and when we waited too long for his burger at the café, but it was worth it (I managed to dodge the fists). I took Dad to play cribbage at his friend's house, while I relaxed and read the newspaper. The odd thing was that Dad spent more time worrying about me having something to do than he did on the game. He was fidgety and I'm not sure how much he related to his friend or the game. Well, it was a good try.

What a happy occasion when Dad's other kids and the grandkids come to visit! I rush to ready my camera for that hoped for glorious smile of recognition the moment Dad sees Janny or Jim or the kids. I make sure I frequently show him pictures of them to keep his memory of them alive as long as possible. I send many Daddyupdates to the siblings chronicling every adventure, every mishap and all the monitoring of Dad to keep them in the loop. Family is a valued and supportive part of the team. Here's a sample Daddyupdate:

"Hi Siblings...Dad really enjoyed when we talked on the phone yesterday. He grabbed the phone and held it to his ear, so I know he really listened. When I told him that he has three kids and six grandkids, he said, 'Really?'"

“It was tense leaving Dad last week. It’s been six years since he’s been at his residence and sometimes he still freaks out. As I tried to leave, he said, “I’m gonna go home with you...take me home...I know you have to go back to work...you can drop me off on the way...I want to go home...” I said, ‘We had a good day, didn’t we Dad—getting your teeth cleaned, and a yummy lunch, and the movie.’ Nothing calmed him. Finally a caregiver bribed him with a snack and diverted his attention and I escaped. I suspect I tried to do too much with him. Maybe he was overtired, sort of sundowning like residents do in the evening, and that was why he got cranky.

“Guess what? Yesterday, when I took him back after a movie, he was totally different. As we pulled up to the curb, he said, “You can drop me off here.” Remarkable. He even called me a gem when I unfastened his seat belt.

I must remember there will be ups and downs and not to panic at every little thing.  
Looking forward to your visit in July! ...Love, Jody”

Some residents have no one. Staff has become their family. Caregivers tell me that they like to learn little things about their charges’ lives, pre-memory loss, so they can relate to them. What were their favorite things? What used to comfort them or bring a smile to their face? When Dad first moved into his new home, we filled out a personal profile that detailed Dad’s history and personal likes and dislikes. Staff can learn about their residents from family photo albums and collages, or shared stories of careers, athletic feats, community work and favorite hobbies.

I love it when a caregiver sits with Dad and points out pictures of him on his big collage, “Larry, is that you throwing the football? Is that you flying in a jet over Mt. Fuji? Is that you in a barbershop quartet?” Sometimes they relate to a bulletin board that shows each family member with their name in big letters. “Larry, who is that?” “My mom and dad,” he says with a grin. Of all Dad’s photos and signs, the maintenance man chose this one first to put back on Dad’s wall after Dad was moved to a new room:

*All Gamblers  
And Fancy Women  
Must Register  
With the Captain  
Before This Boat  
Leaves the Dock*

It's a good thing, I muse, that Dad has a whole team on his side. What a challenge it must be at any dementia facility to keep track of hearing aids, glasses, watches, jewelry—things that residents rely on for their quality of life. We once found a hearing aid of Dad's underneath some dried flowers in the bottom of a glass. We found one in the tip of a dirty sock. Another time, when we gave up looking and bought new ones, he suddenly could hear really well. "Stop singing so loud, Jody!" Dad exclaimed.

Losing expensive hearing aids is a serious thing, so the meds nurse took charge of the aids—putting them in Dad's ears in the morn; taking them out and keeping in the locked meds room at night. That way, she can clean and check batteries, flush out ear wax, and make sure caregivers know how to make sure the batteries are working throughout the day. I always check to make sure the aids are working every time I visit, and sometimes I need to clean the aids again or replace batteries myself. It could be that someone forgot to check them, or simply that Dad's ears are so darn waxy.

Once, when a physical therapist attempted to engage Dad, she was ready to give up because Dad was unresponsive. Fortunately, a caregiver thought to check his hearing aids, and they needed batteries. Dad wasn't hearing a word she said. Yay, teamwork!

This monitoring, though, is an ongoing challenge. Our new system of caring for and monitoring the hearing aids worked well for awhile. Then, all of a sudden, both the right and left hearing aids were found in separate rooms, broken. No one saw how it happened. The meds nurse had a clever thought; "I think I've heard somewhere that little loops can be attached to the aids and a string used to clip the aids to the resident's clothes, so even if the aids fall out or are taken out, they will stay attached." Sure enough, the clever specialist at the Speech and Hearing Center had the manufacturer install the loops and she created the nylon string and clip. It's working! So far.

Even though I hold my breath every time I get a call from Dad's place, the calls could mean anything and I am glad for the staff vigilance. I am grateful for the protocol calls about hearing aids, falls, skin tears, colds or scabies. Of course, when scabies breaks out (scabies—very itchy skin caused by mites, and very contagious), the whole place is quarantined and everything is washed. Sometimes, behavior changes like combativeness are due to medical issues or discomfort. Thankfully, the professionals know to investigate. Is he sick—does he have a UTI or an infection? Is he cold, or hot? When Dad was unusually fidgety in the car one day, I discovered that his pants were all bunched up under him and were pinching his privates. Noone likes that. Easily remedied.

Staff monitors bodily functions—regular toileting and cleanliness. I am touched when someone cleans chocolate off Dad’s shoes or dribble down his front. I am thankful to be called when I am needed to supply anything that helps my dad’s health, safety and comfort.

Every time I talk to staff, I learn something else about Dad or about ways to relate to him and other residents. Norma Brownell, Executive Director of several Alzheimer’s Residential Facilities for Health Care Group, agreed to an interview with me. I compliment her and the staff on maintaining the usually calm and serene mood in the Great Room. “How do you do that?” I ask.

“We have regular meetings,” Norma tells me. “We talk about any issue that I think needs to be brought up. But, every time we talk, we always bring up ‘approach’, because to me, approach is number one with people who have dementia. I tell them the story: Picture yourself: You wake up one day and you open your eyes and you look at your surroundings and nothing looks familiar to you. The room has walls and windows, but nothing that you can say, ‘Yes, here I am.’ And then someone opens the door—someone you’ve never seen before, and comes walking toward you and starts speaking in a language you’ve never heard before. This is what’s going on. They walk over to you and start taking the covers off and you don’t know what their intent is.

“So, you have the person who, number one, has no memory. When they open their eyes, it’s like a new day; it’s a new room; it’s a new space. And then you walk in and they don’t remember who you are. You could be their daughter. You start to speak, but because they have receptive aphasia, the words don’t make sense. You know, I could say, ‘Good morning, Dad, it’s me, Jody. I’m gonna help you get up today.’ And you say it with a face that is blank. The words don’t have any meaning for him. He just sees a person coming toward him. Then when you start to touch him, he’s going to defend himself. So, I say, approach is everything. It’s not what you say; it’s how they perceive what you’re saying or what you’re doing. That’s the important thing. So, you need to wait for them to respond to you before you do anything. You approach them with a tone of voice that’s calm and friendly, with a smile. You look right at them. You look right in their eyes...stay just enough distance so you’re not threatening, and maybe just put your hands out. It doesn’t matter what I’m saying to you; it’s here.” She put her hand over heart. “That’s where they get their message. So, then, it’s ‘I don’t know who this person is...but it doesn’t look too bad...maybe this is going to be okay...’ Approach is everything.”

When I ask Norma how we as caregivers can let go of the anguish and grief of having placed our loved ones in a facility, she tells me there is no answer, but that we must try to understand what they are going through and be part of the team—that we can offer quality one-on-one time. “You can give a change of face...A person with dementia lives in the moment and that can change in an instant. If you can get them in a good place, mentally, socially, that can last awhile...”

I ask Norma if there are any no-no's for family caregivers. She replies, “It's one thing to understand that Mom or Dad has dementia. But emotionally, we still want to think that they can do better or be better than they are. I have seen family members who get cross, ‘Oh, don't say that...don't do that...’ There are a few words and phrases that are destructive: No. Don't. Stop.” She cautions that our tendency may be to want to fix it—or to want them to fix it. But we need to realize our loved ones are in a different place mentally; their agenda is not our agenda. “They're only in the emotion of the moment; not in the cognitive reality of the moment. You have to keep it light; keep it simple; keep it loving.”

In 2009, I had an opportunity to try and walk in Dad's shoes by participating in a “virtual dementia tour.” ([www.secondwind.org](http://www.secondwind.org)) Each participant wore rubber gloves with popcorn kernels in the fingertips and several fingers taped together; goggles that were scratched and foggy, and headsets that played confusing background noise of cars crashing, glass breaking, sirens and garbled conversation. We were each given three tasks that we strained to hear and understand. One-by-one, we were ushered into a darkened room to perform our tasks. Moments into my challenge, I became disoriented, confused and could barely remember what I had been told.

After completing my first task, which was to find and put on a white sweater, I felt very proud. Then I couldn't recall what to do next. I mumbled as I shuffled along in the darkness, “Wow, so this is what it's like...wow—I feel so spacey, confused.” Noticing a table with writing utensils on it, I had an aha moment and recalled my second task. I promptly sat and wrote a three-sentence letter to my family. Then my mind was really fuzzy and I hadn't a clue as to my third task. So, I began to fold socks and towels that I discovered on yet another table. Is this what I'm supposed to do? I don't know...well, I'll just do it and maybe something will come to me. Wow—so this is what it's like. Eventually, I saw another table and it came to me—my third task--set a table for four, which was very difficult to do with taped fingers and popcorn kernels. Finally, someone tapped me on the shoulder, smiled kindly into my eyes and said, “Your time is up.” I proceeded, somewhat dazed and wobbly, to the follow-up room.

This experience helped me physically and emotionally learn for myself the lessons that Norma taught: the importance of engaging with a smile; speaking slowly and clearly; conducting one task at a time. I felt such confusion and disorientation. What must Dad and the other residents feel all the time?

Ever-changing physical and mental conditions pose real challenges for both staff and family. How nice to have professionals trained in all levels of dementia to care for my dad and the other residents. As Conservator for Dad, I was kept informed as to any change and recommendation for medical adjustment. I could make decisions for Dad. I agreed to have the facility order all Dad's medications in convenient bubble packs from one pharmacy source recognized by his insurance. At first, I took him to his usual neighborhood doctors and dentist and hearing specialist for check-ups and maintenance. For some time, he knew them and said hi, and he was very cute.

"Dad, relax, the doctor will see us soon. He will keep you ship-shape." That stopped working when Dad swung out at the hygienist who poked at his gums and sprayed water onto his palate. He flailed at the ophthalmologist as he puffed air into Dad's cornea. Dad did well, remarkably, with his cataract surgeries. After the surgery on the second eye, his ophthalmologist announced, "He doesn't need glasses anymore." That made life simpler for Dad and us, too.

After awhile, we engaged the services not only of the mobile primary doctor and psychiatrist, but also of the mobile dentist. We discovered that the teeth cleaning works best when I am present, helping to calm Pop. Some physical and occupational therapy can be covered by Medicare. A massage therapist even visited the residence.

It is a very good thing if the doctors communicate with each other about their patients' treatments, since they are an essential part of the care team. Sometimes communication happens. I really like it when the doctors respond to my calls and they keep me informed, too. Fortunately, the nurse at Dad's residence usually coordinates care between Dad's doctors, and keeps me in the loop.

Dad's condition, both physical and mental, can change at any time and in so many different ways, and back again. There is a gradual decline with this terminal disease, but there are ups and downs, too. He can start falling and have trouble walking. He may have trouble eating. More than once, I become distressed and alert the siblings to prepare to fly home. Then the next day, Dad is his perky and sassy self, walking, talking and eating just fine. I try to resist panicking; rather, to patiently trust our team and to do my best to observe Dad myself.

Catlin; Sharing the Journey

In late 2008, Dad began exhibiting brand new debilitating symptoms. Staff observed increasingly agitated behavior as Dad started falling with an alarming regularity. The protocols for deciphering symptoms commenced. Is it physical? Mental? Behavioral? Something simply resolved? Can it be that his body is developing resistance to some of his medications or that the medications are causing the symptoms? Can it simply be that Dad's Alzheimer's disease is in another steep decline?

A near disastrous confrontation was about to erupt between me and management; and between me and Dad's psychiatrist.

I breathe deeply. In my mind I say, I will fight for you, Dad. I will fight for our team. I am your wing-man, and I won't let you down.

## Chapter 32

### **Conflict and Confrontation**

Dad's back in the psychiatric hospital due to "episodes" of aggressiveness. I think it's all wrong.

Early evening, the day before, I incorrectly assume we have succeeded in handling a situation of combativeness and avoiding the hospital. But, around 7:00 p.m., the new young director calls to tell me she is sending Dad to the Psych hospital. I keep her on the phone for a long time pleading with her to not put Dad through such an ordeal. She finally gives me two hours to find a one-on-one nurse to stay with him and help him behave. The nurse must start the next morning. A friend who works at a nursing agency and I scramble to make calls and, by 9:00 p.m., we succeed. The primary doctor had already ordered resumption of a discontinued Psych med, in small increments. The medication is scheduled to arrive the next morning as well.

The first one-on-one nurse arrives at 8:00 a.m. I rendezvous with her at Dad's place and sit with her and Dad in the Great Room. At 8:30, the new young director enters, saying to me, "I didn't know you'd be here. I just left a message on your home phone. Has anyone filled you in?" I reply that I had been chatting about Dad with the nurse, but the nurse didn't say anything. "What do you mean by 'filled me in'?" The director replies, "There was a second episode with your father this morning, and we are sending him to the psychiatric hospital." I follow her into the Family Dining Room to chat. I fantasize grabbing her neck and throttling her.

I knew about the first episode, a couple of days earlier, when Dad bloodied a caregiver's mouth as she walked by. A program leader's rendition of the story suggested to me that it could have been avoided. (This, after all, is an Alzheimer's facility.) She told me, "I was standing guard at Larry's lunch table, because I could see he was over-tired—that's when agitation seems to happen; that and over-stimulation. There was a lot of activity around him. I was called away for another resident issue, and it happened, one-two-three, real fast. When I turned around it was too late." Evidently Dad and a resident were fiddling with their eating utensils and Dad was getting more confused and agitated. (Just the day before, for the first time, Dad didn't know which utensil to use). When a caregiver walked by in the midst of this confusion, Dad flailed out and popped her in the mouth. The program leader returned, took Dad by the shoulders, looked him in the eye and said, "It's OK, Larry. You're OK." She said his eyes changed instantly and he looked sweet again and asked, "What happened? What did I do?" The program leader said, "You didn't do anything. It's all right." Fortunately, the caregiver whom Dad hit was all right and went home for the day.

So; I follow the director into the Family Dining Room for our chat. She says, "Larry is aggressive, with no triggers, and is hitting people at random." I disagree, and explain that the sock in the mouth could have been avoided. I protest that the second episode this morning wasn't an episode at all. I assess the incident as it had earlier been described to me. I tell the director that the caregivers may have had difficulty dressing him, but when he scratched himself with his watch while they tried to pull his shirt over his head, it was an accident, and he was the only one hurt. I mention meds have been ordered and a one-on-one has arrived. "We are on the right track," I tell her.

She disagrees, "I cannot take the risk. I have to protect my caregivers and residents. It is my decision and I am not changing it." She says further, "If Larry hits a resident and does serious damage; that would be very bad. He would have to leave, and he could never come back here."

I believe she means it. I am scared. I relent. I say, "Then I must accompany Dad in the ambulance." She agrees to follow and then bring me back for my car.

I know this will be a huge disruption of routine for Dad and I am hoping this will not cause him to decline disastrously. I am anxious to spend time with Dad and to connect with doctors and nurses and the psychiatrist.

Talk about ups and downs—Dad had been in good shape for a long while and then, back in August, he developed weakness and started to fall a lot. After the fourth fall in a row, Dad became very pale and frail and was sent to the ER. It was an excruciating experience for him. He was like a frightened, fighting little wild animal, chafing at the restraints on the gurney, attempting to escape; resisting any attempts to calm him. Finally gaining space in ER after hours in the hallway, Dad was put through several tests. The doctor said, “I don’t want to admit him overnight unless we have a good reason. Someone with dementia will go rapidly downhill in the hospital and his dementia will increase considerably.” Sometime later, the doctor returned and asked Dad, “How were your tests?” Dad looked her right in the eye and answered, “Tapioca pudding.” She rolled her eyes and told me the tests were all normal, and she sent him back to his residential facility.

The morning after Dad returned from the hospital, Dad’s primary doctor assessed Dad’s repeated falls, decline in ambulation, increased confusion and jerky movements of his arms, and diagnosed him with either Parkinson’s or Pseudo-Parkinson’s. He decided to re-evaluate all meds. I applauded this prudent course, and hoped for the pseudo rather than the real Parkinson’s because if it were Pseudo-Parkinson’s, Dad’s meds could be the cause of his symptoms and changing the meds might alleviate them.

The doctor said, “I know why your dad fell. His blood pressure went too low. His heart rate went too low. He got dizzy and he fell. Your dad has a particular danger because of his coronary artery disease. He must remain on his heart medication. We must try to keep his blood pressure normal.” The focus would be on the psychiatric medications.

The doctor studied Dad’s chart, examined him, then discontinued or titrated down (gradually decreased) medications that were, in his opinion, superfluous or contraindicated. He would continue to monitor blood pressure and blood labs and to see Dad regularly in order to assess the need for adding or reinstating other medications. The doctor warned me, “Because of your dad’s heart disease and his other issues, a disaster could happen to him at any moment. You need to prepare yourself for that.” Well, I pretty much knew that, but I appreciated his honest talk.

I was thrilled that Dad’s mobile physical therapy, three times a week, had begun, since one of the side-effects of some of Dad’s meds is muscle weakness and exercise might help his ambulation.

It worked. Sure enough, with the changes in medications, the Parkinsonian symptoms disappeared and Dad gradually became more lucid, more mobile, and resumed effectively feeding himself without jerky movements.

“But, Doctor, what if he gets very agitated when you stop or decrease his psych meds?” I had asked. The doctor answered, “Hold his hand. Redirect him.” Indeed—key techniques in dealing with dementia, but what if a trained staff member isn’t present when Dad becomes agitated and slugs someone? What if there is not enough staff or there is frequent turn-over of staff and new ones are not fully trained? What if Dad becomes more high-functioning due to the medication adjustments, but, at the same time he becomes too agitated for staff to handle? My hope is that all of our team-monitoring will lead to a sustainable, albeit delicate, chemical and behavioral balance for Dad. As it turned out, the road to there would be very bumpy.

Here’s a real rub. Dad’s two main doctors; the primary physician and the psychiatrist, disagreed on what caused Dad’s symptoms and on what medications to continue or not. (The primary physician had seen Dad regularly; while the psychiatrist, very seldom.) The psychiatrist would maintain that the medication changes were all wrong. He scoffed, “A specialist, [meaning him], is consulted for a reason!” He said the primary doctor could call him. I don’t think they communicated. The nurse informed me that the primary doctor has the final say; plus, what he was doing made sense to me (I’m the Conservator, so I have a say); and, it was working.

With Dad once again stabilized, our adventures resumed; road trips, lunches at restaurants, family fun, physical therapy, and another trip to the golf course. Gradually, Dad started fidgeting more—getting up and down at restaurants, pacing, grabbing at his seat belt in the car, scratching his legs. We put lotion on him and made sure he drank plenty of water.

Drugs are surely tricky. Who knows who was right, the primary or the psychiatrist? Maybe the titrating-down of one of the meds was too fast. While Dad was walking better, he was also starting to sweat and get antsy again. Was he experiencing withdrawal? I asked questions.

When the primary doctor reexamined Dad, he said, “Larry is doing better...no spasticity...definitely not Parkinson’s—symptoms were drug-induced. He’s much more mobile now—not even using the walker, and he’s talking more now, too.” Because of increased agitation, the doctor prescribed a small dose of an agitation medication. I showed him the pictures of Dad at the golf course, and he was pleased. He said to do that more. I said, “We will!”



Then Dad started swinging at people again instead of golf balls.

It was 2002 when Dad was admitted to the psychiatric hospital the first time, changing his life forever. It was then and there that Dad was deemed a danger to himself and others and considered incapable of conducting his own daily activities. From that place, Dad was driven to the secure alien residence that would become his home.

Now it is October 28, 2008 and, for questionable cause, Dad is re-admitted to the psychiatric hospital.

After processing and paperwork, Dad settles into his hospital room without incident. The director drives me back for my car. I spend a couple of hours at home calling and conferring with family members; then drive to join Dad again at his latest incarceration site.

This is awful. Well, in my mind, it is. I forget that Dad doesn't remember much of anything. Maybe it's just me who is distraught right now, whereas "distraught" is Dad's state often and wherever he is. What a state of affairs.

I am surprised when the staff is the same as before, in 2002, and they greet us with open arms. Oh for heaven's sake, it's like a family reunion. The staff is kind and they know just what to do. When Dad doesn't want to take his meds, they put them in ice cream and he eats them right away.

I bring out the binder I brought from Dad's residence room; the one that says on front: "Hot-shot pilot, Superman, Twinkle Toes, Captain Larry." It has all sorts of family and Navy and golfing photos and awards. The nurse is delighted. He takes it and comments on every page. "Larry, is this you? Did you get a hole-in-one?" Dad perks up and speaks, "The first one was in Scottsbluff, Nebraska; the second one was here." I chime in, "I never knew that!"

The staff informs me they are having a relatively calm day, "Last week it was packed and really busy!" Two days later it would be packed again, and I will be glad that I come so often to make sure Dad doesn't get lost in the shuffle.

"I need to potty," Dad announces. A good opportunity for me to depart without drama. It is 7:30 p.m., and pretty soon it will be bedtime for Dad. A caregiver escorts Dad to the bathroom. Staff tells me the psychiatrist will visit Dad early in the morning and I resolve to meet him then.

No such luck; I just miss the doctor when I arrive and am told to leave him a message. Dad had been restless and up-and-down much of the night and is fast asleep, so I return home. I am pleased when the doctor returns my call a few hours later.

"Doctor, thank you for calling me back. I'd like to know about Dad's plan of care..."

Before I can finish, the doctor interrupts with a strident tone, "I have put him back on all the meds you stopped. You made a huge mistake when you took your father off all the meds I had put him on. You are responsible for him being here. It is your fault that he is so agitated."

I am mortified.

"But, Doctor, it was because of the drug side-effects that we took him off the drugs—he fell four times and ended up in the hospital..." He interrupts again, quite shrill, "This is all your fault. You are responsible..." I interrupt him, "But, Dad has a cardiac condition and I was concerned about drug contraindications..."

The doctor's decibel level rises, "This is your fault and your responsibility!" I attempt to continue, "...and there were triggers for the incidents..." I want to tell him that Dad shouldn't be here at all. The doctor says, "He just attacked a nurse right here, unprovoked." "Oh," I say. Then he repeats yet again, "You are responsible for his being here. It is your fault for discontinuing his meds!"

I can't stand it. I spit back, "So then, if my Dad falls and breaks his hip—that is your fault and your responsibility!"

That's it. The psychiatrist says, "It will be impossible for me to work with you. And it will probably be impossible for you to work with me." I protest, "It will be fine to work with you. I think we should be a team working for the best interests of the patient." I try to ask if there couldn't be some intermediary drugs prescribed that wouldn't leave Dad non-ambulatory... The doctor doesn't respond. He declares, "I am unwilling to work with you. I will transfer your case to one of my associates. I ask, "Would you have the doctor call me?" He huffs, "I will tell them about your case." I say thank you and we hang up.

I am shaking. I just spat back at a doctor! He dismissed us. I feel like a train wreck. Who can I call?

When the secretary of our primary doctor promptly gets back to me, she soothes "Oh, Jody, he should never have spoken to you like that. It's not you, it's him." I babble about all the stories I had heard in the last two days about others who were dissatisfied with this doctor who just dismissed us. One dementia patient's daughter had said to me, "I would never let that doctor touch my mother with a ten-foot pole!" A caregiver had told me about how the doctor prescribed a contraindicated drug for a heart patient with disastrous results. I had ignored the complaints and had chosen to expect supportive care from the doctor. Now I was beside myself. The secretary said she knew very well who I was referring to, but she could say no more. She said she would have the primary doctor's assistant get back to me pronto.

I make more calls in the meantime, and a hospital worker knows all about our now ex-psychiatrist, too, saying, "He is not known for his good bedside manner." With his tantrum-like behavior and Napoleonic tirades, our ex-psychiatrist seems more like his patients than his peers.

When I inform the primary doctor's assistant of the psychiatrist's actions, he says, "Oh no, if your dad is put back on all the meds that's a shame, because we just had him walking better; the other symptoms had disappeared; we were on track to stabilizing his mood. Now we'll have to go back to square one." I wail, "What can I do?"

After helpful recommendations and deliberations, I make preparations to move Dad into his new residence. I discover, with surprise and great relief, not only that a bed is available at the place of choice, but that the director of the new residence is the same wonderful one who was the original director of Dad's old place. A nurse, and an experienced administrator, she is highly trained in dementia behavior and keeps her staff well-trained as well. She is compassionate and kind with residents and family and staff. There is hope.

I call the director of Dad's old place and relay what I have been advised to say, "I don't feel Dad's current residence is a safe environment to bring him back to. I want to relocate." The relocation is set in motion.

I learn that Dad must have three days of stable behavior before he can be admitted to his new residence, so he needs to stay in the Psych hospital for awhile. I learn, too, that I may have to arrange transport to Dad's new location AMA (against medical advice), if the new psychiatrist does not support the change. I breathe deeply and prepare to meet the new guy.

Just as I am beginning to think all psychiatrists are self-involved and non-communicative with Napoleonic complexes (or maybe it's just me), I come face-to-face with Dad's new psychiatrist, and he is good. He is a stellar specimen of compassionate humanity. What's more, he is a team player, and is even anxious to talk to me.

The new psychiatrist, the staff social worker, the nurses and I have ongoing conversations. We are a team. They adjust Dad's medications and monitor him carefully. I share my wish with the psychiatrist for communication amongst doctors. I try to be diplomatic, saying, "I realize how difficult that is since doctors have so many patients and are so busy." "Yes," the new psychiatrist replies, "we rely a lot on faxes and emails."

Advocating for Dad and visiting often is a good idea for many reasons. When I visit the next night, Dad has on socks but no shoes, no handkerchief (I had specified that was a habit of Dad's); no clip on the back of his pants so they don't fall down. (I was told belts are not allowed; that they use clips). All is corrected. When I arrive for dinner one time, Dad says, "Oh, I'm so glad to see you—every time."

When one caregiver stands in front of Dad, he starts singing to her, "You are my lucky star..." There are good moments and stressful ones. I know there are times when patients just sit and stare for long periods and I know there are not enough staff to watch my dad every moment, so I go every day and sometimes sit with him at a group session (I am told he doesn't sit still for these much), at meals, or walk around with him.

I invent a card game that Dad can play, since he has forgotten how to play Uno, like we played last time he was here. I think I am brilliant. I place one card of each suit on the table and give Dad one at a time, looking at him and saying, “Dad, which pile does this go on?” He either points to the hearts, diamonds, clubs or spades stack; or sometimes he takes the card and puts it right on the stack. I praise him. The nurse tells me he watched us playing cards and calls me a “devoted daughter,” saying “he must have been a great dad.” I let him read Janny’s “Superman” essay about Dad and he says, “I hope my children say things like that about me.” (“Superman” follows this chapter.)

A new medication is prescribed for Dad’s agitation. The benefits and minimal side-effects of the drug are touted by the doctor and several staff. It takes a few days to determine the correct dosage. It is trial-and-error. First he sleeps way too much. Then, when awakened, he jumps up swinging. After a few days, Dad’s mood starts to even out. I am heartened. A nurse says she shaved him, had him brush his teeth, changed his clothes, and “he let me do everything,” instead of fighting. A passing caregiver asks, “Are you talking about Larry? He just blew me a kiss.”

A psychiatric hospital team, trained in dementia care, is better equipped to deal with agitated, combative, childlike behavior of an Alzheimer’s patient, than a general hospital. Of course, if a medical problem occurs, the Psych patient must be sent to the regular hospital where they are equipped with IV’s and medical equipment to address physical ailments. I find myself wishing that all medical schools would include courses on dementia care. With the baby boomers like me hitting our 60’s, I am hoping this will come to pass.

Finally, Dad is deemed stable enough to transfer to his new residence and I am allowed to drive him there. The new home for Dad looks very much like his old one, so he doesn’t seem to be concerned about the change. Nevertheless, the entire ordeal has taken its toll.

I gave up on taking Dad to movies some time ago—he became way too restless. He had ants-in-his-pants and bees-in-his-bonnet, as Mommy used to say. I am still hoping to take him out to lunch, though. I drool at the sight of all the neat restaurants very close to Dad’s new place. A trip to the Red Lobster nixes that. Dad is a jack-in-the-box and sits in my seat, then his seat, then my seat, then tries to toddle around the restaurant, then is a very cranky eater. OK. He fares better with the routine of eating at his place. This is not for my entertainment, I tell myself. Must do what is comfortable for Dad.

At least I can plop Dad in the wheelchair that used to be Mom's, and wheel him around the blocks surrounding the residence. It is a little adventure. Dad pets the passing dogs; I point out the flowers and the apartment building that looks much like a place Dad and Mom lived in years ago on Willoughby Spit. Dad smiles.

As his energy increases and his mood calms, a trip around the block just doesn't seem enough adventure for my dad. We successfully resume our road trips. From the Embarcadero on San Diego Bay, we spy "Diego," the whale who veered from his pod for a couple of weeks to flirt with a submarine and keep his eye on beachcombers who watched him from the shore. I drive us to see the seals at La Jolla Children's Pool. I settle upon what would become our new routine: hot fudge sundaes and people-watching at Seaport Village. If I don't take Dad right away for his hot fudge sundae, he drags his feet and points in the direction of Ben and Jerry's. Dad's selective memory seems to kick in. Dad raises his hand to wave at passers-by, just like he is a normal person out for a walk and wants to chat. I quickly wave too and am hurt for him if people don't wave back. We recognize the big dog Scarlet, and the man with the twelve big birds recognizes us. Dad likes to see the little kids and watch the kites. (I think.) We take Jim and Kim when they visit.



Larry, Jim and the bird.

Dad gets more restless. He walks a lot, which is good, unless he gets tired and falls down. He resists caregiver efforts to get him to use his walker. We all try to use behavioral techniques of directing and re-directing without agitating Dad and causing him to swing out. In other words, he sort of gets to do and go where he wants. I give the caregivers chocolates to put in their pockets so they can bribe him to do what they want him to do. At the dining table, he pushes his chair back-and-forth; forward to get to his food, and back, so he can cross and un-cross his legs. He stands up and sits down repeatedly. Sometimes he gets a rash because he is so restless and sweaty. The nurse tells me it is good he is active—better than sleeping and drooling at the table all the time (like I have seen him do)—or falling down.

More than once, I am warned, “If your Dad injures someone, there could be a problem—just giving you a heads-up.” (Oh, no—not the psychiatric hospital again.) My brain flips back into tizzy-time, “Oh dear—what about more meds?” The nurse says no; she is pleased that he is active—more meds could sedate him too much and increased meds would need to be monitored at the hospital—they will focus on the behavioral monitoring. She reminds me that more meds could be problematic for his heart and his kidneys, too. She says the excess sweating is due to his heart condition. Should I be doing something more? Am I micro-managing too much? Should I trust the staff and let them do their jobs?

I am hoping some deep breathing and TV-watching will calm my own agitation. My life is passing before me and I am dwelling on all the mistakes of my past. Am I getting depressed? This is freaking me out. OK, a good night’s sleep does the trick. There will be some small medication adjustments for Dad, after all, and they help to even out Dad’s moods.

I am treasuring our trips to Seaport Village more than I know. I find myself in an odd reverie and with a goofy smile on my face as I bask in the sunshine, blink at boats on the bay, and walk side-by-side with Dad, as I push his wheelchair with one hand. Dad looks up at me and says in full voice, “Happy?”

“Yes, Dad. Happy.” I could do this forever.

## Chapter 33

**Superman**

by Jan Baumgaertel

[ Here is Janny's essay, *Superman--Favorite Memories of my Father*, which she wrote for a Fathers' Day service at her Unitarian Church in 1999.]

I am actually living through times with my dad right now which will probably eventually be "Favorite Memories of My Father." My cocky little fighter pilot dad, with a successful thirty year Navy career, who was told early on that the births of his children were not good reasons for him to miss work; who then could hardly change a diaper without fanfare and accolades; who then retired successfully to many years on the golf course; has now metamorphosized into the primary caretaker of my ailing mother, his wife of 55 years.

I am very impressed and very grateful for all he is doing. I know it is not easy. We are very sad to watch my mother lose her independence, mainly. And, he is simply doing so much.

"It must be difficult, Dad. How do you do it?" I asked him.

"Whenever it gets hard or sad," he told me, "I just remember how she took such good care of my three kids when I would be away from home for nine months at a time on Navy deployments; how she took care of me through my heart attacks and back surgeries; and, then, it is easy."

He had done super things before. We kids loved to hear him tell the story, which he loved to tell, about how, when he was in junior high school in Scottsbluff, Nebraska, he was such a fabulous football player that they asked him to play on the high school varsity team. Five years he played on the championship varsity team. He was a hero in town...and they called him "Superman."

Of course that was a persona he enjoyed and hung onto as long as he could. We three kids had no problem, and had fun, indulging him. We watched *Superman*, the show on TV when it came out, and we read the *Superman* comic books together.

In other words, he was a fun Dad. He paid a lot of attention to us. We went fishing, hiking, camping, skiing. We went to church, to movies, and to plays. We did gymnastics in the living room and on the front lawn. He helped me write my eighth grade graduation speech. We played lots of board games. He was very competitive. It took me years to figure out we played all those games so he could win. And...and...he sang to us. To me, he sang, "When whipporwills call..." and other songs...every night...and eventually to my baby boy. He was Mario Lanza, Al Jolson and Joe Feeney rolled into one.

He insisted we all go to college. When I came home at the end of my freshman year and said, "Dad, I want to change my major from Elementary Ed to Anthropology," first he said, "Anthropology!!!!?????" Then he said, "Well, I'm not sure it is a good idea, but if it is what you really want to do, I support you 100%." After another year of college, it was the late 60's, I came home with some, to him, radical ideas and he said, "I disagree with you, but I will fight to the death for you to say what you believe." When I came home from college after graduation and was looking for a way to support myself and pay for the five to eight years more of school I would need to be an anthropologist, it was suggested I try being a flight attendant for a little while to save money and plan. I don't think he meant for me to do it this long, but then, neither did I.

My dad has affected my life in many ways, good and bad, actually. These are just a few of my favorite memories. I don't think it is too late for me to continue to learn from him and him from me. I have sent him cards and gifts for Fathers' Day this year and I look forward to a few weeks from now when I will be able to visit and stay with Mom and Dad. I will take over as many jobs as he will allow me to take over. I will stay with Mom so he can golf. And... I will tell him I love him and I will say, thank you for being such a super man."

## Chapter 34

**Death of a Daughter**

“This can’t be happening...this can’t be happening.” Jim wandered from room to room, still not able to comprehend that our sister Janny had died two days before. Jim and his wife Kim called from Washington to see how we were doing. It all seemed to happen so fast; diagnosis in November, 2009, of stage four ovarian cancer, and she died on June 14, 2010. We had hope up until the end.

The chemotherapy not only did not work, but the cancer spread. I flew to Baton Rouge to drive Janny to M.D. Anderson Cancer Center in Houston. Everyone there was compassionate and hopeful with us. In Janny’s last minutes, her son Nik held her right hand; her boyfriend Scott, her left. I held her right foot; and Yvie, her left. I wonder if Janny thought we were trying to tie her down with us, to keep her there, but I’m pretty sure she knew we were just loving her with all our might and sending our love on with her. Janny said earlier, “I have more to do...I want to see Nik’s hair turn grey...I want to see Yvie’s career blossom...I want to see Daddy again...I want to see Harry Potter...I want to see Barack Obama...” (She stretched out their names in a comical yearning, “Pooooootter”...”Obaaaama”).

Janny showed us how to die, even as she had shown us how to live, with gusto and unconditional love. I can still see her wearing a hundred Mardi Gras beads or funny Santa hats, layers of colorful clothing and bearing bouquets of flowers as she greeted me curbside all those times at the airport. In the hospital, too, she was full of style and humor, despite her pain. Atop her balding head, a jauntily tied turquoise scarf. When the therapist said to get exercise, Janny sashayed to the bathroom, IV pole in hand, and danced a little jig—step, step, step--kick; step, step, step--kick, as she tossed a grin and a wink over her shoulder. Her favorite doctor said “It is an honor to know you.”

Janny looked like a regal Cleopatra reclining on her good side as she was wheeled back to her room after a CT scan. She did the queen wave to all and we chuckled. Her nurses cried and waved when she was moved to a palliative care floor.

Her psychotherapist said, “I’m not picking up anxiety, depression. Do you have fear?” Janny said, “After my divorce, I learned to wake up with joy every day. From my church, I learned we are not alone. When I was diagnosed, I learned that every day that you can wake up and see a loved one and the sun is a good day. I take one day at a time.” The other doctor chimed in, “...one moment at a time—a day is a very long time...”

Janny said, “I’m so grateful to be here. I feel good as long as there is a plan.”

The therapist said to Janny, “I can’t think of a thing you could be doing different. In fact, you could probably teach a class. I can do nothing but validate you.”

The therapist also told Janny that her patients had taught her “There is always hope.” Even when the doctors said there was no more hope for any treatment, Janny and all of us still hoped to get her home on Hospice. Nik said, “We’ll have to get out the velvet ropes.” That made Janny laugh—the thought of her friends lined up at velvet ropes and Nik directing the traffic.

When we returned to her home without her, a hundred friends came to celebrate her and choose a hat or scarf memento. Two months later, over two hundred friends came to the Memorial Service at the Unitarian Church. Janny had asked Yvie to curate a one-woman show of her paintings; and even told her how to do it, so she did. Janny’s art work hung on five walls of the church, and later, thanks to a dear friend, in a gallery and on the web.



[Janny’s friends wanted copies of this picture of Janny with alligator, taken 2006]

Thankfully, just about the whole time surrounding Janny's death, Dad was in good form and in good hands back at his residence. I was gone almost a month; first, with Janny at her home in Baton Rouge; then sleeping in the hospital room with her; then with Nik and family and friends again in Baton Rouge. I hadn't begun to think about what I was going to tell Dad.

About 10:30 the night before I was to return to San Diego, the med tech from Dad's place called. "We have to send him to the hospital. He fell and has a severe gash on his hand."

"Wait. Can't you treat it there? Can't you call the nurse? It will be devastating for Dad to go to the hospital again. (I felt like a broken record). If he has to go to the hospital, someone has to go with him." I was frantic.

After several calls between the med tech and the nurse; and messages I left begging a friend to go with Dad, if need be, it was agreed that Dad did not need to go to the hospital; that the med tech would put pressure on the wound and dress it. The nurse would attend to Dad in the morning. I left another message for my friend. She did, however, meet me at the airport the next morning to take me quickly to Dad, who had been whisked to Urgent Care by the time we arrived.

There would be considerable blaming and chastisement of various staff for not sending Dad to the hospital. Even the doctor at Urgent Care scowled and told me at subsequent follow-up visits that Dad should've been sent to the hospital. He said it made the wound more difficult to treat and would take longer to heal. I fell over myself praising staff and writing a letter of commendation for the nurse who got blamed. I spoke with the powers-that-be to support the actions that had been taken. Despite the protocol stating that Dad should have been sent to the hospital, I was glad the way things happened. I felt sure things could have escalated disastrously.

At least dealing with Dad kept me distracted from grief for awhile. Losing Janny was so hard. At the church service directly after Janny died, the spasms in my stomach would not let up. I had told Janny in the hospital, "Janny, this is much harder than Mom or Dad." She said, "I'm sorry." I instantly felt bad. I said, "I say that only to let you know how very much I love you." When she was gone, the waves of grief would not subside for a long time.

Mom and Dad had showed us by example when they recovered from a friend's or relative's death that life goes on. But those people had lived full lives and were much older when they died. How do people survive the loss of a sibling, or even harder, I imagined, of a child? I tried to be philosophical and say, "It was her time." I was struggling. It was my sister. It was Dad's little girl. What do I say to him?

Dad was considerably more frail now, and his memory was nearly non-existent. I went back and forth in my mind. Should I tell him or not tell him?

What if he still has some memory of Janny and wonders where she is? What if he senses something? What if he needs closure? He is clearly agitated. Is that about Janny, or about my being gone so long, or because his hand hurts? I needed help. I talked with friends. I sought advice from nurse and the director and the caregivers.

My first instincts were not to tell him. During a discussion with a friend, a brilliant idea came to me: I will say, as I often did with Dad, "Let's call Janny." I would secretly call my own phone number, pretending that it was Janny's. Of course, she would not be there, and neither would I. We would leave a message like we did when Janny was gone, usually on a flight. Clever me, I would say to Dad, "Dad, Janny is on a trip; let's leave a message." We would both say, "Hi, Janny. I love you, Janny." My friend thought that was brilliant, too. "She said, 'That's true, actually. She is on a trip. A very long trip.'"

There were other friends who emphatically advised the opposite, "Yes! You must tell him. I would."

The nurse and director at Dad's place calmed me. They live with him 24/7. They have had experience with this sort of thing. They told me, "Larry does not have the ability to reason and make sense of his daughter's death. He does not have memory of her. He does not ask for her. He deals in the moment. If you tell him and he does remember, what will be his response? It will definitely not be positive, will it? If he does understand, he will not react well. We don't know what his behavior will be, and for how long it will persist. We don't want him to have to be sent back to the hospital, do we?"

Regarding those who wanted me to tell him, the staff said, "Any other person must walk in your shoes before they are able to understand this challenge with your father, Jody. They do not know. You must trust your connection and your own assessment."

I realized that if I told him, it might make me feel better, but it could cause him harm. I had to be the adult here. Someone else's situation could be completely different. It would not be for me to decide for them, and I must finally decide for us. I am just glad that I was not alone in the sharing of the sorrow.

Seven months after Janny's death, Dad still had not asked about her once. I finally decided to share pictures of Mom and Janny. Doggone, I thought, the family is disappearing and I want to share good times with Dad! It has been okay. I show him Patty and Janny and recall sweet moments or fun adventures. He does not exhibit recognition of them, but he doesn't get agitated either. I imagine that somewhere inside he feels remembered joy, if only from the emotion I relate.

Sometimes, I hold up a picture and he suddenly points at someone. I say, "Yes, Dad, that is Jim, your son." Or, "Yes, Dad, that is me. I'm your daughter."

Not too long ago, on one of our Seaport Village jaunts, at a promontory jutting out into San Diego Bay, I parked Dad's wheel chair and sat beside him for a rest. We looked out over the calm bay toward the island of Coronado where we lived many years ago. Out of the blue, Dad surprised me with an utterance unlike anything I have heard from him in a very long time. He looked up at me and spoke in a clear, lucid, full sentence. He said to me,

"We've had a good ride, haven't we, Jody?"

## Epilogue

Years before, at a beachside women's retreat, Janny and her friends stood around a glowing campfire under a crisp Autumn sky, and Janny recited from memory the following excerpt from a Sufi poem. The words always filled us with a Janny-like celebratory spirit whenever she recited it, which she did at our request whenever we asked. After Janny's death, when her friends invited me to one of their meetings, they asked me to read it in her place. My grief got in the way of my first reading, so the ladies exclaimed, "Read it again!" So I did—and with gusto, just like Janny.

*O keep squeezing drops of the Sun  
From your prayers and work and music  
And from your companions' beautiful laughter*

*And from the most insignificant movements  
Of your own holy body.*

*Now, sweet one,  
Be wise.  
Cast all your votes for Dancing!*

Hafiz ~ 14<sup>th</sup> Century Sufi Poet

### Resources

(Use these sources or your phone book to access your local contact information.)

**AARP:** American Association of Retired Persons [www.aarp.org](http://www.aarp.org)

Toll-Free Nationwide: 888-OUR-AARP (888-687-2277)

601 E. Street. NW

Washington DC 20049

**Alzheimer's Association:** [www.alz.org](http://www.alz.org)

24/7 Alzheimer's Association Helpline: 800-272-3900

**National office:**

225 N. Michigan Ave., Fl. 17

Chicago, IL 60601-7633

**tel:** 312.335.8700

**tdd:** 312.335.5886

**fax:** 1.866.699.1246

**AOA: Administration on Aging:**

Office of the Assistant Secretary for Aging: 202-401-4634

Public Inquiries: 202-619-0724

Eldercare Locator (to find local resources): 800-677-1116

AOA Fax: 202-357-3555

Mailing Address: Administration on Aging, Washington DC 20201

Physical Address: 1 Massachusetts Avenue NW, Washington DC 20001

**FCA: Family Caregiver Alliance:** [www.caregiver.org](http://www.caregiver.org) 800-445-8106

180 Montgomery Street, Suite 900

San Francisco, CA 94104

**NAMI: National Alliance on Mental Illness:**

Information Helpline: 800-950-NAMI (800-950-6264)

3803 North Fairfax Drive, Suite 100

Arlington, VA 22203

**NAC: National Alliance for Caregiving:** [www.caregiving.org](http://www.caregiving.org)

Catlin; Sharing the Journey

**National Association of Area Agencies on Aging:** [www.n4a.org](http://www.n4a.org)

1730 Rhode Island Ave. NW, Suite 1200  
Washington, DC 20036  
Tel: 202-872-0888, Fax: 202-872-0057

**NCOA: National Council on Aging:** [www.ncoa.org](http://www.ncoa.org)

202-479-1200  
1901 L Street, NW, 4th Floor  
Washington, D.C. 20036

**National Stroke Association:** 800-STROKES 800-787-6537

9707 E. Easter Lane  
Centennial, CO 80112

**National Parkinson Foundation:** [www.parkinson.org](http://www.parkinson.org)

Helpline: 800-4PD.INFO (800-473-4636)  
1501 N.W. 9th Avenue / Bob Hope Road  
Miami, Florida 33136-1494  
Toll free Helpline: 1-800-4PD-INFO (473-4636)  
National Headquarters: (305) 243-6666; toll free: 1-800-327-4545  
Fax: (305) 243-6073  
E-mail inquiries: [contact@parkinson.org](mailto:contact@parkinson.org)

**Roselynn Carter Institute for Caregiving:** [www.rosalynncarter.org](http://www.rosalynncarter.org)

(229) 928-1234; Fax: (229) 931-2663  
800 GSW Drive  
Georgia Southwestern State University  
Americus, Georgia 31709-4379

**Senior Citizen Baby Boomer Humor:** [www.pmcaregivers.com/Humor.htm](http://www.pmcaregivers.com/Humor.htm)

**Silverado Senior Living Corporate Office** [www.silveradosenior.com](http://www.silveradosenior.com)

6400 Oak Canyon, Suite 200  
Irvine, CA 92618  
(949) 240-7200 or (888) 328-5400

**Southern Caregiver Resource Center:** [www.caregivercenter.org](http://www.caregivercenter.org)

858-268-4432, Fax: 858-268-7816  
3675 Ruffin Road, Suite 230  
San Diego, CA 92123

**Resources: Local Services**

**\*Check the national resources on previous pages for your local contact information**

**Southern California/San Diego Resources**

[www.alzheimerscaresolutions.com](http://www.alzheimerscaresolutions.com)

**Eldercare Directory:** Obtain complimentary copy, visit local libraries, senior citizen centers or the Mission Valley Office of *The San Diego Union-Tribune U-T*. To order delivery to your home of the current *Eldercare Directory* by mail, send a check for \$10 to:

SignOnSanDiego ([www.eldercare.signonsandiego.com](http://www.eldercare.signonsandiego.com))

San Diego Eldercare Directory

P.O. Box 122512

San Diego, CA 92112

**Silverado Senior Living Corporate Office** [www.silveradosenior.com](http://www.silveradosenior.com)

6400 Oak Canyon, Suite 200

Irvine, CA 92618

(949) 240-7200 or (888) 328-5400

**Southern Caregiver Resource Center:** [www.caregivercenter.org](http://www.caregivercenter.org)

(800) 827-1008 (in CA); (858) 268-4432

3675 Ruffin Road, Ste. 230

San Diego, CA 92123

**Aging & Independence Services** for San Diego County:

[www.ais-sd.com](http://www.ais-sd.com)

Or: [www.agingandindependence.signonsandiego.com](http://www.agingandindependence.signonsandiego.com)

For information or to report elder abuse: AIS Call Center: 800-510-2020

Other Telephone Numbers:

Ombudsman: 800-640-4661 or 858-560-2507

Public Administrator/Public Guardian: 858-694-3500

Retired and Senior Volunteer Program (RSVP): 858-505-6399

In-Home supportive Services: 800-510-2020

Outside San Diego County, call toll-free 800-339-4661

For more information call 800-510-2020

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**California Department of Aging (CDA):**

“The Department administers funds allocated under the federal [Older Americans Act](#), the [Older Californians Act](#), and through the Medi-Cal program.

The Department contracts with the network of Area Agencies on Aging, who directly manage a wide array of federal and state-funded services that help older adults find employment; support older and disabled individuals to live as independently as possible in the community; promote healthy aging and community involvement; and assist family members in their vital care giving role. CDA also contracts directly with agencies that operate the Multipurpose Senior Services Program through the Medi-Cal home and community-based waiver for the elderly, and certifies Adult Day Health Care centers for the Medi-Cal program.” (quote from the CDA website)

Senior Information Line: 800-510-2020

[www.ca.aging.gov](http://www.ca.aging.gov) From this site, you can link to:

- \*Adult Protective Services
- \* Area Agencies on Aging (AAA), by County
- \*Directory of Legal Service Providers in California (PDF)
- \*HICAP Number (Medicare Beneficiaries and Long-Term Care Information)
- \*Long-Term Care Ombudsman CRISISline

\*This site also provides an Eldercare Locator which provides lists local agencies for Eldercare Services. Or you can call: 800-677-1116

**Administration on Aging:** [www.aoa.gov](http://www.aoa.gov) Department of Health and Human Services

**California Health Advocates:** Medicare policy, advocacy and education:

800-434-0222: Help with free Medicare counseling

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## Remember...

- ~~ Embrace your team--Share caregiving with family, friends, professionals
- ~~Ask questions
- ~~Ask for help
- ~~ Savor your solitude--let yourself be alone but not lonely
- ~~ Pray, meditate, think, focus—let yourself be still and quiet
- ~~Dance and sing and be loud
- ~~Ask yourself: What would I do if anything were possible? Dream
- ~~Organize the basic stuff: legal documents, medical history and medications—make lists
- ~~Simplify
- ~~Feel and share gratitude
- ~~Enjoy nature







## **Jody Catlin**

**Daughter of Patty and Larry Baumgaertel**

*Sharing the Journey:*

*Becoming a Caregiver for Your Parents*

“Jody’s narrative account of her caregiver journey is told with love, joy, sadness, and trepidation. She maneuvers her way around uncharted territory with a brave exuberance. Her account will make you laugh and cry...sometimes simultaneously.”

~~ Norma Brownell, LVN  
Executive Director, ActivCare

“*Sharing the Journey; Becoming a Caregiver for Your Parents*, by Jody Catlin is a heart-warming account of living and dying. It contains precious loving moments as well as overwhelming experiences of crisis and terror. Also compiled are lists of valuable resources. This book is so well written it should be utilized as a college textbook. Informative, resourceful, passionate...It is a must-read for caregivers.”

~~ Mary Unterwegner, L.M.F.T  
Office of the Public Conservator, San Diego County

“A beautiful book, with the intensity and drama of the everyday life of a devoted daughter caring for her elderly, disabled parents. You will laugh, cry, and learn from it. A must read for anyone who is now a caregiver for loved ones, or who will become one in the future.”

~~ Shelly Chandler, Ph.D.  
Professor Emeritus, Sociology

“Dealing with families whose loved ones have become caregivers is a trying job, many times because of all the legal issues involved. Jody has set down on paper the methods for dealing with these legal entities with compassion, never losing sight of the great love the caregivers have for their loved ones. I would highly recommend this book to everyone who may need to go through the tough road that Jody has traveled.”

~~ Marcia Fram  
Retired Probate Assistant

“I honestly loved it. I don’t know whether it’s because I work in the health care industry or if it is a personal thing. It is as if Jody is talking directly to me. I couldn’t put it down. When my husband said, ‘Okay, the movie’s ready,’ I said, ‘No, not yet, I have to finish this chapter! I’ve got to know if they found another gun!’”

~~ Bonnie DuBois, Radiology Technologist